FORUM *on* END *of* LIFE

Bás in Eireann

IN IRELAND

Perspectives on End of Life
Report of the Forum
2009

THE IRISH
HOSPICE
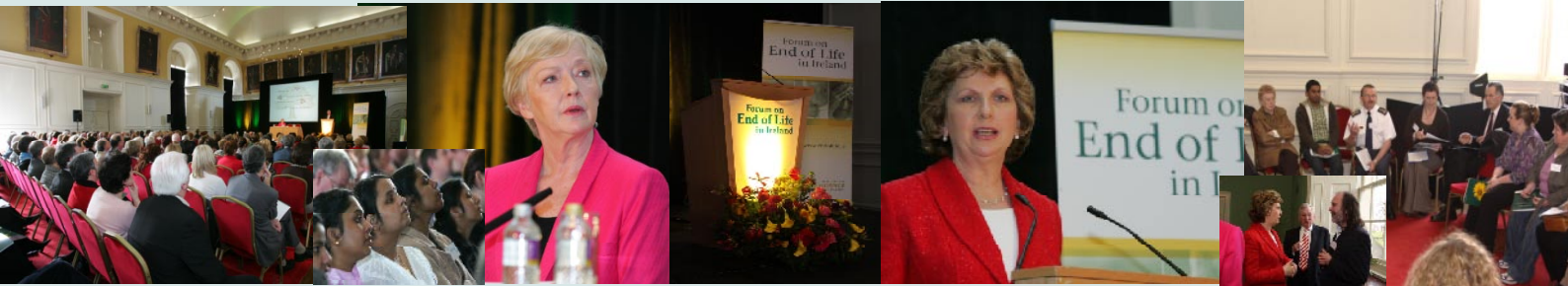FOUNDATION

Contents

CONTENTS

CONTENTS

How we deal with death and dying has been described as a measure of our humanity. In other words we should treat our going out with the same respect and even awe that we attach to our coming in, our birth. Both occasions are momentous. Both are part of the life cycle. Yet we often fail to face the one inexorable fact of death: it faces us all.

People in Ireland often believe, too, that they are good at death. Large funerals and the associated hospitality can, however, give a distorted impression. There is still a considerable taboo about discussing death issues. We say we are sorry for "your trouble". We can hesitate when a person is dying to say just that. We have varying practices, understandings and protocols concerning death, dying and bereavement. Some are good and some are bad. When they are bad the main sufferers are the dying patients and their loved ones.

The Irish Hospice Foundation aims to ensure that no one will die alone and in pain. It also wants to change the culture of death, dying and bereavement. To continue with this work, however, there was a need to discover what people in Ireland believed about death. The first task of the Forum was to listen and discover the perceived issues. Some of these have, of course, been emerging in the work of the Hospice Friendly Hospitals Programme, in the National Audit on End of life Care in Hospitals, during consultations on quality standards, work on the Palliative Care for All Programme and in the IHF's extensive bereavement work. In one sense the Forum's job is only beginning.

ACKNOWLEDGEMENTS

The Forum on End of Life in Ireland wishes to acknowledge the assistant of the following people or organisations:

ACKNOWLEDGEMENTS

THE FORUM ON END OF LIFE IN IRELAND: PROCESS, PARTICIPANTS AND PERSPECTIVES

"I think that's what the End Of Life programme is about. It's not an event. It's a process."

Introduction: The Forum on End of Life in Ireland

In 2008, the National Council on Ageing and Older People (NCAOP) and the Irish Hospice Foundation's Hospice Friendly Hospitals Programme (HFH) published a study, detailing the results of research which focused for the first time on the quality of life and quality of care at end of life for older Irish people in different care settings[1]. Following a seminar to mark the publication of the study and to consider the implications of its findings, the two agencies published a joint statement[2] which proposed a new initiative to promote reform of end of life care in Ireland. It stated:

> *"Reform of end of life care in Ireland is driven primarily by the hospice and palliative care movements and by those committed to, and engaged in, promoting standards of quality in long-stay residential care. The NCAOP and the Irish Hospice Foundation (IHF) recommend that this advocacy base be broadened to include all those agencies with a stake in promoting quality of life at the end of life in Ireland"*

[3]As a first step towards realising this goal the Irish Hospice Foundation inaugurated a Forum on End of Life in Ireland at the beginning of 2009 to identify what matters most to the public regarding end of life from a wide range of perspectives: social, health, economic, legislative, administrative, educational, cultural and religious.

The aims of the Forum were:

- To promote a national conversation on dying, death and bereavement

---

1 O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ni Leime, A., Keys, M. (2008) End of Life Care For Older People in Acute and Long-Stay Care Settings in Ireland. Dublin: National Council on Ageing and Older People and The Hospice Friendly Hospitals Programme.

2 Irish Hospice Foundation (Hospice Friendly Hospitals Programme) and National Council on Ageing and Older People, (2008), End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland: Joint Statement

3 Ibid. p. 19

- To ascertain the key issues at end of life

- To explore the views and concerns of the public and varying organisations

- To ensure that a wide range of views are heard

- To report on the issues emerging from the Forum workshops and submissions

- To prepare the ground for a National Coalition to advance the views emerging from the Forum. [4]

Forum Launch and Invitation to Participate

In January 2009, the Irish Hospice Foundation established a dedicated Forum website and placed advertisements in national newspapers inviting submissions from a wide range of organisations and individuals to help shape the work programme of the Forum. It particularly emphasised that it would like to hear from individuals and families with suggestions on how the experience of death and bereavement might be improved.

The website made it clear that the proceedings and outcomes of the Forum were to be governed by the principles and values of hospice and palliative care. "Life," it said, "is affirmed and dying is regarded as a normal process. Death is neither hastened nor postponed. Pain and other distressing symptoms are relieved." [5]

People and organisations were invited to contribute to the work of the Forum in 2009:

- by attending its launch and inaugural meeting on 11 March 2009

- by making submissions to it

- by presenting a paper to or participating at Forum workshops convened throughout the year

- by attending public meetings organised by the Forum around the country during the year.

More than 300 people attended the formal launch of the Forum by the President, Mary McAleese, on March 11, 2009 in Dublin at which she observed, "Occasionally I get to launch things that are truly life-changing. This is one of them and ironically its ambition is to be death-changing."

---

4 www.endoflife.ie

5 *Ibid* and *Report of the National Advisory Committee on Palliative Care* (2001). Dublin: Department of Health and Children

Figure 1. End of Life Forum Submissions

Legend:
- Personal Experiences of Death of Loved Ones
- From Individuals on Various Issues
- From Health Professionals
- From Other Professionals/Academics
- From Organisations
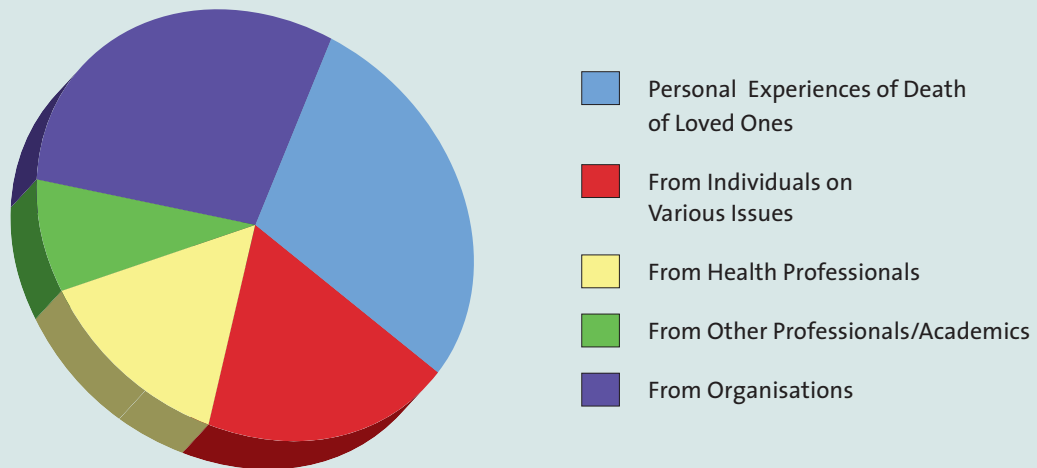
Submissions

The response to the Forum was most encouraging. 167 submissions were received:

- 48 personal submissions from individual people about their experiences of the death of a family member or close friend. Forty of these were from women - mothers, daughters, sisters of deceased persons for the most part; eight were from men

- 32 submissions from individual people about end of life matters of concern to them

- 23 submissions from health service personnel

- 14 from other people, including academics

- 50 from professional, statutory and voluntary organisations.

What was particularly gratifying about the submissions received was the wide range of perspectives represented. Detailed accounts of personal experiences complemented analyses of policy, practice and service provision issues, and vice versa.

Workshops

Following the launch of the Forum and throughout the rest of the year, a series of 23 Workshops were organised at which 108 presentations were made on how the challenges of dying, death and bereavement should be addressed in Ireland today. The workshops brought together groups and experts involved in hospice and palliative care; illness and disability

services; health statutory agencies; gay and lesbian groups; specialist medical/nursing services; children's care services; bereavement services; older people's organisations; religious, spiritual and faith groups; carer organisations; housing and environmental groups; homeless persons and traveller groups; representatives of nursing homes and other residential care facilities; emergency services; education and psychology services; legal and human rights experts; ethicists; patients and family groups; volunteers; and experts from abroad.

Public Meetings

Nine public meetings were also organised around the country to facilitate participation in the Forum. They were in Dublin (2), Galway, Limerick, Cork, Dundalk, Sligo, Waterford and Tullamore. Short presentations from professionals, such as palliative care consultants, solicitors, chaplains, funeral directors, bereavement counsellors, and emergency medicine consultants, were followed by lively discussions, grounded in the life experiences of the participants.

Perspectives

The heterogeneity of identity and consequently of perspective of contributors to the Forum on end of life issues evident at the Forum was striking. Some people identified themselves as having a serious illness or suffering a bereavement. Many spoke and wrote submissions from the perspective of personal experiences of the death of close family members or friends, and they made invaluable observations and recommendations on the basis of those experiences. Others provided a wide range of views based on their professional experiences of service to people at end of life in a wide range of settings, including many from medical, nursing and other health service backgrounds. Others, in submissions and in numerous contributions to Forum workshops, presented the perspectives of their organisations on end of life issues and on how the Irish Hospice Foundation's vision, that 'no one should have to face death or bereavement without appropriate care and support', might be realised.

Many who made contributions to the Forum did so because of their concerns for those at end of life, because of their conviction that dying is a sacred time in a person's life and because they believe that the dignity of the person at end of life must be honoured and protected by society and by those institutions and individuals who represent society with the dying person and with those closest to him/her at this critical time.

The heterogeneity of perspective evident in the contributions to the Forum reminds us that awareness of 'difference of perspective' is important at end of life, particularly in regard to

decision making. The perspective of the dying person faced with his/her imminent death may be very different to his/her perspective earlier in life. Likewise the perspective, the point of view, of the care provider, no matter how well educated and informed, is confined and limited. The better this is realised by those in positions of power and authority, the more likely wise decisions will be reached through consultation - and vice versa.

A Unique Endeavour

The Forum's aspiration to engage 'with all sectors of society' was ambitious, but one which was largely realised. Its special invitation to individuals and families to contribute, as well as to experts and specialist organisations, made it a true engagement by society with death and dying. In this sense it was a unique national endeavour, not carried out to date in any other country, to the best of our knowledge.

The Forum Report

The Forum was designed to engender greater public discussion on end of life and the care of those at the end of their lives; and there was indeed a most positive response to the endeavour from some in the media. However, the exercise was also very much a listening one, designed to identify participants' views about end of life issues in Ireland, and their wishes and aspirations for the care and treatment of those at end of life in this country.

This report brings together the views of those who contributed to the Forum by making submissions, by presenting papers to workshops, and by participating in discussions at workshops and public meetings. What follows is a comprehensive analysis of the rich and varied material – factual, experiential, theoretical – presented to the Forum. It is organised thematically into chapters, the themes having emerged organically in the course of the analysis.

The report does not seek to present the latest national or international thinking on any aspect of palliative or end of life care. Its purpose is, rather, to communicate the main themes, messages and issues raised by contributors to the Forum. It thus provides a baseline document, which will inform a Forum Action Plan to be developed on its completion. This means that those who contributed to the process will have played a key role in shaping the future work of the Forum.

The Cycle of Life, Dying & Death

1

1

Chapter 1
DEATH THROUGH THE LIFE CYCLE

Life and Death are One

Life and death are one. Though life comes before death, and though death is the threshold of a new life for some, the progression from life to death is unique to each of us; it can happen at any age, at any time, in any place. It is not as amenable to control, as we might wish. Good management of death - our own and others - therefore requires that we all stand ready for it at all times. It implicates everyone in society, as the sum and breadth of the contributions to the Forum make clear.

Fewer than a quarter of people are likely to die between 9 and 5, Monday to Friday. Likewise, dying, death and bereavement cannot be left to any particular sector or service on its own: to the emergency services, to hospitals, to nursing, to the gardai, to hospice or to palliative care services, to gerontological services, to funeral directors or bereavement services. But all must play their part. All members and sectors of society must be ready to recognise and uphold the uniqueness and therefore the dignity of each of its citizens at end of life and in death. To do otherwise is both to bury our heads in the sand and to betray our common humanity.

The development of high quality end of life care is a public health, population-wide endeavour; it is not a specialism, nor is it restricted to any condition or to any group of people. It is preventive rather than a curative in approach, seeking to minimise and even prevent physical, emotional, social and spiritual pain and to maximise the quality of life of those at end of life. As one contributor wrote:

> *"Life and death are a natural progression. We assist individuals to come into the world and we need to take a much more serious look as to how we conduct ourselves and services when individuals are leaving this world."*

Representatives of medical and specialist agencies and experts from a range of organisations dedicated to the welfare of persons with different diseases, disorders and disabilities forwarded submissions to the Forum and addressed workshops on the special needs of their clients at end of life. While we will learn more about what they have to say on specific end of life needs later in the report, for the moment they serve to remind us that illness and death can occur at any age. The following are some excerpts from contributions which highlight the presence of illness and death in all phases of life.

In Infancy

> *"The next contraction came and (name of child) was born, but because of the compression of the umbilical cord, she had been deprived of oxygen for twenty minutes and had sustained massive brain damage in those precious minutes ... (name of child) got to have the sun on her face ... later that day she died quietly lying between her father and myself. It was so sad ... I have never felt such heartbreak ... It was of all days ... Easter Day."*

In an analysis by Holles Street Maternity Hospital of 92 children who died in in the first year of life, 46% were premature, 44 % had congenital abnormalities and 10% were normally formed[6]. The death of a child is the most tragic and devastating experience that a parent will deal with in life and impossible to comprehend for those who have not experienced it.

Most infants are born well, but approximately 1: 50 will be born with a structural abnormality and 1:700 with a chromosomal or serious genetic disorder. A presentation from Dr Joan Lawlor, Lecturer in Midwifery, School of Nursing and Midwifery, TCD, described women's reactions to a diagnosis they never wanted to hear and experiences of carrying a baby with a foetal abnormality up to the birth, and beyond. Their reactions ranged through disbelief, distress, fear, panic and frozen. Their coping mechanisms varied from one person to the next: some seeking as much information as possible; others avoiding information altogether. In the light of these research findings, a women-centred supportive intervention, called Recasting Hope was designed to assist women to get from one milestone to the next after a foetal anomaly diagnosis.

If a stillbirth is likely the following questions and issues may arise for the mother:

- When will the baby die?
- What will happen?
- Do I have to give birth?
- What do I bring for baby?
- Camera
- Funeral/services available
- Lactation
- Maternity leave
- A little lifetime

---

6   McHale et al. Death in an Irish Maternity Hospital: causes, withdrawal of care and post-mortem examination rates; SPR,. Baltimore 2009.

Chapter 1 DEATH THROUGH THE LIFE CYCLE

If a live birth is likely the issues are different for those carrying a baby with a foetal abnormality. They may include:

- Meeting the paediatrician
- Visiting the Neonatal Intensive Care Unit (NICU)
- Preparing for separation
- Planning the place of delivery and place of surgery if applicable
- Practical tips
- Clothes
- Bathing/crib
- Questions from the public.

One woman wrote of the death of her infant who became ill the day after he was born, of his care in a children's hospital for three months, without which, she said, she probably would not have had him for as long as she did. She related the supports she received and gaps in support available to her having taken him home to die. We will return to the medical and nursing needs of people of all ages at end of life in Chapter 8.

In Early Childhood

There are approximately 1,400 children with life-limiting conditions in the country and 250 children die each year.

The following are some memories of anonymous contributors who made verbal submissions to the Forum:

> "He died when he was four ... Then he was very sick. He had incredible spirit. He fought it. After he relapsed he said he was dying. He was having conversations with angels. He told me. He was having so much fun ... The consultant said 'do everything, go out and be'. If we want to go on holiday do it all and we did.
>
> He went to school. He got on amazingly. The kids were great to him. He could throw up and vomit. They had all protective stuff. It was a huge thing for all of us. The support never stopped. The kids in the class were great. I'd go in and two or three would be beside him. They knew he was sick, understood how to speak to him."

Another person wrote:

> "I had spent some time in the hospital as a child. I remember thinking I cannot believe I am bringing my child here ... The first consultant had originally told us it was operable. When I met him later he said he was sorry he thought it was operable.
>
> This was very traumatic. We took him out, sat up with him all night, looking at him. The GP came out and said this may not be operable. If it isn't, he went through the whole thing. He said Palliative Care. I had no notion. I had a remote idea it could be that ... I felt it was so unfair. I felt frightened. My husband said this is going to be OK. I said it is going to be really, really bad."

Conditions Affecting Teenagers and Young People

Muscular dystrophy is a range of neuromuscular, largely genetic conditions requiring various levels of support. Adult forms are more slowly progressive than those affecting younger people, such as Duchenne Muscular Dystrophy, a condition typically diagnosed in male children between the ages of at 3 - 7 years, who will then require a wheelchair from 10 - 12 years of age. The lifespan of people with Duchenne MD has increased due to new drugs and young people are now surviving into their mid-twenties and even sometimes into their 30s, though sufferers can die at any time from a chest infection. Females are the carriers and the mother of a child or children with Duchenne MD may be hugely affected by guilt.

Cystic Fibrosis is a lung disease. Persons with Cystic Fibrosis suffer chronic disease at varying stages of life, from early childhood into the teenage years and most recently they are living into their thirties and forties. In Ireland we have the highest incidence of Cystic Fybrosis (CF) in the world. A person with CF receiving services in Northern Ireland can expect to live 10 years longer than a person with CF here. The life expectancy of persons with Cystic Fibrosis can be prolonged by avoidance of infection. Approximately half of those on the CF register are under 18 years of age; 57% are male and 43% female.

The provision of education services to children with life-limiting and life-threatening conditions (LLC) has been identified as an important paediatric palliative care issue. It is increasingly seen, not only as a legal entitlement but as an essential component of comprehensive, coherent and continuous support provision.

Chapter 1   DEATH THROUGH THE LIFE CYCLE

Some Conditions through Adulthood

Multiple Sclerosis is the most common neurological disease of young adults, the mean age at diagnosis being thirty years of age. There are approximately 7,000 persons with MS in Ireland, with a ratio of 2:1 women to men. There is no known cause or cure.

Scleroderma is a rare (1 in every 10,000 persons) chronic, fatal disease of the immune system, blood vessels, and connective tissue. While no overall cure exists, successful individual treatments are available for each of the body systems affected, and so early diagnosis is critical to allow for proper control and care. Scleroderma is also known as Systemic Sclerosis, and it is really an umbrella term for a number of different disease presentations. It can start at any age, although onset is most frequent between 25 and 55.

Huntington's Disease is a genetic disorder, each child of an affected parent having a 50% chance of inheriting the disease. The hereditary nature of HD creates generational hardship in families and causes feelings such as shame, guilt, and social isolation.

Intellectual Disabilities: A person who works with older people with intellectual disabilities writes of people with intellectual disabilities:

> *"The changing demography among this population group is altering to reflect that of the general population, with increased life expectancy for greater numbers of people. However, as this group ages they become very vulnerable to health problems (W.H.O., 2000). Conditions such as cancer, cardiovascular and respiratory diseases are leading causes of death (Hogg et. al., 2001). They suffer the additional problems related to "syndrome specific disorders" and sensory defects associated with the aetiology of their intellectual disability."*

Down's Syndrome: Dementia is increasing among people with Down's syndrome by as much as four times the general population[7].

Diabetes: There is no diabetes screening programme, so we don't know how many people in Ireland have the condition, though it has been estimated that perhaps there are 200,000 people who have been diagnosed and an additional 200,000 have the condition but are unaware of it.

---

7   McCarron M, Lawlor B., Responding to the challenges of ageing and dementia in intellectual disability in Ireland. Ageing and Mental Health 2004; 7 [6]:413-417

Heart disease accounts for 65% of deaths of people with diabetes. Risk for stroke is 2 to 4 times higher among people with diabetes. 12,000 - 24,000 persons with diabetes lose their vision each year. Diabetes is the leading cause of kidney failure. More than 60% of lower limb amputations occur in people with diabetes. There will be ten years from diagnosis of Type 1 Diabetes to the eyes being affected and 20 years to the kidneys being affected.

Motor Neurone Disease (MND) is a disease of adulthood in most cases, with a higher incidence in 50 - 70 year olds. There are different types of MND and it has different causes. 70 - 80 people are disgnosed every year, usually on clinical assessment rather than prognostics. It manifests as a weakening and wasting of the muscles and is progressive, incurable, but not untreatable. Life expectancy may be 3 - 5 years.

Conditions Affecting Older People

Age Action Ireland wrote:

The majority of people are aged over 65 years when they die. The World Health Organisation (2004)[8] has identified that older people may have different and more complex needs in relation to end of life care, due to:

- *the fact that older people are commonly affected by multiple medical problems of differing severity*

- *the cumulative effect of these being greater than any individual illness and can lead to greater impairment and need for care;*

- *greater risk of adverse drug reactions*

- *minor problems having a greater cumulative psychological effect*

- *problems of acute illness being superimposed on physical or mental impairment, economic hardship and social isolation.*

Older people are more likely to experience multiple illnesses towards the end of their life. Also their experiences of chronic illness have not traditionally been the focus for specialist palliative care (Age Concern, 2005)[9]. The timeliness of developing appropriate end of life care policies and practices which meet the needs of older people now and in the future cannot be overstated.

---

8 World Health Organisation (2004). Better Palliative Care for Older People. Copenhagen: WHO

9 Dying and Death. Policy Position Paper. London: Age Concern

Chapter 1   DEATH THROUGH THE LIFE CYCLE

Dementia:

> *"Dementia is a group of syndromes characterised by a progressive decline in cognition of sufficient severity to interfere with social and/or occupational functioning caused by a disease or trauma and often associated with increasing age."*

There are various forms of dementia, including Alzheimer's disease and vascular dementia. They are not exclusively conditions of old age, however. (See above reference to Down's syndrome). There are 40,000 people with dementia in Ireland and it impacts on 50,000 carers. The number will increase by 50% by the middle of the century. There is no known cure for the disease, though it can be arrested to some extent by drugs.

The Alzheimer Society of Ireland writes:

> *"Dementia is a condition that is completely heterogeneous in how it manifests itself; there is no single trajectory; the experiences of the condition vary significantly. Dementia is not a classic terminal condition and it is rare that Alzheimer's disease or dementia is recorded as the cause of death. Some advocates in this area argue that dementia should be recognised as a terminal condition." (Mitchell 2006)[10]*

> *People can live up to 20 years after diagnosis. The pattern where someone approaches death with dementia is very different. These characteristics differentiate dementia from other 'terminal' conditions but the fact remains that people with dementia get to the end stage of dementia, whether it lasts a month or a year, it is the end stage, and people need to have a plan in place for their end of life needs including palliative care interventions (Mitchell, 2006)[11] "*

Death through the Life Cycle

In Ireland we have adoped a life cycle approach in national policy and planning:

- in the Social Partnership Agreement, *Towards 2016*,

- in the National Development Plan 2007 - 2013, *Transforming Ireland - A Better Quality of Life for All*, and

- in the National Action Plan for Social Inclusion, *Building an Inclusive Society.*

---

10 Mitchell, S. (2006) "Identifying more precisely the hallmarks of the end of the course in Supporting and Caring for People with Dementia throughout End of Life, Fondation Mederic Alzheimer No 2, June 2006, pp 17 - 23

11 Ibid

Chapter 1   DEATH THROUGH THE LIFE CYCLE

This approach should ensure:

- that no population group - children, younger and older adults of working age, older people or people with disabilities - is overlooked by society

- that an integrated approach obtains across policy areas

- that the citizen rather than the provider is at the heart of public services planning and provision.

Death is of course part of the life cycle - the last part so far as the individual is concerned. However, death can occur at any age and therefore must be taken account of in policies governing all of the above mentioned groups. End of life, death and bereavement must be integrated in planning initiatives for all age groups and that planning must be informed, first and foremost, by the lived experiences of end of life of infants and children, and of their families, of younger and older adults, (whether of working age or otherwise), and of people with disabilities. It is hoped that this report of the Forum's proceedings, which expressly seeks to give equal voice to citizens as to service providers, will prove useful to, and influential with, those responsible for articulating national service plans in all fields and for all groups.

Chapter 2
SUDDEN DEATH, ATYPICAL DEATHS

Introduction

The contributions to the Forum on end of life remind us that death has many patterns. Just as it does not necessarily wait for old age, so too it is not always proceeded by a life-threatening illness. Often death does not even give any notice of its impending arrival.

Many people described sudden, unexpected and tragic deaths of people they loved. Some died as a result of misadventures, accidents, violence or suicide. Each account adds to our understanding of death in our society and how we may respond better to it, especially when it is least anticipated.

'Hidden' deaths

Among the most tragic of deaths are those that are all but invisible to society, those that go unnoticed. The following are two examples described by Alice Leahy the co-founder of TRUST in her submission to the Forum:

> "As I write this submission, my colleague (name of colleague) is attending the funeral of one of our new immigrants, a man who met his death on the streets of Dublin some months ago, but with no family or friends that we knew of. His body had lain unclaimed in a large city hospital for some time. However, after intensive searches by the Gardai, including inquiries abroad his elderly mother was located, living alone on a mountainside in Lithuania. (name of colleague), a social worker and a priest were the only people to say farewell to him."

> "A few weeks ago a woman in her mid 30s and who looked a couple of decades older, and who we have known for years, died suddenly. Her visits always involved talking about the baby she had recently lost, and she always showed us his photo on her mobile. All the data on his short life she asked us to keep safely for her, because she saw us as "my family" and we might not even have heard of her death. The world of homelessness is complex. Sometimes we only hear of the passing of someone we cared for long after they have died.   Hospital and hostel staff often never know of the parallel world we work in, though often when family contact is lost surrogate families take over."

Accidents

The following are two anonymous accounts of tragic accidents and how people remember and continue to live with them for the rest of their lives:

"The ambulance did not get there for five to ten minutes. I thought it was too long. It was 8.15 at night. We [family] say a prayer at that time every night now. By the time the ambulance arrived, I think it was too late. (Name of daughter) was taken to the hospital. I went with her, and the doctor that was with her stayed in the ambulance doing CPR with the ambulance guys. In the ambulance I could feel her foot cooling.

The ambulance only took 20 minutes. It was straight into A&E. (Name of daughter) was brought into the theatre. We were just standing there watching in the theatre. Was anyone talking to us? No, they were all working to [get it right] for (Name of daughter). Did they explain what they were doing? No, but we knew what they were doing. I would rather be there, I saw the effort. I would not want to be told to go into another room.

It was after 10 when they said 'no, sorry', they turned around and said 'we are sorry'. At that time I knew anyway."

"He was knocked down in an accident. He was ten years of age. It was about ten years ago. About 9pm. I just heard my daughter was with my son and their sister. It was a holiday and my daughter brought him out for a treat.

We were at a social function. We rarely socialise. I had just finished the first course and I seen my daughter's friend running in and running through the ballroom. I knew immediately something was wrong and guessed it was an accident.

We drove straight out to the hospital. As soon as we got there, they were there. My daughter was injured and (Name of son) was injured. She did not know how (Name of son) was, he was unconscious which was why he was transferred.

The gardaí were there: they spoke to me. I can't remember who spoke to me in the hospital. They were all kind of busy. They felt they needed to get (Name of son) to that hospital. His sister was kind of stable with leg and chest injuries.

(Name of son) held on. We had him on a machine. My own GP came over. He was very good. He was enquiring off the staff. He was coming back to me and telling me. He said in cases like this they ask for a transplant. You do not have to consent. I said 'yes' to myself, but I consulted my wife. She said 'no' point blank. So we went with all

my family to talk about it.

They came out to me to explain about what is expected. He said the pressure went over and they could not get it back down. They did ask about a transplant and they had a co-ordinator there. They brought us up to a room. I had loads of friends with me. I said explain to everyone how it works. It was amazing, my wife agreed, my family agreed. There must have been about 40 there. She [the co-ordinator] explained and it must have given them all food for thought."

Another contributor wrote about how her concerns about the care and support available for suddenly bereaved parents inspired her to complete a small piece of research with parents who had been suddenly bereaved by meningitis. This study provides insights into the needs of such parents, including their need for continuity of care; empathy; mementos; support and information; a sense of belonging; and not being forgotten or abandoned.

Warning of the dangers of using restraining belts for people in long-stay care, another contributor wrote:

"I have been hugely saddened to read in the newspaper about two deaths in nursing homes due to elderly people strangling themselves with restraining belts. In each case, the report outlined that the person had managed to slip or struggle down in the chair until the belt was at his/her neck, and died in that position."

'Critical incidents' in Schools

One person with a background in post-primary education in a north Dublin boys' comprehensive school said that on numerous occasions over the years she had to deal with the aftermath of deaths in families, many of which were violent and traumatic. Very little was available to support students, their families and school staff, she said.

In a presentation to the Forum, the Senior Psychologist of the National Educational Psychological Service (NEPS) listed the types and numbers of "critical incidents" experienced in primary and post-primary schools in the country in recent years, as follows:

Types of Incidents:

- Suicide
- Attempted Suicide

- Violent Death
- Road Traffic Accident
- Accidental Death
- Drowning
- Sudden Death/Illness

Numbers of Incidents:

- 111 incidents 2007/08
- 118 incidents 2006/07
- 100 incidents 2005/06
- 90 incidents 2004/05
- 60 incidents 2003/04

The role of NEPS in relation to such incidents is to help schools:

- to promote mental health – building resilience and equipping children with coping skills through the Social, Personal and Health Education (SPHE) and mental heath programmes
- to prepare for critical incidents
- to respond to critical incidents with the assistance of Critical Incident Management Teams, that is groups of individuals from the staff of a school who know the community, the students and each other well enough to make the necessary decisions called for when an incident occurs.

Involving School Councils in appropriate ways following critical incidents can sometimes be helpful. There are also times when meetings with parents need to be called to communicate about an incident. Some critical incidents will attract the media to schools. There are guidelines for principals on how to protect children from the media, which should be adhered to.

Dublin Fire Brigade

Dublin Fire Brigade responded to more than 112,000 emergency calls in 2008: 74,500 Emergency Ambulance and 37,800 Fire Appliance incidents. All of its personnel are trained to paramedic level. 35% of its calls were coded as life threatening in 2008. The ending of a life is a

Chapter 2   SUDDEN DEATH, ATYPICAL DEATHS

regular occurrence in the working life of a firefighter in the Dublin Fire Brigade, including deaths resulting from:

- Cardiac Arrests
- Suicides
- Road Traffic Accidents
- Drownings
- Murders
- Industrial Accidents
- Fires

An Garda Siochana

An Garda Siochana too must witness and deal with life-threatening and fatal incidents on a regular basis, as the following Table of recorded crime offences involving death demonstrates:

Recorded Crime Offences	2004	2005	2006	2007	2008
Homicide offences	97	126	137	133	89
Murder	30	52	61	77	50
Manslaughter	15	13	8	7	5
Infanticide	0	0	0	1	0
Dangerous driving leading to death	52	61	68	48	34

Gardai typically attend after a person's death. Gardai have a close relationship with the Coroner's Office. The following deaths must be reported to a Coroner by an officer of An Garda Síochána:

- Accident, suicide or homicide;
- Suspicious circumstances;
- An unexpected or unexplained death;
- Where a dead body is found;
- Where there is no doctor who can certify the cause of death.

- Certain deaths occuring:

   - At home or other place of residence

   - In hospitals

   - In prison;

- Sudden infant deaths;

- Certain stillbirths;

- The death of a child in care;

- Where a body is to be removed abroad.

Gardai in crews based near hospitals are likely to experience more deaths than those in other stations.

Suicide

One of the most tragic patterns of death in Ireland is death by suicide. According to the Psychiatric Nurses' Association of Ireland, there were 2,800 deaths from suicide on the island of Ireland in the four years, 2003-06. The Association said:

> "Tragically, 11,000 people attended accident and emergency units following self-harm. and this comprises approximately 8,500 individuals. They are conservative figures because even some of those who attend doctors are not included in the statistics. The figures only include those who attend accident and emergency units and not those who attend general practitioners. It is conservatively estimated that up to 70,000 people attempt suicide and self harm."

In its presentation to the Forum, the National Office for Suicide Prevention indicated that on average there have been 494 suicides per year in the Republic in recent years and that suicide has overtaken road traffic accident deaths as a leading cause of death in this country. The Irish Water Safety Council said at the inaugural session of the Forum that 75 of the 156 people who drowned in 2007 were likely suicides.

At the Workshop on Education and Dying, the issue of suicide following bullying at school was raised in discussion. The need for clear governance policies on bullying, and helping the child who is being bullied, was stressed, as was the need to ensure the implementation of such policies.

Chapter 2   SUDDEN DEATH, ATYPICAL DEATHS

The Irish Traveller Movement indicated in its presentation to the Forum that anecdotal evidence suggests that in common with the settled community, it is mainly young Traveller men who commit suicide. Travellers have been identified as a "high risk" or vulnerable group. They fare poorly on every indicator used to measure socioeconomic status, health, accommodation, education and employment. Other contributing factors, they said, include racism and discrimination, low self-esteem, poverty, depression, stigma relating to sexual orientation, drug/alcohol abuse or marital breakdown.

The issue of suicidal intentions was raised at one workshop. The presenters were asked how they respond to patients who express suicidal intentions. One said that she tried to maintain a neutral stance by saying how brave the patient is. Another said that she tries to understand the patient better, what brings him/her to this point. She asks "Why do you want to take your own life?" The answer might indicate a fear of choking or suffocating, for example, which demonstrates why palliative care, which can give people more control over their own death is so important. Some patients who imagine a painful or undignified death can be reassured that things will not be as they imagine, because care staff will not let it happen that way.

At a public meeting one woman asked if the Forum would focus attention on the plight of families of suicide victims because, she said:

> *"When it happens to a family they are very reluctant to talk about it because it becomes so personal, particularly in regard to bodies brought to a morgue and families turning up but then being told a post-mortem needs to be done so the funeral service is postponed for a number of hours.*
>
> *Is there a room for them to go, or are they turfed out and have to find a pub or hotel to sit in for those hours? It would be wonderful if your forum could address this and something be put in place"*

On a number of occasions, particularly in the context of discussions on suicide prevention, Forum participants speculated on the causes of suicide. Gender and age patterns of suicides were mentioned. At a public meeting of the Forum, one person said:

> *"We hear so many reasons for why people take their own life ... I don't know why people die of suicide. It's multi-factorial ... They say that only two people really know why someone commits suicide - the person who dies and God."*

Another person said:

> *"Suicide prevention is about tackling the root causes of suicide: mental illness, alcohol abuse, educational disadvantage to name but a few. It's also about making health professionals more adept at spotting signs of suicidal intent. It is about removing the stigma – it is in other words, a complex task."*

Specific measures adopted by the National Office for Suicide Prevention and voluntary bodies, such as Living Links, to prevent or to respond to tragic deaths by suicide were presented and discussed. We will return to these later in the report.

Chapter 3
BEREAVEMENT

"To the world you may be just one person; but to one person you may be the world" - anonymous.

Introduction

The Irish Hospice Foundation Bereavement Section said that it is estimated that 300,000 people are directly affected by bereavement each year in Ireland. It added:

"Normal grief can be defined as the state that occurs when people are deeply affected by the death of a significant person in their life. Typically the symptoms include; intense yearning or intrusive thoughts and images, and/or dysphoric emotions. However, these symptoms subside over time and interest and engagement in daily activities are renewed. While life never returns to the way it was, the loss is integrated into the bereaved person's ongoing life. As this integration occurs, painful feelings lessen and thoughts of the deceased person cease to dominate the mind of the bereaved. The symptoms can recur as important dates such as birthdays and anniversaries, but the bereaved person will report that overall, they are coping better. For a minority of people (10-20%) this integration of the loss does not occur and acute grief is prolonged in the form of complicated grief. The majority of key researchers in this area agree that complicated grief is a true phenomenon that needs specialised treatment."

The Experience of Loss: Grief

Bereavement was a constant theme in Forum discussions and submissions. This was not surprising since most people experience the pain of losing loved ones in the course of their lives. Each bereavement is different and feels different. However, as contributors testified, there are common experiences: the sense of being alone, 'shipwrecked', disorientated, out of control. Sometimes, perhaps depending on the relationship with the person who has died or the circumstances of that person's death, the loss can be excruciating and almost impossible to bear.

One person said at a public meeting that there are no quick words to describe the

overwhelming grief and the awful feeling in the pit of the stomach that comes with the loss of a partner. "It is one of the worst feelings anyone can experience," he said.

Others spoke of the terrible grief of losing children, notably Jane McKenna, who founded the LauraLynn Hospice in memory of her two children who died. Having described other bereavements in her life, including the loss of both of her parents, she wrote:

> "The most awful losses came later though. The first was 10 years ago this August, when we lost our little angel Laura at the age of 4. One year and 8 months later our other angel Lynn, aged 15, died also. It is these losses that brought home to us the true meaning of grief, and one that is pretty unbearable.**"**

However, despite this dreadful grief, she said:

> "We have borne it, and somehow so far, have survived. Thankfully, we have managed to turn our loss into something good, and are well on the way to start build[ing] LauraLynn House at the Children's Sunshine Home - Ireland's first Children's Hospice. Every loss is difficult to live with, but one we all face sometime. There are two choices then - you either survive or carry on or you don't. Most people do, thankfully, and I suppose it is how you manage that survival that's important. I think the experience and support around the end makes a difference to how you cope afterwards, depending on whether it's good or bad. Thankfully, our experiences with our children at the end were wonderful, whilst Laura did die in hospital, and Lynn died at home."

So, despite everything, and though we may need the support of our immediate circle and community, the majority of people do not require professional help in dealing with their grief. The following are the encouraging words of one contributor on the subject:

> "One sunny afternoon, on a hike to the summit of Croagh Patrick in County Mayo, I realized that grief was quite the same as the strenuous climb into uncharted territory.
>
> 'Keep going', [a passing stranger] urged, 'When you get to the top you'll gain a whole new perspective.'
>
> While the loss of my brother left a gaping hole in my heart, his death offered the opportunity to embrace a larger view and appreciate each day of life as a gift."

1

At Risk Groups

A significant number of people, however, do need therapeutic input or may benefit from professional counselling or more informal supports. The Forum was most informative in drawing attention to those who are particularly vulnerable following the death of others.

Children: In its submission, Rainbows Ireland said: "In a changing Irish society more and more families are fragmented by issues of loss and grief, through death, separation, divorce, illness, often there are a complex set of multiple losses within a child's life."

Families of Children who have Died: In its submission and presentation to the Forum, the Dying, Death and Bereavement Committee of Our Lady's Hospital for Sick Children, Crumlin (OLCHC) said:

> "Bereavement may start long before the time of death and support may be needed from the time of diagnosis ... Although not all families will require professional support, the death of a child is a rare experience and therefore few families will have experienced this form of grief and may not have support to draw on from within the community. In the needs assessment parents spoke of the wish to make contact with other parents in the same situation."

The Committee also spoke about the special bereavement needs of families whose children's remains are sent to the hospital for post-mortem examination:

> "Specialist post-mortem services for children are provided at OLCHC. As a consequence of this local expertise and with the increasing reluctance of general adult pathologists in the regions to perform post-mortems on children, there is a significant trend toward referral of children to Dublin for post-mortem examination, often from distances of over one hundred miles. This is a substantial challenge to the pathology and bereavement services of the hospital. In some cases, where the child has previously attended OLCHC, the parents and staff are well acquainted and support is more easily obtained. However, in many cases of sudden death, there is no prior relationship with the hospital or its clinical and bereavement staff, adding further to the disorientation of distressed parents. These parents may need to find local accommodation and balance commitments to other children who may be at home with the need to find professional bereavement support in an unfamiliar environment. Indeed, this problem of managing bereavement at a great distance from home and normal family support is a problem that is more acute in OLCHC than anywhere else."

Chapter 3   BEREAVEMENT

At a public meeting, a HSE Bereavement Counsellor in the North West of the country also highlighted the issue of women in their 40s and 50s being referred to her by their GPs, diagnosed with depression. She said that she often found that they had lost a baby, maybe … years ago - "and it certainly wasn't dealt with well back then. These women never got to say goodbye to their babies, so now, when the rest of the family is reared and they get some quiet time, that grief shows up as depression." This illustrates the importance of how death is managed and grief treated.

Young People with Cystic Fibrosis: A number of people indicated that both families and friends, including other young people with Cystic Fibrosis need bereavement counselling to help them to cope, "but also to continue with a positive outlook on life. One person emphasised the needs of staff following the death of someone with Cystic Fibrosis, "de-briefing after death for the whole team needs to be given greater priority." Another, at a workshop, added:

> "I know Barretstown House has some excellent courses - three weekends in the year. Families with young siblings especially need help and programmes like these should be extended."

Carers: A submission emphasised that on death carers not only lose their loved one, but also their caring role, and recommended that care and support to deal with bereavement should be seen as part of the care plan for carers. At a workshop it was recommended that

> "Support for the family should continue throughout the process of bereavement and loss to facilitate a positive transition through loss."

People with Intellectual and Learning Disabilities and their Families:
In one workshop people spoke about intellectually disabled people being excluded from consideration and participation because of other family members' fears that they would not be able to cope with the parents' deaths, the funerals or new living circumstances. In a submission, a social worker said that families occasionally experience multiple losses and grief from the day a client is diagnosed with a learning disability. Some people with Down's syndrome develop Alzheimer's disease. He said he supported families of people at the end stage of the disease and sometimes they experience anticipatory grief and may have difficulty in making decisions relating to end of life.

Chapter 3   BEREAVEMENT

In her presentation to a Forum workshop, the Director of the National Disability Authority (NDA) said:

> *"There is a commonly-held view that people with intellectual disabilities should be protected from death, that the reality of death is too much for them to cope with. These ideas have been widely refuted in more recent research, which has confirmed that people with intellectual disabilities respond to bereavement and loss in essentially the same way as anyone else.*
>
> *However, as Sheila Hollins — Professor of Psychiatry of Learning Disability, St Georges, University of London – explains, the difficulties that people with intellectual disabilities often face when trying to cope with bereavement relate to practices that families and communities have developed to 'protect' them. In Professor Hollins's words:*
>
> *'The harsh reality of their own and their parents' mortality is a secret they will have been judged too vulnerable to be told. Their death education has often been non-existent, so their bewilderment at the disappearance of a loved one should be no surprise.'*
> *There is need, therefore, for families, carers and the wider community to include people with intellectual disabilities in shared end of life rituals to discuss death, loss and bereavement."*

Muscular Dystrophy In its workshop presentation, Muscular Dystrophy Ireland (MDI) said:

> *"Some conditions, such as Duchenne muscular dystrophy are known to be life limiting, and parents and other family members may have been experiencing anticipatory grief for some time. Even so, the death can occur quite suddenly, possibly due to a chest infection which quickly develops, which can be a great shock for families."*

Bereavement is a major issue given the genetic component of the condition; two male children in one family may have Duchenne MD. So there can be double bereavement and bereavement of surviving siblings. The mother as the carrier may be hugely affected by guilt. And MDI family support workers and Youth/Respite Workers, many of whom may be young themselves, are also very susceptible to the effects of grief and bereavement.

Neurodegenerative Conditions: In its submission to the Forum the Neurological Alliance of Ireland said:

"Research studies with families of people with neurodegenerative conditions point to stages of grief in family members, where aspects of loss are mourned as the person loses key abilities. Families require ongoing support and counselling throughout this period, not just at end of life. However, it is recognised that there will be a particular need for support at this stage. Families can experience complex reactions of guilt, relief for the person as well as a final sense of loss and bereavement."

People Living in Long-stay Residential Care: People in residential care in Ireland still often live in wards or in shared rooms and the loss of a fellow resident can be particularly upsetting for them. According to Nursing Homes Ireland, the average length of stay in private nursing homes in Ireland is 3.7 years, which means that residents are likely to see people die during their stay in residential facilities and some will require bereavement support. The families of those who die, too, will have bereavement support needs. However, the evidence indicates a lack of attention to these needs. The joint report of the National Council on Ageing and Older People and the Hospice Friendly Hospitals Programme, End of Life Care For Older People in Acute and Long-Stay Care Settings (2008) found bereavement support structures and services weak in the sector, with a general absence of bereavement officers/family liaison nurses. The absence of specific or even general memorial services for deceased patients in many facilities across the public, private and voluntary sectors was also 'noteworthy'.

Grandparents - the Forgotten Grievers: Very often grandparents, due to the untimely death of their son or daughter, are catapulted into a parenting role in their grandchildren's life … Often too, they are dealing with their grief and that of their grandchildren and they find it very difficult to know how to cope.

Grandparents also grieve the loss of their grandchildren through miscarriage, stillbirth, accidents, chronic diseases … right up into young adulthood. These grandparents concurrently experience the pain of losing their grandchild, in addition to observing their adult child's grief. Preliminary findings from a study funded by the Irish Hospice Foundation on grandparents' experiences of such bereavements were presented at a Forum workshop. The following, in their own words, are some of the experiences of grandparents who took part in the study, and some of their reflections on their experiences:

"The night we arrived in (name of hospital) and the fear in me that night as I saw (Name of daughter) … It was phenomenal, I was just terrified for her, watching her, knowing that she was going to lose and have to 'let go' her child…"

Chapter 3   BEREAVEMENT

"When we knew that (Name of daughter) was going to be induced and that her baby was dead, it was savage, savage pain ... when any of my daughters go into labour, I go through the labour with them but I am waiting for the arrival of the perfect beautiful newborn baby ... but this time I had to go through that with her, knowing that she was going to give birth to a dead baby - it was devastating."

"When (Name of daughter) could not be present for the baptism and I was there in proxy and the priest used (Daughter's name)'s tears to baptise (Name of grandchild), that was absolutely ... it was absolutely the most horrendous heartache that you could experience."

"Unless you've been through it (the loss of a grandchild), you can't realise, that it would be as easy for me to lose my son, as lose my grandson, there is no difference ... to me a grandchild and your own child there is no difference - where do you draw the line?"

"I was thinking in myself – I don't think I'd ever have the courage to go through that and then remembering that I had done it (this grandmother had lost a preterm baby herself) ... Many times I made that remark - it would be much easier to go through this pain myself than watch your child go through it ... I still look back and say it was harder to actually watch the situation than be in it yourself."

"I would never wish it on anyone, the abiding pain, the pain of feeling useless, knowing that I couldn't stop ... pain. I knew I could do nothing for her. It's the worst thing I ever felt in my life. And it is only going through this that I realised the depth of a mother's love. People say that a mother would kill for a child. Well I know that, I fully understand that now. I would kill for ... in the morning ... my daughter has been through hell on earth and you are not going to do anything else to her."

Same-sex partners: Loss of a partner is an extremely difficult experience and when that partner is a same-sex partner, this trauma can often be exacerbated by the lack of recognition of their relationship. Research, again funded by the Irish Hospice Foundation, "Supporting LGBT Lives: A study of the mental health and well-being of lesbian, gay, bisexual and transgender people, 2009", shows that homophobia directly affects the bereavement experience of lesbians and gay men. The following is a good example from the study quoted at a workshop presentation:

"They were having a meeting for newly bereaved people in the hospice and I went to that. I was opposite a man whose wife had died and I ended up talking to him. And, in the end, he just said to me, 'You've only lost a friend', he said, 'and I've lost my wife'... In the end I just got up and walked out. That was one of the worst times. I never felt as lost and isolated as I did that night ... I didn't think it was an appropriate place (hospice support group) for me to be going – where people wanted to talk about their parents who had died, or their children, or their partner, spouses. I was sort of like a fish out of water."

In a submission, the Gay and Lesbian Equality Network says that when professionals fail to address the support needs of bereaved partners this results in an experience of "disenfranchised grief", such as the following quoted from a recent article[12] by a contributor:

"Although society recognised that the person had lost someone significant in their life, it was not given the recognition that would have been offered to a widow or widower in the heterosexual community."

Refugees and asylum seekers: Another kind of bereavement is that experienced by refugees and asylum seekers. They may have escaped death, but are often in mourning for themselves and their loved one back in their community. A lot are still living in Africa in spirit because they cannot make the connection. Much depends on language and integration.

Bereavement following Suicide: Rainbows Ireland which has provided a peer support service for children, adolescents and people who have suffered loss through bereavement and in other ways said at a workshop:

"In Ireland today, more and more children and young people are experiencing traumatic grief and loss particularly associated with murder and suicide. It is our strong experience on the ground that there is definitely not sufficient professional services to meet these needs around the country. These losses are beyond the remit of Rainbows and it is a constant struggle to locate suitable professional services for such traumatic losses."

One organisation which is trying to respond to the issue of bereavement by suicide is Living Links, established following five deaths by suicide in five years in Cloughjordan. While it is a

---

12   Higgins et al (2008). The grief experience of same-sex couples within an Irish context: tacit acknowledgement. International Journal of Palliative Nursing 2008 vol 14 no 6 pp 297-302

1

Chapter 3   BEREAVEMENT

voluntary organisation and does not provide professional services, it aims:

- To provide a voluntary listening, support and outreach service to those bereaved by suicide

- To increase awareness and understanding of suicide and its effects on individuals, families and communities

- To liaise with and provide families with information on relevant health services available in their own communities and in the region, and the referral pathways to such services should professional advice and support be required

- To provide practical help, advice and support to the bereaved and to have this help immediately available to people in their own communities

- To provide and facilitate a group healing programme, on a needs basis, for the suicide bereaved

- To encourage the suicide bereaved and/or suicide affected to establish and foster an ongoing support group among themselves

- To liaise and exchange information with similar support groups nationally and internationally

- To support and encourage relevant research

- To produce leaflets and associated literature to be provided to survivors.

Living Links is expanding its network in the Republic and in Northern Ireland. It provides information and practical support only when invited to do so.

Responding to Bereaved Persons

Some contributors spoke about responses to bereavement: appropriate and inappropriate, sensitive and insensitive, kind and unkind. As a number of people remarked, it is often the little gestures that make a big difference to people. Responses to the bereaved vary from person to person, as this parent who lost a child makes clear:

> "A consultant called him the wrong name. I said at least get his name right. The social worker sent flowers, the main consultant who had been on holidays rang,

and at Christmas there was a card and at the first anniversary.

"All of these things are important because they were with you at all the bad times, the last people with you with your child when he was dying."

Getting it Wrong

A contributor to the Forum wrote:

"At the time of our son's death my husband was Principal of a National School and I was Deputy Principal of a Secondary school. Even though (name of husband) and I would have given over 30 years of excellent service neither of us got any acknowledgement from the Department re our bereavement. No counselling offered."

Another person spoke of the excellent care her mother received in a hospice, but was disappointed there was no follow-up or enquiries about how the family was coping.

The practice of giving valium instead of appropriate care and attention was criticised by some people as generally inappropriate, 'the medicalisation of grief', they called it. It is only when postnatal depression or other physiological conditions are added to grief that there is a case for medication, they said.

Even those in Bethany bereavement groups may have difficulties in responding appropriately to the bereaved:

"What I didn't like was that there were four women in the group, but I was the only 'client'. I quite liked the opening ceremony where candles were lit etc., but after that, the focus was on me mostly, and   I felt obliged to talk, while the women practised their listening skills on me."

Getting it Right

Of course in many Bethany groups people do get it right and respond appropriately to the needs of bereaved people in their community. Examples of good experiences following bereavement were also described to the forum. The following is from the end of an anonymous parent's loving description of the illness and death of her child:

Chapter 3 BEREAVEMENT

" (Name of daughter) was taken to the chapel of rest on a bed with a duvet cover. All the paper work was so easy. They knew we were going home. Tickets were arranged, we were given money [from a charity fund].

"We got her home the next day. All the family were there to meet us. All around our house there were flowers, with petals up the driveway. We kept her [at home] overnight. We would have liked another night. All (Name of daughter)'s friends came.

"The other hospital sent a bouquet of flowers for the first anniversary and the consultant rang me and invited us to a bereavement service."

Many initiatives designed to respond appropriately to the needs of bereaved people were outlined to the Forum. They included the following:

The Brothers of Charity DVD "After I've Gone" and Other Initiatives The DVD highlights the need to include the intellectually disabled in decision making following bereavement, for example in regard to where they might live or visit following the death of parents. Following training by the hospice, the Waterford Brothers of Charity have developed bereavement policy and guidelines to help staff assess and give support to service users. A forum on bereavement for families is planned in Waterford.

A School's Response to the Death of a Pupil

A former secondary school teacher told a Forum workshop how a child's death was handled by a Secondary School:

"(Name of child who died)'s class were gathered up and were spoken to by the Principal and myself. They were then allowed to take over the Library for the day. We allowed them to decide how they wanted to organise the day and especially the funeral day. In doing this, we felt that we were letting them feel that they had control over events, something which is important in grieving. Their behaviour was very mature, sensitive, and thoughtful – there were a few daft ideas which were knocked on the head. All day, they oscillated between shedding of tears and laughter at happy memories. They were for the most part actively engaged in doing a website and also a memory board which was displayed in their resource area. This involved a collage of photographs, drawings, poems and little memories.

In the weeks that followed, they raised funds for Crumlin Hospital and before

the year ended, her parents were invited in to a Mass which was followed by the planting of a tree in (name of child)'s memory. (Name of child)'s books and the contents of the memory board were also given to her parents. They thanked the students for all their support to them and encouraged them to do well in their exams, and that was what they wanted most for (name of child)'s class."

"....One of the big issues which arose was around who had the right to grieve. There was animosity towards girls who were being upset even though they were regarded as being outside (name of child) 's group. This needed a few interventions from the chaplain and myself."

Ceremonies of Light

MDI (Muscular Dystrophy Ireland) holds Ceremonies of Light in different regions to celebrate the lives of all members with MD and to remember those who have passed away. They provide support for families and staff giving families recognition of their loss.

A Service provided by a HSE Bereavement Therapist

At a Forum workshop a HSE Bereavement Therapist described the service he provides as one of respectful awareness. It receives approximately twenty referrals per month from GPs and other care providers who believe their clients may be experiencing bereavement difficulties or problems. Timely access is therefore a critical issue for some. However, there is a 4 - 6 weeks waiting list for this service which we understand is not a national service. The HSE and the Irish Hospice Foundation have produced a set of 12 leaflets on various aspects of bereavement. These include leaflets on suicide, grieving the deaths of partners, and parents, and three leaflets on children and death.

The Bereavement Care Liaison Project

This is a three-year partnership project of the Irish Hospice Foundation with Laoise/Offaly + Longford/Westmeath Local Health areas. It included a wide-ranging consultation process with 120 individuals and groups and a Bereavement Care Forum was held in December 2008. Its purpose is to develop capacity and co-ordinate efforts around the most appropriate supports for those facing death, their bereaved loved ones and those supporting them in the local areas. The Bereavement Care Liaison Officer works with an advisory group.

1. The Cycle of Life, Dying and Death

. . . .

Chapter 3   BEREAVEMENT

Kapy

A contributor to the Forum wrote as follows of the support he and his wife received in Finland from members of an organisation called Kapy who had been through a bereavement experience:

> "After my wife and I had undergone the traumatic experience of a hospitial-assisted delivery of an already deceased baby, we immediately received a set of documents from the hospital informing us of the existence of an organisation named Kapy (Acorn) which is comprised of a committee and members who have undergone a similar experience. We were asked if we would like to have someone from that organisation proactively contact us; we agreed (in such a situation I think it is better that someone proactively contacts the grieving than *vice versa*).
>
> Then our initial contact person, from the Kapy committee, visited our home a few days later. We talked frankly about our experience. She informed us of a relatively nearby potential "buddy" couple that had gone through a similar experience, and asked if we would like to meet them; we agreed. Quite soon after that we met up and they have been very supportive.
>
> I think such organisations as Kapy are vital support lines and need to be incorporated into any End of Life framework. My personal experience and feeling is that support from family and friends after such an experience as ours is quite limited because they don't and can't fully understand the trauma of the experience and its impacts."

ICU / HDU Bereavement Day

A Consultant in Intensive Care described an initiative of the Intensive Care Unit inviting the next of kin of people who had died in the unit to an ecumenical service. All levels of staff conducted the readings, a Filipino choir sang and there was a candlelight procession. Receiving the invitation was important to those who attended and to those who did not. Those who did atttend were overwhelmingly positive about the event, indicating that it facilitated bereavement.

Others spoke of the memorial services they had organised, cards and wreaths they sent, memorial stained-glass windows installed in a chapel, and photo albums of memorial cards assembled.

Bereavement in the Workplace

In its submission IBEC noted:

> 'While there are practical and legal mechanisms that employers can implement in order to manage terminal illness or bereavement in the workplace, often it is the softer issues around communication and accommodations that make the most difference to the experience from an employee perspective.

However, IBEC admits:

> "There is no doubt that in Ireland, we have some way to go in effectively managing mental health issues, including stress, grief and emotional distress in the workplace. In other countries, notably in the US, bereavement and grief are accepted subjects to be fully understood and actively addressed by HR specialists. A number of studies in the US, and also more recently in the UK, have demonstrated the impact on businesses of not dealing adequately with bereavement and illness. Employees experiencing these processes reported serious under-performance and lack of productivity and motivation for long periods during the illness of a relative or following a death. While this is entirely natural, best practice employers are able to prevent long-term negative impacts by ensuring that employees have adequate time off when needed, have access to Employers Assistance type programmes, or have access to counselling or other 'soft' supports."

The Irish Hospice Foundation, it should be noted, has developed and published[13] an excellent policy to assist employers, unions, managers, workers and all those "whose work centres on best human resource practice"[14] to proactively manage grief at work.

We will return to the subject in Chapter 28, on the management of end of life care.

---

13 Breffni McGuinness (2007), Grief at Work - developing a bereavement policy. Dublin: Irish Hospice Foundation.

14 Ibid: from Foreword by Kieran Mulvey, the Chief Executive of the Labour Relations Commission.

Chapter 3 BEREAVEMENT

End of Life in Ireland

2

Chapter 4
CULTURAL CONSIDERATIONS

"Any man's death diminishes me because I am involved in mankind; and therefore never send to know for whom the bell tolls; it tolls for thee."   John Donne

Ireland is now a Multicultural Society

"Culture is the shared set of assumptions, values, and beliefs of a group of people by which they organise their common life" (Gary Wederspahn)

End of life cultures vary from place to place around the world. Egide Dhalia, Manager of the Centre for the Education and Integration of Migrants in SPIRASI (Spiritan Asylum Seeker Initiative) and Rev. Dr. Michael Wright, International Observatory on End of Life Care at the University of Lancaster both spoke about these differences in their addresses to Forum workshops. Both presentations served to contrast sharply the predominantly communitarian approach to end of life in some parts of the world with the more individualist approach in others.

In Africa, to be is to belong, and an individual exists corporately in terms of the family, clan and whole ethnic group. As Nelson Mandela wrote:

> *"In African culture, the sons and daughters on one's aunts or uncles are considered brothers and sisters, not cousins. ... My mother's sister is my mother; my uncle's son is my brother; my brother's child is my son, my daughter."*
> *Mandela N (1994) The Long Walk to Freedom, Little, Brown p9*

Comparing the West and African cultures, the West's predominent values revolve around the individual and his/her rights, whereas in traditional African communities the extended family and the village have pre-eminence over the individual. There, the individual is part of the community and the community is more important than the individual. The ancestors (spirits) live on in things/animals (animism) and remain an influence in the community. In some cultures autonomy is not rated as highly as a value at end of life as it is in Western countries such as ours.

Chapter 4   CULTURAL CONSIDERATIONS

Contributors to the Forum emphasised that Ireland is now a diverse, multicultural society. This has implications for how it provides for its citizens at end of life and for the bereaved following death. A speaker at the inaugural session of the Forum said that there had been 420,000 immigrants to Ireland in the ten years to 2007 and that 21% of nurses in Ireland come from outside the country.

Another said:

> "In Ireland there are now substantial numbers of immigrants brought up in religions other than Christianity (in rough numerical order these are Islam, Buddhism, Hinduism, Judaism, Baha'i and other - traditional Chinese religion is the largest category of "other"); most of these are marked by enormous internal diversity, so that there is no one authority in a position to speak for all members of a particular religion."

In addition to this, some contributors stated that Ireland was becoming a more secular society, though others preferred to emphasise that it was a pluralist society. This new context of cultural diversity and plurality of belief (and non-belief) may provide an opportunity to forge a new cultural model of end of life specific to this country, as has been done in other countries.

End of life is coloured by prevailing societal values; but also the way end of life is conducted may itself be a catalyst for actualising or developing particular values, such as building social capital in Kerala, India, modelling inclusive community in South Africa or acknowledging spirituality in Eastern Europe. Depending on how it is practised, end of life care may not only provide inestimable benefits to the dying person, but also to the society that takes the trouble to invest in it and in post-end of life care.

Through the Forum we begin to see what matters most to us in Ireland when we think about or when we experience end of life. Certainly, in keeping with our neighbours in the Western world, there is a growing demand for more individual autonomy at end of life, best characterised by calls for a legal framework to underpin advance care directives. On the other hand, the Forum reveals an equally strong, if not stronger, demand for much more and much better communication between every person involved in each end of life story. Clearly, calls for more autonomy and for better communication at end of life are not mutually incompatible. An advance care directive is a form of communication, after all.

Could it be that, following the Forum consultation, we would seek to ensure that End of Life

Chapter 4   CULTURAL CONSIDERATIONS

in Ireland would be characterised by the highest standards of listening and communication between everybody involved in each end of life event? The way end of life care is practised in this country could be a catalyst for the development of better understanding of the nature of communication and of its healing properties in all care settings in Ireland. One person put it this way:

> *"What is most needed is ... to encourage the kind of flexibility in procedures, institutions and laws that will enable those involved in care for the dying, the process of death and the disposal of the body* **to listen** *to the dying person and those close to them about what is most important to them, and to respond effectively to their needs."*

Contributors emphasised the need for greater understanding of people's cultural diversity and differing religious needs, and a number noted with approval the HSE initiative to develop a Health Services Intercultural Guide, under the HSE National Intercultural Health Strategy 2007 – 2012. This was published in November 2009:

> *"The change in population requires continuing ongoing education and the HSE are to be commended on its work in the production of the forthcoming Intercultural Guide. However the presence of this excellent guide works only in the presence of staff members that are sensitive to the nuances of this area of care."*

The Humanist Association of Ireland called for public spaces without religious iconography to be provided to meet their funeral requirements. They also wrote:

> *"We would like to ensure hospice staff are aware of patients' belief systems to avoid distressing them with unwanted visits from chaplains and to be able to provide them with such a service."*

Others requested religious services:

> *"A person's religious beliefs should also be catered for as a very necessary help for a peaceful transition. Catholics should have a chance for anointing and frequent visits from the priest over the last days even if the consciousness is limited. Non-catholics should also be facilitated for visits from their clergy as often as they would be helped."*

"The religious customs of the dying person should be exercised. For Catholics, simple traditions such as lighting a candle in the room of the dying person or bringing in a crucifix can give immeasurable comfort to the dying person. Often the family do not like to cause a fuss or may not have the awareness, so it is necessary for non-relatives or those who know the right thing to ensure that religious customs are followed ... The immediate treatment of the body after death should be respected according to one's beliefs."

A Death Denying Society?

Attitudes to death and dying vary between societies, within societies, and even in ourselves as we age. We need to be wary therefore of generalisations. Some say we are a death denying society; others, such as Professor Allan Kellehear, who addressed a public meeting of the Forum, question this, saying that we are an apathetic, not a death denying society. Whatever is the case, attitudes to end of life care, to dying and to death featured strongly in Forum discussions and contributions. One person wrote:

"I only hope that when the time comes I'll be gracious enough to accept death on my own behalf and generous enough on behalf of my spouse and family. We must remember that life has changed but not ended both for those who have died as well as for those who are left behind."

By contrast, another person said:

"For me the greatest tragedy at this difficult time is the persistent denial by family members (often aided by the medical profession) of the true situation in which they find themselves. This prevents intervention aimed at making life more pleasant for their dying relative/friend.

An elderly lady has several strokes over a period of months; she is admitted to a nursing home for care. In the nursing home, she is taken from her bed each morning, propped up in a chair, and left there until after lunch. Her head nods uncomfortably as she sleeps. She says she wants to die. She is fed, cared for - but not allowed to stay in bed where she would be most comfortable. Eventually, - when an appropriate mattress is available (due to the death of another patient) she is allowed to stay in bed. She develops dehydration. She is hospitalised, tube

fed and a drip set up. This continuous revolving door from nursing home to hospital is sustained for months and months. If the special mattress is not available on her return to the nursing home, she is again subjected to the 'getting up' process each day. The family complain, but are told the mattresses are expensive and there are only two available in the home to serve all patient needs. The woman is diagnosed with depression, and given medication, because she continuously says she wants to die. Yet nothing - absolutely nothing - is done to relieve her symptoms; to offer therapy; to enhance her life for the time she has it. The focus is on preventing death not enhancing life. Tragic. Her family were not willing to let her go."

Others observed:

"The lack of acknowledgement of end of life at medical service, family and individual levels lead[s] to systems failure and inappropriate experiences of end of life."

Another person wrote:

"My observation of the current customs around death and dying in Ireland leads me to believe that that a movement towards a more antiseptic and arms-length process has replaced more traditional rituals."

Yet a Funeral Director spoke at a public meeting of the Forum about challenges facing his profession, particularly with regard to learning and understanding the cultural traditions around death in non-national communities. He also commented on the move from waking the dead at home to the funeral parlour, and a recent return to home wakes.

"Fear", another person said, "is driving the lack of openness about death, fear of dying and sometimes fear of the afterlife. This influences thinking, or more often the lack of thinking about the needs of older people and the provisions we make for them when they become frail and ill."

Death and Dying: Taboo Subjects

In our society we are inclined to keep the subject of death and dying at arm's length, bottled up. As one contributor wrote:

"I think we must look at the social context of dying in Ireland today. In Ireland death has been sanitised, put in the closet, so to speak. Until lately, speaking about death had almost become a taboo subject, resulting in a similar denial and fear of death that is prevalent throughout the Western World."

One submission to the Forum, entitled "Dealing with Death" vs "Getting on with it" had this to say:

"I find this reluctance, or shyness, or perhaps over-reliance on the 'just get on with it' approach worrying, particularly as it affects the way we train and educate those entering the helping professions."

Other comments about our inhibitions about discussing the subject included:

"Due to societal changes and advances in technology, death and dying are often considered taboo subjects with reluctance to both openly communicate about death and ... Accept ... [it] as part of the human life cycle."

"Dying is as much a part of life as living. Generally people avoid thinking about or talking about death and dying (Davies and Higginson, 2004) [15]. Age Concern (2005)[16] explains this lack of discussion as partly due to the settings in which death occurs. They state that because most people die in hospitals and as a result many people have little direct personal experience of death or dying. Concepts of death have therefore changed, moving away from a normal aspect of life to something that represents a failure of treatment and scientific and medical intervention. This medicalisation of death has meant it has become secularised and institutionalised."

Staff Attitudes

Some contributors to the Forum raised the issue of staff attitudes to people at end of life and to their families. In some cases it was put down to staff being run off their feet; in others to staff becoming inured to death and therefore losing an ability to empathise:

"It has frequently struck me that some medical staff may temporarily lose their ability to empathise with, or to simply imagine, the emotional suffering of their

---

15   Davies E. and Higginson I. (2004) The Solid Facts: Palliative Care. Copenhagen: WHO.

16   Age Concern (2005) Dying and Death: Policy Position Paper. London: Age Concern

patients or of their families when death is imminent or has just occurred. Medical staff will witness many, many deaths throughout their careers and will run the risk of becoming somewhat inured to the enormity of the event, yet each of us will die just once and will witness the death of loved ones on relatively few occasions. No one expects a display of extreme grief, but a sensitive acknowledgement of loss is never inappropriate."

A student nurse, who studied student nurses' perceptions of caring for dying palliative care patients in the acute care setting, wrote that "if a student nurse develops negative attitudes towards death and dying, this negativity can prevail when the student is qualified and may lead to the potential isolation of dying patients."

Talking About It

The Irish Hospice Foundation decided to challenge this taboo and presented the Forum on End of Life as a national conversation about death and dying. At its opening on 11th March 2009, President Mary Mc Aleese suggested:

> *"This Forum will help us to open up the worries, fears, desires and ambitions about the end of life that we often keep firmly locked up ... From this Forum and the debate it is carrying forward will come the insight necessary to help us face into this great cultural taboo."*

And so it turned out. One person said at a public meeting:

> *"Society is unsure about how to deal with death or talk about it. This is the first time that I have been in a room where everyone wants to talk about dying and death. It's a kind of holistic experience. It's good this is happening."*

At the same meeting, someone else said that, the previous day, she had been with someone whose son, a young man, was dying:

> *"She was sitting at the side of his bed and he said, 'I'm dying' and she said, 'no you're not'. She couldn't deal with it. She didn't know what to say. If he got upset she would get upset. It's like we're not educated around death and dying and emotions."*

2. End of Life in Ireland

. . . .

Chapter 4   CULTURAL CONSIDERATIONS

2

Another person said we must question our mindset as a society:

> *"More than training is required. Communication and conversing about death is a societal issue relevant to all our lives. We need to change our comfort level with death and philosophy of care."*

In his Keynote address at the Launch of the Forum, Dr Maurice Manning said that he was struck by the significance of one particular quote from a study of healthcare professionals' perspectives on patient autonomy at end of life, as follows:

> *"Many of the participants felt that culturally, the whole country would make a big leap forward if we could and did talk openly about death."*[17]

Dr Manning also said that a 2007 nationwide public opinion survey, and prior focus groups with the public, found that awareness levels for many of the terms related to end of life are quite low. The Irish Council for Bioethics in 2005 also found the Irish public's knowledge and awareness of various bioethical areas to be quite limited in most instances, with the majority claiming to know 'just a little or nothing' about end of life issues.

As IBEC said in its submission:

> *"Death and dying impact everyone in Irish society at some point, yet there is a lack of public discourse about these subjects, possibly because they are considered private. However, as the Hospice Foundation is highlighting, there are structural and policy dimensions that need to be discussed and agreed in order to ensure that adequate services and support mechanisms are in place to help people through the processes. Many organisations have a role to play, including faith groups, health service providers, legal professionals, patient groups and others."*

---

17 Quinlan C., and O'Neill C., (2009), Practioner Perspectives on Patient Autonomy at End of Life. Draft. (Ethical Framework). The Hospice Friendly Hospital Programme. Dublin.

Chapter 5
RAISING PUBLIC AWARENESS

Raising Public Awareness of End of Life Issues

Contributors to the Forum also identified the need to raise public awareness about a number of specific issues relating to death and dying in Ireland. One submission emphasised the need for creativity in raising public awareness about experiences of the final months of suffering from Chronic Obstructive Pulmonary Disease (COPD) and other chronic illnesses. This is needed both to raise awareness about end of life support needs, and also to lessen the sense of isolation experienced by patients and their carers. Articulating this suffering and what it means to be at the end of life is often difficult, is challenging for patients, for caregivers, family, friends and healthcare professionals. Yet understanding this experience seems necessary if support is to be improved.

A similar issue was raised at a workshop, namely the need to make the general public much more aware of the living circumstances of people with some of the lesser known neurological conditions which are incurable, even if treatable, and therefore of the need to ensure the best possible quality of life at end of life for them.

The following recommendations were made by contributors to the Forum:

> *"The INO calls for more public awareness and open communication regarding end of life issues and choices, options for places of care, thus ensuring patients and families make informed decisions about their living and dying."*

> *"The INO calls for wider national recognition and dissemination of the three levels of palliative care service that are outlined in the Report of the National Advisory Committee on Palliative Care (DoHC 2001). Such publication may promote healthcare professionals' awareness of their responsibility in delivering palliative care appropriate to the level of expertise."*

> *"I recommend that programmes of public awareness and public education/support groups be provided so that family and friends can grow in their confidence and knowledge on how best to be present for their loved one who is terminally ill."*

The Citizens Information Board (CIB) is developing a strong information component in relation to dying and death on its website (www.citizensinformation.ie) to ensure that its Citizens Information Services and its Information Phone Services are in a position to deal adequately with queries from the public relating to dying, death and bereavement. It has also the following guides:

- *When someone dies in Ireland*

- *Information for those affected by bereavement.*

However, as the CIB says in its submission:

> *"It is clear that much more work is required to have end of life issues included in both public and policy discourse and on people's personal agendas. For example, National Council on Ageing and Older People research[18] found that only a quarter of people over age 65 had ever spoken to either family or health professionals about their preferences if they were no longer able to make decisions for themselves."*

Contributors identified a number of other areas where lack of public and professional awareness was prejudicial to the interests of people at end of life or their families. Carers, for example, are vital to the quality of end of life care. There needs to be a greater national consciousness and public awareness of the role and contribution of family carers.

Dealing with grief and bereavement is a significant and important investment leading ultimately to lessening pressure on the psychiatric services. Everyone suffers grief and loss in their lives. Much could be achieved through public education and awareness raising to promote community support for bereaved persons.

There needs to be some kind of campaign to raise awareness in the public domain around the role of the Coroner and the deaths that need to be reported to the Coroner and will require a Post-mortem.

In the absence of open discussion it is difficult to establish people's preferences for end of life care and services, either at a national level or an individual one. In England, the government is making end of life care a priority. However, as it admits,[19] government action alone cannot

---

18 Garavan, Winder and McGee, (2001), Health and Social Services for Older People (HeSSOP), National Council on Ageing and Older People Report No 64, Dublin: NCAOP

19 Department of Health, End of Life Care Strategy - promoting high quality care for all adults at the end of life (2008), p.38. London: DH

2. End of Life in Ireland

· ·

Chapter 5   RAISING PUBLIC AWARENESS

change attitudes towards death and dying, nor raise awareness of the issues involved. It therefore states[20]:

> *"The general public, professionals, independent groups, voluntary sector and statutory organisations …. need to work together in partnership to deliver improved awareness of the issues involved with end of life and to change attitudes."*

The National Council for Palliative Care (NCPC) is therefore leading a national coalition, called Dying Matters to raise awareness of end of life issues in England. According to Ms Tessa Ing, Department of Health, London, who heads the End of Life Care Strategy, *Dying Matters* already had 1200+ members in October 2009, when she addressed a Forum Workshop. A similar initiative might be considered by the Forum on End of Life in Ireland.

---

20 ibid

Chapter 6
QUESTIONS OF ATTITUDE

Attitudes Affecting Minority Groups at End of Life in Ireland

Negative attitudes (prejudice) and stereotyping can be serious issues for a number of groups in our society during life and at end of life. Prejudice and stereotyping may lead to discrimination at end of life for groups such as travelling people, gay and lesbian people, people with haemophilia, people with AIDS and people with dementia, and homeless people.

Older People

In in the case of older people, negative attitudes, stereotyping and discrimination contribute to the widespread ageism in society. Two people in their sixties wrote:

> *"While we haven't anyone elderly in our care at present we take note, increasingly, as we get older, as to how our elderly are treated by both society and our government ...You'd only have to go into a nursing home, hospice or home for the elderly to see, hear and understand how our elderly are treated ... Societies will ultimately be judged on how they treat their unborn and elderly.*"

People with Haemophilia

There is still a strong stigma attaching to haemophilia which has practical consequences, for example in reconciling the public health infection concerns of hospitals with sensitivity to the needs of the family, that is in regard to the treatment of the body after death, the use of body bags and the conduct of funerals in the country areas where the undertaker may not be practised in dealing with these issues.

It was suggested at a Forum workshop that new National Guidelines on the Management of Death from all Infectious Diseases, together with the audit of end of life services in acute and community hospitals under the Hospice Friendly Hospitals programme, would indicate how these issues affecting haemophiliacs and their families might be addressed.

People with HIV/AIDS

While AIDS related deaths have decreased significantly since the mid-1990s in Ireland, stigma and discrimination have not. There is an urgent need to respond to the changing face of HIV

in Ireland, according to the Dublin AIDS Alliance, who say we need to accept our multicultural society and accept the challenges.

Women infected with Hepatitis C through contaminated Anti-D Blood Product
These women suffer from prejudice, stereotyping and discrimination. There is a stigma attaching to those infected through no fault of their own. Some dentists will refuse to treat them and they have difficulty getting Life or Mortgage Protection insurance. Their employment, particularly in the medical sector, may be at risk.

The use of body bags by hospitals is unacceptable to Positive Action, the support group for women who contracted Hepatitis C through contaminated blood products. Two hospitals have discontinued the practice and the matter has been taken up with the Consultants (Management of Death) Committee of the Consultative Council on Hepatitis C.

Lesbian, Gay, Bisexual and Transgender People
Those representing lesbian, gay, bisexual and transgender people (LGBT) at the Forum emphasised the heterogeneity of the group and what might be their wishes at end of life. However, they said these wishes were sometimes ignored at funeral services, for example, regarding the identification of a partner rather than 'next of kin', or chosen family rather than 'family of origin'.

As already discussed in Chapter 3, a study funded by the Irish Hospice Foundation, shows that homophobia can have a negative impact on the bereavement experience of lesbians and gay men. A surviving partner may not be treated as having the same status and therefore deserving of the same respect as a widow/widower.

> *"The non-recognition of partners as partners at funerals ... may have a very negative emotional impact on the surviving partner. There may be an absence of clarity, too, about what is the 'allowed' role of lesbian mourners. Cultural models may be absent: few narratives of death and dying for LGBTs exist (other than regarding HIV/Aids). For example, models of lesbians growing older with dignity are absent."*

The Gay and Lesbian Equality Network recommended the following steps to address negative attitudes towards Gay, Lesbian and Bisexual people (LGB)

- acknowledge and challenge the existence of homophobia, including within health and social care services

- acknowledge and challenge the presumption of heterosexuality

- respect the individual's identification of 'next of kin'/ partner, and respect his/her expressed wishes regarding 'families of origin' and chosen families

- develop a code of good practice to reflect the needs of LGB people

- ensure that pastoral care provision is appropriate and sensitive to the needs of LGB people

- consult specifically with the LGB population.

Persons with Dementia

Dementia is a greatly feared but little understood gradual, terminal condition often accompanied by co-morbidities and stress. Ageism and the stigma of mental illness associated with dementia may result in a lack of public and professional awareness of the needs of people with dementia at end of life, resulting in 'therapeutic nihilism' and a denial of equity of treatment and respect at that time when they are most vulnerable.

Much needs to be done to improve public and professional awareness and understanding of dementia and the needs of people with dementia at end of life.

Travellers

The culture and customs relating to dying, death and bereavement in the Traveller community are often different to those in the settled community, as was explained at a forum workshop:

- When a relative or friend is ill and dying in hospital, Travellers will come from all over the country or from abroad out of respect for the family

- Visitors will stay for days in or around the hospital until that person dies

- Masses and prayers will be said, both in the hospital and at local churches and prayers will be said in the car parks

- The room or ward will be full of holy objects, candles and prayers. A priest is usually present all the time

- If it is your own family member there is a tradition of fasting out of respect. For non family members they won't eat around the family

- There can be a stigma for Travellers who move their loved one into a hospice or hospital when dying. This can create huge pressure on family members caring for their relative at home.

- This can create problems between Travellers and the hospital or service provider.

- Services can't handle the large numbers and it can be a negative experience for Travellers as they have to wait outside and security is brought in to control the numbers who congregate. People don't feel welcome or respected.

- After death funerals and burials play a big role for Travellers and many families traditionally want to be buried in their home county. New policies are making this more difficult.

- There can be huge pressure to live up to the expectations to have elaborate headstones on graves.

- There can be huge pressure to grieve in an appropriate way, to wear black, not to socialise.

Those representing Travellers at the Forum made the following recommendations:

- Recognition of Travellers as an ethnic group would give recognition to Traveller culture and identity and create better conditions to accommodate difference in end of life services.

- Travellers and senior hospital staff should meet to look at culturally appropriate services.

- Hospital staff should consult with families about their wishes and how to manage the visitors.

- Counselling should be offered to families, especially children, during illness and after death.

- Solutions should be found to facilitate Travellers to be buried in their home county.

It was suggested too that the Traveller movement needed to have an End of Life Forum of its own to consider the cultural issues raised at the Forum. This might focus both on issues faced by individual Travellers as a result of Traveller cultural pressures, as well as a result of discrimination and practices of the settled community.

Homeless People

The Director of TRUST, the organisation that provides services to homeless people, said:

> *"We have long been concerned to ensure that everyone we meet should have the right to die with dignity when their time comes. Many years ago, I made contact with Bishop Desmond Williams, a real friend of the poor, to look at how many people who are homeless are buried without a service of their denomination, in a pauper's*

grave. In recent years TRUST was given a plot by the Committee of Glasnevin Cemetery to help us ensure that we can arrange a funeral service and make time to reflect and pay our respects to people we have known for many years, and who often die in tragic circumstances."

Awareness of Hospice and Palliative Care and Attitudes to them

At one of the public meetings of the Forum, a Palliative Care Consultant said:

"Having services that are adequate for people and having people aware of services that are actually there, this issue arises a lot even when I just introduce myself to people in hospital, and discover they are unfamiliar with the term palliative care and what it is about."

A contributor to the Forum outlined findings from her doctoral research on attitudes to palliative care and the potential impact of health promoting palliative care. A survey of health professionals (working in three counties in Ireland in 2006), found that there is also an urgent need to increase awareness around the availability of local palliative care services as many health professionals surveyed appeared unclear exactly what services were available in their local area.

The terms 'hospice' and 'palliative care', if they are understood, can conjure up negative images in some people's minds. There is often a fear of palliative care and a refusal to accept support. Does palliative care need a change of image? Does it need to be seen not as the last phase, but as that part of a twin-track approach which focuses particularly on the quality of life of the person with the illness, the other part being the disease, specific medical interventions. That at least would be a step towards the inculcation of a quality of life culture within all health and social services, including within medical specialisms. Indeed, one of the issues raised in a workshop presentation on Motor Neurone Disease [MND] was that some neurologists do not refer MND patients to palliative care until the terminal phase of the disease, when in fact they should have access during the pre-terminal phase.

Healthcare Professional Attitudes to Palliative Care

Even among healthcare professionals there can be a poor understanding of palliative care and of Specialist Palliative Care services in particular, including how they support professionals,

patients and families and when referrals are appropriate:

> *"Some see us just as the syringe drivers, those who are around in the last 48 hours. However, palliative care is not to be equated with terminal care ..."*

The 2006 survey of health professionals mentioned above identified a perception by some respondents that clinicians may not take palliative care sufficiently seriously ("just an extra bit of TLC"). It also identified a perception that referral to palliative care somehow signifies a failure on the part of the health professional. The author of the study says that these findings raise questions about beliefs and understandings about palliative care and that they are important cues to action because such beliefs may determine referral to palliative care. The author says that "normalisation of death as an important part of life needs to be addressed"[21] , and makes the following recommendations:

> *"Develop a national directory of palliative care services and circulate to all GPs and hospital clinicians (I am aware of the IAPC directory published since this 2006 survey – it may need updating, recirculation and PR on an annual basis.)*
>
> *Conduct a national survey to assess attitudes toward (incorporating fear and stigma) death, dying, loss, disposal and care and implement actions based on findings – possible action include making a DVD for health professionals to show to patients potentially requiring referral and roll out of a national public health campaign re: death, dying, loss, disposal and care."*

Consultants' attitudes to partnership with palliative care consultants in shared care and developing knowledge about end of life symptom management in chronicity and particularly complex co-morbidity was another issue raised. The principle of extending palliative care to all needs to be promoted in media campaigns so that shared care, especially at end of life, becomes an expectation. This should help bring pressure to bear both on the HSE and consultants to drive and implement a shared care approach.

---

21 International Work Group on Dying Death and Bereavement, Charter for the normalisation of death, dying and loss. Mortality, May 2005; 10(2) 157 -161, Routledge Taylor and Francis group

Chapter 7
COMING TO TERMS WITH DEATH

Looking at Death

Quoting a Francois de La Rochefoucauld maxim, Dr Maurice Manning began his Keynote Address at the launch of the End of Life Forum by suggesting that 'Death, like the sun, cannot be looked at steadily'. One contributor to the Forum, a Clinical Psychologist and Psychotherapist, also used the analogy of the sun, but as representing "the bright incisive clarity of the logical and rational"; the moon by contrast, the illuminator of the night, "contains the wisdom and depths of the intuitive". With the help of this analogy she explains that it is possible to make the extraordinary transition to acceptance of death:

> "As I write this, the days are crisp and bright and cold, but I noticed on my walks that the tide is high with the pull of the full moon, a reminder that she is around. The sun dazzles with its brilliance, showing off a little, strutting about like a proud thing. The moon is altogether shier and softer. She likes shadow and half shadow. She likes the way things look in the half light of a Rembrandt painting. What she reveals is thoroughly different from the sun. Sometimes she disappears and we think she is gone from us for good, but she has just averted her gaze for a while, and comes back again like an ever faithful mother, gentle in her touch.

> Her place is to guide us through the night when we are closest to our own inner depths, in dream and sleep. Her task is to help us when the sun is gone from us. The unconscious is a vast reservoir of deep resources. It is possible to make that extraordinary transition to acceptance of death. When the ego finally surrenders, peace and serenity can be the loyal protective caretakers on the final journey. There is a sense of mystery and silence ... words are less important than touch and quietness. Some people make this transition weeks before death, some only hours before it, some not at all. No two people ever die the same way. We cannot control someone's emotional and spiritual journey. What we can do however is stop running from our own fears and cultural fears, and learn to be present and kind and brave and aware ...

Chapter 7   COMING TO TERMS WITH DEATH

"Science and medical advances have done much to make the quality of life much better. There is however a down side to this, because death has come to be experienced as medical failure. There has been an omnipotent delusion that all is curable or should be curable. This is of little help culturally in finding the resources to face what is, after all, the greatest challenge of all. For centuries now there has been a split in Western culture. There has been an elevation of the rational, of logic, of man's ability to reason and understand. At the same time there has been a devaluing of the intuitive, the imaginative creativity, the power of symbol and ritual, the wisdom that comes not from learning, but from something much deeper and more mysterious."

Aware of the limitations of looking too steadily at the sun, of over-reliance on the rational, contributors to the Forum submitted views on social, psychological and spiritual needs at end of life and in bereavement, which we will come back to. Others forwarded poetry they had written or the poetry of others which conveyed their sense of truth about death, and issues to be taken into consideration by the Forum.

One person wrote:

"Important as the science of Thanatology is, the Arts and Humanities have an enormous contribution to [make to] our understanding of death and dying. Tolstoy, Shakespeare, de Beauvoir and Lewis can still speak to us as eloquently now as they did when they first wrote so many fine pieces of literature, elucidating what scientists 'discovered' so very much later. Painters such as Barry, Jack Yeats, Hugh Douglas Hamilton, to name just a few Irish artists, have much to contribute to the education of doctors, nurses, physiotherapists, social workers, chaplains and others."

Another person emphasised the potential of the arts to increase awareness of what it means to live with and die from chronic illnesses:

"Artists, writers and poets can be encouraged to explore death from chronic illnesses, particularly those that are historically poorly represented (such as COPD) in the media. Exhibitions could be arranged that focus on end of life, the act of bearing witness to a long illness journey and end of life for caregivers, families … family networks, and healthcare professionals."

The arts can also be of great benefit in helping people make sense of life at end of life and meaningful access to the arts for people living in continuing care was recommended in one workshop. At one of the public meetings of the Forum a speaker advocated a model of care which recognises the aesthetic, psychological, philosophical and spiritual aspects of the person, body, mind and soul. The work of the Waterford Healing Arts Trust at Waterford Regional Hospital was commended in this regard in view of its well-documented benefits to patients of the hospital. This view was supported by a bereavement counsellor, who said she frequently used music and the arts as a way of reaching out to children but it was also very useful for adults. She described how at times when communication was difficult, people could be given alternative means of expressing themselves. There were many different ways in which people could be helped and she suggested a broader view needed to be taken.

The publication of a compendium of poetry and of readings from contributions submitted to the Forum is recommended to increase awareness and understanding of end of life and death in Ireland today and to assist people at end of life.

A 'Good Death'

At the launch of the Forum, President McAleese also said:

> "Most of us would admit to hoping for a 'good' death'. How many of us in the past heard our parents and grandparents pray for the gift of a 'happy death'? In their day, when the drugs and treatments we take for granted were not available, they knew a silent thing or two about suffering and deaths that were hard on the dying and hard on those left behind. Behind that prayer was a world of dread."

Throughout the year, at public meetings, workshops and in submissions people spoke frequently about 'a good death', and even a 'beautiful death':

> "Where I live, people will say, 'Mammy had a beautiful death' (usually in old age) and mean it. I used to wonder how could death be lovely, but now realize that it is indeed a God-given gift and should not be denied to the elderly or terminally ill. To everything a season, "a time to be born and a time to die". (Ecclesiastes, 3. 2). "Death is better than a miserable life and eternal rest than chronic illness." (Ecclesiasticus, 30. 17).

Sometimes a 'good death' is equated with coming to terms with one's mortality:

> "It is very important for a person to have a good death, by which we mean that they

have come to terms with their eventual death. They also get the opportunity to work through their fears and anxieties and grief about their death, and to have dealt with any issues that need to be sorted out so they can let go and die with ease."

Sometimes it is spoken of as the fulfilment of an important personal goal in life:

"Feeling that one has done everything one can, that one's life is in order and that one can leave the world in peace, is an essential precondition for a 'good death'."

However, while death is conceived of as a particularly sacred personal moment in life, it is not just that; it is also a social event, a moment in the life of mankind, and all the more sacred for that.

"We die with the dying:

See, they depart, and we go with them.

We are born with the dead:

See, they return, and bring us with them."

T.S.Eliot, Four Quartets

So, many contributors to the Forum perceived the context of their loved ones' deaths as important. Did mankind remember that it was one of their own who was 'passing on' at the time? How well were they supported in their needs by those around them? Thus, the concept of a 'good death' has social and indeed environmental connotations. It is after all those who stay behind who pass judgement on whether or not a death has been a 'good death'. Dignity in death is often achieved or prejudiced by others. Many personal stories were told at the Forum illustrating circumstances favouring or prejudicing - as each saw it - a 'good death' of loved ones or persons known to them. Following three such narratives, one submission stated:

"These three experiences were selected randomly but what is particularly striking is that none of the people concerned died a 'good death', as identified in the NCAOP and the Irish Hospice Foundation's 'End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland' Report."

The above report[22] favours the definition of a good death that is provided by the US Institute of Medicine Committee on End of life Care, namely:

---

22 O'Shea et al., End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland (2008). Dublin: Hospice Friendly Hospitals Programme and National Council on Ageing and Older People

"one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural and ethical standards."[23]

A survey conducted for the Irish Hospice Foundation[24] indicated an even simpler and more accessible definition of a 'good death', namely a death:

- free from pain

- surrounded by the people that I love

- conscious and able to communicate with them.

---

23 Field, M.J. and Cassel, C.K. (1997). Approaching Death: Improving Care at the End of life. Washington, DC: National Academy Press

24 Weafer, J.A. (2004) Nationwide Survey of Public Attitudes & Experiences Regarding Death & Dying. Dublin. The Irish Hospice Foundation.

Chapter 7   COMING TO TERMS WITH DEATH

Needs of People at End of Life

3

Chapter 8
MEDICAL AND NURSING NEEDS

Introduction

In this chapter and the following ones we focus on the needs of people at end of life, as described by contributors to the Forum. It is in the contexts of needs and of rights that we can best judge how to respond appropriately to people at end of life and to those who are closest to them.

Conscious that there is no universally accepted definition of 'end of life', the Forum on End of Life in Ireland adopted the following definition for its purposes:

> "all deaths - sudden, traumatic and expected - and the aftermath. It also refers to matters that emerge during the extended period of one to two years during which time a person, their family or healthcare professionals become aware of the life-limiting nature of their illness."

Many contributors to the Forum emphasised the importance of focusing attention at end of life on the needs of the whole person at end of life, rather than just on his/her medical condition(s). Some contributors distinguished between physical needs of persons at end of life and their emotional, social or spiritual needs at this time; others distinguished between pain and suffering, between treatment of pain and healing of suffering.

Children

> "The ... Hospice came to visit us and explained to us that they were geared towards adults in the last stages of their lives as opposed to the child dying at home ....
> I had been able to ask some friends of mine - some general trained and some paediatric - to do some night duty, otherwise I was on my own. A little daunting as I am a general trained nurse and I had never experienced a child dying never mind it being my own son. My husband and I feel that it would be a good idea to have a paediatric nurse on the hospice team in all parts of the country even if it was to give reassurance to someone on the end of the phone."

In 2005, the National Palliative Care Needs Assessment for Children[25]   found that palliative

25   Quin, S, Clarke, J & Murphy-Lawless, J (2005) Report on a Research Study of the Palliative Care Needs of Children in Ireland (Dublin: Department of Health and Children, the Irish Hospice Foundation and the Faculty of Paediatrics, Royal College of Physicians of Ireland).

care services then provided to children in Ireland with life-limiting conditions were seen to be inequitable, differing significantly according to diagnosis (malignant versus non-malignant) and according to geographic location. This, the assessment said, posed challenges, particularly for parents of children with non-malignant diseases.

In 2009 a constant theme of contributions to the Forum from both the experts in the paediatric field and from families of children who had died was the need for equity with adult palliative care services.

A number of people highlighted that there was no Paediatric Palliative Care Consultant in the country. This gap was cited as the reason for the lack of development of palliative care services for children in the community. However, it also affects paediatric hospital care. Children with palliative needs should be nursed on a ward where staff have the training to meet their specific needs and where facilities are available. Our Lady's Children's Hospital, Crumlin, has two sessions a week from an Adult Palliative Care Consultant, who nonetheless makes a big difference. There are Palliative Care Clinical Nurse Specialists attached to Crumlin Hospital and Temple Street Hospital supported by the Adult Palliative Care Consultant. However, specialist paediatric palliative care nursing needs to be better developed nationally. There are limited paediatric palliative care courses available for training such nurses. The Trinity MSc in Palliative Care, which has just finished its first year, is for all disciplines.

Forum submissions and discussions did not give clear direction on where Paediatric Palliative Care Consultant post(s) should be located. What appeared to emerge in discussion was that specialist consultant and palliative paediatric care nurse services should be linked to hospices rather than developed as a new or separate service.

The importance of establishing a national perinatal palliative care team was also emphasised, particularly as there are Irish people who have trained abroad who could do this work.

 It was said that proper guidelines on discharging a dying child home to the community services were badly needed within the acute hospital services. This is particularly so given views about the lack of appropriate community services. As one person said, "people are going out the hospital door into nothingness". GPs without experience of paediatrics, it was also said, were unwilling to take on seriously ill children. The primary care teams are limited in what they can offer and they should be supported by paediatric expertise instead of general consultants. Others said that simple communication in advance, rather than sudden discharges by hospitals, would make a big difference in setting up supports in the community.

The Jack and Jill Foundation said that each individual organisation strives to achieve the optimum care for the dying child and their family, but on an ad-hoc basis because they work independently of each other. They expressed the view that it was ultimately families taken under the wing of the local hospice home care teams for [children's] end of life care who have received the most complete appropriate service, with other agencies, such as the Jack and Jill Foundation supporting them.

Whatever the case. multi-agency integrated pathways for the care of dying children, from diagnosis to end of life, need to be agreed and established country-wide.

Chronic Obstructive Pulmonary Disease/Respiratory Disease (COPD)

One in five of all deaths is due to respiratory disease. The Irish Thoracic Society in its submission to the Forum said that when considering respiratory disease in the context of end of life care:

> "it is important to recognise its complexity and particularly the difficulty in defining or individualising prognosis in patients with chronic lung disease. This has a particular bearing on the timing of referrals for palliative or end of life care. It is the view of the Irish Thoracic Society that all such referrals for patients with advanced or end-stage Chronic Obstructive Pulmonary Disease (COPD) should only be made as a result of a respiratory assessment carried out by a respiratory physician."

Cystic Fibrosis

Persons with Cystic Fibrosis live with the possibility that they may die young, while retaining hope of a second chance of life through transplantation. Because there are ways in which persons with Cystic Fibrosis and medical professionals can control the condition to some extent, this focus may overshadow planning to meet medical, nursing and other needs at the end-stage of the illness.

This may manifest itself as a fear of palliative care among families of young people with Cystic Fibrosis or those with Muscular Dystrophy or Duchenne disease, for example, and a refusal to accept support. Perhaps this reflects a natural reluctance by young people and their families to countenance the possibility of death at the same time as trying to survive for as long as possible with their condition. And who's to blame them?

In its submission to the Forum the Cystic Fibrosis Association of Ireland said:

> *"People with Cystic Fibrosis (PWCF) are cared for in hospital by the multidisciplinary CF teams, these teams could learn from the experiences of other palliative teams, so the multidisciplinary teams can make the last journey more comfortable for the PWCF and [they can] support the families they know personally from dealing with [them] throughout the life of the PWCF. In the larger CF centres we need to train the specialised CF nurses in palliative care so they can provide the best end of life care possible.*
>
> *The experience of the palliative care staff would be best served out in the community as a home care team. The home care team could use their experience to help not only the PWCF but also the families at such a difficult time."*

In a presentation to a Forum workshop a representative of the Cystic Fibrosis Association of Ireland suggested that some medical professionals may fail to recognise that death is imminent and continue to adopt an aggressive approach to treatment rather than the more appropriate palliative approach, with a focus on the comfort of the patient. At the same workshop the following shortcomings in end of life care for persons with Cystic Fibrosis were identified:

- lack of discussion and thus lack of advance care planning

- lack of full Multi-disciplinary involvement

- lack of specialist home care services for persons' final stage

- lack of support for staff and family / friends when a person with Cystic Fibrosis dies.

Palliative care for PWCF is still very underdeveloped nationally; there is a need therefore for all involved in the care of persons with Cystic Fibrosis to direct more focus on this.

Dementia

A contributor to the Forum wrote:

> *"It needs to be recognised that the person with Alzheimer's has the same end stage needs as the terminally ill patient with cancer. Therefore the same approach to treatment and care is needed."*

The person with Alzheimer's disease should therefore be automatically assessed for the bed, the modified chair, the pain relief, that a person with cancer at end of life should expect to receive. However, in one Workshop it was said that services for people with dementia in all stages of the illness were limited and inconsistent throughout the country and that palliative care was either lacking or non-existent.

A person working with people with intellectual disabilities said in a submission that introducing palliative care in supporting people with end-stage dementia will definitely challenge the way clinical and palliative care services are traditionally delivered, because of the variability of its presentation. She added:

> *"Studies suggest that where a palliative approach was not incorporated in end-stage dementia, analgesia was infrequently used, and the dying phase was not even recognised." (Tuffrey-Wijne et. al., 2007).* [26] *"*

The following end of life care issues for younger and older persons with dementia were identified:

- recognising pain (with the assistance of protocols and otherwise) and relieving it: a pain-free end of life is a right for all, including those with dementia. It has been shown that those with dementia receive less pain relief than those without dementia. People can die from dementia, though it will not necessarily be recorded on their death certificate

- recognising the end of life phase for those with dementia

- early diagnosis to facilitate choice

- ascertaining the wishes of the person in advance, when often the person with dementia does not accept he/she has it

---

26 Tuffrey-Wijne, I. (2002). The palliative care needs of people with intellectual disabilities – a case study. Int. Journal Palliative Nursing: 8 (5), 222-232

- addressing stigma by helping the person die with dignity, with loved ones in familiar surroundings**.**

Diabetes

There are no clinical guidelines for the management of diabetes at the end of life. The representative of the Diabetes Federation of Ireland said that co-morbidities should not be treated ahead of the continuing management of a person's diabetes, even at end of life. At that stage blood sugar levels are often not attended to as a first priority by medical personnel, who often focus primarily on the co-morbidities. Terminally ill patients are unlikely to be participating in any significant physical activity, and their diet can be liberalized to focus on patient likes and dislikes (short of causing troubling symptoms).

Huntington's Disease

The following information was provided to the Forum by the Huntington Disease Association of Ireland in a submission. HD is an inherited disorder of the central nervous system. It is caused by the destruction of brain cells which can manifest as motor, cognitive and psychiatric symptoms. It is a chronic, unremitting, fatal illness. To date, there is no cure and no effective treatment. People with HD may live for 15 - 25 years after diagnosis.

By the late stages of Huntington's disease, affected individuals will have little control over voluntary movements and may not be able to walk, talk, or eat. Chorea may be suppressed, or may be severe. Death, when it comes, is usually due to the consequences of the immobility, general debilitation, and malnutrition. Pneumonia, and heart failure are typical immediate causes of death.

The Association emphasises that the palliative care needs of a person with HD may be considerable and they need to be thought about and discussed in advance. HD is likely to require consideration of cognitive difficulties, dementia, behavioural difficulties, communication problems, competency and legal capacity, swallowing problems, involuntary movements and incontinence. The person with HD and their family will also need to consider the following medical and nursing care issues: in-home versus outside care, tube feeding, life sustaining emergency measures and use of antibiotics to treat infections.

Intellectual Disabilities

A Clinical Nurse Manager wrote about the challenges nurses face when caring for people with intellectual disabilities who are diagnosed with life-limiting conditions. People with intellectual disabilities, she said, tend to be excluded from the best of palliative care, and they have special needs that are still not met by existing services:

> *"They receive fewer health screening tests and fewer health investigations, thus resulting in the late presentation to specialist healthcare services. This reduces the potential for early detection of serious ill health, and so produces less favourable outcomes. Whilst it is accepted by most General Practitioners that they should meet the medical needs of people with intellectual disabilities as part of their role, many do not believe they should be the ones providing ongoing health screening for this group. They feel this should be done by specialist services, who should co-ordinate healthcare for this particular group. Read [27] contends that specific knowledge around intellectual disability itself amongst primary and acute care personnel may affect whether staff feel competent and confident enough to support this group. Diagnostic overshadowing, i.e. attributing symptoms to the disability rather than looking for an underlying physical cause can and does affect decisions and palliative care."*

On diagnosis of a life-limiting condition decisions about treatment options and commencing palliative care should be made as soon as possible "in an ethical decision making collaborative framework".

Nurses working in the palliative care services who are unfamiliar with this client group, face significant challenges in providing and delivering high quality palliative care. Often people with intellectual disabilities, for example, are unable to express their wishes or let carers know when they are in pain.

Chronic Kidney Disease

End-stage Renal Disease(ESRD) is the fifth and terminal stage of Chronic Kidney Diease (CKD). In its submission to the Forum, the Irish Nephrology Nurses Association (INNA) said that being diagnosed with severe stage 5 CKD can be considered worse than a diagnosis of cancer

---

27 Read, S, Thompson- Hill, J. (2008). Palliative Care Nursing in relation to people with intellectual disabilities. British Journal of Nursing; Vol 17 No. 8

or acquired immune deficiency syndrome (AIDS), with the five-year survival for patients with severe CKD or ESRD being roughly half that of patients with cancer. The INNA continued:

> "When ESRD is reached the usual medical intervention is to commence Renal Replacement Therapy (RRT) such as Haemodialysis, Peritoneal Dialysis or Transplantation. At this point dialysis is considered a life-sustaining intervention. (Kuebler, 2001)[28]."

> Conservative Management of ESRD is considered a reasonable option for some patients who believe that the burden of commencing on dialysis will impact negatively on their lives, challenging their ability to maintain an acceptable quality of life. Conservative Management of ESRD does not mean not–for–care but rather active disease management, usually in an outpatient setting."

In an earlier submission to the joint Health Service Executive and Irish Hospice Foundation inquiry on Integrating Palliative Care into Disease Management Frameworks[29] the INNA had written:

> "In Ireland there are currently 3,000 people receiving RRT, dialysis or transplantation. The prevalence and improved management of significant co-morbid conditions, for example Diabetes Mellitus and Ischemic heart Disease, is impacting on the epidemiology and age profile of those with CKD ... While dialysis for this population can be a viable option, there needs to be considered thought put into the complexity of co-morbidities and patient choice ... Patients need to be informed that the dialysis treatment that they will embark on is not a definitive cure and that their prognosis may be limited (Nobel et al, 2007)[30]. Norton (1969), as cited in Ashby et al 2005, defined haemodialysis as a 'palliative treatment' but with technical advances the notion of dialysis being a death delaying treatment has shifted to an almost routine life-sustaining treatment (Ashby et al, 2005)[31]."

The INNA concluded that the epidemic of CKD requires that all modalities of treatment of ESRD, dialysis, transplantation and conservative management, are viable options for patients.

---

28 Kuebler, K. (2001) Palliative nursing care for the patient experiencing end – stage renal failure Urologic Nursing, 21, (3), 167 – 168, 171 – 8, 183 – 4.

29 HSE and IHF (2008), Palliative Care for All - Integrating Palliative Care into Disease Management Frameworks. Dublin: HSE and IHF

30 Nobel, H., Kelly, D., Rawlings-Anderson, K., et al (2007) A concept analysis of renal supportive care: the changing world of nephrology. Journal of Advanced Nursing 59, (6), 644 - 653.

31 Ashby, M., Op't Hoog, C., Kellehear, et al (2005) Renal dialysis abatement: lessons from a social study. Palliative Medicine, 19, 389 - 396

And it recommended inter alia:

- that those patients with CKD opting for conservative management must be offered ongoing support by the multidisciplinary team in liaison with community and hospice services as required

- that the expertise of palliative medicine specialists and nephrology healthcare providers need to be combined to ensure that renal patients and their families receive the best care and the best quality of life

- that, in an effort to maintain patients in the community and reduce hospital admissions, ease of access to palliative care teams is essential with the development of a formalized streamlined route to access these services for ill and terminally ill patients with CKD

- that renal palliative care teams be developed

- that standards of best practice in conservative management need to be in place to ensure a well-organised and efficient transition from supportive care to palliative care, thus ensuring a 'people centred service' with reorientation of services to streamlined access to palliative supportive services along the complete trajectory of Chronic Kidney Disease.

Patients with ESRD deserve optimum care during the last weeks and days of their lives. Systematic services must therefore be put in place to ensure that they maintain an acceptable quality of life and they must have access to both renal and palliative care to alleviate the physical, psychological and spiritual suffering associated with their illness.

Motor Neurone Disease (MND)

Palliative care needs among people with long-term progressive neurological conditions may be present from diagnosis but people with multiple sclerosis, Parkinson's disease and Huntington's disease may live for as long as 15 to 25 years after diagnosis. In contrast, people with motor neurone disease may live for only a few months, with very rapid deterioration.

In their presentation to the Forum, the two Motor Neurone Disease Nurse Specialists who cover the country described MND as "a devastating terminal neuro-degenerative disease with a highly predictable clinical course such that palliative care should begin at or soon after

diagnosis."[32] Quoting David Oliver, of Wisdom Hospice,[33] they said:

> *"The treatments that can currently be offered for people with MND will at best delay the progression of the disease process, are never curative and so the care of these patients is palliative from the time of diagnosis."*

They identified an under-provision of neurologists with expertise in MND and related disorders as a problem. Another difficulty is that some neurologists may wait until the terminal phase of the disease before linking into palliative care, rather than doing so from the time of diagnosis (the pre-terminal phase). In addition, they claimed some GPs are unaware of MND sufferers' entitlement to palliative care from the time of diagnosis.

Pre-terminal care is therefore not attended to as it should be due to an insufftency of appropriate services and it is left to two Clinical Nurse Specialists to provide this care nationally. Since progression of the disease is variable, regular assessment is required by them.

Multiple Sclerosis

In its presentation to the Forum, the MS Society provided the following table comparing the incidence of debilitating symptoms for MS sufferers with those of people suffering from cancer, heart disease and respiratory disease. It illustrates the importance of active holistic care of all patients with life-limiting conditions regardless of their diagnosis.

Symptom	MS (1)	Cancer (2)	Heart Disease (2)	Respiratory Disease
Pain	68%	35-96%	41-77%	34-77%
Fatigue	80%	32-90%	69-82%	68-80%
Nausea	26%	6-68%	17-48%	not known
Constipation	47%	23-65%	38-42%	27-44%
Breathlessness	26%	10-70%	60-88%	90-95%

(1) King's College London MS/Palliative Care Project

(2) Solano Gomes, Higginson, Journal of Pain and Symptom Management 2006, 31, pages 68-69

32 Hiroshi Mitsumoto, MD, DSc; Judith G. Rabkin, PhD, MPH (2007) Palliative Care for Patients With Amyotrophic Lateral Sclerosis "Prepare for the Worst and Hope for the Best" JAMA. ;298: 207-216.

33 Reference not provided

Chapter 8   MEDICAL AND NURSING NEEDS

Indeed the MS Society presentation served to highlight other common interests of people with life-limiting conditions following diagnosis, and particularly at end of life, as follows:

- Care must be determined by individual need rather than diagnosis

- Pain and other distressing symptoms must be expertly managed

- Many aspects of palliative care are applicable earlier in the course of the illness - in conjunction with other treatments

- All have the right to the best quality of life with the necessary support for themselves and their families

- Palliative care may be needed alongside disease-modifying interventions, e.g. neurology and specialist pain management

- Palliative care in practice should provide:

  - Expert control of pain and symptoms

  - Communication and decisions about goals of care with patient and family

  - Co-ordinated care across fragmented healthcare system

  - Practical support for patient, family and professional caregivers.

Palliative care in MS requires a clear pathway that recognises potential trigger points and ensures:

- Access to timely care

- Symptom control: to promote comfort, provide emotional support, prevent complications and improve quality of life.

Many with advanced MS fall out of acute care follow-up and represent a silent minority who may benefit from specialist palliative care.

An MS sufferer, a journalist, was in touch with the Forum to say that he had been prescribed medicinal cannabis in the Netherlands, but that, while he can enter the UK if he keeps his papers with him, he cannot enter this country with the drug.

Specific Palliative Care Needs in the Advanced Stages of Neurological Conditions

In its submission to the Forum, the Neurological Alliance of Ireland said that the palliative care needs of people with long-term neurological conditions require consideration of the following aspects of their condition:

• Cognitive difficulties, dementia

• Behavioural difficulties

• Communication problems

• Competency and mental capacity

• Neurological symptoms relating specifically to the neurological disease, including:
  - Pain
  - Breathing and swallowing problems
  - Spasticity and involuntary movement
  - Side-effects of medications, muscle weakness and loss of muscle tone
  - Seizure control
  - Bladder and bowel control

• Slow disease progression.

Scleroderma (SSc)

In a presentation to the Forum, the representative of the Irish Raynaud's and Scleroderma Society described Scleroderma as a chronic, fatal disease of the immune system, blood vessels, and connective tissue. While no overall cure exists, successful individual treatments are available for each of the body systems affected, and so early diagnosis is critical to allow for proper control and care.

A hospice nurse who has cared for patients with scleroderma has said that its symptom burden is far greater than that of cancer, and specialists agree:

> "During the final years during which we are asking for palliative care to be made available to those whose condition warrants it, a patient may suffer from self-poisoning due to collapse of kidneys and bowels, malnutrition due to malabsorption and difficulty in eating, pain at the site of innumerable ulcerations, dry eyes that feel as though they have glass shards in them, difficulty in breathing, abdominal blockage, a disabled digestive tract all the way from the mouth to the anus... "

The multifaceted nature of scleroderma obliges the patient to attend many specialists for treatment. This situation continues until end of life. With no one person taking care of the patient's overall care, the patient is likely to become isolated with no one to refer to for advice, comfort, and encouragement. Care can become fragmented and often conflicting.

As there is no cure for SSc., the emphasis is on care rather than cure, and there is a duty of care to help patients cope with their illness. Ideally this would come from a doctor but as doctors do not have the necessary time, this role should be filled by a specialist scleroderma rheumatology nurse or palliative care nurse, the Irish Raynaud's and Scleroderma Society suggests.

The Society says that routine access to palliative care for patients with systemic sclerosis throughout their disease trajectory has not been available, even though it would appear that the symptom burden they experience can equal or even exceed that of people who have a malignant disease. The complexities of the disease may put off palliative care specialists from taking persons with it in charge. They may therefore prefer to adopt an advisory function only.

Older People

The following is an excerpt from a report of a public meeting:

> *"One speaker who lost her mother six months ago described caring for her at home for 10 years with the assistance of her two sisters ... She felt a lot of the supports on offer centred around cancer. When she went looking to see what help she might receive she was told it was nearly unfortunate that her mother didn't have cancer."*

Standard 4 : End of Life Care, from Practice Standards for the Care of the Older Person (An Bord Altranais), states:

> *"The older person receives comprehensive, compassionate end of life care that is person-centred and responds to the older person's unique needs and respect for their wishes. "*[34]

The rationale for this standard is that:

> *"Many older people have an advanced, progressive, life-limiting illness whose condition deteriorates over an extended period of time with a long lead time to*

---

34   An Bord Altranais (2009), Professional Guidance for Nurses Working with Older People - First Edition. Dublin: An Bord Altranais.

death (O'Shea et al 2008)[35] Adopting a palliative approach to care throughout
the older person's illness trajectory (O'Shea et al 2008)[36] enables staff to move
away from viewing palliative care as restricted to the care of the dying person
only (Phillips et al 2008)[37]. End of life care is a vital and integral part of all clinical
practice, whatever the illness or its stage, informed by a knowledge and practice of
palliative care principles (DoHC 2001[38]; O'Shea et al 2008)[39]"

An Bord Altranais continues:
"Older people have special needs at the end of their lives due to:

- Being more commonly affected by multiple medical problems

- The cumulative effect of these may be much greater than any individual disease
  and typically leads to greater impairments and need for care

- Greater risk of adverse reactions and iatrogenic illness

- Minor problems may have a greater cumulative psychological impact.

Problems of acute illness may be superimposed on physical or mental impairment, social
isolation and economic hardship (Davies and Higginson 2004)[40]."

However, as noted both by the Irish Medical Organisation and by the report, End of life
Care for Older People in Acute and Long-Stay Care Settings in Ireland (2008)[41], low access to
Specialist Palliative Care for patients with non-malignant life-limiting diseases is a significant
barrier to good end of life care for older people.

In its submission, the IMO continues:

> *"End of life care involves more than just the transfer of hospice care principles*
> *to the acute hospital and long-term care setting. End of life care for old people*
> *suffering from non-malignant chronic diseases is a particular area of neglect and*

35 O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ni Leime, A., Keys, M. (2008) End of Life Care For Older People in Acute and Long-Stay Care Settings in Ireland. Dublin: National Council on Ageing and Older People and The Hospice Friendly Hospitals Programme.

36 Ibid

37 Phillips, J.L., Davidson, P.M., Jackson, D., Kristjanson, L.J., (2008) Multi-faceted palliative care intervention: aged care nurses' and aged care assistants' perceptions and experiences. Journal of Advanced Nursing 62 (2), 216-227

38   Department of Health and Children (2001). Report of the National Advisory Committee on Palliative Care. Dublin: DoHC.

39 Op. Cit.

40 Davies, E., Higginson, I. (2004) Better Palliative Care for Older People. WHO: Regional Office for Europe, Denmark

41 O'Shea et al. Op. Cit.

mirrors the under-assessment of older people's wider needs often encountered in the health system.[42]

"End of life care needs to take into account the long-term and unpredictable trajectories of chronic non-malignant diseases affecting older people. The most common causes of death amongst older people are cardiovascular disease including stroke, cancer and chronic obstructive pulmonary disease (COPD). Old people often suffer from one or more chronic diseases making it difficult to ascertain the actual cause of death. Similarly, dementia and frailty are also important and increasing causes of death among older people, but are not generally recorded as the primary cause of death.[43]

The disease trajectory of cancer is characterised by steady progression ending in a short period of evident decline when palliative care services need to be mobilised. The trajectory of people suffering from heart failure or COPD shows a pattern of gradual decline with intermittent exacerbations often requiring emergency hospital admission and ending in sudden death. While the trajectory of those suffering from dementia, frailty, disabling stroke and motor neurone disease is of prolonged decline from an already low baseline of physical or cognitive functioning."[44] [45]

End of life care needs to incorporate palliation as a during-life component of elderly healthcare, starting at a low base, and rising to eventually become the predominant theme.[46] Because of the unpredictable and long-term trajectories of non-malignant diseases, geriatricians are faced with the difficult task of negotiating the juncture between being gravely ill and dying.[47] For such diseases it is often appropriate that non-specialist or specialist palliative care should be provided alongside disease modifying and life-prolonging interventions.[48]

42   AGS Panel on Persistent Pain in Older Persons. The management of persistent pain in older persons. Journal of the American Geriatrics Society, 2002, 50:S205–S224

43 Irish Hospice Foundation, A Baseline Study on the provision of Hospice/Specialist Palliative Care Services in Ireland. 2006: Dublin, p.30.

44 Lynn J, Adamson DM. Living well at the end of life: adapting healthcare to serious chronic illness in old age. Arlington, VA, Rand Health, 2003

45 HSE and IHF, Palliative care for all- Integrating Palliative Care into disease management frameworks, 2008

46 Lynn J., Adamson DN. (2003) Op. Cit.

47 Finucane TE. How gravely ill becomes dying: a key to end of life care. JAMA. 1999 Nov 3;282(17):1670

48 HSE and IHF (2008), Palliative Care for All - Integrating Palliative Care into Disease Management Frameworks, p15. Dublin: HSE and IHF

Chapter 9
PAIN AND SUFFERING AT END OF LIFE

"First of all I incline to equate the life of hope with the life of the imagination, that is to say with the realistic imagination, with an imagination that in the word of Martim Buber, imagines the real … Let us only say now that hope imagines, and that it refuses to stop imagining, and that it is always imagining what is not yet seen, or a way out of a difficulty, or a wider perspective for life or thought."
- William Lynch SJ, Images of Hope

Introduction:

The experience of terminal illness and the awareness of the proximity of one's death can give rise to a variety of emotions; sometimes these may be overwhelming. Accompanying dying people may also have huge emotional impacts on family, on friends, and on carers and service providers. The focus of this chapter is on Forum contributors' perspectives on the psychological and emotional needs of dying persons. We will return later to the emotional impact of dying on family, friends and care workers.

Some contributors spoke of pain at end of life as negative physical, emotional, social or spiritual experiences which could be named, isolated and be the focus of particular treatments or interventions. Others, spoke of suffering, when they wished to imply the particular 'angoisse' of the individual as a whole person. Quoting Dr Larry Dossey, The American Book of Dying[49] says, " 'Bodies do not suffer, people do'. This implies a shift in modern medicine from basic concern with disease to a greater focus on the total human person." People even choose suffering for what seems to them a good cause.

Suffering calls for healing, rather than cure. Healing however cannot take place unless suffering is acknowledged and its 'particularity' becomes a focus of attention in its own right, separate from medical interventions designed to cure physical illness, to repair injuries or relieve physical pain.

---

49   Richard F. Groves and Henriette Anne Klauser, (2005). The American Book of Dying, Celestial Arts, Berkeley.

Is this suffering the elephant in the medical closet, as a medical sociologist claims[50], or is it the elephant in all our closets? Clearly, much is required on all our parts to realise the vision of the Irish Hospice Foundation that "no one should have to face death or bereavement without appropriate care and support". Bearing in mind that healing of another person's suffering cannot be effected without the co-operation of that person, we can nonetheless contribute to that healing. In this context, the following words of Mother Teresa, provided by a Workshop speaker, are particularly pertinent:

> " I cannot take away another's pain, I can only allow myself to be present with that pain. I cannot create healing: I can only encourage the desire to do so. I cannot convince another that it will be better, only that it will be different. The most difficult thing to do is nothing ... more is spoken with silence and gesture than with words."

One submission quoted Dr Christina Puchalski, who has been training health and spiritual care workers for many years now, as saying:

> "Patients learn to cope with and understand their suffering through their spiritual beliefs, or the spiritual dimension of their lives. And it is also through that dimension that I think the compassionate, caring part of the doctor/patient relationship is enacted."[51]

In their contribution to the Forum, the Irish Catholic Bishops Bioethics Group wrote:

> "In addition to the associated physical manifestations, this end stage of human life can give rise to a variety of emotions in the person who is dying: sadness, anxiety, depression, resignation, peace. Just as some people drift through life while others engage fully with it, so it is with the end of life. It is possible to speak of the dying person as participating more or less actively and freely in this as in any other stage of his or her life, because in the midst of all the physical and emotional changes the identity of the dying person - and his or her status as a person - remains unchanged. To participate actively and freely in the end of life in this sense is to choose life, even while accepting the inevitability of death."

---

50 Arthur W. Frank, (2006). Suffering: The Elephant in Medical Sociology's Closet www.medicalsociologyonline.org/archives/issue1/suffering.html

51 Puchalski C. Taking a spiritual history allows clinicians to understand patients more fully: An interview with Dr. Christina Puchalski, by AL Romer, Innovations in End of life Care, 1999;1(6), www.edc.org/lastacts].

Fears at end of life

A Clinical Psychologist and Psychotherapist said in her submission:

> "To be afraid of death is neither a sign of weakness nor a reason for shame. It is part of what it is to be human. It is about the only thing in life we can be completely certain of. Most of the time we are protected from thinking about the enormity of what it is to die. That is probably a good thing, in that it keeps fear at bay. But many people this year will have to face the prospect of their own imminent death. Illness or accident will begin to close down the time left on this earth and the reality of death becomes unavoidable. What then?

> "There are many fears; of physical pain and discomfort, of the dying process itself, of separation from loved ones and all that is dear in the world, of the grief and sadness of others, of facing the great unknown. As children we were afraid of the dark. This primal fear of the unknown is common to all of us. The conscious "ego" part of us is happiest when in full control of a world that is predictable and familiar and safe. It is profoundly threatened by the helplessness of death and the chaos of the unfamiliar. It rails against it, fighting to outwit it or submitting to depression and fear."

Others spoke of the fears and anxieties of particular groups of persons at end of life:

> "Prisoners who are dying need much reassurance. They often fear that as they are prisoners they will be left to suffer. The care staff play an important role in showing the prisoner that they care and that they will act as advocates in the pursuit of their comfort and meeting their needs.

> Prisoners also fear that they will die alone. By offering reassurance they can relax and learn to trust the staff."

Another person asked:

> "What priority does palliative care give to psychological pain, I'm thinking here of that felt by patients in long term care, in comparison to the pain experienced by patients with more acute illnesses."

The Lesbian and Gay Federation drew attention in a workshop presentation to the increased impact of dying and death on the emotional health of LGBTs given other social stresses and the impact of historical stigma.

At a public meetings, one person spoke of the fear her mother, a religious person, experienced:

"My mother was always very afraid of death after a number of sudden death experiences in the family. Her biggest fear was what if I died without absolution."

Anxieties

People spoke of anxieties in the face of death. Many said that what people are anxious about is dying and the dying process, rather than death itself. The questions in people's minds are:

- Will I die in pain?
- Will I die a dignified death?
- Will I lose control?
- Will I be abandoned?
- Will I get to say goodbye to my family?
- What's on the other side?

"Whether being rushed into A & E in hospital, moved into intensive care with all the attendant noise, bustle and surrounding high-tech equipment, or the hopelessness of being admitted to a hospice, all induce a lot of anxiety. Added to this the white coated staff, some with masks …This is accompanied by apprehension about pain, loss of control over our bodily functions, loss of mental competency and loss of dignity and authority. How long will it take, what will happen to me and how will it end are often not answerable and always anxiety producing (questions)."

Coming to Terms with Terminal Illness and Death

Time permitting, it is important therefore that people should have the opportunity to work through their fears and anxieties and to deal with any outstanding issues they may have. They should be afforded the possibility of doing so in their own time and at their own pace. How well they adjust may ultimately depend on how sensitively they are treated by others, particularly in relation to whether and how a diagnoses or news of a terminal condition is communicated.

In a study of the lived experience of palliative oncology patients,[52] a number of themes were identified. Three of them described participants' experiences of living with terminal illness, namely:

---

52 Living with Dying: An Interpretative Phenomenological Analysis of the Experience of Palliative Care Oncology Patients in a General Hospital

- finding a way of understanding one's position as a dying person,

- the process of accepting one's prognosis, and

- a desire to live the remainder of one's life meaningfully.

These themes can help us to better understand the experiences of palliative patients "that are dynamic and responsive to change from both within the individual and from the environment in which he or she lives".

Some contributors to the Forum emphasised the importance of openness and honesty in communication about end of life. One submission, for example, said that when patients have a better appreciation of the nature of their illness, it is possible to explore their concerns and wishes in a realistic manner. Others stressed that there are some people who do not want to be informed of a terminal diagnosis or acknowledge that they are dying. We will reflect further on this dichotomy in Chapter 11. It is certainly legitimate to question whether coming to terms with death requires formal, articulated acknowledgement of one's dying state.

However, if it is a condition of palliative care that those wishing to avail of the services must acknowledge their terminal status in advance, then this carries with it the significant responsibility to ensure that the person has the opportunity to fully explore his/her hopes, fears and anxieties with suitably competent and compassionate people. It's not sufficient under those circumstances to provide only physical palliative care.

Hope

A number of people spoke of the role of hope in coming to terms with death. "Yeats," President Mary McAleese said in her address at the inaugural meeting of the Forum, "captures the human condition elegantly and movingly when he says:

> 'Nor dread nor hope attend
>
> A dying animal;
>
> A man awaits his end
>
> Dreading and hoping all.'"   [W.B. Yeats, Death, 1929]

Some participants raised the issue of the relationship of 'hope' and 'truth'. At a public meeting a member of the audience said that "hope does not come from fudging the truth but from the support that patients receive after they are given their long-term prognosis." Another person echoed this sentiment, saying that death is natural and that she believed that the vast majority of

people would want to know that they were dying so that they would have an opportunity to explore the concept of death and prepare themselves and their families for it. She went on to describe the experience of her father's death, of his telling her frankly that he would be dead in two days. This knowledge allowed her to talk to her father in a way that she might not have, and these conversations provided great comfort to her after his death.

Whether hope is equated with expectation or is understood as an act of the human imagination, it is the antithesis of despair and the antidote to fear and anxiety. It is sacred at end of life and should not be prejudiced or challenged, even if not considered realistic by the observer. The following is an account of how one man's hope was dashed by a hospice nurse:

> "My Dad had been ill … for about five years … [He] never openly faced into the fact he was dying. …. In the latter stages of the illness, when we knew it was terminal but he did not, he asked the hospice nurse when he would be able to drive his tractor again. Her blunt reply that was witnessed by us was " J, you will never drive that tractor again". It was like a kick in the stomach to him, said so bluntly, it took away all the hope he had. This was so wrong, I understand Hospice policy about being honest, but there is no reason to take away hope, all humans need hope, something to cling to."

While every effort should be made to reconcile different moral values, when it comes to end of life it may be an abuse of power to seek to impose one's values on dying persons or their families, even for the sake of truth.

Holistic End of Life Care and Having the Time to Listen

At various meetings of the Forum contributors cited experiences of different people at end of life and spoke of the value of pastoral care and the ability to listen without pretending to have the answers to people's questions about the afterlife, their fears, etc.

This view was endorsed by a person speaking of cancer care services at a public meeting of the Forum:

> "Even though there have been vast improvements in recent years, there are still key elements absent. We are dealing with people at a time of their lives when they need a presence of other people around them. It's not about knowing the right thing to say because often there isn't a right thing to say. It's just about providing some

consolation and we want to make that journey as easy as possible.”

Another person wrote in a submission:

> *“ … we need to look at the total person, physically, spiritually, emotionally, family
> situations, etc. The kind of question we ask, the little remarks we make seem to
> touch something that makes the patient feel that there is an understanding
> of them as real people and often because of this, out comes the hurts, the
> disappointments, the frustrations in life, things they wished they had done and
> have not done. Bringing out these deep-seated hurts that may have been bottled
> up for years result in a release and relaxation and often greater peace. Likewise they
> may want to talk about all the blessings they experienced during their life or some
> practical matters such as funeral arrangements and even making their will.”*

Emphasising that the care of the dying and their families requires attention not only to the
physical elements of care, but care of the social, psychological and spiritual aspects of the
person, the Irish Nurses Organisation proposed that nurses, and midwives, input into such care
should be nurtured and encouraged, adding that:

> *“The delivery of holistic care requires the building of relationships, ability to [be]
> present with patients’ families and above all the availability of time.”*

Sadly, it added:

> *“The current climate of resource curtailments is not favourable to the development
> of nursing care that is responsive to individual needs of patients and their families
> at the end of life.”*

Counselling

A number of contributors raised the issue of the provision of professional counselling and
social work services. The Irish Catholic Bishops Bioethics Group wrote:

> *“In the last days of life patients and their families are faced not only with physical
> symptoms, but also with life-cycle changes and role reallocation brought about
> by the patient’s imminent death. Counselling can be particularly valuable to those
> most vulnerable of patients who have no social support other than that provided*

by the multidisciplinary team. Given that there appears to be a link between improved pain management, additional psychosocial support and a reduction in requests for euthanasia it is vital that counselling is offered to these patients as part of good palliative care."

The Ombudsman, Ms Emily O'Reilly, wrote:

"We receive complaints about the absence of appropriate counselling or social work services to meet the needs of the dying and of their families. Often we hear that there was no counsellor or social worker available. Sometimes management tell us that nursing staff were available to provide this function, but elsewhere in the same case, nursing staff may have told us that they were so busy, there was a delay providing any non-emergency services to patients. I am very aware that hard decisions have to be made in the allocation of resources, but, in large hospitals where a significant number of people die every year, there is a responsibility to provide psychological support, when it is needed, to patients and to families.

The Humanist Association of Ireland (HAI) said that the provision of secular counsellors by the Health Service is an issue which needs to be addressed, especially given the size of the non-religious community. The Mothers Union said that counselling services need to be improved, especially for children whose parents are seriously ill or dying.

A Principal Medical Social Worker summarised the "Role of the Carer in facilitating 'Dying Work' as:

- Facilitating the patient progress through successful emotional stages of adjustment to death

- Responding to the terminal patient's growing awareness of his/her condition

- Aiding the patient to balance hope and fear

- Facilitating the reversal and relinquishing processes involved in terminal adjustment

- Ensuring unimpeded detachment from human relationships

- Providing a climate in which spiritual issues may be explored.

It must be remembered, however, that the Carer cannot heal the patient of suffering in the

way that a doctor can cure a physical illness or injury by means of a therapeutic intervention which he, the doctor, initiates. The process is well described by Balfour Mount and Michael Kearney[53], as follows:

> "In contrast to the familiar Hippocratic approach where therapeutic change is initiated by the caregiver, the locus of control that enables healing is within the patient him or herself. While the caregiver-healer does not heal the patient, per se, he or she can facilitate the process by providing a secure environment grounded in a sense of connectedness that Buber termed 'I-thou' relating[54] in what is referred to as the Asklepian approach[55]. This term refers to the ritual practices associated with the Greek God of healing, Asklepios, which can be understood metaphorically as attempts to activate the innate healing principle within the patient's soma and psyche."

Suffering at end of life calls for compassion and kindness above all. As the Clinical Psychologist and Psychotherapist, quoted earlier, wrote:

> "It is possible to help someone transform the agony of impending death to a meaningful and peaceful experience and to die with dignity and grace. But how? This is when we can use intuition, quietness, touch and comfort to be a meaningful presence. It is the time for the wisdom and light of the moon. The sun has had its day. During these days the dying person can move below the everyday reality with its personal ties, and spend time in the deep inner spaces of themselves … "

Facilitating people to find integrity and wholeness in the shadow of death must be the ultimate objective of end of life care. This is an altogether different mission to that of preserving and saving life, or even of alleviating physical pain, though the two should not be separated one from the other, as if in competition with each other.

---

53 Healing and palliative care: charting our way forward, Editorial, Palliative Medicine 2003; !7: 657 - 658

54 Buber M, I and thou. (trans Smith RG) Edinburgh: T and T Clarke, 1973

55 Kearney M. A place of healing. Oxford: Oxford University Press, 2000: 91 - 102

Chapter 10
PSYCHOSOCIAL NEEDS

People experiencing difficult emotions at end of life, such as fear of abandonment or fear of being a burden, may have especial need of social contact. One contributor listed ways caregivers can provide comfort as follows:

- Keep the person company—talk, watch movies, read, or just be with the person.

- Allow the person to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen.

- Be willing to reminisce about the person's life.

Another said that carers must ... "trust themselves in their capacity to care and to cope, to trust themselves in unforeseen circumstances in the belief that sometimes their feelings are more true than reasoning".

Another person suggested:

> *"What people who are conscious of coming to the end of their lives want and value is someone, outside of their own family, and with no obvious agenda, who will listen to them, or perhaps just sit with them. Maybe there is a role here for some sort of volunteerism, or low-key support workers. I haven't thought this one through, I'm afraid, but perhaps my concerns are sufficiently clear for the time being."*

Another person said:

> *"At the end of life, 'little things' mean a lot. This was known in homecare settings of long ago. A quiet space, help from families and neighbours, visits from Pastor of Religion, kindness of children, and later the home being the place of repose."*

In this context, a widower wrote of his surprise and disappointment at the almost complete lack of support from his community and neighbours, following the death of his wife. He was not sure why this was ..."as we were very active in the community and my wife had many friends." He concluded that "the notion of community as it was in the past in Ireland is quickly becoming a thing of the past and I think that this is a major loss to all of our lives".

No one should have to die alone

No one should have to die alone. Yet this is often the case. One person writes in her submission to the Forum:

> "I have worked with dying patients in the States and in Ireland North and South
> [and] the one common factor is that nobody wishes to die alone. [Yet] the reality is
> that even in hospitals some people still die alone."

She concludes:

> "I would support any group that would highlight the need for every dying person
> to have the option of a relative or someone respectful to hold their hand or be
> alongside them as they approach their final hour."

Another person writes in the same vein:

> "Some patients have the benefit of 24 hour care from family and friends in their
> final weeks and days, to complement the nursing care. Others are hugely dependent
> on busy staff. They can be quite isolated, unable to seek help, and rely on regular
> staff visits, which are not always possible. The call bell by the bed can become their
> only link to assistance. We have received complaints where this very basic, but
> vitally important link with help, was placed out of their reach, or was not working,
> leaving them helpless and in some distress. A small thing to rectify, but a huge
> distress to the patient if it isn't. "

Those at particular Risk of Isolation at End of Life

In her presentation, the Director of TRUST said: "Death for people who are homeless on our streets, like much of their lives, can be their ultimate lonely experience." She added:

> "Some use the phrase "difficult circumstances" to describe how the bodies of the
> people we work with are often found. Sometimes decomposed beyond recognition,
> others battered and bruised, unknown even to us that they had passed away; as it is
> not unusual for the people we work with to disappear for months or even years at
> a time."

While not presenting information on lesbian, gay and bisexual people's end of life experience per se, GLEN, the Gay and Lesbian Equality Network said in its submission that research in New York had found that older lesbians, gay men and bisexuals have significantly diminished support networks when compared to the general older population. This translates into a lack of traditional support networks that may not be replaced by the strength of other close friendships or the size of informal support networks within the lesbian, gay or bisexual community. In consequence, 20% of older lesbians, gay men and bisexuals indicate they have no one to call on in a time of crisis or difficulty – a rate up to ten times higher than that seen in the general older population.

There are prisoners in Irish prisons who have served in excess of thirty-year sentences. Some prisoners may lose touch with their relatives. The Chief Nursing Officer of Arbour Hill Prison indicated in a submission that maintaining a secure environment in prisons can present challenges to care. It is the norm for the prison regulations to control what the inmate eats, when and where they sleep, what they wear and what they are permitted to do. At the best of times, she said, this can be restrictive; however, for someone who is dying, these limits present huge difficulties. Prison management may amend the regulations to provide as much flexibility as possible. However, it is other prisoners and staff who often respond to the psycho-social needs of prisoners. She said that a listening service is operational within many Irish Prisons where other inmates are trained by the Samaritans and make themselves available to lend support or often just to sit with the patient and be company for them. She added:

> "Discipline staff are a huge support at this time, augmenting the care of the nursing/medical staff and are often on hand to assist with repositioning a patient or assisting them with their hygiene needs. Perhaps simply encouraging fluids by offering a drink."

These simplest of kindnesses are invaluable in this isolated environment. Prisoners are often surprised by the kindness of staff and remark on it.

"Social Disrespect"

At a Public Meeting of the Forum, a person with Chinese parents complained strongly about how her mother was treated by hospital consultants, how "they acted like Gods" and the poor communication generally. A panelist at the meeting said that sort of behaviour is reprehensible and that it is what is now being called "social disrespect". Respect for others is one of the values underpinning human rights, he said.

Chapter 10   PSYCHOSOCIAL NEEDS

3

Respect is intrinsic to good communication between people about any matter. It is essential in end of life situations, where there may be great disparity between the power of the clinician and the vulnerability of the dying person, who relies on his/her judgement and care. We will return to this subject of social disrespect in Chapter 18, where we address questions of communication at end of life in greater detail.

3

Chapter 11
SPIRITUAL NEEDS

Definitions

Spirituality and the spiritual needs of people at end of life were raised in submissions, workshops and at public meetings of the Forum. Definition of terms was an important concern for some, particularly those who wished to emphasise that religion and spirituality should not be equated. It was often repeated that everyone - people with religious affiliations and those with none - have spiritual needs. However, not all will wish to discuss them with chaplains or ministers of religion.

In a joint presentation, three representatives of the National Association of Healthcare Chaplains quoted the following definitions of spirituality:

> *"In every human being there seems to be a spiritual dimension, a quality that goes beyond religious affiliation that strives for inspiration, reverence, awe, meaning, and purpose even in those who do not believe in God. The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite, and comes essentially into focus in times of emotional stress, physical illness, loss, bereavement, and death."*
> *- R.B. Murray and J.P. Zentner, (1989)[56]*

> *"Spirituality ... involves that deep inner essence of who we are ... it is the act of looking for meaning in the very deepest sense, and looking for it in a way that is most authentically ours."*

The following definition by the Dalai Lama, was provided by another contributor:

> *"Spirituality I take to be concerned with those qualities of the human spirit - such as love and compassion, patience, tolerance, forgiveness, contentment, a sense of responsibility, a sense of harmony - which bring happiness to both self and others."*

---

56 Murray, R. B. & Zentner, J. P. (1989) Nursing Concepts for Health Promotion. London: Prentice Hall.

Another person said in a workshop:

> "The word "spiritual" refers to the domain of human existence that lies beyond the material—the aspects of life which give a sense of meaning, connection, integrity and hope. The spiritual domain includes religion, because some draw their sense of connection and meaning from a belief in God or a higher, absolute truth. At the same time, those who are not affiliated with a formal religion (especially those who are ill, dying or bereaved), may still experience spiritual needs which are universal."

In her address to the inaugural session of the Forum, Dr Margaret McCurtain emphasised that spirituality belongs to everybody. Those of all faiths and none have spiritual moments, she said. "The search for spirituality is both intimate and personal and may be heightened as one confronts death," another contributor said. Yet another person wrote in a submission:

> "Everyone has a spiritual dimension. Spirituality is that innate human condition that is derived from being part of something that is larger and more enduring than we are ourselves. It is unique to each individual. It is at the core of all religious traditions and may be expressed through various religious rituals. However, it may equally occur without any specific religious belief."

Speaking at a public meeting of the Forum, a hospice chaplain said that spirituality is more than a person's religion. It is the mysterious centre of a person's life and very important in coming to terms with mortality.

Life and Death are One

A number of contributors emphasised that life and death are one, and that death is part of being human. One wrote:

> "As far back as Celtic times, death and dying were treated as a continuation of life and thus as being sacred. We had a great and strong tradition of midwives for the dying as we had midwives for those giving birth. These were often the same person. These Anam Cara assisted the person on their soul journey through dying and death. They shared a collective wisdom and insight into the relationship between physical pain and spiritual suffering which is as true today as it was then. Similar common parallels on the art of dying can be found in almost every culture throughout the world."

Philosophy/Religious Beliefs and Spirituality at End of Life

The increase in diversity of religious beliefs in Ireland in the last decade was remarked upon by some. While we report elsewhere on matters of culture and religion raised by contributors, here we note something of what people have said about the relationship between one's philosophy or religious belief and one's spirituality at end of life. At public meetings people may have struggled for words to express their views on the connection:

> "People have very different beliefs. It's important to work according to their own spirituality … certainly there is great variation in people's understanding of spirituality. In regard to the afterlife, you have a certain amount of people who are certain about an afterlife then others who are unsure. But most don't know and yes, it's a struggle. We have been listening to people and exploring it with them. It is very important."

In workshop presentations and submissions there were some clearer enunciations:

> "Zen Buddhist philosophy is radically different from mainstream Western (and especially Christian) philosophy in several ways: it has no concept of an enduring self or immortal soul, no idea of another world or life after death, nor any notion of a creator God or transcendent deity. To the extent that Zen Buddhism is also a religion, it is thoroughly this-worldly in its outlook, and puts at the centre of its thinking the apparent truth that nothing lasts forever, that all things in the world of experience arise and pass away."

> "Quakers approach all human relationships with a profound belief that there is that of God in each person, and that therefore people must be treated with reverence, dignity and understanding."

> "The spirituality of those facing death imminently is an essential component of caring for them." All have different beliefs about the afterlife: some don't believe it exists, others have questions and others still are entirely confident, looking forward to reuniting with loved ones who died earlier. "It is valuable to have family, friends, or staff, who can listen without dogma at such times."

> "The death of Jesus on the cross is inextricably linked to his resurrection. In the same way, for a Christian, the true meaning of death and dying can only be understood against the background of the Resurrection. In the light of the resurrection the experience of dying can be lived differently, precisely because it is not the final chapter in the life story of the person who is dying."

Spiritual Pain

One submission refered to The American Book of Dying: Lessons in Healing Spiritual Pain[57], which says (p. 43) that "in all the books of the dead, regardless of time, place or culture, the experience of spiritual pain is related to one of four timeless qualities:

- Meaning
- Forgiveness
- Relatedness
- Hopelessness"

A number of contributors also spoke of spiritual pain. A priest said at a public meeting that, rather than than trying to define it, he would give examples from his experience. He said:

"I think it shows itself in a loss of a sense of trust. The person's familiar framework for life and understanding themselves and their world is shaken badly by the experience that has begun from that first day of diagnosis or subsequently. But as the journey progresses and the hopes that have been built up in terms of recovery fade - and as a person begins to realise their journey is coming towards an end - maybe a good while away or sooner - they can find it very hard to make sense of their situation. They're deeply hurt because their trust in the goodness of life has been affected; their trust in the fairness of life.

"And if they are people coming from a religious background, their trust in the goodness of God is shaken and they experience a crisis of trust. For those for whom God is a personal presence and reality, their trust in his willingness to listen to them, to their prayers, to the prayers of all the neighbours and the Masses that are offered - there is loss of trust in his care, his providence, his not rewarding us for our efforts to live a good life.

"This is a very recurrent theme in the Irish Catholic tradition - the why of my suffering. There must be a reason, people say. I'm suffering because of something. Or, it is very sad to hear the word, but the word 'punishment' can come into people's fears; this is because of something I said or did; an assumption that God is in some way doing this, not just allowing it, but in a way that some of us sitting here in our health find difficult to understand. Why is God doing this?

---

57 Richard F. Groves and Henriette Anne Klauser (2005). The American Book of Dying: Lessons in Healing Spiritual Pain , Celestial Arts, Berkeley:

"And then the spiritual pain of the family is no less difficult to respond to. 'My mother worked hard all her life.' How many of you nurses have heard that? I was standing near a room where a young man was dying and a friend of his, who would have made a good second row forward - he was finding it very difficult. And he said to me: 'What did he ever do to anyone?'"

At another public meeting a hospital chaplain said the search for meaning is very real. He highlighted the example of a parent with a dying child trying to understand why it is happening. He described the shock and anger and sadness people deal with. He also said that he believed the traditional religious approach had not done enough for them. We have to accept people where they are at as they struggle with ill health and struggle to find meaning, he said. Quoting the 23rd Psalm, another priest said that people needed to know that when it comes to death they are OK, "whether they have faith to beat the band or have none". In a similar vein, a doctor working in a regional hospital said the one question he was asked more than any was 'when will it be?' He found that depended on the person. But often the time comes when the person has made their peace. They are ready and the gentle passing of the person occurs. So the answer is that the person goes when they are ready.

Spiritual Needs

Everybody's spiritual needs are different; they are specific to the individual person. However, as indicated by the National Association of Healthcare Chaplains they can be particularly acute at different times:

- Time of change
- Recognition of ageing
- Time of illness
- Terminal illness
- In bereavement.
- As death approaches**.**

"Confronting mortality brings spiritual issues into sharper focus and often leads to the rediscovery of a spiritual language, imagery and memory, previously submerged in the busyness of life."

One workshop presenter provided the following list of "Universal Spiritual Needs":

- The need to experience a genuine connection with others
- The need to find meaning in life
- The need to find a way to transcend suffering
- The need to find a refuge or source of peace.

A pastoral care educator and chaplain said in a submission that progress has been made in broadening the understanding of the religious and spiritual needs of patients:

> "While in the past both terms were viewed as synonymous, practitioners in the area of palliative care can differentiate between spiritual and religious needs. The practice of 'one size fits all' in terms of meeting patient needs is on the wane. Carers have grown in the awareness of the population of the New Ireland and how no longer the call for sacramental anointing is the sole role of the chaplain."

Spiritual and Pastoral Care

The National Association of Healthcare Chaplains said that spiritual care is something we all give when we give our full attention by the quality of our presence, by accompaniment and by companionship. Pastoral care is the emotional and spiritual support of people in their search for meaning. It addresses both the spiritual and religious needs. Pastoral care should be available in such a way that a person who does not want it should be able to refuse it easily.

A chaplain is a person appointed to provide spiritual and religious care to all patients, visitors, staff and volunteers in the healthcare setting regardless of faith or no faith. A chaplain can be ordained or lay (Standards for Hospice and Palliative Care Chaplaincy, UK 2006). The patient has a right to be cared for holistically, ie. body, mind and spirit. Chaplains care for the religious and spiritual needs of the patient if they so wish, recognising the difference between religious and spiritual care.

A Chief Nurse Officer in a prison emphasised the important role of prison chaplains:

> "Prison chaplains play a pivotal role in the care of the patients' emotional and spiritual pain. They often forge strong links with the prisoner's family and often facilitate reconciliation where there seemed little hope of previous communication. They become advocates on the clients' behalf and make representation for them. This is a service that spans all denominations. The religious needs of the client are

respected and facilitated and the chaplain spends long periods with the patient both when they are in the hospital but also sitting with them in the prison setting."

At the first Forum workshop a palliative care consultant said that spiritual care is very much part of palliative care. Pastoral care, said another, is not about churchgoing or religion, but about listening to people.

A chaplain described his former role as part of a healthcare team providing holistic care to cancer patients in a Canadian hospital, as follows:

"As Chaplain I:

- *attended all rounds and was expected to reflect on the spiritual needs of each patient*

- *charted fully all my patients encounters within the nursing notes*

- *was part of patient care at the beginning of the palliative process (diagnosis) rather than being introduced at the active dying phase*

- *was involved in staff support in the face of multiple deaths*

- *was part of the research group operating within the hospital and unit*

- *provided care across the faith traditions – for those of any and those of no specific faith groupings*

- *provide[d] education to all staff on how we meet the religious and spiritual needs of those within our care. Such education was deemed essential for new staff induction".*

Are chaplains accorded similar opportunities and resources in their work in this country? It was not clear from the Forum that they are.

Competent Spiritual Care

The same chaplain said that he regarded self-awareness as the most important competency in chaplains:

> "The need for the professional carer to be self aware of their own opinions and practices around difference and diversity needs to be ensured … A central tenet of education for those who are certified[58] as chaplains is that essential quality of self awareness. I do believe also that chaplains can help provide and nurture such skills and practices within their healthcare colleagues".

A person presenting at a workshop, quoted from Father Laurence Freeman, *A Short Span of Days,* as follows:

> "If the care given is going to be truly efficient from a simple human point of view, it must be efficacious for the wholeness of all the human beings involved. Then clearly we have to operate from a different mindset, a different attitude than this egotistical, controlling one. Meditation allows that shift of position to happen. It allows for taking off the controls and becoming more receptive, more intuitive to the real needs of the person."[59]

Care of the Human Person

The contact person for the Irish Catholic Bishops Bioethics Group wrote:

> "The human person is a unique combination of body and spirit, neither of which is complete without the other. For that reason, a comprehensive approach to healthcare must take account of the spiritual needs of the patient. "Spiritual" in this context does not necessarily mean "religious". Some people do not identify with organised religion, or think of themselves as religious, but every person is spiritual and has spiritual needs."

Nursing authorities and interest groups strongly emphasised the importance of spiritual care at end of life in their submissions. They also emphasised the importance of nursing

---

58 Either by Healthcare Chaplains Board (HCB) for Roman Catholics Tradition and the Church of Ireland Accreditation Board for all other Church traditions

59 Laurence Freeman (1991) A Short span of days - meditation and care for the dying patient, family and care-giver. Ottawa: Novalis

involvement in such care. The All Ireland Gerontological Nurses Association wrote:

> Nurses must provide culturally sensitive and holistic care that respects spiritual
> and religious beliefs. A caring and supportive environment that acknowledges
> the inevitability of death helps family members to accept and deal with loss and
> grieving. In the past, an openness about dying prevailed with people sustained in
> bereavement through religious rite and social ritual. Today finding shared social
> meaning in personal experiences can be a challenge and nurses need to be sensitive
> to spiritual needs of patients who have only a loose affiliation to any particular
> faith system. Ireland's multicultural workforce need to be prepared for varied
> spiritual beliefs and practices. Access to hospital chaplains and clerics of other
> denominations is important and may present new challenges in future years if
> resources are not on site."

> Gebhardt (2008) found that nurses defined spiritual nursing as 'being respectful',
> 'being supportive' and 'building a relationship' and 'being open to beliefs of the
> patient and family'. Consequently spirituality was addressed in everyday activities.
> Standards of Care refer to the importance of recognizing and addressing spiritual
> pain. The nurse's role in palliative care is to observe and interpret cues that
> reflect the patient's experience of being or not being in a peaceful state, and to
> intervene appropriately, responding to physical, emotional and spiritual needs of
> the dying patient and supporting family members in their grief and loss. However
> on occasions, finding sufficient time to be with a dying patient can be stressful
> for nurses, with limited resources and competing needs of other patients. Where
> possible, no one should die alone unless it is their expressed wish and there should
> be provisions for additional resources where needed. In the absence of family, the
> role of carers or trained volunteers who have the time to sit and be with the dying
> patient should be explored further". [60]

The Irish Nurses Organisation said that nurses and midwives have a responsibility to be
receptive to aspects of patient care that extends beyond the physical. In its submission, the
INO asked the Forum to place emphasis on the need for nurses and midwives to attend to
aspects of suffering that are not responsive to pharmacological interventions alone:

---

60 Gebhardt, M.C. (2008) Rehabilitation nurses' experiences providing spiritual care. Spirituality and Health International 9 :230-240

"In particular, this involves addressing the spiritual needs of patients facing death and supporting their families. However, as there are no Irish guidelines, competencies or standards guiding the practice of spiritual care, much of this care is left unattended. Therefore, the INO recommend that this deficit be addressed in the Forum."

In this context, the National Association of Healthcare Chaplains proposed the N.I.C.E Guidelines (UK):

Key issues in delivering effective spiritual and existential support to those experiencing illness or treatment or who are approaching death, as follows:

·   Listening to the (person's) experience and the questions that may arise

·   Affirming the (person's) humanity

·   Protecting the (person's) dignity, self-worth and identity

·   Ensuring that spiritual care is offered as an integral part of an holistic approach to health, encompassing psychological, spiritual, social and emotional care, and within the framework of the (person's) beliefs or philosophy of life.[61]

They also listed the objectives of the Guidelines, as follows:

1. Patients and carers receive support, if sought, to make sense of difficult life events through an exploration of spiritual and existential issues, including an effort to foster hope and promote well-being within an integrated care approach.
2. Health and social care professionals are able to acknowledge spiritual issues among patients and carers and to respond in a flexible, non-judgemental and non-imposing way.
3. Spiritual needs of staff are recognised, with support available to them in working in this area of care.[62]

Assessment of Spiritual Need

Others referred to spiritual assessment tools, including those developed by Richard Groves to assess the levels of meaning pain, forgiveness pain, relatedness pain and hopelessness pain, as described in the American Book of Dying, referred to above. The chaplain who worked in

---

61 National Institute for Clinical Excellence (2004). Improving supportive and palliative care for adults with cancer. 7.6 p. 94. London :NICE

62 Ibid, 7.10, p. 97

an oncology hospital in Canada said that he was facilitated to introduce a specific Spiritual Assessment Tool (SAT) into each patient's chart:

> *"It was a simple A4 two-sided document that had all the pertinent information around patient spiritual / religious needs and a simple SAT that had been devised by medical practitioners. Subsequent research[63] with the multidisciplinary team staff showed clearly the benefit of such a change in practice. The SAT was further developed into a 6 page document that covered the Living, Dying and Death Plan for each in-patient. The work was completed by a designated nurse and myself as chaplain."*

Rites and Rituals

A number of people spoke about end of life rites, rituals and sacraments, chiefly Roman Catholic. They focused particularly on the symbolism and meaning of different rites, often in terms of spiritual healing. "The sacrament of the anointing of the sick," one wrote, "is the celebration of Christ's healing presence with the person who is sick. It expresses our conviction that, even in the final stages of illness the patient will be touched and healed by Christ, whether this healing is of body, mind, or spirit."

---

63   Pierce B, Koning F. The introduction, implementation and evaluation of a Spiritual Assessment Tool into a Palliative Care Unit, Scottish Journal of Healthcare Chaplaincy 2004 Vol.7:2

Chapter 12
INFORMATION NEEDS

Introduction

Information was a constant theme throughout the Forum inquiry. In this section we focus on what people said about the information needs of people at end of life and of those who are supporting them. Views on the important role of information in increasing public awareness of end of life issues are reported in Chapter 5. However, it is appropriate to note one particular suggestion here, namely that the Forum take an initiative "to persuade those who organise pre-retirement courses to include a module on death and dying in all future courses."

In its submission, the Citizen's Information Board said that people should have clear and transparent information available at all stages of the end of life process. It said this should include:

- information on diagnosis and prognosis

- the different end of life care options available

- the range of support services available under various options

- the name and contact number for a link person in relation to care and nursing/ medical services being made available.

In a presentation to a Forum Workshop on dying and death in Intensive Care Units (ICUs), a Consultant in Intensive (Critical) Care Medicine spoke of a study of family satisfaction with ICU. This included satisfaction with information provision (largely positive), in the following domains:

- Ease of getting information

- Understanding information

- Honesty of information

- Completeness of information

- Consistency of information.

These categories provide a useful model for the evaluation of information provision in other end of life settings settings.

Informed Choice

Patients and their families need to have sufficient information to allow them to make informed choices. The Neurological Health Alliance emphasised that individuals and health professionals need access to services which can provide information and guidance on issues such as legal capacity, consent and power of attorney to allow informed decision making about their options.

The National Council on Ageing and Older People in its presentation to the Forum said that it is important that we provide information for older people on all matters relating to end of life decision making – advance care planning, consent, communication, bereavement, and spirituality - to support them as equal partners in their own care, whether they choose to have a direct involvement in decision making or not, and to ensure that their dignity and autonomy are respected.

Understandable Information

The language used in any discussions of matters relating to end of life must be simple, clear and understandable to all. In this regard, it was noted that the Citizens Information Board guidance on information giving for the diversity of people in Ireland, including people with disabilities, would be very useful. Reference was again made [see p. 48] to the HSE Intercultural Guide, featuring information on 21 different religious groups, 3 ethnic groups, Travellers , Roma and Chinese and Non-believers including Atheist, Agnostics and Humanists.

Information Technology

A retired journalist with information technology expertise wrote:

> "IT offers practical solutions to the capturing, preservation and provision of ready access to essential records that may be required in end of life situations. Living wills, patient instructions on invasive procedures, medical records, funeral wishes, wills and testaments, allergies, next-of-kin, banking and insurance details, inventories and family birth, marriage and death records are among the more obvious of these."

Others emphasised that information and communication technology could be better utilised to provide good quality care in the home - including links and access to supports and advice.

End of Life Information Needs Identified

Contributors identified from their experience specific needs in particular circumstances, as follows:

On Palliative Care: The need for information when palliative care is being considered was emphasised:

> "This is a time of heightened need with patients often uninformed about the introduction of palliative care or of the meaning of this in terms of prognosis. Thus information provision and integrated care planning are particularly critical at this juncture."

It was also suggested that the directory of specialist palliative services in Ireland (Irish Association for Palliative Care) may need updating, recirculation and PR on an annual basis.

On Neurological Conditions: At a workshop a presenter said that specialist information, training and counselling for people with neurological conditions and their families around symptom management, end of life planning and bereavement is very limited in Ireland.

On Alzheimer's Disease and Dementia: A number of people requested more information, direction, and advice on the progression of Alzheimer's disease and assistance to family members on how to handle it. In addition, recent research was referred to at a workshop, which found "that family members want more information about the symptoms of advanced dementia, including treatment options and advanced planning, with a small number indicating they found it distressing to discuss their relative's future. A lack of understanding of the natural history of dementia has been identified as a major barrier to improving end of life care for patients with advanced dementia."[64]

Following Diagnosis of Foetal Abnormalities

Reference was made in Chapter 1 to a Forum workshop presentation on women's experiences of carrying a baby with a foetal abnormality and of their coping mechanisms, some seeking all the information they can get, others avoiding information altogether. The following quotations from women in this situation were provided by Dr Joan Lalor, School of Nursing and Midwifery, TCD, who made the presentation:

> "I thought I was the only one in the world that this had happened to. If you could

64 From research proposal, ESTABLISHING A FRAMEWORK FOR PALLIATIVE INTERVENTIONS WITHIN DEMENTIA CARE developed by the Irish Hospice Foundation and the Alzheimer Society of Ireland (referred to in Discussion at Workshop 13).

just let women know they are not alone, they are not freaks - I just wanted to hear that this had happened to someone else and hear how they dealt with it."

"I wanted information about the autopsy - does the full autopsy need to be done? [We want] as little interference [with our baby] as is necessary."

"I felt I couldn't cope with any more information, I didn't want any more - I thought my head would explode, but my husband was full of questions."

"I haven't asked anymore about the problems. I felt there was nothing they could do until the birth. I don't ask too many questions it's just my way. If they [the twins] could have a bit more weight on them they might have a chance."

"The more information we can find out the better in terms of whether we can try again ... What is the [likely] outcome? Is the labour going to be horrible? Will we ever have children? You need information on a personal rather than a medical level – not just counselling but practical advice."

The above quotations demonstrate how important it is to tailor and provide information to people based on their needs at each stage of their painful journey, including:

Pre-scan:

- Information leaflet on availability and content of scan

Getting news of the initial scan:

- Written information on the specific condition for parents, which can also serve to inform families
- Contact number for health professional for support and opportunity to ask questions before next planned visit

Waiting to meet the expert:

- For the information seeking person: guide and support her with multiple information sources, ie discuss scientific literature, websites and referral to other experts
- For the information avoidance person: allow her to opt in to information, ie provide written information that they can read when she is ready**.**

Carers' Information Needs

A submission emphasised that family carers caring at home for a someone at the end of their life need practical information as well as training on how to deal with critical situations which may arise, for example, when the person they are caring for:

- is in pain, discomfort - despite medication
- has fallen
- is depressed, suicidal
- is having trouble breathing, etc.

At a Workshop the following information needs of family carers were listed:

- Pain management
- Effective communication
- Information sharing.

It was also emphasised that families need to be kept informed of any deterioration in the patient's condition.

A Programme Development Manager at the Irish Hospice Foundation said:

> "The wide range of support needs required by carers of people with life-limiting illness includes information on:
>
> - *The disease trajectory, including symptom control*
> - *How to assist with patient care in the life-limiting phase*
> - *Dealing with change in financial circumstances and related legal issues*
> - *What steps to take and what help is available when the person they care for passes away".*

Information provision by Living Links *(see also Chapter 3)*

Following a suicide or attempted suicide, the organisation Living Links will, when invited, provide information and practical support on the following:

- the funeral
- the inquest
- entitlements

- what to say to children

- how to deal with the neighbours.

Information provision by pharmacists

The President of the Irish Pharmacy Union said at a Forum workshop:

> *"As the most accessible of healthcare professionals, community pharmacists, who often have a long established relationship with patients and their carers before palliative care is required, play a central role in ensuring that the patient and their carer remain informed and supported as the disease enters end of life stage."*

Following Death

While we will have discussed bereavement in an earlier chapter, here we note that bereaved people need information not only on services available, but also practical information on the steps to take following the death of a relative. One woman said that when she looked for the number of a funeral home following the death of her mother in a university hospital she was handed a telephone directory!

Other persons said:

> *"Relatives need to be informed of what the next step is following a doctor certifying death with reference to burial, cremation, etc."*

> *"At a minimum, a list of relevant support groups should be made available to families of dying patients."*

At a public meeting, a representative of Nursing Homes Ireland said:

> *"After death, practical information on what to do and on understanding loss and bereavement is offered [by their nursing homes]. How to register the death etc … It is also required to inform the Coroner's Office of time and date of death. HSE are also informed."*

Information and Power

At a Forum public meeting a HSE Bereavement Counsellor said:

"It's not about dying as much as the best way to live with the time left. From my experience people need time, compassion, space, respect and information.

You don't know where to turn, who to ask; everybody you see as authority figures, you feel you have to please them. You can't be seen to be weak.
I remember a woman in the midst of tears, whose little baby died. Her husband had googled the baby's condition and he would use these words he had seen to consultants and she said, he didn't even know the words, and told him to 'shut-up, they'll think we're idiots'. So it's about that vulnerability and how do we mind it.

We must all ask ourselves the question - how would I like to be treated if I'm ever in this position. One client, whose little boy who was nearly 4 was killed in a road traffic accident - the parents were just a bit too late to pull the child back from the car - the ambulance came and took the boy but nobody told the parents they could travel in the ambulance as well. It was only later they realised they could have and that Mum then felt really guilty she wasn't there and even listening to her, you could hear the ache in her heart and her eyes - wanting to hold that child.
So from that point it's about information and awareness."

In its submission, the Citizens Information Board (CIB) indicated that it would be pleased to work with the Irish Hospice Foundation and other relevant agencies to explore how its information content and delivery could be enhanced in the light of the deliberations and outcomes of the Forum on End of Life. In this context the CIB noted that the end of life themes already covered by it on its information website on the subject of preparation for dying include making a will, power of attorney, legal arrangements for incapacity and advance care directives. Similarly, the themes covered in relation to after a death – registering a death, funerals, burials and cremations and the deceased's estate are geared towards helping relatives to deal with the practicalities of the post-death situation which some people will be dealing with for the first time. It will be important that other information needs identified by contributors to the Forum be discussed with the CIB as soon as possible.

Chapter 13
FINANCIAL CHALLENGES AT END OF LIFE

Introduction

People's financial circumstances and the costs they incur at end of life may give rise to significant financial needs at a time when they and those close to them have so much else to contend with. Contributors identified some of the major financial strains which may beset people at end of life in Ireland. Some relate to the costs of services; others are financial challenges faced by certain groups of people; others relate to the financial effects of illness and death on families, and on family carers in particular.

Hospital Car Parking

One of the more unfair costs identified by contributors is the high cost of car parking imposed on the families of people dying in acute hospitals. One person noted for example that in a particular hospital there is a facility for family members who visit their relatives on a regular basis to get a fixed price weekly ticket. However, information about this facility proved difficult to get and, when received, it then proved difficult to buy the weekly ticket, even with the reluctant sanction of the ward sister.

Costs of Home Care Services

At the inaugural meeting of the Forum the lack of recognition of the additional costs of full-time care in the home for terminally ill people was raised. A person said in a submission:

> "He too died with dignity, peacefully at home but this was only possible as he could afford the payment of a nurse for the night-time care. This was over a short period of time, but not many people would have the means to facilitate this, especially in today's climate."

In its submission to the Forum, the Money, Advice and Budgeting Service (MABS) said that, in its experience:

> "the financial costs associated with long-term critical illness care place a considerable burden on low-income families in particular and can be a cause of great anxiety for the person who is ill. Where the critically ill person is a spouse/

partner/parent there can be considerable anxiety as to the cost of care, loss of income, the financial security of the family after death, debts that have been growing during an illness and debts that may be incurred on dying."

MABS therefore recommended:

"that at this vulnerable time, an opportunity should be provided for families including the terminally ill person to discuss, in a structured way, the financial issues that will arise. Counsellors dealing with people at this time should have at their disposal appropriate skills and information to assist the critically ill and their families to put their financial affairs in order and so increase their peace of mind."

Costs of Funerals and Other Services

According to Conor Pope in an Irish Times article, [65] a Dublin funeral will cost at least €4,000, with many estimates putting the final bill at closer to €6,500. Burial outside the capital will cost €3,000. "There is a state grant of €850 available to cover funeral costs but it barely makes a dent in the cost associated with burial," he says. "The costs are split roughly 60-40 between director's charges, which cover the coffin, embalming, removal, hearse, pall-bearers and other transport; and payments known as disbursements which cover services such as grave purchase, grave opening, cremation fees, newspaper announcements and flowers."

The Association of Funeral Directors is aware that the cost of funerals is a live topic and it says that all Funeral Directors must provide an accurate estimate of costs to client-families at the time of making arrangements. It adds, ominously, that, though this is a tenet of its members, non-member funeral directors have no such obligation.

MABS in its submission said:

"The cost of a funeral can place a considerable burden on low income families. In our view appropriate generic information should be available on the costs of funerals. In MABS we are aware, from our experience, that many people from low income families incur considerable costs when purchasing funeral services ... In MABS experience, there is a risk that in these circumstances family members may go to illegal money lenders to borrow money for a funeral ... Appropriate savings products should be identified for people who wish to put money aside for funeral costs."

---

65 Funeral costs have survived recession's deflationary grip, Irish Times, April 26, 2010

One submission draws attention to the high financial cost when death occurs abroad. Airline tickets, accommodation, etc. have all to be purchased at the highest cost and this must put a huge burden on families, apart from the general expenses themselves. One way of easing the burden would be if families could claim tax relief on such expenses in the same way as business people can.

Financial Challenges faced by Particular Groups

The costs of long-term care for people, largely older people, who are unable to continue to live independently due to the effects of a stroke, Alzheimer's disease or other illness was raised on a number of occasions. On 27 October, 2009 the Nursing Home Support Scheme, or "the Fair Deal", as it is known, came into effect. This introduced new financial arrangements for all new residents of residential care facilities, including public nursing homes, where substantially increased charges now apply. In essence, if the Health Service Executive (HSE) decides a person needs residential care services and if that person's weekly assessed means (income, cash assets and other relevant assets - including the family home - computed in accordance with detailed rules) do not meet the weekly cost of that care, then the state pays the difference. However, the HSE may stop paying state support on behalf of the person assessed as needing residential care if that person does not pay the allocated amount to the care facility.

Older people

An older person who wrote of the difficult circumstances surrounding the deaths of her mother, her husband and two of her brothers added

> "It is also worthy of deliberation that many people of my vintage have lost their savings in the financial debacle. The appalling vista widens further when one factors in our Government's attempt to withdraw the medical Card for the over-70s."

Many older people transfer properties on the basis that they are giving away the property in exchange for care, love and attention when they are unable to live independently due to disability or ill health. Financial abuse may occur when a person coerces an elderly person into making a will against that person's best interests. To guard against being taken advantage of financially, independent legal advice should be provided to older people when making wills transferring their interests to a third party, including family members.

People with disabilities:

One contributor said that because people with learning disabilities do not contribute towards PRSI, their families are not entitled to get the full funeral grant. However, they may get a contribution from (the) Community Welfare Officer (CWO) "at their discretion."

Travellers

The families of Travellers at end of life must conform to cultural norms which may put them under considerable financial pressure. 98% of travellers rely on social welfare and many are unable to access financial services. Under pressure to arrange elaborate funerals many resort to moneylenders, who may exploit them by offering instant solutions with promises to manage all aspects of the funeral and to cover all the costs. Large bills are then presented following funerals and inability to pay has severe consequences.

By tradition, Traveller families are required to erect headstones within a year of the death of the family member. These have been growing increasingly elaborate and expensive, particularly during the boom years. Cultural demands have resulted in strong pressures on families to match commemorative headstones already erected. Costs of €18,500 and up to €40,000 were cited at a Forum workshop which discussed these issues.

It was agreed that, in the wake of the banking crisis, now was an opportune time to address questions of exclusion and discrimination against Travellers in the financial sector. Research to identify policies and practices damaging to the interest of Travellers, particularly at the times of vulnerability, such as bereavement, should be undertaken. The MABS Traveller Group made other recommendations including:

- that a study of Traveller end of life culture be undertaken
- that a study of funeral societies, funeral plans and group funeral saving schemes be undertaken
- that undertakers expand payment options
- that a state subsidised insurance scheme be introduced to avoid unnecessary debt related to funeral costs.
- that the issue of exclusion of Travellers from the financial sector be addressed.

Parents of children with life threatening illnesses

In addition to all of the emotional strains experienced by parents of children with life

threatening illnesses, they have also to deal with very difficult practical problems, including financial ones, as the following quotation from a submission to the Forum illustrates:

> "With regard to financial help we found there was no one to assist you during hard times. We found it very difficult to keep up with running two households here at home and staying in Dublin for the three months. I was not working at the time as we have another son at home and my husband works in Dublin. When he did take time off he was not paid for this and only for the goodwill of our families we would have been in financial difficulties. We are still only now catching up on our bills."

Families/Carers

In its submission, MABS said:

> "Coping with the death of a loved one is difficult enough without having the added stress of dealing with money matters. Not only do surviving spouses/partners have to practise debt management skills on one income, but in many cases, they may also be responsible for handling their spouses' outstanding debts. Many are under the impression that when a person dies their debt dies with them. This is not the case in most instances ... Having independent advice available is very important. We would recommend that clear basic legal and financial information be made readily available on the following:
>
> *   Funeral service and burial costs
>
> *   Budgeting and current bills (rent, mortgage, credit cards
>
> *   Estate, will matters - intestacy, probate, etc
>
> *   Income and employment matters, pensions, social welfare benefits
>
> *   Investments, insurance, tax documents (income and property related
>
> *   Miscellaneous expenses.

One person wrote:

> "The carer is very vulnerable to becoming overburdened and burnt out due to the demands. Their needs may include ... financial assistance to enable delivery of care at home and, when the time comes, with funeral costs ... Loss of entitlement to the

carers allowance/benefit and any other associated benefits may have significant financial implications for carers following the death of the cared for person."

Another said at the inaugural meeting of the Forum:

"The financial and economic implications of bereavement include out of pocket medical bills, health and social care costs for care at home, executor costs, fuel costs, transport. The surviving partner also faces the challenges of dealing with banks and navigating the welfare system."

Forum participants provided the following contrasting responses of financial service providers to vulnerable people around the time of a close relative's death:

"The Manager of the Bank was very helpful and gave us sound advice when we knew Dad was dying. This advice included what would happen with probate and how my mother could access what she needed to live on till this was processed, which was just as well as probate took two years."

"What of the financial services industry and the banks? Why is it that a grieving mother of a son killed in traumatic circumstances had to make dozens of phone calls to a leading financial institution before she finally managed to stop an incessant flow of letters and circulars about life insurance? Was it because of the heartlessness of individuals, which I personally doubt, or because their customer focused rhetoric didn't apply to the bereaved and no one was empowered to change procedures."

Partners

In its submission, the organisation Marriage Equality, said that partners do not have the same inheritance or tax rights as spouses:

- if partner dies intestate

- if the deceased partner has an ex-spouse, their rights may rank in priority

- under inheritance tax rules, even if everything held in joint names, surviving partner treated as 'stranger in law' and Capital Acquisition Tax is applied

- if property transferred inter vivos by partners Capital Acquisitions Tax is applied, unlike for spouses

- furthermore, any disposal or transfer to a partner is subject to Capital Gains Tax, even if it is a gift

- the special income tax rules that apply to a spouse in the year of death do not apply to partners

- there are no automatic leave entitlements for partners of deceased persons

- a partner will not be recognised as a spouse for pension rights purposes, even in the case of compulsory payments by public servants into a widows and orphans fund

- if you have dependent children, the Widowed Parent tax credit available for five years after the death of a spouse is not available after the death of a partner

- children of the relationship are not recognised in law as children of the non-biological parent and therefore do not have the same rights under the Succession Act as the legal child or children

- provisions made for the non-biological children in wills will be subject to Capital Acquisitions Tax as 'strangers in law'.

Dying Intestate

The financial and other consequences of dying intestate were highlighted in submissions, workshop presentations and at public meetings. People do not like making wills and consider it something to be done when a person is old, sick or dying. However, younger people die every day either on the roads, through illness or other calamity. They leave young children, wives, husbands or partners. A solicitor said in her submission:

> "It is incumbent for us to consider whether society is aware of the effect of the Succession Act on their particular family group. They may not be aware that on the death of one of the parties, the people that they care most about are left with nothing. If one dies intestate, stepchildren, foster children, people for whom the deceased has acted in loco parentis may be left homeless or penniless. A more common problem is that in long-term non-marital unions where there are children and where one of the parties dies, the surviving partner may be left unprovided for in the estate of the deceased."

A huge quandary may exist for parents of incapacitated children who will never be independent or capable of looking after their own needs. How do we deal with the estate in that case? Legislation alone will never be able to deal with it. Levels of incapacity range from mild to profound. Each family is different. In some cases there will be other siblings who will be very involved in the care of the child; in other cases there will be none. In some cases the child is able to live in sheltered accommodation; in other cases where the disability is profound, the child will be in a long-stay facility.

Parents may fear that the incapacitated child may lose a benefit or service if they have a significant inheritance. This possibility may become too much for some parents who end up not making a will as a result. In cases where there is this difficulty, a discretionary trust is an excellent vehicle for providing flexible care for the child during their lifetime.

Public Awareness of the need to make a Will

We need to consider what would happen to our children in the event of our death whoever we are, but particularly if we are 'single' parents or parents of incapacitated children. People need to be made aware of their choices in this matter and how best to ensure that their choices are respected. When this is achieved and a person has provided properly for their family in a will, this can be a great comfort for a person at death. Remember too that a marriage annuls previous wills and that stepchildren will be treated as natural children under the Succession Act only if they are named in a valid will.

A solicitor wrote:

> "There is a difficulty in administering some estates in tracking down the assets of the deceased. This is because the deceased did not leave any documentation setting out where the various assets are. This can relate to bank or building society accounts or even title documents ... The outcome of this is that a widowed spouse can be held up in the disposal of the home while efforts are being made to reassemble the title."

He added:

> "There is no depository for title documents. Lending institutions have now reversed their attitudes and are now anxious to return title documents to individuals as soon as the loans have been repaid ... Hence the title documents are returned to individuals. They have no place to put them. If they leave them in their house then

they could be stolen or go on fire. This should be addressed."

And he asked:

"Should there be a register of wills? Should every will be registered to confirm its validity? I don't know the answer to this but I do have an uneasy feeling that I have wills in my safe of people who are deceased and that the deceased's estate was administered without contact being made with me."

Advice on Money Management

In its submission MABS made a generous offer of assistance, which like that made by the CIB, should be taken up by the Forum as soon as possible. It said:

"MABS provides advice on money management issues at key stages in the life cycle and also in relation to key life events; in this context MABS would be willing to contribute its money management expertise to a relevant publication which might be provided to a person coming to the end of life or to their spouse/partner, providing guidance on some of the major money matters described above. It would also be appropriate to include within such a publication specialist information on relevant legal and social welfare issues.

Subject to resources, MABS would also be willing to provide an input into the training of people working with those approaching the end of life to enable them to provide any relevant guidance on the money matters mentioned above."

Being Human, Having Rights

4

Chapter 14
AUTONOMY

Introduction

An important, frequently mentioned issue in Forum submissions and discussions was autonomy in end of life care. In truth, while there was discussion of the meaning and definitions of autonomy, the central issue was decision making - who makes end of life decisions and how are they made? In a workshop presentation, one person said:

> "Ethical decision making depends upon the ability to recognise that a moral issue exists, how to take appropriate action – to do this one must have moral sensitivity, moral reasoning, moral motivation and moral character."

> "Decision making is increasingly influenced by social, cultural, religious, ethical, legal and political values".

Definitions of Autonomy

As one contributor wrote in a dissertation provided to the Forum, modern thinking about autonomy has been influenced by John Stuart Mill's 'liberty principle':

> "... The only part of the conduct of anyone, for which he/she is accountable to society, is that which concerns others. In the part that merely concerns himself/ herself, their independence is, of right, absolute. Over himself, over his body and mind, the individual is sovereign." (On Liberty, London, 1859).

Nevertheless, and paradoxically, as the contributor pointed out, he recognised limits to that autonomy:

> "The only purpose for which power can rightly be exercised over any member of a civilized community, against his/her will, is to prevent harm to others." (op cit.)

Another contributor said:

> "Autonomy is to be highly valued, provided it is understood as Kant understood it and as including "due recognition and respect for the rights and freedoms of others

*and of meeting the just requirements of morality, public order and the general
welfare in a democratic society."[66]   Freedom is the right to do what is consistent with
the truth. It requires, in the first instance, that decisions about the human person
take into account the nature and dignity of the person, both the one most directly
concerned and any other persons on whom decisions may impinge."*

At a Forum workshop, Prof David Smith, Associate Professor of Health Ethics at the Royal
College of Surgeons in Ireland, defined autonomy as 'an individual's right to think and act as
s/he wishes, free from external influences and provided those wishes do not inflict harm on
others'.

Patients' Rights

 Autonomy then is an important, but not absolute, right. An individual cannot compel
another to act against his/her conscience. Nor can he/she put undue pressure on healthcare
professionals to meet unrealistic or illegal treatment demands. The above mentioned
dissertation[67] says:

> *"On the face of it the right to refuse treatment appears absolute. However, the law
> recognises limits to the patient's rights - K v Coombe Hospital, as yet undecided, is a
> case in point. His freedom may also be restricted in the case of 'notifiable' diseases -
> he cannot be forced to undergo treatment but infectious or violent patients can be
> confined or restrained to prevent harm to others. However, with these exceptions the
> patient's right to refuse treatment is absolute."*

As Prof Smith noted in his presentation, a competent and informed patient's right to refuse
medical intervention has been well established in bioethics and Anglo-American law for more
than a decade. There is less clarity, he said, on the role of patient consent in withholding and
withdrawing treatment at the end of life and of the ethical and legal status of patient requests
for treatment. Ethically, it would appear that, on the basis of a person's rights to autonomy, a
patient's consent is required for the withholding or withdrawing of treatment, he said.

In its submission, the Bar Council said that in the case of Re a Ward of Court No. 2 [1996] 2 IR
79 the Supreme Court held that no one can be compelled to undergo medical treatment even

---

66 Universal Declaration of Human Rights, Article 29.2

67 Marie O'Mullane, Life-ending Decisions: The Rights and Responsibilities of the Patient, The Family and the Medical Team (p. 15)

where the absence of such treatment may lead to death:

> 'The consent which is given by an adult of full capacity is a matter of choice. It is not necessarily a decision based on medical considerations. Thus medical treatment may be refused for other medical reasons or reasons most citizens would not regard as rational, but the person of full age and capacity may make the decision for their own reasons' (Denham J).

Infringements of Personal Autonomy

A number of contributors cited examples of infringements of patients' autonomy rights. Understandably, such infringements reinforce calls for greater control by individuals over what happens to them at the end of their lives. Reference was made, for example, in a Workshop to an audit carried out on residential care in the West of Ireland,[68] which found that one-third of applications for residential care in Galway were made without the knowledge or agreement of the person, even when they were able to communicate a clear and consistent preference. The next example speaks for itself:

> "When it became clear he was dying, the doctor felt he had 'failed' (name of person)'s father and could not bring himself to tell him. This delayed access to palliative care and left (name of person)'s father unaware of his imminent death. Her father had always been open about his death, even preparing an Advance Care Directive through a solicitor. This was dismissed out of hand by the palliative care doctor, who made it clear it had no legal standing. A lack of co-ordination and communication between doctors and nurses resulted in treatment being attempted that was unnecessary and distressing to (name of person)'s father and family. When the nurses were finally informed by the doctor that he was to receive palliative care, they continued to give him blood plasma, oxygen, and refused to give him morphine too often in case it damaged his organs, which only prolonged his suffering. What angers (name of person) and her family most is that he was denied every opportunity to be aware of or control any aspect of his own death. Consumed with pain, he was unable to fully comprehend or contemplate deeply what was happening to him. He was left to die confused, terrified, and in agony. 'In 2007, it should have been different.'"

In another instance, a contributor asked, what right had the medics to persist in treatments

---

68 O'Keefe, S. (2008) 'Fair Deal' Bill. Unpublished

and investigations against the wishes of their patient, even if that patient had a communication impairment?

Facilitating Autonomy at End of Life

O'Shea et al. (2008) note in their study[69] that 'the key challenge in enhancing quality of life is the preservation of the person's surviving autonomy and dignity balanced against inevitable paternalism'. They say that if principles of autonomy and self-determination do not hold from the outset, beginning at admission to care facilities, it is difficult to give them meaning at the end stage of dying and death.

Speaking at a public meeting about measures to protect the autonomy of residents in private nursing homes, a representative of Nursing Homes Ireland was more reassuring. She said:

> "Their wishes and choices regarding end of life are discussed and in so far as possible are implemented and reviewed regularly with the resident. These include their preferred religious, spiritual and cultural practices and the extent to which their family are involved in the decision making process. If, due to an absence of capacity, the resident can no longer make decisions on such matters, the representative is consulted."

Age Action Ireland said in a submission:

> "A principle of adequate end of life care should be autonomy, being given the opportunity to make decisions about this aspect of one's life. Part of this is the accurate and automatic documentation of people's preferences for care recorded on admission to acute and long-stay units ... Staff may need guidance and assistance on how to do this ensuring a practice of comprehensive care plan recording. Anecdotal evidence suggests that care plans are not standardised practice in documenting people's preferences for care ...

The Citizens Information Board said that support services for end of life care should be ... delivered in a manner which maximises privacy, personal autonomy and personal control over decision making.

---

69 O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ni Leime, A., Keys, M. (2008) End of Life Care For Older People in Acute and Long-Stay Care Settings in Ireland. Dublin: National Council on Ageing and Older People and The Hospice Friendly Hospitals Programme

Exercising Autonomy at End of Life: Advance Directives

The exercise of autonomy at end of life raises complex legal and ethical questions relating to matters such as Advance Directives, assisted suicide and euthanasia. We will return to these matters in Chapters 20 and 21. However, we do need to refer to Advance Directives here, in so far as Forum contributors linked them to autonomy.

An Advance Directive is a statement made by a competent adult relating to the type and extent of medical treatments s/he would or would not want to undergo in the future should s/he be unable to express consent or dissent at that time. One contributor wrote:

> " This relatively recent extension of the patient's right to autonomy originated in the USA in the 1950s and 1960s. The right in itself is an equally recent phenomenon; the doctor was always the 'senior partner' in the fiduciary doctor-patient relationship and the patient's family and the 'public good' (read 'preference' or 'convenience') allowed him little control over his own fate in the event of incapacity."

The subject of advance directives was raised frequently in the course of the Forum's deliberations. While some questioned the terminology, most of those who spoke about the concept as defined above were broadly in favour, recognising advance directives as an expressions of autonomy and as "a useful tool enabling control over medical treatment into the future, when individuals may lack the capacity to express autonomous preferences".

Others appeared to go even further by implying that the responsible thing to do is to indicate care preferences in advance, including indicating a wish not to be resuscitated, should this be an issue at end of life:

> "Do we not however have some responsibility to put our affairs in order - to indicate our preferences for care, even if what we desire may not always be deliverable? Of course if we as health service users do become more responsible we need to be sure that health service providers will also become more responsible. I understand that in one Irish long-stay hospital it was established that only 3 out of approximately 100 patients would want to be resuscitated. The problem is that to establish people's preferences in this regard takes time and skill. Whose responsibility is this? "

Autonomy - the Pre-eminent Determinant of End of Life Outcomes?

Others went even further. Though the work of the Forum is governed by the principles of hospice and palliative care, it did receive a submission from the Humanist Association of Ireland stating:

> "In a world where medicine can prolong life artificially and machines perform many functions once only open to the human body itself most Humanists would hope that such modern medicine, not able to guarantee pain-free end of life treatment to all could be used where clear, unequivocal wishes have been stated and registered to enable dignified end to suffering. Autonomy of the individual must supersede emotion in regard to end of life issues."

Here it is implied, not only that ending life in this fashion provides a 'dignified' end to suffering, being based on the principle of the autonomy of the individual, but also that the judgement of those not in favour of this solution is clouded by 'emotion'.

The Irish Catholic Bishops' Bioethics Group took a different view saying:

> "Decisions about care, whether present or future, are authentic expressions of personal freedom when they are consistent with an integral vision of the human person. They miss the point entirely if they refer only to physical needs and treatments. Likewise they exceed the proper scope of personal freedom if, instead of taking responsibility for life in the context of serious illness – actual or anticipated – they are oriented towards ending life."

A representative of the Church of Ireland said at a workshop:

> "For people as they get older their desires are to remain independent, that is preserve freedom and dignity and not be a burden. But Christian belief raises hard questions about our present ideas, attitudes and practices in respect to chronic illness, dying and death.
>
> First of all we cannot elevate autonomy to its present secular level, of total centrality. Through our creation, though we have autonomy, it is limited both by our belonging to God and as humans we are dependant both on God and on each other as social animals. It is impossible for us to claim the autonomy of personhood

in all dimensions of life especially at the hour of death. We cannot escape the dependence and interdependence that is a part of the good life given us by God, and it is through death that we enter into eternal salvation."

Limitations to the Exercise of Autonomy

In the reality of daily living, autonomy is limited by circumstances - financial, social, physical, to name but a few. Autonomy is limited too by one's mental and physical development and capacity. Those who are confused, who are suffering from dementia or who are unconscious may have little or no autonomy to make treatment or care decisions.

Dr Brian Maurer of the Irish Heart Foundation presented a physician and cardiologist's perspective on dying from a chronic illness at a Forum workshop. He emphasised that dying from a chronic disease is not a voluntary act. Those with a chronic illness have limited and decreasing autonomy and a concomitant increasing reliance on others, such as physicians in whom they place their trust, a trust which must not betrayed, he said. Perhaps it is the development of this trust, the building of partnership and joint decision making at end of life which requires our particular attention.

Challenges and Choices

Some people decide against a certain treatment because it is, or might become, too onerous, but they treasure the days remaining to them despite the pain and challenges of their circumstances. Others, facing the prospect of end of life, want nothing more than to be relieved of their suffering, to be at peace, and to have a choice in how it ends.

These people in particular challenge those around them and challenge society itself. Do we confirm their despair by offering to help them end their lives, or do we try to the respond to the suffering that causes them to question life itself? Does society provide euthanasia and assisted suicide to meet the demands of some, thereby jeopardising the lives of others, or does it channel its energies and resources into the development of palliative and quality end of life care for all on the basis of need? As individuals and as a society these are the choices which have to be made. The choices we make will find their expression in the legal and ethical frameworks governing end of life care in Ireland. They will also influence policy on the development, financing and provision of high quality end of life care for all on the basis of their physical, psychological, social and spiritual needs.

These issues are being considered and discussed in other countries of course. In the final of

issue of an American series of briefs profiling promising policies and practices in end of life care, called State Initiatives in End of life Care, 'thirty-five leaders' mapped the way forward, the future of reform, as they saw it[70]. Their conclusions on the subject of autonomy are thought-provoking and merit serious consideration in this country.

In common with some experts, they appear to question the bioethical and legal foundations of healthcare decision making autonomy because they believe that autonomy has been defined too narrowly and legalistically.

 "As a result." they say, "patients are viewed inaccurately as isolated, mostly rational beings, oriented toward facing death squarely, with unchanging treatment wishes that are best determined exclusively by themselves for themselves." They add:

> *"Families - too often defined exclusively as blood or spousal relations- are at worst seen as untrustworthy or at best seen as mere mouthpieces for their dying loved ones, without caring intuitions or moral claims of their own. Typically "erased" from consideration are cultural differences, the serious health risks imposed on caregivers (especially elderly ones), and the financial burdens of families and society."*

They agree with those who advocate rebuilding, reinforcing and reinterpreting laws, institutions and practices around the acknowledgement that dying is an interpersonal affair, that is not undergone strictly by individuals.[71] The reformers add that "while many of the implications of such an acknowledgement remain to be imagined, some already seem clear:

> *"The core values of hospice - with its focus on the whole family - must be defended and infused into other care settings and perhaps even integrated into chronic care approaches.*
>
> *Surrogates need to receive more respect within healthcare settings, more training and counselling, and ... greater legal discretion to do their difficult work.*
>
> *Group decision making models deserve further exploration; family conflict mediation services must come into wider use in medical settings; "family" must be more broadly defined to include same-sex partners and others with caring*

---

70 State Initiatives in End of life Care 25, "Focus: The Way Forward Thirty-Five Leaders Map the Future of Reform", (published jointly by The Robert Wood Johnson Foundation and the Center for Practical Bioethics, May 2006)

71 B. Jennings, G.E. Kaebnick, and T.H. Murray, eds., "Improving End of Life Care: Why Has It Been So Difficult?" (Garrison, N.Y.: The Hastings Center, Special Report, November-December, 2005), S54

connections though not blood relationships.

Cultural differences should be understood and accommodated to the greatest possible extent.

The moral claims of family caregivers whose lives are often cut short by long-term care-giving must be confronted, and the broader economic consequences of decision making will also have to be debated, particularly as baby boomers age.

Finally, emerging research suggesting that a patient's treatment preferences shift predictably over the course of a terminal illness deserves serious attention. "During the illness, as they lose capacity, patients come to look for more input from the family, trusting in its ability to decide what is best for them," says Daniel Sulmasy, MD, PhD, director of the Bioethics Institute at New York Medical College.72 Such findings argue for a wider application of the "best interest" standard of surrogate decision making, Sulmasy says."

---

72 The quotation from Daniel Sulmasy was originally published in State Initiatives in End of life Care 23 (published jointly by The Robert Wood Johnson Foundation and the Center for Practical Bioethics, (2005), 6.

Chapter 15
PERSONHOOD AND DIGNITY

Human Rights and the Dignity of the Human Person

Human rights and human dignity are intimately connected. Human rights are based on acceptance of the intrinsic dignity of the human person. As the Irish Catholic Bishops' Bioethics Group said in its submission to the Forum:

> *"Human dignity is not dependent on capacity to function, on how we are perceived by others, or indeed on how useful a person may be to society. Dignity derives from who and what we are. A person who is no longer competent to make decisions remains a person and retains all the dignity that is inherent in being a person."*

The very first Article of the Universal Declaration of Human Rights was quoted at public meeting , as follows: "All human beings are born free and equal in dignity and rights." The purpose of human rights is to uphold the dignity of every person by promoting recognition and respect for each in his/her own right.

Human Rights at End of Life

The Irish Hospice Foundation website reminds us that to die with dignity is a right, not a privilege. One contributor to the Forum, probably speaking for many, said, "If there's one thing I want in this world, it's to die with dignity.

> *"This leads me to hope",* another said *"that society will become more sensitive to the needs of the dying person rather than to their disease. Health professionals and all those involved in the care of the dying must pay attention to the <u>unique</u> status of each dying person. The capacity to effect this attention is enhanced when helpers are trained to listen and hear in an active fashion."*

Dr Maurice Manning, President of the Irish Human Rights Commission, said at the inaugural meeting of the Forum that the right to full human dignity, which lies at the core of all international human rights treaties, cannot be enjoyed by those suffering unrelieved yet treatable pain. He added that the rights of people with life-limiting illnesses are not, however, limited to relief from pain or even access to health services. Palliative care emphasises all

Chapter 15   PERSONHOOD AND DIGNITY

aspects of a person's life, which should include the enjoyment of a full range of legal and human rights.

However, the exercise of these rights remains a long way off for some:

> *"While I have not observed it directly, I understand that the ethos of the hospice system is to provide whatever palliative care is necessary to allow a person to die free from pain and with human dignity (and if that care hastens the demise of the person, that is an unfortunate but necessary consequence in preserving the dignity of the person). Unfortunately, what I observed in relation to the death of my own father seemed far from this goal."*

People wrote and spoke of their understandings of dignity at end of life, variously emphasising dignity in the final illness, dignity in dying and dignity after death. Some emphasised that dignity in death is a basic human right that must be recognised and respected. Others said that how the body is treated after death is very important: "treating remains with respect, so that rights in life are extended to persons after they die."

Others voiced concern for the dignity of certain groups at end of life. Alice Leahy of TRUST, and herself a member of the Human Rights Commission, said of homeless people, "we try very hard to ensure that they receive in the last days and hours the respect they often probably never knew in life."

Representatives of intellectually disabled people and people with chronic illnesses expressed concern for the realization of their rights to dignity and a good quality of life at end of life. At one workshop it was emphasised that no one has the right to deny a person essential healthcare, including palliative care at end of life.

Particular concern was expressed also for the rights older people. Professor Des O'Neill, the then President of the Irish Gerontological Society said at a Workshop that older people had the right to adequate treatment and the right to participation at all stages of life; the main risk was under-treatment, he said. Dr Maurice Manning asked why are these, the oldest children of our nation, cherished so unequally. "Another person said in a submission:

> *"I do not have the answers but I know that the dignity of our parents is eroded, their families traumatised as hospitals fail to cope with the complexities of ageing and the end of life."*

Chapter 15   PERSONHOOD AND DIGNITY

The Patient as Person

Quoting from a number of sources, a consultant representing the Irish Palliative Care Medicine Consultants Association (IPMCA) emphasised how important it is in medical and nursing settings to treat patients as people:

> William Osler, who said "It is as important to know the person who has the disease as it is to know the disease."

> Ken Wilber, who said in his book, Grace and Grit, "Around the tumour there is a human being."

> Cecely Saunders, who said, "You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you to die peacefully, but to live until you die."

Affronts to the Dignity of the Person

While there were many testimonies of outstanding treatment provided to people at end of life and to their families, there were, worryingly, other examples of treatment in healthcare settings which could only be described as affronts to the dignity of the person. The following are some examples:

> *"A man changed my aunt's nappy. My aunt, if she knew that! Everyone knew what motion she had, or the lack of it, and when she got her enema."*

A person spoke about treatment in the aftermath of a person's death, as follows:

> *"Just before we were leaving we went to look for the nurse again. I asked what should we do with my mother's belongings and she told me to take them with us. They gave me a black plastic bag. I cannot still explain how I felt about that gesture. I wish now I had said that we would come back with her case, which we had brought home.*
>
> *We put all her belongings into that black bag and carried it out of the hospital. Her clothes and all her little mementos and treasures so dear to her in a black plastic bag similar to the ones they used on the wards for rubbish. I still get upset at the indignity of it."*

Chapter 15   PERSONHOOD AND DIGNITY

Muscular Dystrophy Ireland said that families have reported being asked to clear out the person's room or locker within a few minutes of their death. Tact and understanding should be shown to family members at this time.

The Ombudsman, Emily O'Reilly, wrote:

> *"A number of complaints to my Office have dealt with the way in which personal possessions were dealt with after the death of a loved one. In a number of instances, extremely soiled clothing was bundled into a plastic bag and left for collection by the family. The soiled clothing was a painful and stark reminder of the suffering of their loved one in their final days and hours. These actions failed to demonstrate a respect for the dignity of the deceased or their family."*

A Clinical Services Manager listed some of the challenges she faces in her service, including:

- *Funeral Directors have put a child's remains in the boot of a car or have brought an adult coffin which has caused extreme distress for families*
- *On occasions coffins have been too small*
- *Children have been taken away in a body bag*
- *When a child has to be taken to hospital for post-mortem taxi men find it difficult, as have gardai, when they have to identify a child*
- *When a child presents with HIV it is impossible to find an undertaker.*

Conclusion

The meaning of the term 'dignity' must continue to be associated with upholding the sacredness of the life and of the death of each person; it must inform the care and treatment of the dying person and of his/her remains after death; it must also inform communication with those present at end of life and following death of a loved one. Clearly an urgent reappraisal of the dignity of the treatment of those at end of life, of their remains, and of their families must be undertaken in all institutions where people die in Ireland. Standards protecting the rights of those at end of life and particularly their rights to person-centred care and dignity must be upheld. Where such do not exist, they must be developed, implemented and regularly reviewed.

Responses to the Needs and Rights of People at End of Life

5

Chapter 16
FAMILIES, FAMILY CAREGIVERS, SUPPORT ORGANISATIONS, VOLUNTEERS AND ADVOCATES

Introduction

One of the most striking discussions to emerge from the Forum was that relating to the place of families in end of life care. At times, the perceptions of family members of their rights and their role in end of life care appeared to be at odds with those of medical professionals. Some contributors even appeared to suggest conflicts of interest between families and professional caregivers in end of life situations. Is this a significant issue? If so, how should it be addressed?

Families

Over the past three decades there have been major changes in the structure of Irish families. Families come in all shapes and sizes and death touches all of them.

When we speak of families in this chapter we mean the intimate circle of people closest to individuals at end of life. These include, married people and their children, partners and their children, single parents, grandparents, the widowed, single people, friends and neighbours - anyone, indeed, related or particularly close to a person at end of life.

Most people have many relatives. However, some do not; and they have special concerns about end of life:

> *"I live alone. I don't have a partner. My parents are dead. I have no brothers or sisters. My nearest relative is a cousin, significantly older than me, who lives in the UK."*

> *"What price the quality of the last few years of one's life, especially for those who are not supported by their family, or who don't have one?"*

Some have surrogate families, for example, homeless persons who visit TRUST or the Simon Community, or those without relatives, or out of touch with relatives who are visited by Friends of the Elderly or by neighbours.

Or some in prison:

> "In the prison environment the term family can be redefined. There are some
> inmates who would no longer have contact with their relatives. Other prisoners
> become their 'surrogate family'."

Views on Family Involvement in Care

Some contributors emphasised that families are the primary carers. Family Carers are
defined as family, friends or neighbours who provide care for children and adults with severe
disabilities, frail older people, and people who are terminally ill. In a workshop discussion there
were opposing views on whether our society values family caring more or less today than in
the past. In another workshop some said that families were pulling out of care and handing
over their relatives to society; while others were saying "Don't professionalize end of life to the
exclusion of the family" and "Wouldn't it be marvellous to find a way to empower families."

And, while the Mothers Union was recommending more family involvement in the care of
patients and that they should be kept informed of the patient's condition, a retired consultant
physician had this to say:

> "A recurrent major difficulty in the Irish context in the physician/dying patient
> 'relationship' is the frequent interference by relatives (who, other than a spouse,
> may have no rights) insisting that the dying individual must not be told of his/her
> situation. This can create a major barrier between the carer and the patient. What
> ensues between relative and patient one never or rarely learns but the distrust now
> becomes trilateral! In my experience this interference arises most commonly from
> the least well educated, often rural, traditionally religiously orthodox individual."

Others were not particularly positive either about the part played by family members at end of
life, as the following excerpts indicate:

> "But for me, the greatest tragedy at this difficult time is the persistent denial by
> family members (often aided by the medical profession) of the true situation in
> which they find themselves. This prevents intervention aimed at making life more
> pleasant for their dying relative/friend."

> "Many years ago making funeral arrangements with a family they told me how a
> short while before their father died, they had asked him if they could do anything
> for him. His response, "Why don't you ... off and let me go peacefully!" They

realised that they were holding him back, as he wanted to die quietly and without them being too near.

Others were concerned about prejudicing professionals' ability to get on with their clinical responsibilities in the interests of their patients. Speaking about, what he termed, Advance Care Preferences (APCs), another person said:

"While the autonomy of the patient is to be protected from 'professional paternalism,' it must be acknowledged that healthcare professionals have a certain expertise which most patients and their relatives do not possess and it is important that ACPs do not have the effect of preventing healthcare professionals from seeking to use their expertise in the best interests of their patients ...

... Notwithstanding the existence of an ACP, healthcare professionals remain personally and professionally responsible for the clinical decisions they make, or fail to make, in the care of their patients and this responsibility cannot be abdicated to the proxy any more than they could be to a competent patient."

Family Care Provision - the reality

However, to focus only on those who provide professional care services would to be to completely distort the reality of how acute, chronic and end of life care is delivered in Ireland. More than 40,000 people in this country give more time, 43 hours per week, than the average worker gives to his job to "regular unpaid personal help for a family member with a long-term illness, health problem or disability, including problems which are due to old age and providing help with basic tasks such as feeding or dressing".

The Carers Association estimates that Family Carers provide over 3.7 million hours of care each week and save the State over €2.5 billion per year.

According to the Carers Development Unit, HSE South, in the region of 5,400 people aged between 15 years and 19 years gave unpaid personal help to a family member or relative each week, just over 1,000 of these young carers said they devoted in excess of 15 hours a week to caring, while almost 500 young people between 15 and 19 gave 43 or more hours a week to looking after family members.

Many carers face a daunting challenge in looking after a family member. Sometimes this challenge can arise very quickly and unexpectedly, such as in the case of a person who has previously enjoyed good health suffering a stroke or other medical incident and concerns may

present themselves for which the carer may be unprepared or feel unable to cope. In other situations, the caring role may evolve gradually over time, it may also continue for many years and often in the case of dependent children may continue into their adulthood and their parents' old age.

The levels of support required will vary depending on circumstances and the carer's situation, whether, for example, the carer has found him/herself in that position due to

- The onset of dementia in a family member

- Acquired brain injury

- Stroke

- Cancer

- Neonatal care

- Any other reason.

In a submission, an HRB Research Fellow and member of the Respiratory Nurses Association (ANAIL) gave the example of care of persons with advanced COPD, which, she said, often extends over many years:

> "Those with advanced COPD who are oxygen dependent are frequently dependent on caregivers for help with basic activities of daily living. These caregivers are intimately aware of the individual's care needs, illness experience, desires and symptom management. However, they are rarely consulted by healthcare professionals, their caregiving is rarely acknowledged, their information needs in relation to treatment plans are rarely met and their loss and grief are rarely acknowledged.

> "Caregivers need to be more actively acknowledged by healthcare professionals than is currently the case. This needs to be done well in advance of end of life stage so that they are informed about what to expect and how to access help. The caregiver acknowledgement and role needs to be debated in relation to complex decision making such as ventilation near end of life."

Mental Health Ireland adds:

> "The way the non-professional caring role is viewed by the medical profession and by the state needs to change. The role of carers in providing and enabling quality

care for people nearing end of life needs to be recognised and valued. Carers provide enormous benefits to the State through the care they deliver."

Parity of Esteem and Partnership between Family and Professional Carers

It is clear that family caregivers not only need to be recognised for the role they play in caring for people with disabilities, serious illnesses and those at the end of life, but they also need to be treated as equal partners in the care process for the sake of those they look after. Though it applies to family caregiving in all situations, this point was well made by the Alzheimer Society of Ireland:

"In any debate about the end of life needs of people with dementia the central importance of the unique role of the carer in the life cycle of dementia must be recognised. They should be ... [treated as] core member[s] of the end of life care planning process and be involved in the decision making processes."

Given current models of acute, chronic and end of life care it was therefore not surprising that a wide range of issues affecting non-professional caregivers were raised in Forum workshops and in discussions at public meetings, including:

- that adherence by medical practitioners to the principle that their legal responsibility is to the patient can sometimes effectively isolate family carers from the care process to the detriment of that process, where their knowledge and understanding of the patient can be very important;

- that family carers often can't access critical care and services for family members at the end of their lives during holiday periods, weekends, etc.;

- that unilateral decisions by medical or nursing staff to reveal a terminal or end of life diagnosis to a patient who has not requested it, without any consultation with close family members, is wrong;

- that the characterisation of communication between medical/nursing staff and family members about a patient at end of life as "collusion", and inherently damaging to the interests of the patient, is also wrong;

- that terminology used by medics when they do communicate with patients and family members is often unhelpful;

- that physical facilities and opportunities for next of kin to communicate with medical staff, who have immediate responsibility for decision making in respect of a family member who is critically ill, are often absent;

- that the absence of joined up working between community, medical, pharmaceutical and other service providers, on the one hand, and the acute and long-stay medical facilities, on the other, places unnecessary strain on family carers and robs them of time with those at the end of their lives.

In a Position Paper,[73] the American College of Physicians says:

> *"Although hospice and palliative care address the impact of illness on both patients and families, historically the patient-physician relationship has focused on the patient and his or her rights and interests with less attention to the patient's experience within the context of his or her family and social relationships. Contemporary bioethics, with its emphasis on patient autonomy and confidentiality, has supported this model but is beginning to recognise the need for a family-centred approach. Caregivers require information, access to resources and support to facilitate their role ... Integrated healthcare models such as the Advanced Medical Home model directs physicians to 'create an integrated, coherent plan for ongoing medical care in partnership with patients and their families'.[74]*

However, the American College of Physicians says that an expanded patient-physician-caregiver relationship may present ethical challenges. It therefore developed ethical guidance in conjunction with ten other professional societies with a view to fostering mutually supportive patient-physician-caregiver partnerships. The guidance is based on four primary principles for physicians, who may face ethical challenges collaborating with patients and caregivers, while preserving the primacy of the patient-physician relationship, as follows:

- Respect for the patient's dignity, rights, and values should guide all patient-physician-caregiver interactions.

- Effective communication and physician accessibility are fundamental to supporting the patient and family caregiver.

- The physician should recognise the value of family caregivers as a source of

---

73 Mitnick S, Leffler, C, and Hood VL, for the American College of Physicians Ethics and Human Rights Committee. Family caregivers, patients and physicians: ethical guidance to optimize relationships. J Gen Intern Med. 2010; DOI 10.1007/s11606-009-1206-3.

74 Barr M, Ginsburg J. The advanced medical home: a patient-centered, physician-guided model of healthcare. Policy monograph. American College of Physicians: 2006.

continuity regarding the patient's medical and psychosocial history and facilitate the intellectual and emotional transition to the end stage of serious chronic illness.

- When the caregiver is a healthcare professional, the physician should draw appropriate boundaries to ensure that the caregiver is not expected to function in a professional capacity in relation to the patient and that the caregiver receives appropriate support referrals, and services.

This guidance should be studied by the appropriate medical and nursing authorities and carer organisations in Ireland with a view to identifying how more effective partnerships between medical and nursing practitioners and family caregivers can be systematically established in Irish healthcare provision, particularly at end of life. Particular attention should be given by physicians to validating the carer's role and establishing what specific commitments, if any, the caregiver may have made regarding how he or she will manage the patient's care.

Family Caregivers and the Residual Model of Care in Ireland

Tessa Ing, Head of End of Life Care, Department of Health, London, addressed a Forum workshop in October 2009. She said that the British National Health Service End of Life Care Strategy (July 2008) includes a chapter on support for carers and families. An aim of the Strategy is to ensure that appropriate advice and support is available for carers at every stage of the end of life care pathway. This is in keeping with the NHS Constitution Handbook, which says, "The NHS commits to work in partnership with you, your family, carers and representatives." She said that the strategy for carers, *Carers at the heart of 21st-century families and communities* (2008), committed the British Government to ensuring that by 2018 "carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role".

In this country there is no published national Carers Strategy as noted by contributors to the Forum. Nor is there any commitment to respect carers as expert care partners, as in Britain. This is because we continue to adhere to a short-sighted 'residual' model of care in Ireland. The Carers Development Unit, HSE South states in its submission:

> "All commentators agree that the carers' role can be isolating and stressful and can have a detrimental affect on the health of Carers. The Equality Authority in 2005 stated that 'there are compelling reasons to give a high priority to the Caring issue at this point in the development of Irish Society' and further states that ' a key

*policy challenge will be to address the persistence of the ' residual ' model of care in
Ireland. The role of the state in relation to family care has been primarily a residual
one, with an expectation that families provide care with little state support. There
is a need to develop a greater role for the state in relation to the provision of care
services that are appropriate, adequate and accessible.' (2005)[75] "*

It is not surprising then that a carer should write to the Forum expressing dismay at the lack of
support for some caregivers who take responsibility for relatives dying at home:

*"It was her wish and mine that she should die at home. However, I did not get the
support that was needed to go the full journey.*

*This is my story and I tell it just to outline my experience of where the system fails
and give some idea of what it is like to be the caregiver and take responsibility."*

A carer, whose mother had died some months previously, said at a workshop that she felt that
no one in the health services was interested in her opinion. "I was disempowered," she said.
Her experience of the system was of 'a one size fits all' approach. Because of staff shortages,
staff did not have the time in any event to provide person-centred services, she felt.

Issues for Family Caregivers

In its presentation to the Forum, the Carers Association enumerated end of life issues for
family carers, as follows:

- Enabling the patient to be cared for in a place of their choosing

- Providing a level of care which ensures the maximum comfort of the patient

- Ensuring carers have the skills necessary to provide end of life care

- Balancing caring with work and family responsibilities

- Additional costs of caring

- Health and well-being of the Carer

- Legal and financial concerns

- Life after caring.

---

75   The Equality Authority (2005). Implementing Equality for Carers. Dublin: The Equality Authority

5

The Caring for Carers organisation listed the following issues for family carers:

- Time and logistics, physical, financial and emotional issues, health risks
- Accessing treatment
- Feeling of being left behind
- Hovering beside their loved ones
- Waiting for death
- Being experts and protectors.

Caring for the Carers

The Programme Development Manager, Irish Hospice Foundation listed health and care services and supports needed by family carers, as follows:

- Regular respite is required for carers of people with a life-limiting illness and healthcare workers providing this respite must have palliative care training
- Health and care services must consider needs of carers when assessing health service needs of people with disability
- Health and care providers must include information support (directed at both carers and patients) as part of the service they provide. Such information provision needs to be available in a variety of formats, and cover the broad spectrum of information needs, including advance care plans.
- Where the person with a life-limiting illness requires to be cared for in a hospital, nursing home or hospice, the needs of family carers should be accommodated. For example there should be family accommodation, tea/coffee making facilities etc. As far as practical they should be allowed to remain involved (if they so wish) with the practical aspects of caring in this care setting.
- When their loved one dies, suitable private facilities should be available for carers.
- Appropriate bereavement support should be available to carers of family members.

Supporting Families in the Provision of End of Life Care

The family, as one speaker said at a public meeting, is the primary carer, not the nurses, doctors or priests. However, as a workshop participant put it:

> *"The diagnosis of a critical or life-limiting illness in a child for a number of families will mark the end of normal family living as they know it, and the beginning of another family life filled with what the future may now hold."*

Another contributor added:

> "Practitioners need to appreciate that the family does not come to the palliative care team for help in changing their family system. Rather, they come for help in dealing with the death of a member in a manner that supports the integrity of their family as much as possible. The function of the family is to be a support to its members at time of trouble and, when we offer ourselves as healthcare professionals in this role, we are offering to become an extension of the family."

Some organisations indicated their commitment to the support of families in caring for members at end of life. For example, the CARA (St Michael's House) nursing staff and the multidisciplinary team who run the special unit for Down's syndrome clients with Alzheimer's disease work in partnership with families and involve them in decisions that affect those clients. Families are encouraged to make frequent visits, attend reviews and planning meetings. Guidelines are in place in relation to end of life decisions. Facilities are available for the families in the times of need such as overnight stays. Pastoral care is provided to offer support to the families if it is needed. Regular family meetings are held to give family members an opportunity to share their experiences, feelings and concerns with each other and with staff.

Other organisations, including the Carers Organisation, Caring for Carers, ARC, the HSE South Carers Development Unit, and Mental Health Ireland - to name but a few - enumerated the ways they support family carers in their caring role generally, and at end of life in particular. Given that it is the desire of most people to die at home, the home care packages, the respite and other practical and emotional support services provided by these organisations are important contributions to those attempting to realise this aim with the aid of their families. However it was equally clear from their contributions that this aspiration is not realisable for most without 24-hour access to palliative nursing care services and universal access to appropriate end of life home care packages available on the basis of need.

IBEC, in its submission, highlighted the importance of carer's leave for the support of families in the provision of care at end of life

> "Under the Carer's Leave Act 2001, an employee is entitled to 104 weeks of leave to provide full-time care and attention to a person who needs constant supervision or frequent assistance during the day. Employees must have one continuous year's service to obtain the leave and the Department of Social and Family Affairs decides

*whether the care is required. Employees give six weeks' notice of intention to take
the leave. Where the person requiring care is a child, then of course parental leave is
another option for employees."*

The Contribution of Volunteers to the Care of the Dying

One contributor remarked that he saw no reference in Forum documentation to volunteers who
work daily and nightly in hospices, which could not function without them and he asked whether
these volunteers could be allowed a voice in the Forum.

Another person who moved to Ireland from Canada sought to undertake hospice volunteer work
that she had been trained to do in Canada. She said that she was extremely disappointed to
discover that no such voluntary force exists in either of two counties in which she has lived since
coming to Ireland.

There are, of course many voluntary organisations and organisations engaging volunteers,
such as those listed above, which provide invaluable support to people at end of life and to the
bereaved. Rainbows Ireland, for example, a volunteer organisation with charity status which
provides peer support to children, teenagers and adults who have suffered a significant loss in
their lives has 1,500 to 2,000 volunteers. None the less, as indicated by the person who moved to
Ireland from Canada, there are significant gaps to be filled by properly trained volunteers. As she
said,

> *"I feel certain that the number of healthcare professionals involved in the care and
> support of the dying and the bereaved cannot be available in sufficient numbers to
> meet the need, and I submit that the introduction of voluntary assistance could be of
> great benefit."*

Volunteers also play a very important role in befriending and supporting people who are
bereaved.

The Carer as Advocate

Just as the family carer should be considered an equal partner in the care process by professional
carers, so too, in many cases, the carer should be recognised as the legitimate advocate for the
person at end of life. The Alzheimer Society of Ireland in its submission makes this point:

> *"In the dementia care model, the role of the carer is of paramount importance; they
> are not only the carer in the traditional sense but are also acting as the voice of the*

*person with dementia and being their advocate. The importance of biography is
core to providing person-centred care and this fact equally applies to the terminal
stages. Carers are often faced with difficult end of life decision making and research
carried out in Canada highlights the importance of including family caregivers'
experiences in working towards caregiver/medical team consensus around
treatment decisions at the end of life in dementia (Caron, 2005)."* [76]

A Programme Development Manager, Irish Hospice Foundation wrote:

*"There are certain situations where persons with life-limiting disease require
their informal carers to act as their advocates, due to ill health or deterioration in
cognitive ability. Carers in this situation may often require guidance, direction and
assistance to carry out their role as advocate effectively and this should be actively
supported. Information pertaining to legal status and power of attorney should be
fully explained to family carers who find themselves in this situation."*

A daughter of a person with Alzheimer's disease who has spent seven years in a nursing home
wrote:

*"We are her voice. Only her three daughters can understand her wishes. We feel a
responsibility towards her. We have had to lobby for a special bed for her, a special
chair, neck supports, psychiatric assessments and most recently we had to request
that she was assessed by a palliative care team."*

At a workshop discussion the importance of advocacy for the critically ill and older people was
underlined:

*"Being ill is disempowering, so everyone needs an advocate, for example to look to
mouth care, personal care, medication, hygiene, false teeth, feeding etc. Sometimes
PEG feeding is used because it is easier for staff, who don't have to spend so long
feeding patients. One person said, 'To me it is awful except in cases of cancer of the
oesophagus.' Being over 65 can mean that you are regarded as a bed blocker. So you
may have even more need of an advocate."*

---

76 Caron, C.D., Griffith, J., and Arcand, M. (2005) End of Life Decision Making in Dementia; the perspective of family caregivers. Dementia,
international journal of social research and practice, Vol 4 (1) 113 - 136

The primary objective of advocacy is to protect the patient's rights and to represent patients' interests – it is not to impose decisions on patients but is to protect their dignity, their freedom of choice, their privacy. This is the responsibility of healthcare professionals in the first instance; and many will see it as their job to support patients in their decision making and to act on their behalf, on behalf of children in their care, for example:

> *"Parents cannot necessarily insist on enforcing decisions based solely on their own preferences where these conflict with good medical evidence, or where these decisions would put the child's life at risk."*

Independent Advocacy Services

Thinking of her future, a person who has no family wrote:

> *"One of the few real worries I have in my life (lucky me!) concerns who will advocate for me in later life, and particularly in any future life-threatening illness.. I've already had cancer, so I know full well how incredibly hard it is to keep track of what's going on and advocate for oneself when you're ill, not just with medical personnel, but also with everyone else … But it's not just the social aspects that concern me. In fact, more than that, it's the endless negotiation with medical personnel and social services, the scrum to get appointments, to be seen, the way of getting to them, the decisions that have to be made, and all the other paraphernalia that accompany the approach to the end of life."*

So it is that where there is no family member or close friend to protect the patient's rights or to represent their interests, an independent advocacy service should be provided to represent those interests, very particularly where mental capacity is impaired. "The support of an independent advocate should be viewed as an essential good practice element for the person during all stages of their dementia, but in particular at the advanced stages," said the Alzheimer Society of Ireland in its submission.

The Citizens Information Board (CIB), which at the time of writing was funding 46 voluntary/community disability advocacy projects, said in its submission to the Forum that it believed there is a need for further exploration of how the independent advocacy role can be developed in acute hospitals where 40% of deaths occur and in nursing and residential care settings, where 35% of deaths occur:

"While healthcare professionals generally see themselves as acting as advocates for their patients, there is an overall advocacy function that is, perhaps, not well provided for under current arrangements. This is understandable to some extent as the acute hospital ethos with its clear emphasis on healing may not give sufficient emphasis to end of life care. People may need help with negotiating the different daily realities that they encounter in hospital setting dealing with a range of health professionals, dealing with their own families (who may also need support) as well as personal support in coming to terms with the dying state."

The CIB recommended that people be given the option of having an advocate (family member or other individual acceptable to the person) present at meetings when a diagnosis is being communicated and when end of life care options are being considered. The Board said:

"The role of advocate operates along a continuum from the provision of information on rights, options and choices, to providing support and assistance to people in accessing and ensuring equality of access to services, to assisting the person and his/her family come to terms with the end of life situation and plan their responses and coping mechanisms accordingly.

The National Disability Authority noted in its presentation to the Forum in May 2009:

"The Scheme of the Mental Capacity Bill 2008 gives limited guidance on supported decision making, and is silent on the issue of independent advocacy around the process of establishing incapacity (See Chapter 22). Supported decision making is a process, whereby someone with diminished capacity has information concerning their options such as healthcare options explained to them in an accessible, supportive way to enable them to make their own choices. Improved provisions on supported decision making would have significant implications for adults with diminished capacity needing to make choices in end of life situations, such as consenting to invasive procedures."

Patient Focus is a national patient advocacy organisation, initially established following the Neary affair. It is funded by the HSE and it gets approximately 500 calls per year.

•   It supports patients and their families who have been damaged by our healthcare system.

•   It empowers the patient or their family to enable them to pursue constructive

resolution of their grievances.

- It gives people information on different processes available to them to do this.

- It supports them during the process, going the journey with them if that is what they want.

Patient Focus listed end of life issues it commonly came across in the course of its work, as follows:

- Lack of dignity

- Poor communication with patient and families

- Invasive Procedures

- Ageism

- Lack of compassion and kindness by professionals

- Patient a victim of system failure

- Lack of services for the Patient to die in their own home

- Late intervention by Palliative Care

- Lack of public awareness and understanding of Palliative Care – some see it as "giving up"

- Where do you take the little complaints

- Use of catheters and incontinence wear for the convenience of staff

- Inappropriate use of PEG tubes

- Over sedation

- Absence of communication; training for communication

- Noise, need for single rooms, privacy

- Visiting hours.

HSE's 'Your Service, Your Say'

Patient Focus referred to the HSE Consumer Affairs facility for recording comments, compliments or complaints about HSE services. It informs its clients about this facility, as appropriate. Complaints can be made to HSE staff, managers or to

- Hospital Network Complaints Officers

- Primary, Community and Continuing Care Complaints Officers.

Patient Focus also commented that while GPs are generally in good standing, they are less in control than they used to be, with the on-call system and limited access to consultants. They are therefore not so effective as advocates as they may have been in the past.

Chapter 17
PROFESSIONAL CAREGIVERS AND SERVICE PROVIDERS

Testimonies to Staff

Many people contributed to the Forum because they wanted to tell their end of life stories. Some of these were far from happy experiences and their purpose was to suggest reforms in the ways we provide for people at end of life in this country. Some were critical of how they or their loved ones were treated. Others however, while critical of the adequacy of services available, of the organisation of services, or of policies and systems governing end of life care provision, were none the less warm in their praise for the manner in which services were provided by professional and non-professional staff in different settings. The following is a selection from testimonies received:

> "Both our children died in hospital ...The care and compassion shown to us by the staff at the local paediatric hospital was beyond expectation. The dignity shown to our children before and after death was exceptional. We were supported by the nurses to wash and dress our children and prepare them to leave the hospital. We were allowed as much time to do this as we needed and everything that was needed for this was available. When it came time for us to take our children home for the last time the staff lined the corridors to say their final farewell. It was so touching and something we will never forget. The nurses from the medical and palliative care teams in the specialist hospital were waiting in our home for us when we returned with the children. We were given the opportunity to return to the hospital to speak to the teams and ask any questions we needed to after the funerals."

> "(Name of person) received loving, individualised, painstaking care from the palliative care team and the staff of the hospital wing where he spent his final weeks. People took the trouble to know him as a person and this enlarged his life at a time when it was constricting ... The chef paid attention to him and called to his bedside ... a nursing assistant chatted at length with him, sharing her family history, her hopes, details of her studies etc ... Cleaners stopped and chatted with him ... The physiotherapist was supportive and encouraging beyond belief ..."

> "So what that client remembers was the kindness, compassion and time shown to

her and that's where we need to be going and there is huge work to be done."

"I recently lost my grandmother who passed away last May so the issue of end of life is very much to the forefront of my mind. She, at 91, passed away very peacefully at the local Geriatric Unit in (name of hospital). She received the best and most caring attention from the nursing staff which made the whole process very dignified.
This care and attention extended to us her family. Too many times you hear bad stories about the elderly being neglected but 'outstanding' is an understatement to describe our experience."

"The social worker in the first hospital was excellent. She went with us through the ups and downs ... The cancer liaison nurse was really good. I had to train. She came out and supervised me here and saw how (name of the person being cared for) was doing. She had many a wise thing to say. It was always what we thought. She was very gentle. Her advice was invaluable ..."

"The hospital organised night nursing through the cancer society. There were amazing nurses from the cancer society. She minded all of us. You can't lie to kids; they only take on what they want to have. You go on automated pilot."

"But it's different now. Good things are happening today. I asked my client could I tell a bit of her story here tonight and she said, of course. Her baby died 6 months ago, age 16 months. The baby was born with a condition that required great nursing and care and was in hospital for 8 months. She gave such a lovely description of how she and her whole family ... (were) cared for around that child. She had a traumatic upbringing herself and she said for the first time in her life she felt safe, because of the care, time and respect she got in that hospital. One nurse said, can I call my baby after your baby? My client was broken-hearted of course, but even in her tears she said how much that helped. So we need to be saying the good things as well as the bad things."

"The evening prior to surgery the consultant surgeon who was a true gentleman visited her. He spoke to my mother, explained what he was going to do and treated her so well despite her confusion and age. He was so respectful of her and shook hands with her before he left. He told us he would look after her very well. All these gestures live with us today."

Testimonies of Staff

No doubt there is a connection between how people view their role in the care of the dying and how others, such as the families of the dying, respond to them as carers. A number of contributors to the Forum, who cared for the dying spoke of how they regarded their work as a privilege and as very rewarding. A Clinical Nurse Manager said:

> *"One of the most rewarding tasks any nurse can ever perform is to support someone at the end of their life."*

An Intensive Care Unit nurse said:

> *"It's been a privilege for me and quite a spiritual experience to sit with people who have 3-4 hours to live, the way they talk, the things they say, I don't think I have ever seen those words in a book. They talk around such things as who am I , who was I in my life and what has my life meant to others? I feel privileged to be here and feel empathy for families who miss this time. Maybe I'm just a facilitator sent to them at that time and not a person as such."*

An Emotional Challenge

However positive caregivers and service providers may be about accompanying people at end of life, it is invariably emotionally challenging. Contributors such as the Irish Nurses Organisation alluded to this and called for better recognition of the need for staff support in undertaking this role.

Graduate Diploma in Nursing (Cancer Nursing) students called for recognition that all staff looking after patients at end of life need support, including Healthcare Assistants, household administration staff, etc.

Other submissions said:

> *"Caring for those with long term conditions and those who are terminally ill is extremely demanding and needs much more support ..."*

> *"The potential impact on staff and volunteers of working with dying and bereavement should be considered at organisational level."*

The All Ireland Gerontological Nurses Association (AIGNA) said:

> *"In all hospitals, community and residential care settings, there are experienced knowledgeable nurses whose openness and empathetic response to the individual needs of dying patients and grieving relatives ease the journey. In the continuing care setting where relationships build up over time, families relate to nurses and carers as friends and staff grieve the passing of a resident who they have come to know and care about for months or years. The emotional investment in this closeness (Holman, 2008)[77] requires nurses and carers to be supported. However currently this is provided on an ad-hoc basis ...*
>
> *The emotional health and well-being of staff has a direct impact on team performance and quality of life of residents. There needs to be structured de-briefing and support for staff."*

Stress management, including debriefing, is well understood by agencies whose staff have to deal with critical incidents, such as Dublin Fire Brigade (DFB) or An Garda Siochana. Dublin Fire Brigade personnel deal with both Fire Appliance Incidents and Emergency Ambulance Incidents. They are trained to Paramedic Level. DFB recognises that it is essential to look after staff to avoid burn-out and anger building up. Its measures include:

- education on the effects of critical incidents on the individual

- post incident defusing

- critical incident stress debriefing

- individual counselling

- stepping down a member of staff seriously affected by an incident.

An Garda Siochana has a confidential Garda Employee Assistance Service, which works on the basis of self-referral, and a Garda Peer Support Service, both of which may be called on following traumatic incidents.

---

77   Hollman, C. (2008) Living Bereavement: an exploration of healthcare workers' responses to loss and grief in an NHS continuing care ward for older poeple. *Journal Compilation*: 278-281

A retired Director of Nursing said at a public meeting that a local Hospitals Committee, which was established to promote the Hospice Friendly Hospitals programme, consulted hospital staff about death and dying. It found that people who deal with death constantly in very difficult circumstances often felt vulnerable. He said there is:

> *"Very little training for any staff, medical or nursing - to prepare them for death. It seemed to be it just happened and if it happened to you a few times you were that better able to deal with it. But sometimes staff have found it very difficult to deal with it and I'm sure nurses here (at the public meeting) and care staff could give some examples of that."*

We will take up these issues again in Chapter 28, which focuses on the management of end of life care.

End of life Services: Aims and Roles

It seems from contributions to the Forum that while people may conceptualize end of life care differently and may ascribe different aims to services and different roles to service providers, they generally do acknowledge that "the ultimate purpose of healthcare, is the well-being of the patient, not just as a body, or as a subject of emotions or of physical sensations, but as a whole person".

In his submission, a retired consultant quoted with approval from "Six Days of Dying" by Mary C. Bateson, as follows: "With implicit triage, they shifted from the effort of healing to courtesy to the dying." In the accompaniment of the dying person, this acknowledgement of the whole person, this courtesy, will be demonstrated in different ways by different people.

From a professional point of view, the Irish Nurses organisation says:

> *"Nurses and midwives have a responsibility to be receptive to aspects of patient care that extend beyond the physical. The INO asks the Forum to place emphasis on the need for nurses and midwives to attend to aspects of suffering that are not responsive to pharmacological interventions alone."*

An Bord Altranais believes that nursing care at the end of life should be based upon the values inherent within the Code of Professional Conduct for each Nurse and Midwife, (April 2000). The nurse must at all times maintain the principle that every effort should be made to preserve human life and, when death is imminent, care should be taken to ensure that the patient dies with dignity.

Standard 4, End of Life Care, from Bord Altranais' Practice Standards for the Care of the Older Person says:

> "All nurses can make a difference to older people and their family at the end of their lives by creating and facilitating a therapeutic milieu that addresses their physical, psychological, social, cultural and spiritual needs."

The All Ireland Gerontological Nurses Association (AIGNA) referred to the above-mentioned recently published Bord Altranais guidance for nurses working with older people (ABA, 2009), which states that the older person should receive comprehensive, compassionate end of life care that is person-centred and responds to their unique needs and wishes. This requires meaningful dialogue and individual care planning.

AIGNA also says the aims of gerontological nursing and palliative care are similar, in their focus on quality of life and death issues such as hydration, nutrition, hygiene, comfort, constipation, pressure relief and skin care and symptom management, such as pain control and breathlessness.

At a public meeting, a doctor said that "the doctor's role is predominantly symptom control; the nurse's is care work; the social worker's is social and psychological and the chaplains are also involved". He described palliative medicine as very much an evidence based specialty but also a caring specialty. "I see it as almost one of the purest forms of medicine," he said.

It is just as important to acknowledge the variety of personal and professional contributions of end of life care providers as it is to narrowly delineate their roles. The following are some examples:

GPs

> "I took (name of child) home when I knew he was going to die and without the help of my GP ... and my local pharmacist ... I would not have coped as well."

Dietitians:

> "The unique professional role and responsibility of the qualified Dietitian working in palliative care is to provide expert consultation to patient, family and staff on the creative variety of feasible options that might meet each individual patient's evolving nutrient needs while catering to the patient's food preferences and

tolerances."[78]

Practice Nurses:

> *"Practice nurses ... are privately employed by General Practitioners to provide a nursing model of care to the entire population of a general practice ... As provision of care is increasingly moved out of hospitals and redirected into community settings, practice nurses are now seeing a wide variety of conditions and diseases, including patients at the end stages of their disease ... By providing appropriate multidisciplinary care to a dying patient within their own community, that person and their family are empowered to retain some element of control over their difficult circumstances."*

Prison staff:

> As already mentioned, discipline staff (in prisons) are a huge support at this time (when prisoners are dying), augmenting the care of the nursing/medical staff.

Chaplains:

> *"Many hospitals still do not employ chaplains. The professional role is not understood. I was a nurse ... and loved my nursing, but I saw the need for someone to listen in a professional way to the patient's fears, anger, shame, loneliness, unfinished business etc and so I trained as a chaplain. I am aware of both sides. Chaplains care for the patient pre, during and after death, also for their families/ relatives. Care of the staff is also the role of the chaplain."*

Recognising and Valuing End of Life Care Givers

As a contributor already quoted above says, "the ultimate purpose of healthcare, is the well-being of the patient ... as a whole person". He goes on to state:

> *"In caring for persons in a holistic way, and especially those who are weak or vulnerable, healthcare professionals are the agents not only of the patient and of his/her family, but also of society."*

---

78   O'Sullivan J, King D. Nutritional Care of the Terminally Ill Adult (1993). In Gallagher-Allred C, O'Rawe Amenta. Nutrition and Hydration in Hospice Care Needs, Strategies, Ethics. The Haworth Press, Inc., Binghampton, New York, 38-39.

The concomitant of this, of course, is, that society must recognise its agents, recognise them for their contribution to the well-being of its citizens who are at end of life. It should also value them for the care they provide to the weakest in society. It should acknowledge that their role in this regard is just as important as that of any of other. In a mature, properly functioning society, the role of the care assistant in looking after the basic needs of people at end of life would be considered just as important as that of the banker, the barrister or the car maker. End of life care workers need to be assured that the work they do is understood and valued.

This was emphasised in different ways by a number of contributors to the Forum, including the following:

> "The way the non-professional caring role is viewed by the medical profession and by the state needs to change. The role of [these] carers in providing and enabling quality care for people nearing end of life needs to be recognised and valued. Carers provide enormous benefits to the state through the care they deliver."

> "The INO calls for recognition of the valuable contribution that nurses and midwives make to holistic care provision."

> "There is a need for carers/nurses in long-term settings to be valued for the unique contribution that they make to the quality of life of vulnerable people."

Competences

To carry out their important work for those at end of life, caregivers and service providers must have the requisite competences and skills. This was stressed by a number of the contributors to the Forum, including Prof Des O'Neill, who said that 'elder care' must be competent, as well as humane and compassionate. The Irish Association of Palliative Care reminded the Forum that "the DOHC report of the National Advisory Council on Palliative Care recommends that all levels of palliative care should be available in all care settings, and that all healthcare professionals should have the skills to allow them to practise a palliative care approach."

To take one example, competence in ethical decision making is important in end of life care. This competence will include the ability to recognise that a moral issue exists and to discern what is the appropriate action to take in a given situation. "To do this," as a speaker said at a Workshop on ethics, "one must have moral sensitivity, moral reasoning, moral motivation and moral character. Moral sense involves awareness of situational aspects that affect the welfare and well-being of an individual. Healthcare professionals require insight, intuition, moral knowing and an ability to recognise certain cues in various situations. There is a need to

be able separate legal and ethical issues, while recognising the inter-reliability one has on the other."

The All Ireland Gerontological Nurses Association said that the challenge for nurses who care for dying people in any environment is to learn how to adopt the skills and ideas of palliative care into an approach that embraces a broader spectrum of people dying from a "life" limiting disease.

Another submission said:

> "It is also essential that staff involved in caring for people who are dying and for people who are bereaved are well informed so that they feel confident about the care and support they give. They should have adequate opportunities to develop their knowledge, understanding, self awareness and skills."

Some people may be born with certain competences relevant to end of life care. Other competences may be learnt in the course of life by those who are open to learning from mentors, by those who are skilled at listening, and by the self-aware. Others can be learned in the classroom and or in supervised work experience. But one way or another we need to identify the competances that are particularly important to good end of life care provision. This was not something that contributions to the Forum addressed systematically. However, Tessa Ing, from the Department of Health in London in her presentation of the End of Life Care Strategy in England referred to a programme, Skills for Care and Skills for Health launched in June 2009. Common core competences and principles for health and social care workers working with adults at the end of life are identified to support the Strategy. These are:

- Communication Skills

- Assessment and Care Planning

- Symptom management, maintaining comfort and well-being

- Advance Care Planning.

The following overarching values and knowledge were also identified as important in the context of End of Life Care:

- Understanding and knowledge of:

    - one's own professional/role boundaries

    - legal and ethical issues - adherence to legislation and advisory guidance around e.g. Mental Capacity Act and the Mental Health Act

    - professional codes of practice or conduct, and their impact on practice

    - the role/contribution of other workers and organisations to ensure leadership commitment and innovation

    - the impact of one's own beliefs on practice

    - approaches to risk-assessment, risk-management and risk-taking

    - approaches to and theories of change, loss and bereavement

    - social models of care, and person-centred approaches.

- Person-centred practice that recognises the circumstances, concerns, goals, beliefs and cultures of the individual, their family and friends, and acknowledges the significance of spiritual, emotional and religious support and the diversities in these regards that there might be between family or social group members

- Practice that is sensitive to the support needs of family and friends, including children and young people, both as part of End of Life Care and following bereavement

- Awareness of the importance of contributing to evaluation and change of services, participating as appropriate, and of involving the people who use them in that process

- Taking responsibility for one's own learning and continuing professional development, and contributing to the learning of others.

In this country we need to give dedicated attention to establishing agreement on what competences are considered important to those caring for people at end of life. Education,

training and other means of developing end of life care competences might be reviewed in the light of the findings. We will return to the subjects of education and training in Chapter 19.

Time to Care

A voluntary hospital reviewed its end of life services in consultation with its staff when it joined the Hospice Friendly Hospitals programme. The hospital's Director of Nursing presented some of the findings of that review to a Forum workshop. Two of the most significant findings were related, namely that staff felt that they did not have sufficient time to give to those at end of life and that the staff/patient ratio was inadequate. Clearly, no matter how competent or how well trained staff are, they cannot give person-centred care to those in their care at end of life if they are understaffed and therefore haven't sufficient time to spend with patients. This issue was raised at the Forum on a number of occasions, and in submissions, such as the following:

> "There is a need for staff to have time to be 'with people' as they near end of life. Much of our current systems are 'routine' rather than 'person' driven and this militates against staff being able to spend time with the person and their carers, informing and reassuring them about what is happening."

> "The nursing staff did their best but the ward was very understaffed. During this time a reduction in working hours came into operation for the nursing staff. The staff told me that the Director of Nursing decided that they would reduce by one staff member on the late shift and on the night shift on that ward. I found this upsetting, as there were many patients who required a lot of care and it was not possible for the staff to manage. I worried a lot about my mother at night and we stayed late until she was sleeping."

> "With a (prison) inmate requiring such intense nursing interventions and often requiring someone to sit with them, this can place unusual demands on staff. There are some settings within the prisons where there would only be one nurse on duty each day and thus extra staff would be required to ensure that a nurse was available to assist the patient with their activities of daily living."

> "The retention of pastoral care worker posts is critical in the light of the current HSE policy of not replacing staff who leave posts for whatever reason."

Chapter 17 PROFESSIONAL CAREGIVERS AND SERVICE PROVIDERS

"There need to be more palliative care nurses to allocate the time and care needed as at the moment they have to cover too large an area. They also need to be more hands on. I am a nurse and I was able to take a larger role than normal in the care of my sister ... Overworked and understaffed they cannot possibly give the appropriate care for the dying."

In her presentation, Alice Leahy the Founder Director of TRUST alluded to a book she edited,[79] in which a diverse range of people address what has become one of the greatest challenges of life today: how to make time for others amidst all the pressures. In a modern world where lives have become increasingly pressurised, we find ourselves short of that very valuable commodity — time.

For a person who is at end of life, their final months, weeks and days are very precious. It is indeed tragic if they want to share that time with another person, but that person is too busy to do so.

---

79 Wasting Time with People? (2009), Dublin: Gill and Macmillan,

Chapter 18
COMMUNICATION

Introduction

Communication was a constant theme throughout the course of the Forum, in submissions, workshops and public meetings. Many communication issues were raised and many stories of poor and even hurtful communication were told. Every end of life relationship necessarily raises issues of communication. So those contributing to the Forum talked about communication in the following contexts:

- the doctor/patient relationship

- professional carer/family & family carer relationship

- the patient/family relationship

- the inter-professionals relationship.

Experiences of how life-limiting diagnoses were communicated were related by a number of contributors and they raise serious questions. However, there was no unanimity on any solution to bad communication at end of life. The clear differences of opinion evident in the Forum over proposed "one size fits all" solutions to both how and, indeed, whether life-limiting diagnoses should be communicated, makes it clear that there needs to be much more debate and public discussion on the foundations of person-centred approaches to communication at end of life. In the last chapter we spoke about the competences needed by staff working with people at end of life and identified the ability to communicate as being among the most important. We return briefly to this subject again in this chapter.

Contributors also spoke about communication issues for people with special needs and the critical issues of language and culture as determinants in end of life, as in all, communication.

The fact that so much interest in communication was demonstrated in the Forum on End of Life would have come as no surprise to the Ombudsman, Ms Emily O'Reilly, who said in her submission:

> *"The importance of good communication in healthcare cannot be underestimated. Failures of communication form the core of health complaints received by my Office."*

Others emphasised the importance of the issue in different ways, as follows:

> "Slowly we are recognising that communication is the key factor as to whether an already sad experience is better or worse. Yet so many find it difficult to communicate and share in this experience of loss."

> "Increased communication and discussion between all parties, i.e. individuals, their families and others close to them, doctors, and other healthcare professionals, will not only help to provide an insight into the individual's preferences regarding future treatment and care. It will also enable all parties to be better prepared for these and other future treatment situations."

> "The important thing to remember is we only have one chance to get it right when supporting a person through terminal illness. We have an obligation to be honestly open and sensitive to the needs of families. Communication allows us to make assessments over long or short periods and assists patients set realistic goals for themselves and families. Good communication also enables families to establish important issues and make adaptations they need to make to a disease process. It also gives them a chance to understand their illness and voice their concerns. By so doing we can help with their difficulties."

One speaker at a public meeting described how, as part of a person-centred care programme, a community nursing unit looked at how they would provide end of life care:

> "One thing that came up was communication with the residents and their families or carers and one question was 'is dying discussed on admission or later?' Other questions included what residents would like to know about their condition and how soon they would like to know, if for example, they were going to have to be transferred to A&E."

Good Communication

> "He was under several consultants over that period. But two of them really stuck out in how they communicated ... with my dad, who was in his late 60s."

> "Another group of professionals were the nursing staff on the 3rd floor of (name of hospital) (Oncology Ward) they were super and my Dad over the 5 years he was in and out of there had a very special bond with them. At that time there was very little turnover of staff and the nurses were predominantly Irish. I always felt this

had an positive impact when it came to the palliative care of my father. There was a relationship there and always clear communication and understanding of his needs and how best to provide them.

To see them at his funeral was such a wonderful gesture as they had cared for him so much during this long illness."

It was noticeable that when people talked about good communication at end of life they were often speaking about palliative care:

"By contrast, the ethos of sensitive but honest communication which is so much a part of palliative care, greatly facilitates the spiritual and sacramental care of those who are dying. An essential element of good hospice care is the fact that the patient's questions are welcomed and answered appropriately. Talk of death and dying is not "taboo". This means that if people pray with the patient, they can pray more honestly too."

"Palliative care places great emphasis on the importance of good communication between patients and professionals. The importance of establishing trust between the patient and their healthcare team allows the patient's wishes about treatment to be honoured while they are able to inform the professionals caring for them."

Communication with medical consultants being a two-way process, a speaker at a workshop emphasised the importance of assertiveness in good communication with them:

"Good communication with patient, family and between staff: younger nurses and patients more able to question consultants than older people: Need to be able to say to the consultant, 'I don't understand.' Need to be able to discuss care needs with confidence."

Bad Communication - 'Social Disrespect'

In Chapter 10, on psychosocial needs at end of life, we spoke about disrespectful treatment of patients at end of life. There were many instances and stories of bad experiences of communication told at the Forum. Many related to the communication of 'bad news', which we will turn to in a minute. But some did not. One person wrote:

"With regard to my complaint, it is about the manner in which my mother was

treated by the out of hours doctor in fact, he did not treat her at all, she was dying, and all he said was "that she would wear herself out and go asleep eventually". As a speaker at the meeting said, when someone is dying they need to feel that they will be OK. That is not a huge ask of a civilised society but unfortunately it was too much in this case."

One must ask whether people should be allowed to practise medicine if they are not prepared to take their dying patients seriously. If they discriminate on the basis of the age of their patients, their ageist behaviour should surely be grounds for disciplinary action.

The Ombudsman confirmed the existence of perceived disrespectful treatment of patients by healthcare staff:

"Some complaints concern allegations about the way patients or families were spoken to by healthcare staff. Patients or families alleged that staff members spoke to them abruptly, unprofessionally, rudely, aggressively or disrespectfully. In some instances, following an examination of the complaint, the staff members concerned did acknowledge that this was the case and an apology was offered. In many cases, it is impossible for my Office to establish the facts, as it may be one person's word against another. My Office, however, constantly reinforces the message to Healthcare Management that sloppy, insensitive treatment of patients or families is completely unacceptable, regardless of circumstances."

Breaking Bad News badly

One person wrote bravely to the Forum about the damaging effects that bad communication about her partner's terminal illness had on herself and her partner's relationship at the end of life:

"My problems with this 'end of life' experience are, when I consider them, all to do with COMMUNICATION. Initially, when I was given (Name of partner)'s prognosis, it was articulated in quite a brutal manner and from that second onwards I had no hope. Nor could I go back to (Name of partner) 's bedside and discuss it with him, since hypercalcaemia had, at that stage, brought on considerable confusion. There was no way I could talk with him. I relayed the news to his daughter and we discussed together the best way to tell (name of partner) the news. We considered it was our duty to do so. It was also our RIGHT to do so. However, when we were

with (name of partner) again, and after he had become lucid once more, we found he had already been told.

NOW, months later, I feel that something precious had been taken from us. (Name of partner) and I had a right to hear the SAME TRUTH AT THE SAME TIME. As it was (name of partner) said "I'm dying, did you know that I'm dying" and we acknowledged that we did and that was the end of it. I tried to open up the subject a few times, asking how he felt, if he was afraid etc. but he blocked any real discussion on the matter. He did, however, give directions for his funeral and attended to some money matters. I believe now that if he and I had been together at this most awesome moment it would have freed him to open up more and we might have had the kind of chats that would mean a lot to me now. It's a simple matter really. If hospital protocol required that he be told by staff there and at a certain time, then the option of calling me in to be there at that time should have been explored."

The following excerpt is taken from the presentation of a study of the grief experience of same-sex couples at a Forum workshop:

"I went in ... they were going to see him at ten o'clock, I got there at, we'll say, a quarter to ten. They'd seen him at nine o'clock. And, I thought, when I went in, I just seen this person who I cared about very, very much, and I just looked and seen this person, like, just, totally, totally devastated. He was told by the consultant, "You're going to die. There's nothing we can do. And, we're sending you home," and walked out. And, I remember at the time I was so, so angry about it. And ... it took me a long time to get over that anger... and, they just discharged him. It didn't matter. There was no referral. They didn't care. That's the impression [they gave]"

The Ombudsman, in common with a number of other contributors to the Forum, also spoke of the insensitive way bad news, whether news of a life-limiting diagnosis or even of a death, have sometimes been communicated.

" Breaking news of a death is a difficult and challenging task for hospital staff, especially if the death is sudden and no family members were present. My Office has dealt with one case where a woman was told of the death of her mother over

the phone. In other cases, relatives have been upset by the failure of senior medical staff to approach them and to offer condolences on their bereavement. Whilst this in itself was not the sole basis for their complaint, it merged with a number of actions or inactions which led the family to feel very aggrieved and hurt about their experience, greatly adding to the trauma of their loss.

The communication of a traumatic diagnosis is a common area of dissatisfaction. Some people are given devastating news on a busy ward, by a relative stranger, without a familiar face to share their grief. A busy doctor can underestimate the impact of a test result on his or her patient. A consultant may wrongly assume that another staff member will sit down with the patient afterwards and provide counselling."

Assumptions - at times erroneous - are sometimes made about the amount of information a patient is capable of taking in, or even wants to take in. It is vital to avoid a "one size fits all" approach to the breaking of bad news. There are many good policy documents on the breaking of bad news, but policy isn't always followed.

A person who presented a paper at a workshop contrasted the experiences, particularly the communication experiences, of three mothers whose children died shortly after childbirth. The first dates to the early 1960s.

(Name of mother) delivers her son after 16 hours in labour. She is told her baby is abnormal and will die. The nurse actually said to her "it must be something in the family." (Name of mother) is not allowed to see or hold her baby and he is taken away. She is told to pull herself together and be grateful she has other children at home. Her son was left in a cold corridor where he developed pneumonia and died.

Almost 40 years later (name of mother) found out that her son lived for 11 days, he was buried in the Old Angels Plot in Glasnevin where over 50 thousand infants are buried, each sharing a grave with 69 other babies. Up to 13 babies per day were buried there.

(Name of mother) was prescribed Valium for her sadness and grief and stayed on it for most of her life. She grieved every day in silence for her son who was, as she says, unnamed, unbaptised, and gone to limbo."

The second relates to the birth of her own daughter in the early 1990s, who lived for six weeks. A paediatrician attending her said:

> "In other countries they practise euthanasia in cases like this".

Only much more caring and considerate communication later by another doctor helped her recover from this potentially devastating treatment.

The third was last year when an expectant mother contacted her about the tragic diagnosis: her unborn child had a congenital condition incompatible with life. She would continue her pregnancy knowing that her baby would die at birth or some time after birth. How would she cope with new life growing inside her; feeling her baby kick and her body adjusting to embrace his delivery into this world and at the same time, and by a cruel twist of fate, comprehend his death.

> She asked me, What will happen when he's born? Will I see him? Can I hold him? Can we take a photo of him? Will he look OK? How long will I have with him? Can I bring him home? Will the hospital help me to care for him? Will they let me bring him back when he seems to be near the end if I cannot cope? Does he have to have a post-mortem? How do I organise a funeral? Who will help me?"

The person presenting the paper said that what struck her most about the call from this mother (in contrast to her own experience and that of the mother who went through a similar experience in the 1960s) was that she was able to ask these questions out loud and that no one thought she was crazy for asking them and also that the answers to most of the questions was yes.

She quoted a retired Consultant Paediatric Oncologist (who began his career in medicine in 1966), who said:

> "I cannot recall receiving advice or guidance on a single occasion in relation to breaking sad news or communicating with patients or their parents. At that time, one was supposed to absorb communication skills by observing senior doctors involved in this task. Unfortunately, none of these senior doctors had received any training in this difficult area either and, although many were naturally good communicators, most performed this task badly. Thankfully, there is now much greater awareness of the absolute necessity to communicate sad news in a caring and compassionate manner and of the serious negative consequences of performing this task badly."

Some who continue to have negative experiences of communication with healthcare staff might question whether awareness of the importance of good communication is translating into practice. The very ethos of hospitals, for example, may militate against good communication, as the following excerpt from a submission to the Forum suggests:

> "Doctors are only available while doing their rounds; people are waiting in the hallway in the way of the work going on. Often interns of all nationalities are given the task of speaking to the families. Appointments are unheard of, if made they were at the doctors convenience not when families are available.

> Families were told that consultants were very important, busy exalted people. In my opinion doctors and consultants are very bad at communication and relaying news in understandable English."

Medical staff witness many deaths throughout their careers and they therefore run the risk of becoming inured to the immensity and sacredness of death. It is sobering to read recommendations of graduate student nurses on communication to the Forum, proposing:

- Improved open communication around death and dying and diagnosing dying

- Improved communication strategies and skills for doctors breaking bad news to patients

- Improved communication strategies and skills for nurses who 'pick up the pieces' following doctors breaking bad news to patients.

It is assumed by the graduate students that nurses will continue to have to 'pick up the pieces' following doctors breaking bad news to patients. That is a sad state of affairs and confirmation that more needs to be done to eradicate 'social disrespect' and bad communication by doctors with their patients, where it continues to exist despite all the progress.

Ability to diagnose should not be confused with an ability to make right judgements regarding whether or how diagnostic information is used or communicated. It is absolutely essential to understand that death is not just a medical event. It needs to be reclaimed from the hospitals and from the medics.   Given the tendency to medicalise end of life, we need to remind ourselves that the question of how the most crucial of all personal information - that death may be imminent - is handled, is NOT the province of the medical professionals alone.

Caregiver - Family Communication

We have already adverted in Chapter 6 to the fact that families - and significant others - come in all shapes and sizes and with very different modes of relating to those close to them who are dying. Likewise, they have different views, attitudes and expectations regarding their place in end of life situations and how they should relate to professionals providing end of life care services to the family member who is dying. To this is added the different views and attitudes of professionals towards the families of those they are caring for. So, as quite a few contributions to the Forum made clear, there is the potential for misunderstanding, and sometimes significant upset, when the relationship between the professional caregiver and those closest to the patients they are looking after is not one of mutual understanding and co-operation. This is particularly so when family carers are ignored or treated negatively by doctors and other health professionals, which is short-sighted because family carers very often possess practical knowledge about what care is best or least harmful to their loved one. The following extracts illustrate the problem.

The first is from a submission from a daughter and carer of a deceased person, who said:

> *"I understand that some families do not want to know all of the details and this is why hospice staff only give information in respect of specific questions rather than volunteer updates. However, I wanted all available information and I made this known to everyone I came into contact with at the hospice. I also asked that this be communicated to all staff involved in (name of mother) 's care during their regular meetings. Unfortunately this didn't seem to make any difference and getting any information was extremely difficult and I felt like I was fighting a battle for information all the time ...*

> *... I arrived at the Hospice at 11.30am and (name of mother) passed away at 11.38. I am deeply grateful that somehow I managed to arrive in time without notification."*

The second is from the proceedings of a Forum public meeting describing a husband's feelings about learning second-hand of his wife's prognosis:

> *"An audience member stands to describe his personal experience. His wife had died of cancer 17 weeks previously after a 3-week illness. He describes the way he learned of his wife's cancer - physician in the A&E cubicle had told his daughter-*

in-law that his wife was terminally ill with cancer. A week later his family told
him the diagnosis. He was deeply upset with the way his wife's diagnosis was
communicated to his family before he was told himself."

The third is from a submission in which a mother articulates her resentment and hurt by a doctor who discussed her young child's terminal illness in front of the child against her wishes and insisted that the child be told by the parents that he was going to die.

"I dreaded our weekly meetings with a particular doctor (name of doctor). I found
her very cold, matter of fact, and very dismissive. Now I know she probably deals
with 100s of cases everyday, but a little bit of courtesy would not have gone amiss.
On a particular occasion, she indicated with a pen, touching the side and top of my
son's head indicating where he would have loss of hair, after we had requested that
she discuss nothing in front of (name of son), only to us, as although he (is) over
5 years of age, we didn't want him knowing that he was going to die, we weren't
ready for that journey yet ... this particular Doctor was very insistent that we told
(name of the child) that he was going to die, as she said to us 'well some children
like to arrange their own funerals' ".

Another person said at a workshop:

"Radiographers don't do the communication, which can be problematic because
the screening they do is live and when an abnormality appears on the screen it may
be hard to hide awareness of it from the patient. The best they can do in (name
of hospital) is to match nurses to families to improve the prospects of maximising
good communication."

Some parents and family members report that they were given inadequate or no explanations as to why a particular medical intervention was selected during the person's last days or hours. This lack of communication can lead to confusion, stress and sometimes false hopes of a potential recovery.

Some people also report the use of 'wait and see' style of language by medical personnel in response to specific questions about a family member's likely prognosis. The giving of honest and specific facts tactfully and gently delivered is thought to assist in the subsequent grieving process.

Chapter 18 COMMUNICATION

Two submissions made similar recommendations on how communication with relatives of dying patients might be addressed. They suggested that a staff member (on each shift) would be nominated to liaise with the family and answer questions as necessary.

Communication about Death within Families

Someone said at one of the public meetings of the Forum that we don't like to talk about death even when someone close to us is dying.

> *"My clients," she said "now tell me they regret not being able to talk about death with their loved ones. I do know a lot of people die in denial. They don't want to let it in that they're dying. I suppose in Ireland we're not that comfortable with emotion, speaking about it or showing emotion.*
>
> *In my experience, personally and in work, I know that a good goodbye facilitates a good grief. A badly managed death stays with the person for a long time. I often wonder when does goodbye start."*

The following view was expressed in a submission:

> *"One of the principle obstacles to the spiritual care of those who are dying has always been the inability of patients and relatives to communicate honestly, for fear of upsetting one another. This difficulty is compounded if healthcare professionals themselves are uncomfortable with any reference to death or dying. It was not uncommon in the past for the visit of a priest to be deferred until the last minute for fear that the patient might be upset."*

Another contributor referred to a booklet originally published in the United States to help middle-aged people communicate with older people. It includes "Five ways to talk to your loved one about end of life issues" prepared by a person who "spoons out food for thought in doses that are very easy to mentally swallow", according to one reviewer of "Good to Go - the ABCs of Death and Dying." The five ways are:

- Keep it light

- Immediate family only

- Don't make it an intervention

- Make good use of a holiday gathering

•   Limit initial expectations.

Communication between Professionals

A number of contributors to the Forum, particularly professionals themselves, emphasised that end of life care should be patient focused. Therefore, as the Irish Medical Organisation said, "communication and continuity of care across all healthcare settings needs to be improved."

In the context of end of life services for people with intellectual disabilities, a Social Worker said, "good communication between the members of the multidisciplinary team gives us a broader insight into the client and their family situation.

The Irish Pharmacy Union said:

> *"Prior notice of discharge to local community pharmacists would help to ensure that adequate supplies of medication are available locally. This would involve communication between the hospital and the community pharmacists prior to discharge. This is particularly important at weekends."*

At a workshop a similar point was made:

> *"Effective communication between the specialist palliative care nurse, general practitioner and the community pharmacist should try to anticipate a patient's need for medication and plan accordingly."*

At the same workshop it was emphasised that lack of continuity of care due to poor communication between services is a barrier to good end of life care for older people. Communication and continuity of care across all healthcare settings needs to be improved. Dialogue and collaborative working between palliative care, geriatric medicine, old age psychiatry and general practice should therefore be fostered in order to develop optimal models of palliative care for older people.

The Irish Nephrology Nurses Association added in its submission:

> *"There must be effective communication and collaboration between professional groups and clinical specialities to eliminate failure in providing a service to patients where they choose how and where they wish to die."*

Communication among ourselves: Public Discourse

One person said at a public meeting:

> *"For almost 30 years I have been working in this area and there is a great lack of dialogue on the matter of death and dying ... there are also communication issues in regard to a resistance to communicate, as we find it difficult to be around people at such difficult times, so it can be a very isolated time.*
>
> *If we could just get open dialogue once more, where the community talks freely about death and dying and everyone has an 'anam cara'. But it's not spoken about any more because medicalisation came in and stopped it."*

A number of contributors to the Forum suggested that we are a death denying society and death is a taboo subject in day-to-day conversation. On person said, "Death is the last taboo subject - we are not comfortable with it, we fear what we do not fully understand." At a workshop discussion people suggested, "We are a death-denying society. Communication is the problem," and they asked, "Is there any country that does dying well? There are pockets of good practice."

However, Allan Kellehear, Professor of Sociology at the University of Bath, who addressed a public meeting of the Forum said:

> *"Although it is frequently tempting to think so, we are not a death-denying society. If we were a death-denying society we would not have any funeral services, hospice services, coronial investigations, or cemeteries – to name just a few organisations devoted to dealing with death and dying every day. Biologically and anthropologically speaking, we are not death-denying also because most of our animal ancestors aren't death-deniers either."*

"Knowledge of death and dying is part of our hardwiring," he says, and he contends that we are an apathetic, rather than a death-denying society.

Providing an historical perspective on the social psychology of dying, he said:

> *"Although the stereotype of doctor-patient communication that we receive from that past academic literature often suggested that people went to their death without any knowledge about their impending fate yet a closer and more critical*

reading of that same literature reveals two frequently overlooked facts. First, terminally ill people often found out about their fate from watching their own unusual bodily signs, and from irregular verbal and social communications from other patients, staff, doctors and their own friends. Many people were not uncurious about their persistent and worsening symptoms and, even in an era without the internet, read up about them in covert times and places. And secondly, the longer part of dying was away from professionals and their settings, especially hospitals. It is therefore no more true that silence was emblematic of the 1960s than is the so-called 'open awareness' of today's communication approach to terminal illness.

Then as now, communication about life and death was always fluid, context dependent, changeable, and subject to emotional and social contingencies of hope, acceptance, and the situational needs of self and others. What has changed in an historic way today is who is defined as 'dying'. There is reason to believe that those currently defined as 'dying' are becoming a select and unrepresentative group of all those currently dying in society. Narrowly defined, the dying are not all around us, as they have always been in nomadic, peasant and even urban societies, but are a special species now found only in hospices, and then usually among those with cancer."

Whatever the case, it is clear that much more work is required to have end of life issues included in both public discourse and on people's personal agendas. For example, National Council on Ageing and Older People research[80] found that only a quarter of people over age 65 had ever spoken to either family or health professionals about their preferences if they were no longer able to make decisions for themselves at the end of their lives.

The opening up of a dialogue about death and dying will lead to more open and natural conversation on what for all of us is the most important and only happening in our lives that we can be certain about. One person said in a submission:

"It will enable more open communication between patients and their families and carers. Moreover, it will go a long way in helping to allay fear about death and dying and so be an enormous help to the terminally ill, their families and carers."

---

80   Garavan, R., Winder, R., McGee, H. (2001). Health and Social Services for Older People (HeSSOP). Dublin: National Council on Ageing and Older People.

Another person suggested that the Forum itself can play an invaluable role by normalising this conversation and encouraging a cultural shift which makes it easier. She said:

> *"The Forum can hardly fail to achieve one enormously important objective: to get us all to talk about our last months or years, and about death and all the issues related to it, in a calmer, more rational, more supportive, normalising and useful way. The more we discuss it, the better we will handle it, whether for ourselves or those we care for. That is invaluable and very necessary work. It's the enduring taboos which cause so many of the (avoidable) problems. And it is communication and clarity which will be most useful in eliminating them."*

An End of Life Dilemma: To tell the Truth or to preserve Hope?

In was noticeable that people felt and spoke very strongly about one particular end of life issue, namely whether patients should be informed of life-threatening diagnoses. Many advocated that such diagnoses be revealed on principle. They cited the importance of truth telling and honesty, and warned against collusion in hiding the truth and supporting denial and 'false' hope. The following are some of the views expressed:

> *"Good palliative care encourages open communication between the patient and his/her loved ones. Conflict may arise in situations where collusion is evident i.e. "where a group of people agree to keep information from or to misinform others".[81] The health-professional's training and experience (whether doctor, nurse, social worker, or chaplain) can help him or her to explore these complex issues with the patient and their families, and liaise with the medical team. Palliative care includes consideration of the family's needs before and after the patient's death. The counsellor will negotiate issues of confidentiality, autonomy and consent as part of this process."*

A workshop presenter was forthright in her view on the matter, as many contributors were:

> *"When medical staff are asked questions about whether a person will live or die - and when - it is very important that honesty prevails. People can accept the truth, but lose faith if they are not treated as rational adults. Denial of life-threatening diagnosis is no help to anyone."*

---

81 R.D. Laing "Collusion" in Beneath the Mask: an introduction to the theories of personality

The following are excerpts from the proceedings of public meetings:

> "Families sometimes think they know what is best for the patient and can try to 'fudge the truth' to protect their loved one."

> "An audience member wishes to bring the discussion back to the issue of hope. She believes that hope does not come from fudging the truth but from the support that patients receive after they are given their long-term prognosis. She describes her experience of her husband's cancer. The consultant didn't tell her husband about the severity of his cancer and advised her to keep the full truth from him too. She found this appalling, that a care professional would suggest that she be dishonest with her husband. She believes that this would shatter the trust that had existed between them throughout their marriage. She believes that honesty between families and patients is essential in providing hope and support to patients."

> "Death is natural and she believes that the vast majority of people would want to know that they are dying so that they have an opportunity to explore the concept of death and prepare themselves and their families for same."

> "Our experience is people like to know about their illness, their prognosis. However, some choose not to know so we would always ask whether they would like to be fully informed and if so we have an obligation to deal with this honestly, openly and sensitively. If they do say no, it's important we revisit that question on a regular basis in case they change their minds - and then discuss with the family is it OK to do that."

Others took a different stance on the question of whether people should be informed of a life-limiting diagnosis. One said:

> "There is something of a dogma in Ireland which demands that dying people must 'accept' and 'open up' about terminal illness. This may be quite cruel. People who want to take comfort and refuge in denial of their plight must not be deprived of their entitlement to die in whatever manner they wish."

The following anecdote from a study of the grief experience of same-sex couples was related at a workshop:

> "I said [to the doctor], "Surely her right to not know should be adhered to." And, he

said "No"... and the following morning I went in [hospital]. I was in with her at four o'clock in the morning. And, she was sitting in the chair beside the bed. And, she said to me, "What are you doing here at this time?" And, I closed the door and I pulled the curtains, 'cause I said to the nurses "I've got to go in. If anyone's to tell her, I'd have to tell her". And, I had to tell her ... and, it was the most difficult thing I had to do. (Very upset and tearful) She looked at me and I said "Will you forgive me for telling you?" "But" she said, "I didn't want to know."

In its presentation to a Forum Workshop, the Age and Opportunity organisation said:

"*Determining whether or not a person wishes to be informed about impending death is central to recognizing the person's right to self-determination. When someone is older there can be a tendency to relate to relatives more than to the individual, particularly where there are basic challenges around communications such as impaired hearing and particularly, perhaps, where profound life and death issues are at stake. Staff of hospitals and nursing homes should be alert to the need to listen to the person concerned regarding decisions made about their care.***"*

We will come back to the matter of 'listening' in end of life communication in due course.

At a public meeting there was a discussion on the effect of 'pulling the rug' or removing hope from patients regarding their long-term prognosis. One person said that it is important not to take hope away from patients, another that hope can bring positive energy and can prolong life.

At another public meeting a doctor said there was a misconception in relation to a family's decision not to tell the person they are dying. In his experience, he had never seen this happen when it wasn't out of love "because that's exactly what the person told their loved ones to do in such circumstances".

However, another person at the meeting cautioned against this course and warned that relatives trying to protect the patient by limiting the information given resulted in them feeling isolated and prevented them from voicing their fears. It also denied them "a special time when there may be things that they want to say or do".

"It is important," another person said, "that a false conflict is not set up between patients and their families in relation to the personal wishes of the terminally ill at the end of their lives". In her experience there are many situations where patients do not wish to be conscious of the fact that they are dying. Professionals will have only known the patient for a limited time and they

therefore may not be fully aware of the patient's more long-term wishes in relation to their end of life. She recommended that healthcare professionals engage in in-depth discussion with the families of the terminally ill to try to determine a more long-term sense of the patient's state of mind, particularly when the patient has indicated that he/she wishes to terminate their treatment for an illness.

Responding to a query from the floor at a workshop about what an ill person should be told about their illness, and what information can be given to family members, a doctor said that a balance needed to be struck between being hopeful and positive and saying there is a doubt about the outcome. He said that one of the worst things that could happen is what he called "collusion". While it was always hoped that treatment will work, there's always a chance it won't work.

In a submission one person said that he strongly believed that there should be a standardised method for delivering a terminal prognosis and that it should definitely not be via phone. Another, however, said that there cannot be a one size fits all communication policy.

Yet another wise person asked 'who tells the patient about impending death?" and suggested "probably the relative who is closest to the patient will know what is the best way of breaking the news, or, failing this, a compassionate and understanding doctor or nurse".

A False Dichotomy

We have seen that different people emphasise different values when judging how to react to a diagnosis of a life-limiting condition in another person. While useful for the purposes of conveying very different opinions expressed at the Forum, the distinction between truth telling and maintaining hope in the context of communication with people at end of life risks interposing a false dichotomy. While both are important in communication at end of life, neither defines it.

To put it another way, "To tell, or not to tell?" is probably the wrong question. For communication at end of life, just as at any other time, - but probably particularly at end of life - is not just about 'telling'; it is also about listening, about presence. Any formula for communication at end of life that does not include these components is suspect. A person who cannot be an acceptable listening presence for another at end of life is likely to be the wrong person to be conveying an end of life diagnosis to them in any event.

In the last chapter, the importance of time in end of life care was emphasised. It is reiterated here in the context of end of life communication:

> *"Time" in the words of one contributor to the Forum "is such a valuable commodity and is priceless to us all and this is sometimes forgotten towards the end of life. Rather than always doing, healthcare professionals should afford time to listen to their patients and their families."*

Competence in Communication

In the last chapter we also spoke of the skills and competences needed by those caring for people at end of life. In the next chapter we will focus on end of life care education and training. In the meantime we draw attention to views of contributors on competence in communication, starting with a contributor who says:

> *"Effective communication with patients and families is considered a core competency[82] and the effects of increased awareness and education on patient-practitioner communication and population-wide attitudes, require further investigation, and may build on recognised models of communication skills training.[83]*

The author of a study, *Living with Dying: An interpretative phenomenological analysis of the experience of palliative care oncology patients in a general hospital*, said in a submission that effective communication is a necessary precursor to meeting the needs of palliative patients. She added: "Caregiver education regarding the nuanced and individualised nature of patients' experience, might go some way to providing both caregivers and patients with a framework with which to contextualise their illness experience."

To be effective, education about communication at end of life will need to be founded on a thorough understanding of the nature of interpersonal communication itself. A useful first step may be training staff on how to break the bad news to people who are dying. In such initiatives success will depend on the premises on which the training is based. Communication skills can be learned; though, as one contributor said, one class provided in a medical school is clearly not sufficient. Even those who have experienced the loss of a child need to learn

---

82 De Vlieger, M et al., (2002) A Guide for the Development of Palliative Nurse Education In Ireland. EAPC. And West of Scotland Managed Clinical Network for Palliative Care (2006). Education Core Competencies Framework. NHS Scotland.

83 Fellowes D, Wilkinson S, Moore P. Communication skills training for healthcare professionals working with cancer patients, their families and/or carers. Cochrane Database of Systematic Reviews 2004, Issue 2. Art. No.: CD003751. DOI: 10.1002/14651858.CD003751.pub2.

communication skills, she said.

Reference was made to 'extremely good literature' around communicating end of life issues developed by the Irish Hospice Foundation. The National Federation of Voluntary Bodies drew heavily on the Irish Hospice Foundation expertise when developing their recent publication, *Informing Families of their Child's Disability: National Best Practice Guidelines*. St Michael's House has developed very useful guidance and training for professionals supporting people with intellectual disabilities.

Reference was made in a Workshop to the recently published *Professional Guidance for Nurses Caring for Older People* (An Bord Altranais, 2009). The guidance sets out six standards and five competency domains for nurses working with older people. Standard 4 covers end of life and the third competency domain covers interpersonal relationships, including communication. The following is an excerpt from the document:

> *"It is important to know the older person and to understand his/her viewpoint (Berglund and Ericsson 2003)[84]. This demands skills in verbal and nonverbal communication, listening and presence. Even if their capacity for understanding language is severely impaired, the nonverbal behaviour that accompanies being asked for an opinion and seeking permission will do much to convey to older people that they are valued ..."*

Reference was made in the last chapter to core competences and principles for health and social care workers working with adults at the end of life in England. Under the heading, "Communication Skills", the following competences are listed:

- In relation to End of Life Care (EoLC), communicate with a range of people on a range of matters in a form that is appropriate to them and the situation.

- Develop and maintain communication with people about difficult and complex matters or situations related to EoLC.

- Present information in a range of formats, including written and verbal, as appropriate to the circumstances.

- Listen to individuals, their families and friends about their concerns related to the end of life and provide information and support.

---

84 Berglund, A.L., Ericsson, K. (2003). Different meanings of quality of life: a comparison between what eldrly persons and geriatric staff believe is of importance. <u>International Journal of Nursing Practice</u> 9: 112 - 119

- Work with individuals, their families and friends in a sensitive and flexible manner, demonstrating awareness of the impact of death, dying and bereavement, and recognising that their priorities and ability to communicate may vary over time.

The contributor first quoted in this section recommended the roll out of a national evidence-based advanced communication skills training programme available to all qualified health professionals. She said that Milford Care Centre in Limerick is piloting the Wilkinson model (funded through IHF development award). This recommendation should be further considered in the light of any relevant recent developments.

In conclusion it is important to note that communication skills without compassion are clearly worthless, as one person at a workshop said.

The End of Life Communication Needs of People with Special Needs

The Ombudsman wrote:

> *"I would like to place particular focus in this submission on the issue of people with special needs dying in hospital. My Office received a complaint from family members who witnessed a loved one die in what they perceived as an undignified and extremely frightening manner. They asserted that his special needs had not been identified or addressed. Sometimes he was left alone, feeling very vulnerable and confused on the ward. He was in pain and frightened by the unfamiliar surroundings and the absence of family whose company he would have enjoyed at home. Whilst most of the time, he was given one to one care by a nurse or assistant, often his ongoing difficulty with communication, was greatly intensified by the presence of someone with poor English. His disability required much reassurance, support and assistance. The family alleged that this was not recognised, respected or addressed. On the contrary, their perception was that they were seen to be over-protective and impeding his independence. The level of resources available was undoubtedly an issue in the case, but so too was the issue of communication and structured planning of care with the patient himself and his family."*

In its presentation to the Forum, the National Disability Authority spoke about the difficulties some people with disabilities have in communicating their needs:

"People with a variety of disabilities may have difficulty in communicating their health and care needs to carers and health professionals, and their ability to communicate or receive information may be impaired. People with intellectual disabilities or with dementia may have difficulty understanding what is being said to them, and in turn may have difficulty in making themselves understood. The recent National Disability Survey (2006) showed there are 50,000 people with significant sight disabilities, 58,000 people with significant hearing disabilities, and 35,000 people with significant speech disabilities. About half of those with sight and hearing problems are aged 65 or over. It is important that written or oral information is available in other formats as required to facilitate the needs of individuals."

Communication with People with Intellectual Disabilities

One contributor wrote:

"The ability of people with intellectual disabilities to understand the concept and finality of death, and the significance of a diagnosis of a life-limiting condition does make it more difficult when dealing with their own death ... Health professionals involved in delivering palliative care and staff within the intellectual disability services do need to actively support the person in understanding his/her illness, and must try to help them explore their feeling arising from impending death. Communication in a palliative care context should include the person's ability to express emotions, either verbally or otherwise, and the staff's ability to identify, address and overcome barriers to effective communication."

The Director of the National Disability Authority said that she thought that it would be really useful if appropriate guidance material was developed to inform both professionals and families in communicating end of life issues to people with intellectual disabilities throughout their life course. The National Disability Authority, she said, would be willing to provide expertise as appropriate to this undertaking.

Communication with People with Dementia

Stigma limits communication and the potential to communicate with people suffering from dementia.

Family carers are often very important in ensuring that all those looking after a person with dementia share the life story and are therefore able to communicate better with them. Clonakilty hospital was identified in a workshop as exemplifying best practice in this regard.

In its submission, the Alzheimer Society of Ireland said that it fully supports the range of recommendations in the Palliative Care for All report, (IHF, 2008). It said that it would be active in promoting the recommendations that seek to support initiatives that create greater understanding and methods of communicating with people in advanced dementia and viewing this activity as an essential part of the end of life debate and the extension of the palliative care model in dementia care.

The work of Sonas aPc (activating Potential for communication) was identified for its ground-breaking work with people suffering from dementia and others having communication difficulties. Sonas provides a therapeutic communication activity, which focuses on sensory stimulation in the belief that the senses are the gateways to communication.

People suffering from the Effects of Strokes

A submission reminds us of the communication difficulties experienced by some people who have suffered a stroke, as follows:

> *"Unfortunately, the strokes resulted in (name of person) losing a great deal of her power to communicate … There was a disconnect between the words that came out and what she wanted to say."*

People with Diabetes

A representative of the Diabetes Federation of Ireland said at a workshop:

> *"At end of life there will be changes in mobility for the person with diabetes, and in medication and diet prescribed. The reasons for these changes need to be explained carefully to the person because they have been used to managing their condition*

for all of their lives and such changes may be very unsettling if not properly explained."

Language and Culture

A number of contributors to the Forum adverted to language problems in communication at end of life, as follows:

"Another aspect of clear communication relates to the language used in any discussions of matters relating to the end of life."

"Certain words and titles put people off or frighten them. For example, 'hospice', 'counselling', 'social worker', 'psychologist'. Sometimes it is better to speak of getting or offering 'support'."

Some professional people showed an awareness of the need to question the language they use. One said:

"In regard to people wanting to be treated as equals, my experience as a professional in regard to language use was we don't do this. We need to be aware that we use language that the family and patient understand what we're saying and we check back with them that they do.

Even the terms 'Palliative Chemotherapy Care' - they might think that is a cure. So we need to be absolutely clear so that they can make an informed decision."

A consultant in Intensive (Critical Care) listed terms used by professionals, which are inappropriate in communication with lay people, and also listed alternatives which might replace them, as follows:

Inappropriate Terms	Appropriate Terms
"progressing to brain death"	"deteriorating to brain death"
"legal death"	"death"
"got / obtained consent"	"consent given"
"life" support	"mechanical (ventilatory)" support
"harvest" organs	"recover" organs

"harvesting" of organs	"donation" of organs
"cadaver"	"deceased donor"
"organ yield"	"transplanted organs per donor"

It was also recommended that further work is required in the Irish context to develop language and communication methods in relation to dealing with death by different age groups (and) in coping with bereavement - toddlers, young children, teenagers and adults will obviously react to death very differently and the type of language used and support available clearly needs to be appropriate to the particular age and stage in the life cycle.

Considerable anxiety was also expressed around intercultural communication - accents, intonation patterns which are different from English as spoken in Ireland. Many older people who have not been exposed to people from other cultures sometimes find themselves at end of life in a milieu with few Irish people at all. In some facilities a minority of staff are not able to understand local people or make themselves understood. These conditions can lead to strange, impoverished environments, with very limited communication for those at end of life.

The Meath Community Unit Communications Pilot Project was described in this context. The project was conducted by the Hospice Friendly Hospitals Programme (HfH) in partnership with the Unit and with funding from the Health Services National Partnership Forum. The Meath Community Unit is a community hospital in Dublin with staff of 16 different nationalities:

- 80% of staff nurses were born and trained outside Ireland

- 50% of managers were born and trained outside Ireland

- 40% of care assistants were born and trained outside Ireland

- The 48 residents are Irish.

The pilot project aimed to increase and enhance personal communication between residents and staff. It resulted in "a massive increase in confidence and skill in regard to communication ... This type of communication training around death and dying provides an excellent platform on which to raise awareness and skills of all staff in relation to personal communication."

In recent years Ireland has experienced a rapid increase in immigration from all around the world. Unfortunately it is inevitable that some of these people will fall ill and find themselves in need of hospice care. Not all immigrants are proficient in English and even those who

are may well prefer to use their first language when they are sick. The Irish Translators' and Interpreters' Association therefore recommended that information on the hospice movement be made available in key languages on the IHF website. The key ethical aspects of translation/interpretation are neutrality, accuracy and confidentiality, it said.

Chapter 19
EDUCATION AND TRAINING

Introduction

> *"Throughout both of my children's illnesses and since then I believe there is a 'will' to meet needs. However, goodwill or good intentions alone are not enough; it must be supported by skills teaching and resources."*

Concerned that the competence and confidence of healthcare staff be improved, contributors to the Forum frequently raised issues relating to end of life training and education. Some identified particular areas where improvement is required, without stipulating what groups should receive the education or training proposed. Others were more specific in this regard, and identified what care providers would benefit from particular education and training initiatives. Contributors spoke also of public education needs and the education needs of people not in the healthcare sector. Some made recommendations on models of education/training or on methodologies which might be adopted. Information on current initiatives, pilot schemes or good practices was also provided. Finally a few contributors spoke of the education needs of people with life-limiting conditions.

'Healthcare Professionals'

The following is a contributor's account of her mother's death in the hands of staff unable to recognise she was dying and unable to cope:

> *"Not long after that I noticed a change in my mother's breathing. I felt she became suddenly very unwell and I was very alarmed. I called the nurse from the door of her room and immediately returned to my mother. Two nurses arrived and asked what was wrong. At this stage my mother was semi-conscious and I was alarmed by their reaction and lack of concern. I actually said to them ' Look at my mother, I think she is dying'. They did not seem to realise this themselves. I found this very hard to come to terms with later. These were nurses I met regularly on the ward. They both then left the room and a short while later one of them returned with a monitor. A Healthcare Assistant also arrived. I again said I thought my mother was very unwell and dying and the Healthcare Assistant started to cry and say 'Do not die, do not die'. I also was crying and speaking to my mother telling her that I was there with her. At this stage she was not conscious and limp in my arms. I*

held her in my arms and called my brother and sisters to come immediately. I knew then that my mother was going to die very soon. The nurse put the monitor on my mother's arm and as I held her I saw that her pulse was recording at 38. The nurse asked me what I wanted her to do. I replied 'nothing' as I realised my mother was very near death at that stage. We had already decided if she had any complications during the surgery that they were not to go to extraordinary means due to her physical and mental state ...

"When I look back at events of that morning I am sad that staff did not recognise how ill my mother was when I called them. I didn't want them to do anything different but it was startling that there was no recognition of near death despite the obvious sudden deterioration."

A Consultant Geriatrician & Senior Lecturer in Medicine, comments in a submission that

"doctors and nurses need to be able to confidently recognise end of life status for what it is and plan the care of that person appropriately and proactively, not reactively (which is the norm at present)."

At a public meeting someone said that in the course of her work she meets people caring for people at end of life and sees that there are varying degrees of confidence in dealing with the issues. She added:

"There is very good reasons for this because people my age and over received no medical training on this, so it is very important that from medical nursing students up a good grounding is given in end of life care and the importance of humanity in medicine."

The Irish Nurses Organisation (INO) says that many health and social care professionals have not received education on the palliative care approach, including those whose original education preceded 1995, when palliative care was recognised as a medical speciality in Ireland.

It is essential that all staff, including nurses and care assistants, who have contact with patients with life-limiting illnesses, are adequately prepared to recognise and meet the needs of people facing death and the needs of their families. Hospitals should be required to provide their staff with a minimum level of education and training on end of life issues. A submission says that the Hospice Friendly Hospitals Programme will have identified some of the gaps in education and training and would be able to indicate what this 'minimum level should be'.

The Irish Medical Organisation said that non-specialist healthcare professionals, including GPs, are inadequately trained in palliative care. There is a lack of formal palliative care training for non-specialist healthcare staff. Training programmes for all healthcare professionals should include awareness of end of life issues and all clinical healthcare professionals should be given compulsory training in palliative care provision, it said.

Another submission added that palliative care education for general practitioners is needed to assist them in understanding the role of the home care team and the practice of palliative care.

Referring to its 2008 – 2013 strategy, the Irish Association of Palliative Care said:

> *"By developing the capacity of individuals, a more professional service, more responsive to the needs of service users, will be delivered in Ireland. This will be achieved through the education and training of service providers and the transfer of knowledge and awareness to related providers in the healthcare system".*

The UCD School of Nursing and Midwifery in its submission recommended:

- Dissemination of the principles of palliative care approach to all disciplines, including nursing and medics

- Regular end of life training for all disciplines to ensure patients' privacy and dignity is protected

- Implementation of the Hospice Friendly Hospice Programme, a national programme to mainstream hospice principles in hospital practice.

The Irish Nutrition and Dietetic Institute said that palliative care poses a number of challenges for dietitians and other healthcare professionals working in the acute sector:

> *"At present there is no undergraduate training in palliative care for Dietitians. Undergraduate palliative care training for doctors, nurses and other health professionals is evolving, but the area of nutrition remains largely neglected.*
>
> *Postgraduate training in the area of nutrition and palliative care is evolving. However, deficits also exist in this area. The importance of education in this area is imperative to ensure optimum care for patients.*
>
> *The need for SPC input into the dietetic curriculum both at undergraduate and*

postgraduate level is essential to achieve excellence in dietetic care provision at all stages of the patient's life, from conception to conclusion.

Further emphasis needs to be placed on the development of nutritional care modules for doctors, nurses, care assistants, catering staff and other health professionals caring for palliative patients."

Nurses and Midwives

The INO recommends the development of level two education (continuing professional education in palliative care) for all nurses and midwives in all settings, who care for people with life-limiting illnesses but who do not specialise in palliative care. It welcomes the Palliative Care Education Taskforce (PCET) role in examining end of life education in residential settings. And it also recognises the support and education that many nurses and midwives require in relation to assessing, planning and responding to psychosocial and spiritual issues. Nurses and midwives have a responsibility to be receptive to aspects of patient care that extends beyond the physical.

The All Ireland Gerontological Nurses Association (AIGNA) says that nurses are educated to deliver holistic responsive care but additional training may be required for nurses to gain competency in areas such as administration of subcutaneous fluids and analgesia. Ongoing education for nurses in gerontology and palliative care and access to in-service training on topics such as communicating bad news, supporting bereaved families, medication management and hydration are required , the Association says.

At a workshop it was suggested that maternity nurses have no palliative care education. It needed to be available to them and to other healthcare workers, including those working in the community.

The Irish Practice Nurses Association (IPNA) said:

"Continuing Nurse Education is vital to enable practice nurses to provide evidence-based quality care that is consistent with other members of the palliative care team:

- *while many practice nurses have some training in counselling, it would be important to ensure that all are appropriately trained in this area, with access to refresher courses as necessary*

- *education should include updates on current treatments and particularly*

management of any side-effects of medications

- *practice nurses should have access to the same training in palliative care provision as other community based nurses - this includes access to funding for such training*

- *palliative care needs to be incorporated into postgraduate programmes for practice nurses, to help ensure that new graduates have the appropriate knowledge and skills."*

Some student nurses believe they should be able to obtain training to enable them to care for dying patients and to deal with difficult situations. In addition, the training should enable student nurses to develop their communication skills and to have greater understanding of the psychological and emotional needs of dying patients and their families.

ANAIL, the Respiratory Nurses Association, recommends that the specialist respiratory nurse should be available to provide information and education to community-based nursing and support services on a formal in-service training basis.

The Cystic Fibrosis Association of Ireland said that it needed Cystic Fibrosis nurses to be given increased training in palliative care to aid families in caring for persons with Cystic Fibrosis in the later stages of the disease.

Nursing Home Staff

The National Quality Standards for Residential Care Settings for Older People in Ireland require that staff receive induction and continued professional development and appropriate supervision. Newly recruited staff and those in post less than one year are required to commence training to FETAC level 5 or equivalent within two years of taking up post. Long-standing care staff must have their competency and skills assessed to determine their need for further training and suitable arrangements must be put in place to meet their identified training needs. Residential facilities are required to have in place a staff training and development programme that maintains the skills of the workforce and ensures that staff:

- meet the changing needs of residents

- fulfil the aims and philosophies of the residential care setting

- understand and adhere to the policies and procedures of the residential care

setting and those of their regulatory body

- are suitably competent to carry out their role[85] .

Another Standard (28) requires each registered residential care facility to set out its purpose and function, including the level of needs accommodated and the services and facilities provided. Clearly then staff competence levels must be in keeping with the needs of the patients and the services provided in each home, for example, competence in dementia care or care of people at end of life in facilities where such people are cared for.

At the time the End of Life Forum was in session, public, private and voluntary long-stay facilities for older people were addressing issues raised by the Standards, including issues relating to staff education and training requirements. At the Forum, private sector representatives expressed concern about the lack of a standardised approach to the development and maintenance of skills, and to meeting the education and training needs in the new dispensation.

Nursing Homes Ireland (NHI), wrote in February, 2009:

> *"Staff from private and voluntary nursing homes access education through various means. These are a combination of NHI, HSE, hospice and privately contracted education providers. There is no standardised approach nor is there any guidance on what is considered baseline education in end of life care. The HIQA National Quality Standards for Residential Care Settings for Older People in Ireland recommend that staff is provided with training and guidance appropriate to their role. This is subjective and open to interpretation.*
>
> *Syringe drivers and other resources and skills required in end of life care are not available in all nursing homes such as IV/Sub-cutaneous fluids etc. Further standardized education and guidance is required to enable their use.*
>
> *Suggestion for action: Implementation of a standardized education programme for all staff in residential care settings appropriate to their role."*

The issue of how the employment of large numbers of foreign staff affects the quality of life of residents in long-stay care was raised. While foreign staff in residential care may

---

85   Standard 24 Training and Supervision, National Quality Standards for Residential Care Settings for Older People in Ireland, HIQA, 17 February 2009.

be very gentle and caring, there is a need to ensure that the quality of life (of residents) is not prejudiced by the employment of exclusively non-Irish staff. Appropriate training and education on attitudinal orientation and language is therefore of critical importance to the welfare of the residents.

Intellectual Disability Services Staff

In the intellectual disability field there seemed to be an unease and a lack of staff confidence around caring for older people with intellectual disabilities and providing end of life care to them. The voluntary sector may feel particularly disadvantaged in respect of access to training in these areas, but it may affect all sectors.

One submission recommended that, in order to improve end of life care for people with intellectual disabilities, education and training of staff include:

- concepts of palliative care, assessment and care of the dying

- knowledge of resources available

- skills in communicating with the dying person and their family

- legal issues, ie advance care directives - staff should be aware of all the relevant issues around this.

A core end of life care curriculum for those providing care to people with intellectual disabilities was recommended at a workshop. It was further recommended that staff communication skills should be developed through appropriate education and training. Experiential learning was advocated.

Family Carers

Contributors to the Forum stressed the importance of support, including education and training support, for family carers to ensure that they have the skills and the personal resources necessary to provide end of life care without at the same time imperilling their own physical and emotional wellbeing. Given the variety of situations carers find themselves in, one submission recommends training for carers at two levels, namely

- training specific to the carer's role of care in the home

- training in self care, addressing emotional, physical, social, financial and legal issues.

A Programme Development Manager at the Irish Hospice Foundation recommended that comprehensive training should be available for carers to give them confidence to support / care for their dying relative at home – ie manual handling, basic first aid and personal care. Such training could also include how to prepare for and what to expect when the person they are caring for nears the end of life. This training should also include guidance on self-care for carers. Information on advance care planning should be given to the person with the life-limiting illness and their family carers.

Mental Health Ireland and others placed an emphasis on an interagency approach to the development of nationally consistent education and training packages:

- providing palliative care education for carers to enable them to feel confident and equipped to continue caring for patients as they reach the end of life

- training carers to recognise palliative care emergencies and how to respond to them and to recognise the signs and symptoms of death approaching.

Volunteers

Many people provide valuable help and support to other people at end of life and to the bereaved in a voluntary capacity. This contribution has the potential to grow and flourish with the right support, including training and mentoring, as the following example illustrates:

> *"I moved to Ireland from Canada in 2006 and immediately sought to undertake the hospice volunteer work that I had been trained to do in ... north of Toronto. An intensive ten-week programme (3 hrs per week) of lectures covering all aspects of assisting the terminally ill, the dying and the bereaved family, resulted in a force of volunteers who would be assigned to perform home, hospital and hospice visits. After training, a mentoring programme was in effect for a specified period to ensure the training was not just theoretical ..."*

Non-medical Components of End of Life Education and Training

A number of non-medical topics or subject areas were identified as particularly important in end of life education and training curricula. They included:

- end of life communication

- awareness of the spiritual needs

- awareness of special needs of particular groups

- support for the bereaved.

End of Life Communication

In the last chapter, we identified communication as a critical determinant of good end of life care. The prevalence of poor end of life communication evidenced by Patient Focus, the healthcare advocacy organisation, and by other contributors to the Forum, lends weight and urgency to their calls for education and personal development initiatives to improve communication skills amongst healthcare professionals. One contributor proposed that a national evidence based advanced communication skills training programme should be available to all 'qualified' health professionals. This would include initiatives designed to help healthcare professionals who experience difficulties to improve their ability to communicate bad news in a sensitive manner. The All Ireland Gerontological Nurses Association says that in some areas programmes such as 'Communicating Bad News' are being incorporated in induction and in-service training with significant benefits for the healthcare professionals and recipients of care. This, the Association says, needs to be available for all staff who have contact with dying patients and relatives.

Awareness of the Spiritual Needs

There is a need to increase awareness of pastoral care among healthcare professionals. A contributor recommends that awareness programmes on spirituality and dying need to be available for all healthcare staff and for home help/carers whose work brings them into contact with the dying and their families. In this regard, the INO recommended that healthcare professionals should be trained to recognise spiritual issues.

Awareness of Special Needs of Particular Groups

In the light of many older people's deferential and less assertive attitudes towards healthcare professionals, Age and Opportunity recommend the education/training of staff to ensure awareness of cultural and social differences specific to older generations.

At a Workshop, the co-authors of a study on the grief experience of same-sex couples recommended that there should be training of healthcare professionals which would:

- challenge heterosexual assumptions

- promote understanding of disenfranchised grief

- cover hidden grievers, multiple losses

- foster communication skills to promote sensitive enquiry

- foster active listening and ability to read cues

- acknowledge the sexual dimension of a relationship.

At another workshop, it was recommended that public and professional awareness and understanding of dementia must be improved by a number of means, including through health promotion, undergraduate and postgraduate education as well as in-service courses for health, social and other service providers.

At a workshop, it was agreed that induction courses for would-be doctors and nurses before they begin their training proper would benefit from modules to raise their awareness of communication requirements and other needs of blind people and indeed of other groups of people, such as wheelchair users.

Education for People with Life-limiting Conditions

A Special Education teacher wrote to the Forum to say that no attempt has been made to investigate the workability, in practical and procedural terms, of achieving educational opportunity and equity for children with life-limiting and life-threatening conditions (LLC). Within the field of paediatric palliative care, the provision of education services to such children, is increasingly seen not only as a legal entitlement but as an essential component of comprehensive, coherent and continuous support provision. Yet, she says, arrangements for the provision of comprehensive education services to children with malignant and non-malignant diagnoses are often lacking, inconsistent and inequitable.

Members of the Neurological Alliance of Ireland say that people with neurological conditions need specialist information, training and counselling for themselves and their families around symptom management, end of life planning and bereavement. However, these are very limited in Ireland.

Bereavement Support Education and Training

Education and training on bereavement and support for the bereaved was emphasised in a

number of different contexts. The Bereavement Section of the Irish Hospice Foundation said:

"The ability to identify those who may be physically or psychologically vulnerable following bereavement should be marked as part of health and social care professionals training ... Much of basic education in bereavement is focused on understanding grief, understanding our own awkwardness and reactions and helping to find ways of responding to others' pain. The Irish Hospice Foundation programme 'Grief at Work' (mentioned in Chapter 3) is an example of an initiative seeking to foster this social learning approach. Loss and bereavement experienced by staff can be challenging situations for managers to deal with yet getting it wrong can have wide and long lasting implications. Bereaved employees may feel unsupported and undervalued.

Informed bereavement care should be the aim of all education programmes which encompass a bereavement component. Theoretically sound, competency based programmes for volunteers, for health professionals and for mental health workers need to be developed with accreditation frameworks, as advised in the Petrus report (2008)[86] which reviewed bereavement services in Ireland and included a review and recommendations for training developments."

The Midlands Bereavement Liaison Project said:

"Bereavement training needs are identified in a three tier fashion:

- *General bereavement related training on understanding grief, etc (for a general audience at lunchtime lectures and the like)*

- *Training related to 'risk' in bereavement and information and other supports available (also for a general audience)*

- *Specific training to up-skill staff in their own areas of specialisation."*

A General Practice Nurse said that "bereavement in the general practice setting is not well managed, it requires professional educational support".

The following other observations and recommendations were made:

"Staff in Government agencies should be trained on how to deal with bereaved

---

86 Petrus Consulting, Bates, U., Jordan, N., Malone, K., Monahan, E., O'Connor, S., & Tiernan, E. (2008). Review of General Bereavement Support and Specific Services Available Following Suicide Bereavement. Dublin: National Office for Suicide Prevention.

families and how to show sensitivity in their case."

"While EAPs (Employee Assistance Programmes) … play a part in offering support to a wider group of employees, there are possibly gaps in the knowledge and expertise of HR professionals in managing bereavement among staff. For this reason, IBEC very much supports the work of the Irish Hospice Foundation in providing training and education for HR professionals who wish to learn about the grieving process and how to support employees who are bereaved. This is a specialist area of expertise and one which HR professionals need to be aware of due to its particular sensitivity. IBEC would be pleased to explore ways in which such training and expertise could be delivered more widely to HR professionals and managers throughout Irish business."

"Whatever the future of support for suddenly bereaved parents it would seem that there is still a lot to learn regarding their needs and the seemingly uncomplicated and straightforward ways in which they can be supported on their journey through the grief."

"Teachers and other school staff are in the front line of grief and loss. The reality is that they have children in their classrooms presenting them with changed and worrying behaviour caused by grief and loss."

"We believe that teachers and educators struggle to cope with and meet the needs of many grieving children. Rainbows mainly takes place in schools after hours … All teachers gain experience and skills through teacher training, in-service and continuous professional development. We believe that a great opportunity exists to incorporate the skills knowledge and guidelines that teachers need in order to address grief and loss issues as they arise in the classroom."

"Challenges for the Children's Sunshine Home: Appropriate training for staff dealing with ongoing bereavement issues."

"For those staff who will be teaching about loss and grief, more detailed training is required."

Some Education and Training Related Initiatives Referred to by Contributors

Contributors referred to a number of education or training initiatives taking place in this country, including the following:

- The Milford Care Centre in Limerick is piloting the Wilkinson communication skills training model with funding from the Irish Hospice Foundation.

- Within Geriatric Medicine, so-called Palliative Gerontology is now developing as an important sub-specialty.

- Rigpa's Spiritual Care Education Programme, Dechen Shying Spiritual Care Centre, Allihies, Co Cork. Its programme content covers:
  - Integration of spirituality in caregiving
  - Needs of the dying
  - Methods for healing relationships
  - Preparing spiritually for death
  - Spiritual dimension of burn-out
  - Deep listening skills
  - Responding to suffering.

- A 2005 report on a Research Study87, found that there is substantial need for further education and training for all professionals involved in caring for children with life-limiting conditions. The following year an Educational Framework to Support Excellence in Caring for the Child with a Life-Limiting Condition was proposed. This has led to the establishment of successful educational programmes for:
  - Registered Nurses working in a general healthcare setting who may encounter and provide care for children with a life-limiting condition infrequently (I day)
  - Registered Nurses who work in any general healthcare setting or specialised palliative care where they fulfil the role of a resource person and frequently encounter children with life-limiting conditions requiring

---

87 A Palliative Care Needs Assessment for Children in Ireland Dr Suzanne Quin, Dr Jean Clarke, Dr Jo Murphy-Lawless, Ms Liz Hickey and Ms Patricia Browne [March 2005] (p40)

supportive and palliative care. (15 days.)

- The Hospice Friendly Hospitals communications training programme..

- An initiative to educate and inform clergy about palliative care.

- People who live in nursing homes should have a good death and those who work there should have the education and training to support this. The Irish Hospice Foundation therefore offers an education programme for nursing staff nationwide.

- A joint UCD/TCD chair of Palliative Care Nursing, based in Our Lady's Hospice, established with funding from Atlantic Philanthropies.

- A four-month training course for GPs, Our Ladys's Hospice Blackrock given by a part-time GP and palliative care specialist.

- Suicide Prevention Training:

  - safeTALK, a half-day suicide alertness training programme: 43 trainers.
  - ASIST, a 2-day intensive workshop in suicide first aid, designed to help people become more ready, willing and able to help someone at risk: 12,000 people trained; 110 people working as trainers.

- The Pre Hospital Emergency Care Council (PHECC) is developing and implementing an integrated and comprehensive framework of education and training, assessment, registration, clinical practice, information collection and research. It aims to professionalise pre-hospital service providers.

- Palliative Care Community Pharmacy Network pilot project, developed by Specialist Palliative Care Services and Primary Care HSE, in consultation with Community Pharmacists in the North East of the country. Each of the participating 14 Network pharmacies holds an approved stock of essential palliative medicines and has a nominated pharmacist with training in palliative care.

- The IHF/IAPC/QUALIFAX palliative/end of life/bereavement education and training database: http://www.hospice-foundation.ie/index. php?option=com_content&task=view&id=397&Itemid=264 This database

was developed by the Palliative Care Education Taskforce (PCET), which is a collaborative palliative care education forum of the Irish Hospice Foundation, the Irish Association for Palliative Care and the former National Council for Specialist Palliative Care. On 5th February 2010, the database listed:

- 128 courses under palliative care

- 43 courses under bereavement

- 7 courses under spirituality.

Recommended Developments in End of Life Education and Training

Contributors made a range of recommendations on how they thought end of life education and training might continue to progress. The following were some of their ideas:

- Palliative Gerontology needs to be built into specialist training of physicians and nurses in Geriatric Medicine who will be caring for the elderly patients of the future (the fastest growing sector of the Irish population now and will be for the next 50 years).

- Hospice and disability services need to share training in liaison with all other healthcare disciplines.

- The need for joint training of palliative and other specialists, specifically those looking after dementia patients, was emphasised. Collaboration should be fostered. Palliative care experts can support other professionals.

- Set up teaching units specialising in end of life care affiliated to each university with a medical school and/or nursing school, to ensure that best practice end of life care is taught to undergraduate and postgraduate doctors and nurses. The necessary research dimension of end of life care could also be developed in such teaching units through formal linkage to university departments of Geriatric Medicine and Nursing.

- Develop a postgraduate cross-disciplinary education model in Health Promoting Palliative care.

- Develop training, education and other awareness programmes on spirituality and dying based along similar lines to Marie Curie Cancer Care's excellent "Spiritual & Religious Care Competencies for Specialist Palliative Care" ... Level 1 is aimed

at all staff and volunteers who have casual contact with patients and families; Level 2 is for all staff and volunteers whose duties require contact with patients and families/carers; Level 3 targets staff and volunteers who are members of the multidisciplinary team and Level 4 is explicitly for those whose primary responsibility is for the spiritual and religious care of patients, visitors and staff.

- Promote Practice Development Programmes that help to empower care teams and change the culture of end of life care in long term care settings.

- Utilise the Arts and Media to educate, for example, as with the play, *Cancer Tales* by Nell Dunn presented by Milford Care Centre, University of Limerick and the Irish Hospice Foundation.

- Promote the usefulness of reflective practice for health professionals; develop a cross-disciplinary death education module for health professionals to study at undergraduate, postgraduate and CPD / CME level.

- Standardise all levels of palliative care education for health professionals. Ensure that flexible options for learning are available e.g. online/distance learning and ensure that palliative care is a module within all undergraduate health professional training programmes.

- Adopt and implement the five-level palliative care education framework:

    - Level One: Pre-qualification professional training, the foundations of a 'palliative care approach'
    - Level Two: Generalist Continuing Professional Education (CPE)
    - Level Three: Specialist preparation.
    - Level Four: Post-specialist support for leadership
    - Level Five: General public education and information.

Development of the Palliative Care Education Framework

A review of progress of the Palliative Care Education Framework was presented at a Forum workshop. This identified some of the issues to be addressed and obstacles to be overcome in progressing development of end of life education and training nationally.

Level 1: Undergraduate

A key aim of undergraduate education is to equip students with the appropriate knowledge, skills and attitudes of their chosen profession. The focus on palliative care issues is ad hoc in health and social care undergraduate curricula. Palliative care is not addressed in

physiotherapy or occupational therapy curricula. And only bereavement is covered on the social work curriculum. Undergraduate training issues include: packed curricula; access difficulties; who is teaching palliative care; and evaluation. It was therefore suggested that a common undergraduate curriculum on the palliative care approach needs to be developed, which enables health and social care students to learn about the role of their chosen profession in end of life care delivery. A dual focus is required: that of acquiring the professional skills to provide high quality end of life care, on the one hand, and inculcating the palliative care approach [at the personal level] and the palliative care ethos [at the institutional level].

Level 2: Continuing Professional Education

As is clear from many of the contributions cited already in this chapter, there is a great need for palliative care Continuing Professional Education [CPE], as many health and social care providers have not had education on the palliative care approach. In some areas such as nursing home care and care for the intellectually disabled there is a lack confidence about end of life care among some staff. CPE in end of life care needed to remain competent and informed. Yet palliative care CPE provision is ad hoc and localised.

On the positive side, a national pilot introductory education initiative for staff working in residential care settings for older people commenced in 2009. There is increased provision of distance learning courses offered by Milford Care Centre, Our Lady's Hospice Ltd and also Foyle Hospice, Derry, in conjunction with Donegal Hospice. And the Database of Palliative Care, End of life Care & Bereavement Courses listed above, which went live on the internet in June 2009 will prove most useful to those concerned to provide continuing professional education in end of life care for their staff.

Level 3: Specialist Preparation

Traditionally palliative care education provision has been targeted towards nurses and doctors who specialise in palliative or cancer care. There is a variety of graduate diploma / MSc palliative care courses in the country. However, as is clear from some of the suggestions on the development of end of life education and training made to the Forum and listed above, there is significant potential for further collaboration and consolidation. Standardisation and quality control of Level 3 provision throughout the island of Ireland was recommended, as was leadership in its development.

Level 4: Post-Specialist Support for Leadership

Experienced specialist palliative care professionals who are in management and leadership

roles also need education to lead the speciality, develop services and drive strategic initiatives. At one of the Workshops it was emphasised that there must be maximum co-operation between all stakeholders in the proposed All-Ireland Institute for Education and Research.

Level 5: General Public Information and Education

Education can inform and empower the general public about end of life and bereavement. The role of media in facilitating learning and information delivery on end of life issues must not be underestimated.

Their role in promoting the work of the Forum to date has been considerable and this in turn increases public awareness of priority considerations.

Contributors to the Forum advocated that education on end of life issues should be available to people who do not work in the caring professions, such as HR professionals, as mentioned above. One person proposed that educators provide education opportunities to people in occupations such as floristry and to people in the financial and legal professions who confront death and dying on a daily basis and who may need skill development or opportunities for reflection.

Another person asked, "how willing are we to openly discuss end of life issues before they arise?" and commented that we do not do enough for the general population in terms of 'death education'.

A former secondary school teacher said at a workshop that he considered it important that loss, grief and grieving are subjects which should be explored in school. He said he could not find much reference to education about death in the curriculum. There is some reference to it in the SPHE programme. He said:

> "After that, it is left to the choice of the individual teachers and so references to and involvement with these issues are indeed haphazard and sporadic. Whereas not every teacher will be comfortable with this teaching, it is important that all school staff should have professional development beginning with a session on loss and grief.

> "For those staff who will be teaching about loss and grief, more detailed training is required. It requires a readiness to teach both emotionally and content wise. In her excellent book, Grief in School Communities, Louise Rowling[88] proposes developing the following competencies in students: knowledge about loss and grief, skills to use

---

88 Louise Rowling, (2003). Grief in School Communities (Buckingham,England: Open University Press

*the information to help themselves, how to use the information to understand and
support others, and knowledge and skills to seek help and recognise when support
will be beneficial."*

End of life education needs considerable internal and external support if it is to develop at
primary, secondary and third levels.

End of Life Education Standards

Educators need to be suitably experienced to provide high quality palliative and end of life
education. They need to have competence in facilitating reflective learning and an ability to
promote understanding of the dynamics of communication at end of life. End of life education
must be provided by educators selected for their professional competence and personal
suitability. Palliative and end of life education should be subject to regular monitoring and
rigorous evaluation. Some contributors emphasised the importance of training on site, as close
to 'the patient' as possible.

In 2007, the HSE published a strategy on medical education, training and research (METR).
In a presentation to the Forum the Health Service Executive said that it had established an
Education, Training and Research Committee:

- to advise on and work towards compliance with relevant standards set by
  statutory and regulatory bodies in the area of professional education

- to advise on the planning of education, training and research initiatives and to
  ensure that these are supportive of an interdisciplinary policy approach and are
  reflective of the change and transformation under way in the health sector

- to co-ordinate the alignment of all education, training and research functions to
  ensure the delivery of the highest quality education, training and research relevant
  to the needs of the health services

- to act as a vehicle to allow for communication, discussion, collaboration and
  exchange of information and learning on a multidisciplinary basis in the areas of
  education and training and research.

The proposals of contributors to the Forum on end of life education and training and the
conclusions of the Forum on these matters will be of interest to this Committee.

6

Legal and Ethical Issues

6

Chapter 20
DECISION MAKING AT END OF LIFE: ETHICAL ISSUES

Questions

Contributors to the Forum raised a number of complex ethical and legal issues relating to decision making at end of life, and to participation in that decision making. Who makes end of life decisions? How are they made? On what basis are they made? How well informed are the decision makers? What are the rights and the responsibilities of the different parties?

The President of the Irish Human Rights Commission, Dr Maurice Manning, said at the inaugural meeting of the Forum that public policy, public servants, public representatives and non-Government organisations will increasingly have to engage with these complex legal and ethical dilemmas.

Rights and Responsibilities

The Medical Council's A Guide to Ethical Conduct and Behaviour (Sixth Edition, 2004) states what the responsibility of the doctor is where death is imminent:

> *"Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible. In these circumstances a doctor is not obliged to initiate or maintain a treatment which is futile or disproportionately burdensome. Deliberately causing the death of a patient is professional misconduct."*

A contributor to the Forum states forcefully her perception that the individual has a right to participate in end of life decision making:

> *"At the moment, no matter what the individual does to make their own wishes clear, they may or may not be respected, and power of making informed decisions about one's own life passes to people who know more or less nothing about it. This is intolerable and a demeaning breach of human rights. ...the power passes from the individual to others ... "*

Healthcare Decision Making

A Clinical Nurse Manager said in her submission, that end of life decision-making is not

an event, but an ongoing process involving a series of conversations ultimately leading to decisions based on the person's, experiences, values and beliefs and those of his/her family or guardian.

At a Forum workshop, the Accreditation-Clinical Audit Project Manager at Our Lady' Children's Hospital, Crumlin, said that the main focus of healthcare decision making is to promote health, prevent illness, restore health and alleviate suffering. Decision making is about how care will be delivered, what care to give, who gives it, when to give it, how it should be given and when not to give it. To make these decisions, the healthcare professional must consider various strands of information about the patient, personal issues, the culture and the profession. Decision making is increasingly influenced by social, cultural, religious, ethical, legal and political values, she said.

A Motor Neurone Disease Clinical Nurse Specialist wrote:

> "The development of evidence-based guidelines for end of life decisions in non-malignant terminal illness is overdue. This work will be valuable from a patient, management and health service planning perspective, as it will identify and characterise the current limitations in care for a large proportion of patients with neurodegenerative diseases. Informing and guiding patients and their families through the difficult decision making process to a peaceful death should be integral to medical practice. The end stage management of all neurodegenerative conditions are similar, in that it is imperative to alleviate symptoms, maintain dignity and quality of life, and ensure patient autonomy."

The Irish Nephrology Nurses Association said that clinical guidelines on 'Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis' (2000) indicate a right to refuse dialysis, based on the ethical principle of respect for patient autonomy and the legal right of self-determination. This document has nine recommendations to assist patients, families and the nephrology team in making decisions about initiating, continuing and stopping dialysis. They include:

- Shared decision making: involves the renal care team and includes the nurses and patient and family in healthcare decisions

- Withholding or withdrawing dialysis: describes situations where forgoing or withdrawing dialysis is appropriate.

Culture and Ethics

End of life treatment frequently involves ethical dilemmas. In a presentation to the Forum on End of Life Decisions, Prof. David Smith of the Royal College of Surgeons in Ireland said that, under identical clinical circumstances, healthcare professionals with different religious, cultural and ethical backgrounds may adopt different approaches. "End of life decisions in Europe vary greatly depending on regional cultural differences," he said, and went on:

> *"Significant differences based on the doctor's religious and cultural affiliation are seen in the choice of end of life practices such as:*
>
> * *time of therapy limitation,*
>
> * *time from limitation to death,*
>
> * *the availability of patient's wishes,*
>
> * *the discussion of end of life decisions with the patient's family and other healthcare workers, and*
>
> * *the reasons given for the lack of discussions with families."*

Prof Smith concluded:

> *"Understanding the religious influences on end-of-life choices may explain conflicts and assist in developing a consensus and guidelines for end of life practices."*

He said that the responsibility of the healthcare professional to make decisions in the patient's best interests and to respect the patient's rights, makes it crucial for him/her to weigh precisely the justification of every treatment mode in an end of life situation. He added:

> "Both the patients and healthcare professionals tend to take the following four factors into account when discussing end of life care:
> * The effect on quality of life;
>
> * The emotional, financial and other costs;
>
> * The likelihood of success;
>
> * The effect on length of life."

Decision Making: Weighing Benefit and Futility

Treatment decisions may be determined by whether doctors consider treatments to be beneficial or futile. However, Professor Smith says that the value-laden notion of futility and the ambiguous meaning of patient autonomy suggest the need for further ethical analysis. He adds a number of critical observations about the notions of benefit and futility, as follows:

- As a patient's benefit has a central ethical role, it is important to understand what counts as benefit and futility, and from whose perspective.

- Medical futility does not have a single, universally recognizable and clinically applicable meaning.

- Withholding treatments that are futile (as defined by the healthcare professional) supports the ethical principles of both non-maleficence (do no harm) and beneficence (relieve suffering).

- But, some ethicists argue that invoking the principle of futility solely from the healthcare professional's perspective is in direct conflict with the principle of patient autonomy.

- Physiological-only definitions of futility assume that benefit can be measured without input from patients. This can be the case when it is decided that a treatment is futile because it no longer fulfils any of the goals of medicine, (to cure, to palliate, to improve functional status).

- Unless an intervention is infeasible, some subjective assessment of its benefit must have a role.

- Patients often prefer to discuss outcomes that they would find acceptable. They do not necessarily label treatments as useful or futile, they have strong and definite notions of treatment outcomes that they do and do not want.

- A small physiological improvement might seem sufficiently beneficial to a patient, but not to the healthcare professional (or vice versa).

- Merely postponing an inevitable death might be vital for a patient seeking social, spiritual or any other personal closure, whereas to a healthcare professional the deferral of death is not perceived to be beneficial, as the outcome is the same.

6

Patient Involvement in Decision Making

Professor Smith's observations above lead inevitably to his conclusion that "it is vital, then, that healthcare professionals ask their patients the appropriate questions so that the patients themselves can become engaged in effective decision making about current and future treatment options. Rather than labelling or mislabelling treatment options as useful or futile, healthcare providers must be clear and honest about the range of options, and must take the time and effort to explain each option in terms of the expected quality of life, the emotional and other costs, the likelihood of success and the effect on longevity."

Withdrawing/Withholding Treatment

Dr Donal O'Mathuna, Senior Lecturer in Ethics, Decision making and Evidence in the School of Nursing, DCU, said in his presentation to the Forum:

> "Decisions about withdrawing or withholding medical technology are difficult, but they are made appropriately every day in hospitals all over Ireland. The decisions are always challenging, sometimes unclear and rarely made with total certainty. A decision to withdraw technology should never mean that care is withheld. Part of the transition during the end of life is from medicine focused on curing to medicine focused on caring only. Because healthcare professionals in Ireland are not permitted to end life, we can be more confident that their focus remains on promoting what is best for patients, not wondering about whether it is time to end their lives."

Most guidelines emphasise the importance of discussions with patients before decision making about withholding or withdrawing treatment. Ethically it would appear that patient consent is required for the withholding or withdrawing of treatment.

Critically ill patients however can rarely engage in any dialogue about their healthcare. So proxies are often approached to obtain consent. This may be problematic, if they are unable to accurately reflect the values of family members who are ill. Such a possibility, however, does not warrant decision makers not to consult families at all, as happened to the contributor who wrote as follows:

> "A couple of days before my sister died (she was finally moved to a single room) I arrived at (name of hospital) to discover all foods had been stopped; my sister was in diapers and using a morphine pump. I was shocked, disturbed and was in no way prepared for this. I didn't know such a thing could happen. Her oncologist had

returned from holiday and made the decision alone to effectively end my sister's
life without meeting, talking or consulting with her family. To this day we have not
met him. I had no idea a doctor had the power to do this without at the very least
discussing the case and preparing the family for the next step. In my opinion this is
a form of euthanasia."

In a presentation to the Forum, Dr Dermot Phelan, a Consultant in Intensive (Critical Care) synthesised the the decision making process to withdraw life-sustaining treatment, as follows:

		Principle
Discuss patient's wishes, DNR & have family around	Truth-telling, Dignity	Autonomy
Maintain IPPV Morphine	Benefit v. burden	Beneficience
Stop adrenaline	Futility	Non-maleficence
Remove another patient from Resus Rm for above	Resource distribution	Justice

Chapter 20   DECISION MAKING AT END OF LIFE: ETHICAL ISSUES

He also provided the following table comparing rates of end of life decisions in ICUs in Ireland with those in the three European regions, as follows[89] :

DECISION	IRELAND (n=122)	NORTH (n=1505)	CENTRAL (n=1209)	SOUTH (n=1534)
Unsuccessful CPR	21%	10%	18%	30%
Brain Death	10%	3%	8%	12%
Withhold	36%	38%	34%	40%
Withdraw	33%	48%	34%	18%
Shorten dying process	0	1%	6%	0

The Bar Council said in its submission:

> "The Supreme Court[90] held that medical treatment could be withdrawn in circumstances where the right to life implies a right to let nature take its course and to die a natural and dignified death unless the individual chooses otherwise. In the case of the individual not having capacity the court will approach the matter from the standpoint of a 'prudent good and loving parent' in deciding what choice to adopt.
>
> > 'Since the right of self determination can only be exercised by a person competent to evaluate her condition, a patient lacking capacity forfeits her

89   Sprung et al JAMA 2003

90   Re a Ward of Court No. 2 [1996] 2 IR 79

right of self determination unless the surrogate decision maker, standing in the place of the incompetent, asserts the patient's preference. This surrogate decision maker is embodied in this doctrine of substitute judgment. Courts will rely on the substitute judgment doctrine only when the surrogate decision maker demonstrates the incompetent person's preference with reasonable certainty. When the patient expresses a treatment preference prior to her loss of competence the court views the surrogate as merely supplying in the capacity to enforce the incompetent's choice. Thus, a dying patient's right of self determination outweighs the rights of the patient's family, physician or other care provider to base a treatment determination on their individual interests or ethical imperatives. The irreversible incompetent's right of self determination also outweighs the states interest in preserving life, preventing suicide, protecting third party dependents of the dying patient and preserving the ethical integrity of the medical profession.' "

Hydration, Nutrition

A doctor said at a public meeting that the issue of feeding and fluids, as he called it, was a very complex one, 'a minefield'.

There is debate about what constitutes treatment, especially in relation to artificial nutrition and hydration (ANH):

- Some consider ANH a natural means of preserving life. There is therefore a moral obligation to provide it unless it is overly burdensome on the patient (Medical Council/An Bord Altranais),

- Others consider ANH as a medical treatment which can be refused like any other.

From a legal perspective ANH is considered medical treatment in Ireland. Under the Mental Capacity Act 2005 , the UK requires a specific written signed and witnessed refusal of ANH.

The Irish Nutrition and Dietetic Institute said in its submission:

"In the acute sector the goals of care are to cure the patient and to help the patient achieve maximum potential. Accordingly the goal of dietetic care is to maximise the patient's nutritional status. These goals vary greatly from the goals of the patient with advanced progressive disease, particularly the patient group entering the terminal stage of their disease trajectory where the goals are to optimize

patient comfort and symptom management. This can present a number of problems for those caring for the nutritional needs of the patient if the individual does not have adequate training and experience in the area of palliative care.

Numerous ethical issues can arise if the goals of care are not appropriately adapted. The unrealistic goal of maximising nutritional status may lead to the inappropriate commencement of artificial nutritional support in the palliative patient.

In the patient who is already receiving nutritional support either enterally [def.: pertaining to, in, or by way of, the intestine] or parenterally ethical dilemmas can arise regarding the decision to reduce or discontinue these therapies when considered burdensome to the patient.

In addition, if healthcare professionals do not feel confident in this area family members and carers of patients can invoke undue pressure on the team caring for the patient.

Insistence by family members to continue futile therapies despite increasing discomfort and visible deterioration in the patient's condition can result in quandaries for those with limited palliative care experience."

Family members too can find themselves under pressure, as the following excerpt from a submission indicates:

"We were put under enormous pressure to give permission for a Peg tube but insisted that greater effort be made into assisting with meals and nourishing my mother. I felt that the staff wished to transfer mother more quickly into a nursing home and the insertion of a Peg tube would make this possible. Apparently the nursing home finds it easier to manage patients this way. This was the explanation given."

In the context of preventable malnutrition among older people at end of life, Age and Opportunity said that equity of care depends on sensitivity to physical needs in old age and recommended the implementation of a nutrition action plan similar to the UK, which identifies patients who require assistance, measures older patients' weight and records regular food and fluid intake to ensure optimum chances of recovery.

An individual contributor wrote:

> "Hydration and nutrition do not constitute 'medical treatment', and cannot be considered so, and even when termed 'artificial' hydration and nutrition must be provided at all times, and must not be withdrawn even when it might appear that such provision is not giving a marked benefit to the patient. This is a natural means of preserving life. A person who is in a comatose state is not necessarily dying, and such a person must therefore continue to be given food and water. Only in a case where a patient is actually dying, in the last stage of a terminal illness or organ failure, and unlikely to benefit from an aggressive application of nutrition, is it ethical to cease such provision."

The All Ireland Gerontological Nurses Association said:

> "Nutritional support, terminal dehydration and artificial hydration are controversial topics and data remain insufficient to reach a final conclusion on the benefits or harm of dehydration in terminally ill patients (Ersek, 2003; Fainsinger, 2008)[91]. Since there is no ethically or medically based gold standard, each decision for or against hydration and nutrition at the end of life needs to be taken on an individual basis with the patient perspective central to all decisions. In some areas case conferences and standing committees facilitate an integrated multidisciplinary approach but this needs to be further developed."

The Irish Catholic Bishops' Bioethics Group is unequivocal in its position:

> "The distinction between therapy and basic care should be upheld at all times. Nutrition and hydration sustain life in the healthy as well as in those who are sick. Disease or trauma may be the reason why a person is no longer able to eat and drink independently, depends on the help of others to do so or even requires artificial nutrition and hydration (ANH). There is no disease or trauma, however, for which nutrition or hydration, natural or artificial, is prescribed as therapy.
>
> The provision of nutrition and hydration, by whatever means, constitutes basic care and should not be categorised as treatment. There may be legitimate differences of opinion about how nutrition and hydration can be provided under specific

---

91 Ersek, M. (2003) Artificial nutrition and hydration: clinical issues. *Journal of Hospice Palliative Care Nursing*: 5 (4) 221-230

Fainsinger, R.L. (2008) When to treat dehydration in terminally ill patient?

www.palliative.org/PC/Clinicalinfo/Editorials/Whentotreatdehydration.html

*circumstances, and this includes the question of whether or not ANH should be
initiated when a patient is no longer able to eat or drink even with assistance."*

The Group goes on to say:

*"A decision to withdraw ANH is qualitatively and, therefore, ethically different from
a decision not to initiate ANH. The withdrawal of ANH with a view to shortening
or ending life is a form of euthanasia. The only circumstances in which it is morally
legitimate to withdraw life-sustaining ANH is when the harm or distress caused to
the patient by ANH is disproportionate to the good achieved, e.g., in the final stages
of terminal illness, when the organism can no longer assimilate food or liquid, or
when ANH is implicated in serious recurrent infection. It follows that an ACP which
required the withdrawal of ANH with a view to shortening or ending life would not
be ethical and should not be valid or binding."*

Hypersecretion

A Cardiovascular Nurse Facilitator wrote of her experience of nursing a relative as she
approached death, which raised questions in her mind about best practice in dealing with
hypersecretions in dying persons. She suggested there should be improved discussion of the
realities of the issue and of how best to treat it, whether by suctioning or injecting medication,
both of which may be very distressful to the dying person.

Decision making regarding Pain Control and Sedation

The Forum heard accounts of under-medication and over-medication; of difficulty in getting
pain relief and of excessive use of drugs (particularly for the elderly); and of over-sedation. Each
account, of course, is from one person's perspective, or that of a family, and may not represent
the full picture. Sometimes, people said medical errors resulted in patients being unable to
communicate before death.

Some said that we are good at treating acute pain, but not good at treating chronic pain. A
consultant said that he believed "this (pain relief) to be an exaggerated topic and today readily
manageable. Respiratory death, in my view, was/is more distressing than malignancy. Cardiac
death, when not sudden, can be readily 'controlled' with both patient and relative succour."

The complexity of decision making in regard to pain control and sedation was also raised at
the Forum. Two seemingly opposite experiences serve to highlight how this may affect people

Chapter 20 DECISION MAKING AT END OF LIFE: ETHICAL ISSUES

at end of life and their families. The first is from an account by a nurse of her mother's death, as follows:

> "She was not in distress when the palliative care nurses arrived, inserted a morphine pump without consultation with the family, and withdrew fluid provision. She died less than three days later. The speaker said that neither she, nor her sister, also a nurse, understood why this was necessary, given that her mother was not exhibiting any form of distress prior to the provision of the morphine pump."

The other is from a submission:

> "My gentle father had been in and out of ICU, and despite my efforts to limit the medical interventions he was receiving - I was ignored. I found it very isolating in the hospital and difficult to get guidance. When we were eventually told he had about 3 days left to live, he was obviously in pain. After much begging and pleading (and with advice from one particular nurse) I got a morphine pump for my father. I could not believe how difficult it was to get this for him. I could actually hear the nurse arguing with the on-call doctor (it was the weekend), trying to explain to him that we must care for the dying as we would for the living. I was later told that if he had been dying of cancer this would have been given automatically. "

The principle of double effect was mentioned on a number of occasions in the context of pain control at end of life. Drugs are prescribed to treat the symptoms associated with the process of dying, with the primary intention, and effect, of relieving pain, fear or other distress. While research evidence is lacking, general consensus within palliative medicine is that sedation does not shorten life, Professor Smith says. However, in some instances this may appear to be its secondary effect.

Professor Smith said that sedation at high doses is used in palliative care to sedate patients and on occasion, when all other means of relief have failed, to induce unconsciousness. Deep sleep is deliberately induced and maintained only on occasions of profound anguish that are not amenable to spiritual, psychological or other interventions when the patient is perceived to be close to death, he said. It is used to control refractory symptoms in patients who are in the terminal phase of their illness, that is to say symptoms which could not be adequately controlled, despite aggressive efforts to identify a tolerable therapy that did not compromise consciousness.

6

In his presentation, Professor Smith said that sedation is not any form of euthanasia because its aim is to provide relief from suffering. Death of the patient is never the intent. Death is not necessary to provide relief from symptoms. Sedation is only considered when all other means have failed. Based on suggestions made by Professor Smith, the following are ways of discerning whether best practice is being followed or not:

- Do patient and family wish for sedation rather than endurance of symptoms, and are fully involved in decision making?

- Is the decision made rationally, voluntarily and consistently?

- Is the intention of all the relief of symptoms and not to shorten a patient's life?

- Has diagnostic and prognostic clarity been established?

- Has a second opinion been sought?

- Is there an explicit process for documentation and review?

- Are the symptoms refractory?

- Is there bench marking against others' practice?

- Is regular training undertaken to ensure understanding of effective steps to treat any reversible conditions before commencing sedation?

- Are protocols for the initiation of sedation in place?

Resuscitation and Do Not Resuscitate Orders (DNRs)

Cardiopulmonary Resuscitation (CPR) "can be defined as any immediate emergency treatment aimed at restoring spontaneous circulation and breathing to the patient."

A Do Not Resuscitate Order (DNR) "records a prior decision that in the event of an individual patient suffering a cardiac or respiratory arrest CPR would not be appropriate".

A study of Irish consultant physicians practices[92] found that of the 173 replies received, 85 expressed unsatisfactory understanding of issues relating to Irish Do Not Attempt Resuscitation (DNAR) orders (49%). 116 physicians felt that alert patients preferred not to discuss their own resuscitation (67%). 55 physicians felt that if a competent adult patient is

92 Butler MW, Saaidin N, Sheikh AA, Fennell JS. (2006) Dissatisfaction with Do Not Attempt Resuscitation Orders: A nationwide study of Irish consultant physician practices. Dublin: Irish Medical Journal

the subject of a DNAR order without the patient's knowledge, the reasons for this decision are "almost never" documented in the patient's medical record (32%). 75 consultants "almost never" had advance discussion of resuscitation preferences with the patient (43%). 47 physicians had experienced advance directives for Irish patients (27%). 102 physicians felt that both they and the patient's next of kin had joint responsibility for deciding resuscitation status for an incapacitated patient with no advance directive (59%). 37 respondents described a formal resuscitation policy in their place of work (21%). We feel that physicians require greater national guidance regarding DNAR order-making, and we advocate more widespread use of resuscitation policies.

The Deputy Director of Nursing at Our Lady's Children's Hospital, Crumlin, said:

> *"The decision to not resuscitate a child is not an easy one to contemplate. Sometimes it may not be appropriate to attempt to resuscitate a child with a life-limiting or life-threatening illness. In these circumstances, following discussion with parents/guardians, a Do Not Attempt Resuscitation Order (DNAR) may be made. (It is important to understand what a DNAR entails).*
>
> *The term Do Not Attempt Resuscitation (DNAR) means that if your child stopped breathing, or if your child's heart stops beating, nature would be allowed to take its course. Some people call this allowing a natural death. The hospital staff would not call the hospital's emergency team or begin active breathing support or chest compressions, and a child would not be transferred to Intensive Care."*

The Irish Catholic Bishops' Biothics Group added:

> *"A DNR order would be appropriate if, taking account of the patient's overall condition, the burden of CPR would be disproportionate to its expected therapeutic benefits or if CPR would involve an unreasonable burden on the patient, especially a frail, elderly or dying person."*

One person suggested that DNRs should be called ANDs: 'Allow Natural Death'. At a public meeting a doctor said "people in the area were now talking about the concept of 'allowing a natural death' and the absence of CPR does not mean there is no desire for active care. He said that sometimes CPR can be against the concept of dignity for the dying."

Some contributors emphasised that decisions to resuscitate or not to resuscitate were medical

ones. One said that decisions not to resuscitate:

- must be taken by the doctor who has overall responsibility for the patient as per the BMA/RCN guidelines

- should be discussed with the patient, or with next of kin if the patient has not got capacity to participate in the discussion

- must be recorded in writing

- must be communicated to the team caring for the patient, and

- should generally be reviewed on a regular basis, especially if circumstances change.

However, significant concern was expressed by people with direct experiences of DNRs in practice. Speaking about her deceased husband, one person wrote:

> "When I obtained his notes from the hospital after his death I read to my horror that it had been decided he was not for resuscitation and this had not been discussed with us. This has upset me greatly because if I knew that I would have decided against him having a 2nd course of chemotherapy and I could have had him at home as he did not want to have a 2nd course of chemo."

The Ombudsman wrote as follows:

> "My Office received two separate complaints about the decisions of medical staff to place Do Not Resuscitate orders on their loved ones' medical charts. The actions were taken allegedly without any consultation with the family. They did not know what the order meant, whether it related to cardiopulmonary resuscitation (CPR) or whether it also involved medication, fluid and nutrition. The order traumatised both complainants and caused major distress. Again, I recognise the major ethical considerations here, the importance of the patient's own wishes as opposed o those of the family and the huge level of responsibility placed on a consultant's shoulders in such cases. However, it is all the more reason for a strong, well considered and detailed policy on the use of Do Not Resuscitate orders by every institution and the sharing of this policy with patients and families, in a way that is understandable. Adherence to such a policy is crucial. Communication with the patient and family, where appropriate, should be a central tenet of all such policies."

The All Ireland Gerontological Nurses Association wrote that "there remains a lack of clarity around resuscitation leaving the nurse in a vulnerable position if decisions are not made in advance. Fear of litigation impacts on care of the dying and there is need for guidance on interventions which may prolong life or prolong death." It was mentioned at a workshop that the enquiries database of An Bord Altranais Education Department, which records issues raised by nurses, includes questions relating to DNR policies and the writing of DNR orders without consultation. It would no doubt be instructive to analyse these questions concerning DNR orders.

At another workshop it was explained that Ethics Committees in different hospitals determine protocols and procedures for DNRs in their hospital. But nationally agreed procedures or guidelines on DNRs should be considered. Given the understandable concern for greater transparency in matters relating to end of life decision making, information on the following should be publicly available and easily accessible to all:

- who makes DNR orders,

- under what circumstances they do so,

- what procedures they follow and

- how they record such decisions.

Nursing Homes Ireland expressed especial concern for a standardized process and policy for discussions and decisions around resuscitation in end of life care.

Assisted Suicide

While the work of the Forum on End of Life is predicated on hospice and palliative care principles, a number of participants raised questions of physician-assisted suicide and euthanasia, neither of which is legal in Ireland.

At a Forum public meeting someone said that when friends of hers were ill and passed on there were so many discussions on the subject [of assisted suicide]. The following is taken from the record of the meeting:

> "She described how (if) you have a sick animal you bring it to (the) vet and put it
> down and said that couldn't be done for a human being so their loved ones have
> to sit and watch the pain and suffering that goes on and on. In many instances she
> suspected that if there weren't the sort of barriers – religious, moral, social, legal, -

there would be a significant number of people that would choose this route when the time comes."

A doctor responded:

"The questions we need to be asking is why do they want to do that, what is causing them to suffer and can we support them with that. Being dead might seem a lot easier than trying to live. But when you tease those things out and let someone ventilate, it's amazing what you can support and people don't continue to feel that way."

Another doctor at the same meeting

"shared his experience of meeting a young man who had tried to commit suicide my slitting his wrists. He had gone in to see him before he was being transferred to another hospital and the man said: "Don't touch me, if you do, I'll die." He didn't want to die, yet only a few hours earlier he had tried to kill himself."

At a workshop the presenters were asked how they respond to patients who express suicidal intentions. One said that she tries to maintain a neutral stance by saying how brave the patient is. Another said that she tries to understand the patient better, what brings him/her to this point. She asks 'Why do you want to take your own life?" The answer, she said, might indicate a fear of choking or suffocating, for example, which demonstrates why palliative care is so important. Some patients who imagine a painful or undignified death can be reassured that things will not be as they imagine, because care staff will not let it happen that way. Interpersonal support and commitment can make the difference, she said.

The Humanist Association of Ireland said in the submission it presented that it hoped modern medicine could be used to enable a dignified end to suffering where clear, unequivocal wishes have been stated.

Another submission from the Irish Catholic Bishops' Bioethics Group said:

"The slogan "Right To Die" has an appealing sound to it but few expressions are more poorly understood or are more misleading. The failure of ["Right To Die"] advocacy groups to realise that the greatest risks at the end of life are more likely to relate to inadequate services rather than over-intensive treatment yet again points to the need to ensure that education in ethics has a sound grounding in the evidence base of interventions and prejudice at the end of life."

Chapter 20 DECISION MAKING AT END OF LIFE: ETHICAL ISSUES

While ethical issues are often addressed from an individual's perspective, some contributors emphasised that the social dimensions of ethical issues must also be considered. Some people view life as something they can do with as they want. Those who are concerned for what is best for everyone in society cannot, however, simply confine themselves to saying, 'Don't legalise this or that'. They have to get involved in building the sort of society in which individuals who feel suicidal are cared for - medically and otherwise - valued and cherished, rather than confirmed in their pain by facilitating their death.

Euthanasia

While euthanasia was referred to from time to time in the Forum, there were few detailed discussions of the issue. One person said in a submission:

> "We in Ireland should never forget that life from conception to natural death is a blessing. When we see Euthanasia being promoted or subtly being drip fed to the public I think we are going down a slippery dark road to disregard of the vulnerable in our society. A dignified death is not one that is hastened to suit agendas but one that is respected and cared for in its natural journey."

The Irish Catholic Bishops' Bioethics Group did however address the issue. For the purposes of its submission the following definitions of euthanasia were proposed:

- 'Active Euthanasia' is where death is caused by a deliberate action. The clear intent is to terminate life.

- 'Passive Euthanasia' occurs when death is produced by withholding or withdrawing ordinary means of nutrition or treatment from the patient's condition with the intention of hastening death.

- 'Voluntary Euthanasia' is that which is requested by the subject or agreed by him/her when proposed by others.

- 'Involuntary Euthanasia' is where the agreement of the subject could be sought but is not.

- 'Non-voluntary Euthanasia' is where the subject is unable to indicate a rational agreement.

The group addressed in particular the subject of understanding and responding constructively to requests for euthanasia, as follows:

"It is well known that the request for euthanasia from the patient with advanced and progressive disease is often transient and may coincide with a bad period of symptom control, even a clinically treatable depression. In a study published in 1995, Chochinov found that the desire for death changed with improved pain management and psychosocial support.[93] The study also indicated that depression emerged as the only predictor of the desire for euthanasia. It appears that pain may increase the risk of depression, while increased psychosocial support protects against it."

"Where the request for euthanasia persists despite good symptom control, psychosocial, and spiritual care, the challenge to palliative care is to identify and respond to the suffering of the person. Suffering and the response to suffering can in itself have value and meaning to the person. In the study referred to above patients who reported a serious desire for death during the initial stages of the study differed from the rest of the group on the dimensions of pain, family support and depression, including a much higher prevalence of diagnosed depressive disorders. Good palliative care may reduce the request for euthanasia but some patients will want to end their struggle against serious illness in their own way and at a time of their choosing."

In his presentation to the Forum, Dr Donal O'Mathuna stressed that the answer to our failures as a society to ensure that people die with dignity is not to promote euthanasia in our healthcare system but to promote its ability to ensure dignity in dying:

"Death with dignity is something we all want. Unfortunately, some people find death with indignity, hooked up to all sorts of tubes, and pumps and machines. Some find themselves alone, ignored, and left in their own fluids. Sometimes it seems like there is a medical treadmill running out of control. We don't seem to know how to get off the treadmill safely. So, some say, we need the big, red stop button provided by euthanasia.

"But why would anyone think that we can fix the healthcare system by adding the power to kill innocent people? Adding lethal injections to the doctor's medical bag is not the answer. We need a society where we promote people's dignity in dying, but without promoting death as our ally."

---

93 cf. H.M. Chochinov et al. "Desire for Death in the Terminally Ill" in American Journal of Psychiatry, 152:8, August 1995.

Chapter 21
ADVANCE CARE DIRECTIVES; ETHICAL AND LEGAL CONSIDERATIONS

Definitions

In his presentation to the Forum, Professor David Smith, defined an Advance Directive as "a statement made by a competent adult relating to the type and extent of medical treatments s/he would or would not want to undergo in the future should s/he be unable to express consent or dissent at that time." The Irish Council for Bioethics added, "An advance healthcare directive may be oral, written or otherwise recorded (e.g. voice or video recorded)."

The Irish Catholic Bishops' Bioethics Group would prefer to use the term 'Advance Care Preference'. It says

> "The term Advance Care Directive, which is commonly used, is unsatisfactory in that it suggests a prioritization of any formal statement of advance preferences over the many other important factors which might be involved at the time of decision making, we would suggest the term 'Advance Care Preference' (ACP) for any such formal statement of advance preferences should a person no longer have capacity to participate in specific healthcare decisions."

Interestingly, an omnibus public opinion survey conducted in 2007 found that seven in ten people had 'never heard of' the term 'Advance Directive' but over half claimed to know something about the term 'Living Will'.

ACDs: A means of Safeguarding Patient Autonomy and facilitating Communication

In Chapter 14 we discussed patients' rights at end of life, including their right "to think and act as s/he wishes, free from external influences and provided those wishes do not inflict harm on others". ADs are recognised as an expression of autonomy and as a useful tool enabling control over medical treatment into the future, when individuals may lack the capacity to express autonomous preferences. However, that autonomy is not absolute and it cannot compel healthcare professionals to meet unrealistic or illegal treatment demands.

It is important to emphasise the right to exercise one's autonomy, particularly in relationships where the balance of power is unequal, such as in the doctor - patient relationship, and very particularly when the patient is unable to communicate at all.

Chapter 21 ADVANCE CARE DIRECTIVES: ETHICAL AND LEGAL CONSIDERATION

Advocates of Advance Directives were forthright in calling for their recognition in law:

> "I strongly urge the Forum to recommend that such documents (Advance Directives) be recognised in Irish law. I have had an Advance Directive in place for myself for many years but I am sadly aware that this has no legal force and is only a statement of my wishes which may or may not be respected, should the need arise."

Advance directives also have another important function and value, that of enabling ongoing communication between patients, their relatives and healthcare professionals involved in their care planning. A Motor Neurone Disease Clinical Nurse Specialist put it this way:

> "Perhaps the most valuable aspect of raising the opportunity to write an Advance Care Directive or discuss end of life decisions is in the discussion that it arouses, and the permission that can follow to discuss difficult realities and the options facing patients and their carers."

And the representative of the Church of Ireland added:

> "Within the Church of Ireland we would argue that there is not a need for Advance Directives, as a legally binding contract, but if they aid communication between patients, their families and the caring professions then they could be of value. But if they are available then they should be indicative, helpful in decision making for the health professionals and the family and friends, and ease the pain of the family and friends at a difficult time, to know that the wishes of a loved one were being followed."

Caveats

A contributor cautioned about the complexity of advance care directives and how preferences change over time; people need to understand the procedures they are considering and making decisions about, she said.

Professor David Smith said that an individual's views/values regarding treatment may change:

- with age
- with onset/progression of illness
- with prospect of future medical advances.

And he asked, "Do these changes reflect a change in a person's identity? Should the 'previous self' be able to dictate to the 'future self'? "

He also said that, given the right to self-determination, treatment decisions, particularly refusals

Chapter 21 ADVANCE CARE DIRECTIVES: ETHICAL AND LEGAL CONSIDERATION

of treatment, outlined in an advance directive (AD) should be followed provided they are legal.

A submission asked about the consequences of giving ACDs legal force:

- What would be the legal repercussions of not following them? (eg an assault charge)
- What would be the staff training implications?
- Would continuous assessment of preference/directive not be frustrating for the patient?

At a workshop a hypothetical question was asked: whether someone should be resuscitated who, having made an advance care directive not to be resuscitated, subsequently has a car accident? A contributor noted in a submission:

> *"The Journal of Emergency Medicine reports that even when living wills do not specifically request that no attempt should be made to prolong life, '90% of the emergency medical technicians and paramedics interpreted the mere existence of a living will to mean they should provide only comfort and end of life care and not attempt to save the person's life'."*

Research undertaken for the Irish Hospice Foundation by UCC and the RCSI has sought to explore in-depth what Irish people think about diverse end of life issues:

> *"Some of the research explored people's reluctance to leave instructions as to how they should be treated if they were terminally ill, with most people believing that 'you should not interfere with death' unless you have to. While the notion of advance care directives or living wills may sound rational and reasonable, some respondents wondered what would happen if something goes wrong and 'you change your mind'. Taking everything into account, the general consensus of the focus groups was that it is probably 'safer' to trust in your own ability to make decisions or to rely on your loved ones to make decisions on your behalf. Is it a shrewd pragmatism or simply naïveté that leads someone to say in respect of advance care directives: 'I wouldn't like to linger but I would also be reluctant to write it down'."*

Positions

A number of bodies commented in some detail on Advance Care Directives. Some argued in favour of a legal framework governing Living Wills/ Advanced Directives. The Society of Friends said that they would favour legislation in regard to Living Wills, "so that medical intrusiveness

6

Chapter 21   ADVANCE CARE DIRECTIVES:
ETHICAL AND LEGAL CONSIDERATION

is at a minimum, depending on the wishes of the person". The following are some other positions on the subject:

Age Action Ireland:

> "A legal framework should exist in this country which protects people; assists them in making decisions which reflect their wishes at the end of their lives; and promotes their autonomy and dignity."

The Humanist Association of Ireland :

> "The HAI would like to make the distinction between end of life care and euthanasia/assisted suicide clear; to refuse treatment is legal, on whatever grounds the patient chooses; the autonomy of the individual must be respected. In order to establish what the wishes of an individual are the HAI has been supportive of the creation of an 'advance healthcare directive', completed by people while in a sound mind, duly witnessed and ideally with medical advice … We suggest an advance directive should be reviewed regularly and stored in a national database."

The Church of Ireland

 "As members of the Church of Ireland we feel that, with appropriate communication between patients, their families and the health professions, there should be no need for formal advance directives.

If there are to be advance directives, then:
  • they should apply to conditions that are terminal, incurable and irreversible
  • they should be to list treatments that should not be carried out, in the event of certain events
  • they should not be to force any particular treatment to be carried out
  • they should not be legally binding
  • they should not require an illegal action by others
  • there should be a presumption that the wishes expressed will be carried out
  • but, at the same time, are seen as indicative of a wished course of action
  • they should be time limited
  • they should need positive renewal

- there is a great need for more palliative care physicians and nurses, and other appropriate care workers, to meet the needs of these patients.

The Church of Ireland then listed the problems which need to be addressed as follows:

- Should all age groups be able to sign Advance Directives?

- Should they only apply to certain situations?

- How are the terms "terminal, incurable and irreversible" to be defined?

- How does a person give fully informed consent to an action or inaction for an abstract situation in the future?

- Is artificial nutrition and hydration a medical intervention,(when carried out at home, by family)? If commenced then how is it to be withdrawn, and by whom?

- What is the role of a proxy?

- If a written signed directive, can family overrule it?

Discussions about Advance Directives must not be allowed to be used as a "back door" route, by certain pressure groups, to patient assisted suicide or euthanasia."

Irish Catholic Bishops' Bioethics Group:

The Catholic Bishops' Bioethics Group prefers the term 'Advance Care Preference' (ACP). The Group argues:

- "An ACP should carry significant weight in so far as it refers to certain forms of treatment which a person wishes to exclude (i.e., a negative ACP), but it cannot legally bind a healthcare professional to a course of action or inaction which conflicts with his or her judgement of conscience. Any action of a healthcare professional which conflicts with the terms of an ACP should be noted and explained in writing

- an ACP should not provide for the withdrawal of basic care, including - when deemed necessary - artificial nutrition and hydration (ANH)

- an ACP which specifies certain forms of treatment that a person would wish to have under certain circumstances (a positive ACP) should carry significant weight, and serves as a reminder of the quality of care to which every patient is entitled, including particularly those who are no longer in a position to vindicate their right to care. Access to specific forms of treatment is not, however, an absolute

right, being subject always to respect for the rights and freedoms of others and to the just requirements of morality, public order and the general welfare in a democratic society

- an ACP should ideally be recorded and witnessed in writing or in some other permanent form, and discussed with a senior healthcare professional with expertise in the condition(s) specified in the ACP

- it should be clear how many copies of an ACP have been signed and to whom they have been entrusted

- a period of time should be specified after which an ACP must be reviewed, to take account of the patient's own circumstances and any developments in treatment

- a patient is always entitled to change his or her mind. Current signals and expressions should be taken as the binding new will, in preference to rigid adherence to the previous position expressed in a written ACP

- any copies of an ACP which has been formally revised or revoked should be destroyed."

In the event that advance care preferences were to be recognised in Irish law, the Bishops' Bioethics Group asks:

- whether decisions expressed in an ACP would be legally binding

- whether the scope of ACPs would be limited in any way

- whether they should include preferences for active treatment as well as treatment refusal.

The Group concludes:

> "Unfortunately there is ample evidence to suggest that not only do unacceptable numbers of people die in hospital with inadequate pain relief, but also that the political impetus to develop adequate universal palliative care is lacking. This requires urgent attention, and no legislation to provide for ACPs will substitute for that.[94] "

---

94 cf. Biggar, Nigel. Aiming to Kill: The Ethics of Suicide and Euthanasia. London: DLT, 2004, pp 170-171

Chapter 21 ADVANCE CARE DIRECTIVES:
            ETHICAL AND LEGAL CONSIDERATION

Irish Council for Bioethics:

In its 2007 report, *Is It Time For Healthcare Directives?* Opinion, the Council stated that competent adults should have the right to prepare an Advance Care Directive stemming from their right to self-determination and their related rights to bodily integrity, privacy and dignity. In its submission to the Forum on End of Life the Council says**:**

> *"Accordingly, the Council acknowledges the right of an individual to refuse any form of medical treatment, including artificial nutrition and hydration or any form of life-sustaining treatment, in an advance healthcare directive if he or she so wishes. However, positive requests for medical treatment, made in an advance healthcare directive could prove more difficult to accede to. The Council is of the opinion that such positive requests should be taken into account, but their provision should be based on the relevance of the proposed treatment to the current situation and the feasibility of providing it given the personnel, technical and financial resources available. For example, demands for treatments that the doctors and medical practitioners consider futile (i.e. with a low probability of success) should not be endorsed … "*

And the submission adds:

> *"The weight of legal opinion in the Republic of Ireland recognises the right of competent adults to decide on the nature of their medical treatment. However, the lack of specific legislation in relation to advance healthcare directives in Ireland has created some uncertainty regarding their status here. Consequently, the Council believes that there is both a need and an opportunity to develop a legal framework for advance healthcare directives to facilitate their use and implementation. For instance, where an individual wishes for his/her healthcare directive to be considered legally binding, the directive should state in clear and unambiguous terms both the specific treatments to which it relates and the situations to which it should be expected to apply. On the other hand, some individuals may wish to outline general preferences regarding their future treatment, which they would like to be taken into account as opposed to being strictly legally binding. The Council believes that both forms of directive should be accepted, but it recognises that general statements in advance healthcare directives may require additional interpretation before they can be adhered to."*

Chapter 21 ADVANCE CARE DIRECTIVES: ETHICAL AND LEGAL CONSIDERATION

"Ultimately," the submission concludes, "there is need for increased awareness of and education about the issues surrounding advance healthcare directives for all concerned, from the general public to healthcare professionals and policy makers. The Council, therefore, welcomes the recent consultation paper (entitled Bioethics: Advance Care Directives) produced by the Law Reform Commission. The Council looks forward to their final report, which will, hopefully, help to move this issue forward."

The Law Reform Commission:

In June 2003, the Commission published a Consultation Paper on Law and the Elderly , which made provisional recommendations concerning legal mechanisms for the protection of older people under a number of specific headings. It also set out the Commission's proposed framework for a new decision making structure – Guardianship – to replace the current Wards of Court structure, which is based primarily on the Lunacy Regulation (Ireland) Act 1871.

"The focus of the Consultation Paper on Law and the Elderly was to make recommendations concerning older persons, but the Commission also acknowledged that the recommendations made were also relevant to other adults with decision making disabilities or who otherwise need protection. As a result, in May 2005 the Commission published its Consultation Paper on Vulnerable Adults and the Law: Capacity. This second Consultation Paper provisionally recommended the enactment of new capacity legislation in order to create clear rules on legal capacity which would apply to a wide range of decisions, including making contracts such as buying groceries at a shop, transferring ownership in land, entering into a personal relationship and making healthcare decisions. The Commission also concluded that its proposed capacity legislation would be the appropriate context for establishing the new Guardianship system."[95]

The report, Vulnerable Adults and the Law (2006) brought together the issues dealt with in the two Consultation Papers. It was divided broadly into two parts: first, reform of the law on mental capacity, and, second, the establishment of a new Guardianship structure in place of the wards of court system. It also dealt with reform of the Powers of Attorney Act 1996 to allow attornies make some healthcare decisions.

It led to the Government's Scheme of Mental Capacity Bill 2008. This Scheme did not provide for advance directives, however. The National Disability Authority said in its presentation to the

---

95 Vulnerable Adults and the Law (2006), Dublin: The Law Reform Commission

6

Forum that provisions for advanced directives should be considered as the draft legislation is developed by the Department of Justice, Equality and Law Reform.

In September 2009 the Law Reform Commission published its Report on Bioethics: Advance Care Directives [LRC 94 - 2009]. This recommended that an appropriate legislative framework should be enacted for advance care directives, as part of the reform of the law on mental capacity in the Government's Scheme of a Mental Capacity Bill 2008. It further recommended that the proposed legislative framework should be facilitative in nature and be seen in the wider context of a process of healthcare planning by an individual, whether in a general healthcare setting or in the context of hospice care. The intention of the legislative framework would not be to impose liability or sanctions, but to inform codes of professional conduct and their prosecution. It would not give immunity from other laws nor would it alter or affect current law on homicide, under which euthanasia and assisted suicide are criminal offences. The proposals cover advance care directives involving refusal of treatment, including life-sustaining treatment but not refusal of basic care.

The Commission's proposals in its 2009 report include, inter alia:

- that the term 'advance care directive' be used in any legislative framework that deals with the advance expression of wishes of an individual in a healthcare or wider care setting

- that an advance care directive should be defined as the expression of instructions or wishes by a person of 18 years with capacity to do so that, if (a) at a later time and in such circumstances as he or she may specify, a specified treatment is proposed to be carried out or continued by a person providing healthcare for him or her, and (b) at that time he or she lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued

- that the proposed legislative framework should apply to advance care directives that involve refusal of treatment, subject to certain conditions to be specified in the legislation

- that the proposed legislative framework should not apply to advance care directives involving mental health

- that basic care could not be refused under an advance care directive

- that basic care should be defined to include, but not be limited to, warmth,

shelter, oral nutrition and hydration and hygiene measures

- that palliative care should be regarded as part of basic care

- that an advance care directive may include a refusal of life-sustaining treatment, that is, treatment which is intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are incapable of independent operation.

The Commission proposed that, in view of the complex issues involved in the legislative framework for advanced care directives, a Code of Practice should accompany the statutory framework. The Code of Practice should provide guidance for healthcare professionals and others on a range of matters, including:

- on what constitutes basic care

- on what constitutes palliative care

- on the types of treatment that come within the definition of life-sustaining treatment

- on what should be included in the advance care directive

- on the circumstances in which artificial nutrition and hydration (ANH) may be considered to be basic care and, as the case may be, artificial life-sustaining treatment

- on the types of circumstances in which an unwritten advance care directive would be likely to be enforceable under the proposed statutory framework

- on the process of putting in place a DNR order, including:

  - that before a DNR order is made there is a consultative process,

  - that this is documented on the patient's chart and

  - that it is made by the most senior available member of the healthcare team.

In its presentation to the Forum, the Law Reform Commission emphasised the complexity of the legal and ethical issues involved in Advance Care Directives. It said that it would see the Irish Hospice Foundation and the the Forum having a role in debating and taking forward the matters which it felt could not be incorporated in the legal framework, without making it too cumbersome, namely:

- the Code of Practice to accompany the statutory framework on Advance Care Directives

- the development of agreed Irish definitions of "life-sustaining treatment" and "basic care"

- the process governing "Do Not Resuscitate Orders"

- the need for an ethics famework, including the determination of what this should mean/cover.

Chapter 22
LEGAL ISSUES AT END OF LIFE

Introduction

Just as ethical issues at end of life are complex, so too are legal provisions covering end of life matters. The contribution of legal experts to the Forum were therefore most valuable. In addition to the submissions from solicitors, and solicitors' advice at public meetings and workshops, the contributions of the Law Reform Commission and the Bar Council were most helpful.

A constant theme of discussion on legal matters was the need for individuals to make provision in advance of future eventualities such as their own loss of function/capacity and their death. In addition there was an emphasis on the need to update and reform laws governing mental capacity, guardianship, care provision, end of life decision making and succession.

Enduring Powers of Attorney (EPAs)

In its submission Age Action Ireland wrote:

> "Major decisions, such as end of life care for people who lack capacity ... are currently legislated for under the Ward of Court system or by Enduring Power of Attorney. Evidence suggests that often informal decisions are made without (i) gaining consent from people who may lack capacity, or (ii) applying to become a donee of ward of court on their behalf."

In a submission to the Forum, a solicitor wrote:

> "There is a tendency by people to totally avoid the possibility of having diminished or very limited mental capacity. Up to the passing of the legislation establishing Enduring Powers of Attorney, such persons were made Wards of Court. Now the public have the choice but regrettably and unfortunately only a very small percentage of the public complete an Enduring Power of Attorney ... the bureaucracy of the Wards of Court Office, through no fault of its own, can unwittingly inflict great suffering and hardship on families. All of this could so easily be avoided."

Another solicitor in a presentation to the Forum agreed that EPAs are an efficient planning mechanism and that they are not being used as frequently as they should. She described an Enduring Power of Attorney as a legal document made by a donor, at a time when he or she has full capacity, setting out who he/she would like to make decisions on his/her behalf in the event of he/she being no longer able to manage his/her own affairs. An attorney can make property, financial and business affairs decisions on his/her behalf. He /she can also make decisions about the donor's personal care, but not about their medical treatment. Personal care includes:

- Where donor should live

- With whom donor should live

- Whom donor should see and not see

- What training, rehabilitation donor should get

- Donor's diet and dress

- Inspection of donor's personal papers

- Housing, Social Welfare and other benefits.

In its submission, the Bar Council asks:

> "Is there a necessity to extend/amend the legislation in relation to medical treatment and care decisions or any other issue?
>
> Is there a need to extend the legislation to deal with incapacity by reason of physical disability?"

Mental Capacity Legislation

A number of contributors referred to mental capacity legislation and the need for legal reforms relevant to people at end of life and to their successors following death. Reference has already been made in the last chapter to the Government's Scheme of Mental Capacity Bill 2008, which is based mainly on the Law Reform Commission's Report on Vulnerable Adults and the Law. (2006) and which takes account of the requirements of the UN Convention on the Rights of People with Disabilities.

The intention of the proposed Bill is to change or replace the current Wards of Court system with a system of guardianship. It also proposed to amend the law on Enduring Power of Attorney to bring it into line with the proposed new guardianship scheme[96] . The Law Reform

---

96 See RELATE, Citizens Information Board, July 2009, pp. 4- 7 for an account of the proposed changes.

6. Legal and Ethical Issues

· ·

Chapter 22   LEGAL ISSUES AT END OF LIFE

Commission includes the following recommendations in its legislative framework for Advance Care Dirctives, to be included in the Scheme of a Mental Capacity Bill 2008:

- that the Government's Scheme of a Mental Capacity Bill 2008 be extended to provide that a person may appoint an attorney under an enduring power of attorney (EPA) to make decisions regarding life-sustaining treatment, organ donation and non-therapeutic sterilisation, provided that these are expressly provided for in the EPA

- that, in general, in the event of a conflict between the terms of an enduring power of attorney (EPA) executed under the Powers of Attorney Act 1996 and an advance care directive, the EPA should take priority over an advance care directive

- that, where it appears that a conflict arises between the terms of an EPA and an advance care directive, there should initially be an attempt to resolve any apparent conflict informally, involving the donee of the enduring power of attorney and the relevant healthcare professional, and, where applicable, the healthcare proxy

- that, in the absence of agreement between the parties, the matter should be referred to the High Court for resolution.

The new legislation will replace the rigid 'all or nothing' Wards of Court approach to the determination of mental capacity to make decisions with a functional approach which assesses a person's legal capacity in relation to a particular decision to be made at the time it is to be made.

The proposed legislation is based on a set of principles, including[97]:

- that everyone has capacity unless the contrary is proven

- that a person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success

- that a person should not be treated as unable to make a decision merely because he or she makes an unwise decision

- that account be taken of a person's past and present wishes, where they can be ascertained

- that account be taken of the views of any person with an interest in the welfare of a person who lacks capacity, where these views have been made known.

---

97 See RELATE, Citizens Information Board, July 2009, p. 4 for full list of basic principles

Decisions on whether a person has capacity to make a given decision or decisions will be made either by the High Court (of Care and Protection) or the Circuit Court (of Care and Protection). Major healthcare decisions such as withdrawal of life support will be reserved to the High Court. Enduring power of attorney will be extended to include lesser healthcare decisions. A Nurse Manager in Intellectual Disability Services said that assessing mental capacity is decision and context specific, incorporating both diagnostic and functional testing.

The Neurological Alliance of Ireland (NAI) said that the limited access to formal assessment by a neuropsychologist in Ireland raised the issue of what standard is used to assess competency. In a similar vein, and as already noted in Chapter 16, the National Disability Authority (NDA) noted that the Scheme of the Mental Capacity Bill was silent on the issue of independent advocacy around the process of establishing incapacity.

The NDA also noted that the Bill gives limited guidance on supported decision making. Supported decision making is a process, whereby someone with diminished capacity has information concerning their options such as healthcare options explained to them in an accessible, supportive way to enable them to make their own choices. Improved provisions on supported decision making would have significant implications for adults with diminished capacity needing to make choices in end of life situations, such as consenting to invasive procedures.

The NAI said it is concerned that supportive decision making is facilitated as far as possible by practitioners with an appropriate understanding of the effects of neurological conditions and that those making decisions on behalf of people with neurological conditions are sufficiently informed to make such decisions.

Wills and Succession Law

A constant theme of public meetings was the importance of making wills and providing responsibly in the event of illness or incapacity and death. These issues were also raised in submissions and at workshops.

A will is a legal document setting out how the testator wants to deal with his estate. Failure to make a will means one dies intestate and executors are imposed rather than chosen in advance by the person making the will. Wills are particularly important for those who have assets, for those who want to provide for the special needs of family members. Making a will

is also an opportunity to appoint executors who will be able to work together. They should be informed in advance. Making a will is also an opportunity to manage the assets being disposed of on death in a tax efficient manner. Wills should be reviewed regularly.

A solicitor recommended at a Forum workshop that guidelines on assessment of testamentary capacity be drawn up. She suggested that changes to reduce the chances of a will being open to challenge after death be introduced and that there be contemporaneous assessment of capacity by a medical practitioner.

She also recommended that a Register of Wills be established, because families often do not know a will exists or where to find it.

The Bar Council identified the following other issues to be considered when making a will:

> *"Apart from disposing of property on death, a will can be used to appoint testamentary guardians of minor children. The need for such may arise in single parent families and in circumstances where the parents of minor children are not married to one another.*
>
> *The use of trusts in wills for the protection of children (minors and adults suffering from disabilities which affect the capacity of a child) should be highlighted in order to properly provide for the child and to ensure that the person entrusted with the care of the child has the necessary powers to ensure the [proper] administration of assets for the use of such a child."*

A solicitor emphasised that it is very important to seek good advice when making a will. She said that probate litigation is a costly and destructive process and, as it contains no provision for mediation, it can leave families fractured forever.

The Succession Act 1965

The rights of spouses and children, where there is a will, are set out in Part IX of the Succession Act 1965. The Bar Council asked whether this legislation needs to be revisited, reviewed and modernised in light of changing social circumstances since its enactment more than forty years ago.

Ireland is a hugely changed, less socially homogenous society, yet we are still governed by the Succession Act 1965. Lone parents, parents of disabled children and members of 'blended' families, where succession rights may be an issue, need to ensure that they are providing appropriately for their successors.

A solicitor said:

> "The Status of Children's Act 1987 redefined 'children' to include marital and non-marital children.
>
> Succession law children consist of the natural or adopted children of the deceased. They do not include stepchildren or foster children or people for whom the deceased has acted in loco parentis. It is therefore problematic if people die intestate, without having made provision for these children.
>
> A more common problem that we find is that in long-term non-marital unions where there are children and where one of the parties dies, the surviving partner may be left completely and utterly unprovided for in the estate of the deceased.
>
> In some cases such as where property has been purchased in joint names, property passes by survivorship, but in the main as regards pension rights etc, the surviving partner - who may have been the closest person to the deceased and the person most dependent on them for their care and welfare - may literally be left penniless and homeless, and in some cases, without the sympathy of the deceased's family".

Partners

Another submission stated:

> "In the case of a sudden or unexpected death or where a partner has forgotten to make a will or update a will or make provision for a partner, the surviving partner has no protection, no legal right share to the home they may have shared together or to the rest of the deceased's estate. A spouse has a legal right share whether the deceased spouse dies with or without having a will made."

The recently published Civil Partnership Bill 2009, however, proposes to introduce a statutory civil partnership registration scheme for same-sex couples. The Bill provides that civil partners will have the same legal right to inheritance as spouses and the same rights on intestacy.[98]

---

98 See RELATE, Vol. 37 Issue 2, February 2010.

Chapter 22   LEGAL ISSUES AT END OF LIFE

Separate Legal Advice/Representation

Some people may be vulnerable or naïve in making a will and may therefore be open to financial abuse or deception, as a solicitor makes clear:

> "I have seen elements of abuse of a carer's position throughout my time as a solicitor. For example a nephew, niece or neighbour might bring the client into the office and insist that they want to stay there while the client is making his will. It is essential that young solicitors are trained to deal with such a scenario."

This solicitor adds that, in addition, many people transfer properties on the basis that they are giving away the property in exchange for the care, love and attention of the person to whom the property is being transferred. But then it does not always work out like that.   Much of the time solicitors may get very caught with legalities in ensuring that the title is perfected and may not ask enough questions around the event to ensure that the person giving away their property is doing so for the right reasons and that they are adequately protected.

The necessity for independent legal advice has been made clear by the Law Society and by case law through the years. There has been very little discussion of this in the media, however, and often by the time people attend their solicitors they have completely made up their minds to transfer the property ...The consequences of such a transfer and the necessity of putting in adequate protections may not be seen clearly by the solicitor dealing with both sides of the transaction.

Guidance, support and a formal structure must also be provided for carers who work within the community to ensure that any financial dealings that they have with clients are open, transparent and above suspicion.

Body Ownership and Certification

A retired consultant wrote of his concern about the custom of burial without appropriate medical certification, as follows:

> "Very aware that cremation without stringent documentation is not permissible I was and am bothered about this still extant practice. Certification post hospital death continues to be long delayed ... I attempted to ascertain the official State position. Numerous lawyers appeared not to know. I wrote to the Attorney-General to be eventually informed that this matter was not in his remit."

Another submission adds:

> "Clear guidelines for issuing death certificates [need] to be made available. Ambiguity can cause financial delays and distress, eg words such as "a fall" have to be investigated and an inquest or post-mortem may follow."

At the Inaugural meeting of the Forum, Dr Manning asked in the keynote address "Why does it sometimes take days to certify a death in a hospital which has hundreds of doctors?" And a Hospice Friendly Hospitals Programme Co-ordinator wrote:

> "There ought to be a review of the process around the death certification. Currently a person may be buried before a death cert is issued. In reality families are waiting for months in some circumstances before they are able to register a death as they themselves are waiting for the death notification form to be completed in the hospital. This can lead to immense difficulties, particularly financial stresses as the deceased's accounts cannot be accessed, social welfare payments cannot be processed until a death cert is obtained. Currently there is no pressure on Doctor's to treat this process as an urgent process as there is no legal obligation for a death certificate to be obtained before the person is buried."

The Bar Council wrote that the issue of who is entitled to bury a deceased person is an issue that, while it has not arisen frequently, has arisen in recent times in the most tragic of circumstances. It says that there is no legislation which deals with the question if it arises.

The only manner of dealing with such a dispute is by court determination.

Such disputes arise in cases of simultaneous deaths or consecutive deaths and non-marital relationships where the partner currently has no legal standing. For the matter to be decided by a court is costly and upsetting for those involved.

Proposals for the General Scheme of the Human Tissue Bill 2009

In his presentation to a Forum Workshop, Dr Dermot Phelan, Consultant in Intensive (Critical) Care, alluded to the Human Tissue Bill (2009) and outlined views of the Intensive Care Society of Ireland (ICSI) on it. The proposed Bill will regulate the removal, retention, storage, use and disposal of human tissue from deceased persons, and the use of donated tissue from living persons for the purposes of transplantation and research. Activities covered by the Bill will include hospital post-mortem examinations, transplantation, research, anatomy and education. Issues raised by ICSI include:

- Standardised training of clinical personnel

- Caution with 'opt-out' system

- Threat to clinical trust

- Threat to organ availability.

At a public meeting, Dr Deirdre Madden from the Faculty of Law, UCC and author of the Government report on Post-mortem Practice and Procedures (2006) outlined legislative changes, which, she said, would address the requirement for consent from parents with regard to organ retention from deceased children. In answer to a question, she said that a family can refuse an autopsy if the coroner is not involved in the death. She also said that she was particularly interested in what happens to the body after death, the importance of post-mortem to medical training and clinical audit, and how to balance these issues with the needs of the bereaved family. She believes that it is important that post-mortems take place in an environment that the family can understand.

Service Provision, Standards and Governance

Chapter 23
END OF LIFE CARE PROVISION

"No one should have to face death or bereavement without appropriate care and support." - Irish Hospice Foundation

Purposes and Functions of Health and Social Care

Dr Brian Maurer of the Irish Heart Foundation said at a workshop that, before the time when science began to be applied so successfully to curing diseases, the emphasis was necessarily on the care of the dying patient and on palliation. With advances of modern science, public health improved and the emphasis in hospital medicine and primary care shifted to getting the diagnosis right and applying or prescribing the appropriate cure. Dr Maurer added, "When I began to practise medicine in 1964 we had only 2% of the medical knowledge base that we have now."

Given the very rapid changes taking place in health and care services, there is a need to continuously question society's and the individual's, (including medical practitioner's), understanding of the purposes and functions of the health and social care services.

One submission spoke of the objectives of healthcare, as follows:

> *"Medicine and healthcare generally can be seen to have a number of concrete objectives. Among these are the eradication of disease, the relief of pain, the saving of life, and the restoration of health. We must look beneath these objectives for the ultimate purpose of healthcare, which is the well-being of the patient, not just as a body, or as a subject of emotions or of physical sensations, but as a whole person."*

The provision of person-centred end of life care to those who are dying, must surely rank as an important objective of our health and social care services.

Inappropriate Care

Too ofen the Forum heard stories of inappropriate care in different settings, including in hospitals. At end of life, it is sometimes as appropriate to enhance life as it is to prevent death, as the following account makes clear.

"An elderly lady has several strokes over a period of months; she is admitted to a nursing home for care. In the nursing home, she is taken from her bed each morning, propped up in a chair, and left there until after lunch. Her head nods uncomfortably as she sleeps. She says she wants to die. She is fed, cared for - but not allowed to stay in bed where she would be most comfortable. Eventually, when an appropriate mattress is available (due to the death of another patient) she is allowed to stay in bed. She develops dehydration. She is hospitalised, tube fed and a drip set up. This continuous revolving door from nursing home to hospital is sustained for months and months. If the special mattress is not available on her return to the nursing home, she is again subjected to the 'getting up' process each day. The family complain, but are told the mattresses are expensive and there are only two available in the home to serve all patient needs. The woman is diagnosed with depression, and given medication, because she continuously says she wants to die. Yet nothing, absolutely nothing, is done to relieve her symptoms; to offer therapy; to enhance her life for the time she has it. The focus is on preventing death not enhancing life. Tragic. Her family were not willing to let her go."

Appropriate person centred end of life care must be available for all. That very much includes older people, who all too easily can be the victims of ageism. Age and Opportunity wrote that appropriate care should be readily available to older people when cure is not a clear outcome. This includes appropriate symptom control, especially pain management for chronic conditions, which affect many older people. Pain management should take both chronic and acute conditions into account at end of life. Inadequate pain management may negatively affect a person's capacity to make decisions about their end of life care, denying both self-determination and quality of life when they matter most.

Following an account of inappropriate hospital treatment of a dying woman who did not want further interventions, her sister commented to the Forum:

"To be fair to the nurses, I believe the system they operated in militated against them delivering appropriate end of life care. Their job was to nurse patients back to health. Somehow, once that wasn't going to happen, well, they were out of their depth too. That was really scary for us as a family. What we needed was an acceptance that the last days of (name of patient)'s life were upon us and that we should make the most of this. It's a time out of time and different to what nurses are about. I do understand that nurses, doctors, hospitals want to treat sick patients and bring them back to health. Thank God they do. But dying is not about that. It's not a failure on the patient's part, not an opting out."

End of Life Care

The report, End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland[99] says, that the term 'end of life care' is a relatively new term in the Irish healthcare setting but there is not an agreed definition of the term. The authors of the report say that it is being increasingly used as a generic term in preference to palliative care when considering the needs of people with conditions other than cancer, particularly in community settings and long-stay care settings. End of life care also involves a longer time-period than the days or weeks immediately before death.[100] The report also says:

> "The majority of staff see end of life care as palliative care, while recognising that the latter is mainly directed towards people who are dying from cancer, even if this is a changing phenomenon. They do not immediately see themselves as having a key role to play in end of life care and would not be confident in carrying out such a role even if opportunities arose. Most staff believe that palliative care should be provided by the hospice and palliative care teams and not by themselves."[101]

Palliative Care

The World Health Organisation (WHO) defines palliative care as:

> "The active, total care of patients whose disease is no longer responsive to curative treatment. Control of pain, of other symptoms and of psychological and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families". (WHO 2004)

WHO describes palliative care as an approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The Department of Health and Children's Report of the National Advisory Committee on Palliative Care 2001 said that palliative care services are structured in three levels of ascending specialisation. These levels refer to the expertise of the staff providing the service. The Irish Association of Palliative Care (IAPC) added that all three levels of palliative care should be available in all care settings, and that all healthcare professionals should have the skills to allow them to practise a palliative care approach.

---

99 O'Shea et al (2008), End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland, Dublin: NCAOP & IHF p. 168

100 Ibid, pp 25, 26

101 Ibid, p.154

Level one   Palliative Care Approach

Palliative care principles should be appropriately applied by all healthcare professionals. The IAPC adds that the palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.

Level two   General Palliative Care

At an intermediate level, a proportion of patients and families will benefit from the expertise of healthcare professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level, the IAPC adds. This intermediate level expertise may be available in hospitals or community settings, it also says.

Level three   Specialist Palliative Care

Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. The IAPC adds that these services are involved in the care of patients with more complex and demanding care needs, and consequently, require a greater degree of training, more staffing and other resources. Specialist palliative care services are analogous to secondary or tertiary healthcare services, because of the nature of the needs they are designed to meet.

The Irish Nurses Organisation called for wider national recognition and dissemination of the three levels of palliative care in its submission and it proposed that all nurses and midwives should have appropriate knowledge about the principles and values of hospice and palliative care according to their expected level of palliative care.

The Irish Palliative Care Medicine Consultants Association adds:

> *"Specialist palliative care services are of primary importance in delivering high quality and timely 'end of life' care. Their remit is however broader than 'terminal care' and encompasses earlier intervention with patients who require their specialist input i.e. symptom management during active treatment."*

Quoting David Oliver, Wisdom Hospice, the Motor Neurone Disease Association said that

> *"the treatments that can currently be offered for people with MND will at best delay the progression of the disease process, are never curative and so the care of these patients is palliative from the time of diagnosis."*

The IAPC adds the following observations on the 'relevance of end of life in palliative care':

- Palliative care philosophy is an important element of ensuring good care at end of life.

- Good end of life care should support people to live their lives as fully as possible, and plan ahead in the face of a life-threatening illness.

- Palliative care professionals can assist in enhancing end of life care in all care settings through education, collaboration and shared care models, advocacy for enhanced services, supporting research and developing standards of care.

- IAPC recognises that the demand for palliative care services will increase on account of the ageing of the population, and will be offered to patients experiencing a greater range of diseases and at an earlier stage in their treatment plan.

- The IAPC has a key role to play in delivering in these areas, as outlined in their strategic plan.

Hospice Care

Hospice care is the total, active care of patient and family at that stage of serious illness when the focus has shifted from providing treatment aimed at cure to ensuring best possible quality of life.[102]

Hospices care for the whole person, aiming to meet all needs - physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them. Nearly half of all people admitted to a hospice return home again.[103]

---

102 Irish Hospice Foundation http://www.hospice-foundation.ie/

103 Help the Hospices, http://www.helpthehospices.org.uk/

End of Life Care - A Public Health Issue

A number of contributors to the Forum emphasised the public health dimension to end of life care and care of the dying. In his address to a Forum public meeting Allan Kellehear, Professor of Sociology and Head of the Department of Social & Policy Sciences at the University of Bath, said:

> *"For end of life care, we are where we were in healthcare in the 1960s. There is no sense that quality of life for those with terminal illness can be improved with community programmes that emphasise prevention, harm reduction or community partnerships. If you are old, dying or grief-stricken you need a service or an institution.*
>
> *We still cling to a series of end of life care myths: that hospice is an adequate and sustainable response to the end of life; that death is somehow different from other health matters; that ideas such as prevention and harm reduction do not apply to the grief, sexual dysfunction, stigma, discrimination, depression, anxiety, anger, social destruction or social isolation that is commonly associated with death, dying and loss."*

End of life care is not a specialism; it goes right across all services. This being so we need to engage society in discussion about it; the public, private and voluntary sectors need to be creative in thinking about it and that thinking needs to be translated to chronic illness care policy and planning.

The public health approach emphasises community engagement in addressing end of life issues, rather than relying only on formal service provision, institutionalisation and the effective sequestration of those at end of life. This approach requires investment in community development and capacity building, education and the promotion of participatory approaches to healthcare practice and policy development. We will return to this subject in Chapter 29 when we look at new models of end of life care provision, and specifically at adopting a compassionate community-based approach to end of life care.

Rehabilitation

A number of contributors highlighted the importance of rehabilitation at the end of life. Early referral is essential to maintain and improve a patient's quality of life. "It is difficult," one said, "for patients to adapt to their physical decline and rehabilitation enables patients to live out their lives fully and achieve their potential." Another person added:

7

"I really think that a 'palliative rehabilitation' strategy with a view to providing the services needed to maintain a healthy population for longer should be part of an overall End of Life Strategy. Just to put this into real terms ... at age 20 we have 100% of our muscle mass, by age 60 we have 80% and by age 80 we have only 60% of our muscle mass. In order for us to perform everyday tasks 40% of our muscle mass is required. That means that it wouldn't take much, maybe a day in bed with the flu, or a small bit of weight loss due to poor diet to deplete the reserves of muscle mass in an elderly person to render them incapable of performing their everyday tasks."

Another person said that her mother who died aged 86 had her physiotherapy unfairly withdrawn because she was 'not performing'. It raised the question of equity in rehabilitation service provision. Justification of a decision to withdraw rehabilitation on the basis of a judgement sometimes recorded as "Rehabilitation potential exhaused" needs to be particularly transparent when applied to those who are physically the most vulnerable.

Conclusions

We must plan and provide much better for end of life than we do at present, so that together as a society we accord as much importance to improving the quality of life of those at the end of their lives as we do to cure and saving life. To do this we must have a more sustained focus on end of life:

- by being more conscious and aware of people who are coming towards the end of their lives

- by identifying their physical, social, psychological and spiritual needs, and

- by estimating and providing the human and economic resources required to meet these needs to the highest standard.

Without public and private reassurances of solidarity and evidence of the availability of physical, social, psychological and spiritual support, the fear of a painful and undignified death will increase, particularly among older people and those suffering chronic illnesses. The risk of depression and suicidal tendencies will also grow and there will be an increased acceptance of assisted suicide and euthanasia.

There is a need to make the general public much more aware of the living circumstances of people with some of the lesser known neurological conditions which are incurable, even if treatable, and therefore of the need to ensure the best possible quality of life at end of life for them.

There is also the need to ensure that end of life/palliative care is incorporated in all disease specific care pathways.

And finally society's and individual's, (including medical practitioners), understanding of the purposes and functions of the health services must continuously be questioned. Does holistic end of life care have parity of esteem and purpose with curative care? Do care pathways give equal prominence to health promotion, illness and accident prevention, rehabilitation and palliative care services as they do to curative services?

Chapter 24
CARE SETTINGS AT END OF LIFE

Introduction

Contributors spoke about where they would like to die if they had the choice, and the suitability of the places where people actually die. The

Irish Hospice Foundation's 2004 public opinion survey finding that 67% of people would like to die at home and only 10% of people would like to die in hospital or a hospice was frequently referred to.

There were just over 28,000 deaths registered in Ireland in 2007, of which more than three-quarters (21,824 or 78%) were aged 65 or older.[104]
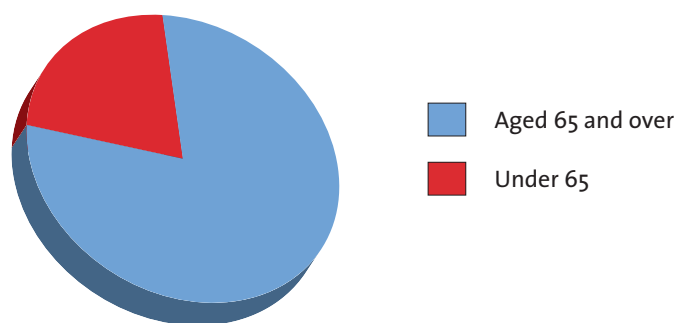
Figure 1. Deaths in Ireland by Age

Approximately two-fifths of these older deaths occur in acute hospital settings, with roughly the same number dying in public and private long-stay facilities. The remainder died at home.[105]
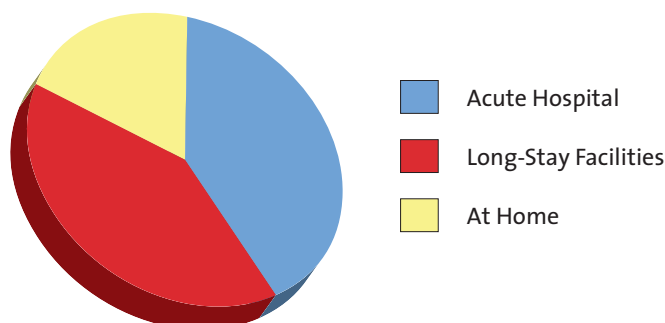
Figure 2. Location of Older People's Deaths in Ireland

---

104   Central Statistics Office (2008)

105   www.cso.ie; O'Shea et al., (2008) p.29.

Chapter 24   CARE SETTINGS AT END OF LIFE

In a presentation to the Forum, the head of End of Life Care in the English Department of
Health said that while most people would probably like to die at home, only around 19% do so,
though about 17% die in care homes. In England 58% of all deaths occur in acute hospitals and
only 5% in hospices.

It is clear from many of the submissions why people would prefer not to have to die in
an acute hospital. This was ably summarised by a presenter at one of the workshops who
contrasted the suitability of care settings for those who are dying, as follows:

Acute Hospitals
Noisy
Little privacy/mixed sex wards
Lack of single rooms
Difficult for visitors
Multiple tests/Doctors' rounds
Staff more geared to saving lives than assisting with dying
Lack of training around dignity and respect in end of life care
Tendency to continue treatment and tests even when death is inevitable:
orientation towards saving lives
Battle between MRSA people and those responsible for the dying
Reliance on tests rather than direct diagnosis
Lack of understanding of older people, for example that constipation can cause
confusion in older people
Can easily die alone in a busy hospital

Hospices
Good environment
Staff specially trained
Good pain relief if required
Visitors are made welcome
Not over-treated or under-treated
Problem with accessing the service

Home
Familiar surroundings
No difficulty with having visitors

7

Need for medical and nursing input

Can be difficult for relatives as they may be elderly themselves

Need for adequate pain control and access to medical assistance/hospital.

The following are some of the experiences of contributors and some of their comments and opinions about where end of life takes place in Ireland and end of life care in those settings.

Dying in Hospitals

"The A & E setting for unexpected, unplanned, sometimes traumatic deaths: overcrowding is a serious problem, especially for patients and families facing imminent death."

"I think no one should have to die on a hospital ward with up to twelve other sick people in the room and nothing but a curtain to give minimal privacy and no room for the family to even sit comfortably at the bedside. It is neither dignified nor healthy and not what any of us would want for the end of our lives."

"I have always felt that hospitals were no place to die, but after my sister's experience I absolutely know that nobody should die there."

"Her final two weeks of life while dying in (name of) hospital was so terribly disrespectful, impersonal and traumatic. We felt she was treated like she was nothing more than a number."

"The reality is that even in hospitals some people still die alone."

While many people who die in hospitals do not enter them as dying people, a significant proportion do. This is not always appropriate. So we must ask how can inappropriate admissions of dying people to hospitals be reduced? To answer this question we must first look at why this is happening. A consultant geriatrician identified the issue as follows in a submission:

"The great majority of people who die in Ireland today are elderly and the great majority of these die in general hospitals. A very high proportion of these elderly people who die in hospital have, in fact, reached end of life status well before they are admitted to hospital as an 'emergency', where they suffer the indignity and

discomfort of having to come through A&E departments and onwards to busy, open
wards where they live out their last days, usually without quietness, peace or dignity."

Contributions to the Forum illustrated some of the reasons why this may be happening, as
follows:

"While the majority of referrals to general hospitals from nursing homes are
appropriate,[106] in the final stages of their illness many older patients are transferred
needlessly to general hospitals due to understaffing and lack of training in long-stay
facilities.[107] This often results in discontinuity of care and the disruption can also
cause confusion and deterioration of their condition."[108]

"We often find there is conflict between the resident and the relative such as in
relation to transfers to acute hospitals when they know they are dying and would
prefer to remain on in Palliative Care and with friends, so to speak. In that case we
get the doctor to advise."

"Three days before she died, in consultation with her GP, I had to have my mother
admitted to hospital through casualty. Purely on a social basis they would give her
a bed ... I was aware of death and it was her wish and mine that she should die at
home. However, I did not get the support I needed to go the full journey."

"It has been my experience that the unprepared or frightened individual prefers
death in a hospital setting because he/she fears being uncared for or given
inadequate pain (relief) or other solace."

The issue of the denial of imminent death by family, leading to unnecessary hospitalisation
and treatments ,was described by a number of professionals at a public meeting. A doctor said
that ever since man landed on the moon, the pressures were on family to take the key decision
in relation to allowing their loved ones die at home rather than undergo futile treatment.
However, often when it comes to it, they panic and send their relative to hospital.

"An audience member comments that she believes that guilt has a huge role to play
in the decision to take terminally ill and dying patients to hospital at the last minute.
Guilt is a huge thing for the people left behind and people want to feel that they did

---

106   P Gallagher, N O'Riordan, O O'Sullivan, C Henry Analysis of admissions to an acute hospital form long-term care facilities Irish Journal Of Medical
Science, Vol. 174 No. 3 Sup. 2 p38.

107   Ibid, End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland, Dublin: NCAOP & IHF p. 49

108   O'Shea, et al (2008) p 48-49

everything they could to prolong the life of their loved one. She believes that very often families want the decision to allow the patient to die to be taken from them and that this is not a 'denial of death' as suggested by a previous speaker but a relief of their own guilt."

The admission of dying people to acute hospitals <u>because</u> they are dying, rather than for treatment, happens because:

- palliative care and other care services appropriate to the dying person and his/her condition are not provided, or not adequately provided, in settings where people would otherwise die

- those who care for the dying in other settings do not always have the competence to do so, or do not have the confidence to do so

- family carers are inadequately supported

- relatives and friends of the dying are unprepared for the possibility of the death of the dying person, unable to recognise that the person is dying, or unable to accept the reality that the person is dying.

These reasons for inappropriate admissions of dying persons to hospitals have implications for policy, service provision, funding, training, community development, and for public education and awareness raising.

Even were these issues adequately addressed, many people, including, and particularly, older people would continue to die in acute hospitals in considerable numbers. Hospitals must therefore be as fit for the purpose of the care of the dying as they are fit to fulfil their other functions. The evidence of the Forum is that that is not the case, by and large, though great improvements continue to be made despite very considerable challenges. The following are a few of the observations and recommendations made by Forum contributors on dying in a hospital setting. (Others are provided elsewhere, for example in Chapter 27, on the care environment):

"Healthcare professionals don't have the physical space or time to have that engagement with family. He believed hospitals were making great efforts to bring the hospice practices into the hospitals and he hoped that today's situations wouldn't be the same as 15 or 20 years ago ..."

"... but one third of our members (Cystic Fibrosis Society of Ireland) are passing away in hospital, where facilities are totally unsuitable, particularly when a lot of

them are very young."

"End of life may take place in hospital where the atmosphere may be noisy and distracting for everyone. A clergyman or spiritual support should be available if required."

"There is a need for improvement in providing privacy, including availability of a quiet and private space for patient and family.
More family involvement and support with access to support groups is of huge importance for families who have lost loved ones.
Families need to be kept informed of the dying person's changing condition."

At a workshop a participant spoke about the changes taking place in the hospital where she worked:

"Something as simple as a candle being lit on the ward when a person was dying was making a real difference so people know what's happening. A room was ... designated as a family room with a shower and facilities. Things are changing but there is a long way to go. Traditionally in a hospital the aim had always been to get a person in and out but now it had to be about giving death and the families affected the respect they deserve."

Dying in Nursing Homes

In its submission, Age Action Ireland addressed the question of the adequacy of end of life care in nursing homes, as follows:

"It is known that 15% of people die in private nursing homes. The provision of palliative care in these setting is therefore important. Often residents of nursing homes are transferred to acute hospitals as they near the end of their life. If adequate end of life care is to be provided in these settings residential care staff will need greater medical support and residents will require greater symptomatic relief and appropriate facilities to die with privacy."

A representative of Nursing Homes Ireland said at a public meeting, however:

"Every resident will continue to receive care at the end of his/her life which meets his/her physical, emotional, spiritual and social needs and that respect

his/her dignity and autonomy. The resident's palliative care needs are assessed, documented and regularly reviewed ... I would like to see us getting more palliative care in nursing homes and community care so that we could lose some of the stigma."

Another person asks about palliative care "in geriatric care, particularly in long-term geriatric care institutions:

"Are individuals in long-term care not entitled to the services of palliative care?" she asks. "What priority does palliative care give to psychological pain?" she adds. "I'm thinking here of that felt by patients in long-term care, in comparison to the pain experienced by patients with more acute illnesses."

Dying at Home

Nowadays there are many very ill people living at home. This trend is likely to continue because of:

- the reorganisation of health services
- people's preferences to stay, and to die, at home, if possibe
- medical advances and increases in survival rates
- demographics.

Most people, if asked, will say home is where they would like to die. A number of contributors to the Forum described their experiences, both good and bad, of assisting relatives to die at home, as follows:

"We took him home. We wanted him home. He wanted to be home. He came home on the Monday. He hated hospital. We went back for the stitches and then to the cancer consultant who was brilliant. He talked to (name of child) and he was really honest about what he had wrong with him. He asked him about his mother and father being worried and why did he think that was so.

We brought him home in the car. I worried he would die in the car. He was in the back, in my arms in a blanket. We brought him home and took him to bed. He was on morphine. He did not wake up that night. I was afraid he would be cold. We were afraid to close our eyes ...

He would talk about being happy and being at home and that was where he wanted to be. We would talk to him and we knew it was going to stop and we used every minute. People were very good. They did not come. He drew pictures and coloured them for us. He knew he was going ... (name of child) died at 7 in our arms ... Mum, Dad and brother. "

"What I would like to highlight is the desire of many dying patients to go home to die and the many obstacles that are put in their way. I recently looked after two men who knew they were dying and who wanted to go home... They were under two different consultants - one who was concerned with medical and insurance issues and the other who immediately discharged the patient and all arrangements were made so that he was in his own home within the hour."

"From a personal perspective my father was cared for and died at home which was his wish. It was wonderful that this could come to pass. With some support from other family members, and my mother's experience as a nurse, my father's wishes were fulfilled. The family had significant support from Dad's general practitioner, but alas other services were very minimal and disappointing."

At a public meeting a person with experience in palliative care relived her own experience when her mother died 15 years ago of cancer. She recalled that while there was no formal palliative care services her mother received good care in hospital. However, the family brought her mother home for her final weeks where she was taken care of by an aunt who was a nurse and the family GP. Her mother who was very active in the family farm was still able to stay involved in what was happening. When she had to spend most of the time in bed, a monitor was set up in her room so she could even watch the cows calving and it helped her to feel she was retaining her role as the farmer's wife and mother and involved in the every day. It was very special.

However, dying at home is the exception rather than the rule and will remain so without appropriate chronic illness specialist support together with adequate hospice, palliative and community care supports and services. This is emphasised in the following contributions:

"Home is the preferred place of care for the death of a child yet the majority of children with non-malignant disease do not die at home. Through our experience in Jack and Jill we have found that families taken under the wing of the local hospice home care teams for end of life care, have received the most complete appropriate

service, with other agencies such as ourselves supporting them. "

"In (name of county) there was no back-up or palliative care for my mother. She arrived home for a period before the hospice with 48 tablets which we were unable to administer. The local GP/care doctors do not have the relevant experience to back up the service if there is a problem."

"There was a meeting held around his bedside, attended by senior members of the palliative care team, some junior doctors and nurses, myself and my son and (name of patient)'s daughter, nine people in all. Discussion on the possibility of his going home was on the agenda, and I was asked for my input. I wanted (name of patient) home but had no confidence that I would be able to deal with him on my own, and since I had not been guaranteed any particular level of support, I felt I was speaking in a vacuum. All I could say was that I was afraid of letting (name of patient) down. Very inadequate now, I see ... and it need not have been like that if it had been clarified for me what was and was not possible, what was and was not available, and maybe how others in similar circumstances had coped."

Dying at Home: making it a Reality

A Hospice Friendly Hospitals Programme Development Co-ordinator said that since most people want to die at home this should be the gold standard and there should be increased efforts to ensure that it is an achievable reality for people in Ireland. This would include having home care services in place, having an equipment bank so that delays in waiting for equipment are avoided and having clear arrangements for ambulance/paramedical staff to transfer a 'dying' patient. Currently some ambulance services will not transfer dying patients.

At a public meeting, a retired GP said that the introduction of syringe drivers has made it much more possible for patients to live out their last days at home. A community nurse added that death in the community is becoming more and more reliant on all sorts of medical and technical expertise. A person without medical expertise described the sheer panic of trying to administer medication under difficult circumstance and how the district nurse came to the rescue.

Ultimately what is required is the implementation of the Department of Health and Children's Report of the National Advisory Council on Palliative Care, which recommends that all levels of

palliative care should be available in all care settings.

In addition, a Palliative Care Needs Assessment for Children (DoHC & IHF, 2005) emphasised the provisions which need to be put in place to enable children to die at home, when that is the wish:

> "There is need to have an emergency care package to be made available in the event that a family wants to take their child home to die with 24-hour nursing support available if necessary."

The Caring for Carers group said at a workshop that we can make it possible for more people to die at home by providing the following services: information; practical help; financial assistance; and ensuring better co-ordination and collaboration between healthcare professionals, service providers family carers and those for whom they care.

Rodd Bond of the Dundalk Institute of Technology said at a workshop that the Netwell Centre, a collaborative demonstration project aiming to support older people to age in place, tries to bring together the care model, and the ergonomic/environmental features needed to enable people to continue to live at home in old age and to die there.

The Irish Wheelchair Association recommended:

> "Persons with disabilities who are nearing end of life should be facilitated in their home to die with dignity in familiar surroundings with personnel that are familiar with their needs; and that those agencies that provide personal assistance to persons with disabilities in their homes are included in the end of life process instigated by the Health Service Executive and/or Palliative Care Teams. Often the personal assistants are the people spending most the time with the person. Supports are needed at this time and the agencies/personal assistants could be included in the processes and be part of the multidisciplinary team. This inclusive approach would ensure a more personalized and individual provision of service to the person at the end of life."

Chapter 25
CARE SERVICES: ACCESS AND QUALITY

Introduction

Contributors to the Forum spoke at length about end of life services. Some described services they provided; others commented on services received. The quality and adequacy of services were issues for some; access to services was, however, the predominant service issue.

In the last chapter we saw that the adequacy of services and supports for family carers is one of the factors determining whether some people can realise their preference to die at home or have to be admitted to hospital. One contributor noted that the biggest problem she had when looking after her mother at home was the availability of a doctor to visit her when she was too ill to go to the surgery:

> *"This was a problem during the normal working hours of a doctor's surgery, but in the other 130 hours or so of the week it was a disaster. The thing about sickness is that it does not know the time. It has no respect for weekends and can strike when it least suits everyone, particularly the person who is sick."*

Services

A very great range of services - public and private, voluntary and commercial - are provided to people at the end of their lives, to their families and to their bereaved relatives and friends. Many of these were described throughout the course of the Forum, including medical and nursing services at primary, secondary and tertiary care levels.

The development and availability of general and specialist palliative care services was a constant issue in the discussions. Similarly, the availability of services that respond to the psychological, social and spiritual needs of people at end of life was also a theme in the Forum's discussions.

A surprising range of voluntary organisations respond to the needs of dying persons, to their families and to the bereaved in a myriad of important ways. They need to be considered collectively as well as individually, if the true potential of the voluntary and community sector in facilitating quality of life at end of life for all in this country is to be achieved.

We have seen in Chapter 23 that dying is a public health matter; it concerns all of society.

The commercial sector too has its role to play, and the Forum discussed the role and the performance not only of funeral directors/undertakers, but also of bank managers, solicitors and others. The quality of those services can make a big difference to people dealing with painful practical and emotional end of life situations. It is unfortunately beyond the scope of this report to give a detailed account of all the services described by the organisations which contributed to the Forum. However, palliative care and other services needed by people at end of life are described here, with particular reference to their availability and access to them.

Palliative Care Services

Policy Context

The demand for palliative care services is increasing because the population is ageing and the numbers of older people rising. In addition, demand is increasing from patients experiencing a greater range of diseases who also need the services at an earlier stage in their treatment.

The Irish Palliative Medicine Consultants' Association commented that the Report of the National Advisory Committee on Palliative Care (NACPC), (Department of Health, 2001) had received international praise as a model of how palliative care services should be developed. It said:

> "This report outlines in detail the various levels of palliative care required and proposes a framework for delivering an equitable, high quality palliative care service to all patients and families in Ireland."

However, the association added that the report has not been fully implemented and there are still areas of the country where access to a full specialist palliative care service is lacking. As already indicated, restricted access to services, particularly palliative care services, was a continuing theme throughout the Forum process.

In November 2008, the Health Service Executive and the Irish Hospice Foundation published Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks. In the Foreword, James Conway, Assistant National Director for Palliative Care and Chronic Illness, Health Service Executive, noted that the report provided the rationale and signposts for palliative care to be delivered in all settings and at all levels.

In his presentation to the Forum in May 2009, Mr Conway said that 38 out of 51 acute general

hospitals had varying degrees of access to Specialist Palliative Care teams. The majority had it 5 days a week with a 24/7 SPC on-call service. There were significant variations in staffing levels of the SPC teams in acute hospitals across the country. In some hospitals the weekend and out of hours services were provided by the clinical nurse specialist in the community or the home care nurse. He also said that there were 8 Specialist Palliative Care In-Patient Units in the country, but none, however, in the North East, South East or Midland areas. Accessibility and availability were huge issues. There were six specialist palliative day care services serving 2,600 patients. Almost all local health offices had access to specialist palliative home care teams working in the community.

In July 2009, the HSE published Palliative Care - A Five Year/Medium Term Development Framework, based on a Baseline Study on the Provision of Hospice / Specialist Palliative Care Services in Ireland (2006) and a HSE Audit of Palliative Care Service Provision (2007). The purpose of this document according to the HSE website,[109] is not to replace the recommendations of the NACPC (2001) Report from a policy context, nor does it represent a new national strategy for palliative care. The document details the required actions and initiatives necessary to address the gaps in palliative care service provision against the recommendations set out in the NACPC report.

Palliative Care for All

There is great disparity in hospice and palliative care services across the country. There is not ease of access to these services, even for those with cancer. We therefore need a system to determine eligibility for critical end of life care services. These services must be multidisciplinary to meet the particular needs of each person as they arise.

On the subject of multiple organ failure, one contributor questioned the equity of palliative care services in this country and said that access depended on where the person lived. Palliative care should be extended to all, regardless of diagnosis, he said. Another person said in a submission:

> *"In Ireland, as elsewhere, oncology patients account for approximately 95% of all referrals to specialist palliative care services (Department of Health and Children, 2001; Kuebler, et al., 2005). The small number of hospice inpatient services means that hospice care is available for only a minority of palliative patients (4-5%) and is usually only provided in the final weeks or months of life (Gomes & Higginson,*

109   www.hse.ie, as updated on 9/10/'09

7. Service Provision, Standards and Governance

. . . .

Chapter 25   CARE SERVICES: ACCESS AND QUALITY

7

2008).[110]*"*

The following are other contributions from agencies providing services to people with life-threatening and chronic illnesses, emphasising that palliative care should be available at end of life to their clients no less than to people with cancer:

Children

The Dying, Death and Bereavement Committee at Our Lady's Children's Hospital, Crumlin, said in its submission:

> *"Currently children with life-limiting illnesses are heavily dependent on existing adult services and the services available to children are dependent on diagnosis (cancer vs. non-malignant) and geography."*

A number of contributors emphasised the urgent need for Paediatric Palliative Care in Ireland, especially for palliative care services for children in the community . They emphasised the concomitant need for a paediatric palliative care consultant and specialist paedriatric palliative care nursing. The Palliative Care Needs Assessment for Children said:

> *"In paediatrics, unlike for most adults, the duration of life-limiting conditions can extend from days to years. This has led to the significant increase in the need for palliative care services to be available to these children and their families when necessary. The preference of most families is for these services to be provided in the child's own home. This includes care at the end of life and families require supports in caring for their child through the dying phase."*

The Jack and Jill Foundation listed the following additional gaps in current services:

- No paediatric trained Palliative Care Nurses in Ireland attached to any service

- No proper guidelines within the acute hospital services when discharging a dying child home to the community services

- Limited primary care teams within the community services

---

110 Department of Health and Children (2001). Report of the National Advisory Committee on Palliative Care. Dublin: Department of Health and Children. Kuebler, K. K., Lynn, J., & Von Rohen, J. (2005). Perspectives in palliative care. Seminars in Oncology Nursing, 21(1), 2-10. Gomes, B., & Higginson, I. J. (2008). Where people die (1974-2030): past trends, future projections and implications for care. Palliative Medicine, 22(1), 33-41.

- No clear care pathways for the care of a dying child as recommended by the "Marie Curie Palliative Care Institute 2006"

- Each individual organisation strives to achieve the optimum care for the dying child and their family, but ultimately it's on an ad-hoc basis because we work independently of each other.

People with Intellectual Disabilities

Quoting the World Health Organisation (2004), a Clinical Nurse Manager said that people with intellectual disabilities "do tend to be excluded from the best of palliative care, and they have special needs that are still not met by existing services."

People with Neurological Disease

The Ombudsman, who chaired one of the workshops, said that people with neurological disease were marginalised, under the radar. The lack of access was a repeated theme at the workshop: access to transport, neurologists, palliative care. Members of the Neurological Alliance of Ireland expressed concern at the significant lack of appropriate inpatient and home-based facilities and supports for the care of people with end of life neurological conditions.

The Neurological Alliance of Ireland acknowledged the excellent service provided by palliative care services, including hospice home care teams and hospice respite care.

> "However," it said, "people with neurological conditions have difficulty in some parts of the country accessing palliative care services as the limited service is under pressure to provide care to a range of patients, predominantly cancer patients."

> From reports of NAI member organisations, there appears to be little co-ordinated specialist support available to enable people with neurodegenerative conditions to be cared for in their own homes.

> There is a significant lack of neuropsychological input to assess and manage cognitive and behavioural changes as a result of neurological conditions. This affects all stages of the care pathway, from helping people to deal with their initial diagnosis to providing appropriate advice on later stage care and capacity to consent."

People in Long-stay Facilities

The Irish Medical Organisation and Age and Opportunity both referred in their submissions to the study, *End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland*[111], and its finding of very low levels of access to consultant-led palliative care teams in long-stay facilities. In addition, while Nursing Homes Ireland acknowledged the value of support provided by Palliative Home Care Teams, it understood that these services:

- were restricted to people with a cancer diagnosis only

- were not provided out of hours

- could only be accessed through a medical referral, and

- gave care direction, rather than palliative care provision.

Nursing Homes Ireland was concerned by these limitations. It proposed that nursing homes should have 24-hour access to specialist palliative care advice (via a dedicated telephone line or through local hospices) which would enable healthcare professionals, residents and their relatives/carers to obtain up-to-date and practical advice which would inform their decisions.

People with Chronic Kidney Disease (CKD)

In a submission to the Irish Hospice Foundation "Palliative Care for All", which it forwarded to the Forum, the Irish Nephrology Nurses Association said that to maintain patients in the community and reduce hospital admissions, "ease of access to palliative care teams is essential, with the development of a formalized streamlined route to access these services for ill and terminally ill patients with CKD."

MS and Palliative Care

In its presentation to the Forum, the Multiple Sclerosis Society of Ireland said that equitable access to palliative care based on individual need should be promoted and provided on a nationwide basis in response to the assessed needs of the individual and his/her family. The Society also advocated that holistic and alternative therapies should be available if required.

---

111 O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ní Léime, A. and Keys, M., 2008. End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland. Dublin: National Council on Ageing and Older People/Irish Hospice Foundation.

7. Service Provision, Standards and Governance

Other End of Life Services

Emergency Services

Pre-hospital emergency services are provided by six groups of people. Guidelines have been continuously updated and prepared for each of six levels of responder and practitioner. The six categories are:

Practitioners:

- Advanced Paramedic
- Paramedic
- Emergency Medical Technician.

Responders:

- Cardiac First Response
- Occupational First Aid
- Emergency First Response.

The role of the Advanced Paramedic is been developing. It now may include making critical judgements based on the recognition of death or the inappropriateness of resuscitation, thus avoiding the necessity of people's remains being sent to hospital emergency departments.

Dublin Fire Brigade (DFB) has an ambulance service as well as a fire service. In 2008 it took in excess of 112,000 calls, as follows:

- 74,500 Emergency Ambulance Incidents
- 37,800 Fire Appliance Incidents
- About a third (11,500 approx) were Ambulance Assist

All DFB personnel are trained to Paramedic Level.

Pharmacy Services

Community pharmacists have an important role in facilitating those at end of life in the community with their medication requirements. They can also provide support and advice to them and to their carers. They can advise on problems encountered with syringe drivers at weekends when specialist palliative care nurses may be unavailable, for example. Advice is also provided to out-of-hours GPs and nursing services about the compatibility of mixing

selected injections in syringe drivers.

Most community pharmacists give the carers of a palliative care patient a mobile number to use in cases of emergency and this informal arrangement serves most patients well even though it is done on an informal and voluntary basis. Community pharmacists can facilitate the safe disposal of unwanted and unused medication if the medication is discontinued or remaining after the patient's death.

The following challenges need to be addressed however:

Specialist Medication
The medication used in palliative care is not generally prescribed and as a result may not be routinely stocked by either a community pharmacy or a wholesaler, making prompt procurement difficult. Equally the medication may have a short shelf life and this may contribute to difficulty in procurement, leading to a delay in dispensing the medication to the patient.

Unlicensed Medication
Some of the medication used in palliative care is not licensed by the Irish Medicines Board, for example, Dexamethasone Injection, Fentanyl Injection. Procuring an unlicensed medicine is more difficult than procuring a licensed medicine and this can lead to a delay in dispensing the medication to the patient.

Reimbursement
Not all of the medication routinely used in palliative care is reimbursed by the State under the Community Drugs Schemes, for example, Glycopyrronium Injection. In these instances, community pharmacists must seek approval for payment on a case by case basis from the Health Service Executive (HSE) before dispensing the medicine. Such approval is only available during normal working hours and frequently prescriptions are presented at weekends or after 5 pm. This unnecessary bureaucracy can contribute to a delay in procurement, leading to a delay in dispensing the medication to the patient and must be altered.

General Practitioner Services

There is huge trust among older people in GP services. As indicated in the Introduction to this chapter, some people experience difficulties in reaching doctors out of hours. Other contributors spoke of GPs' end of life care training and the need for further investment in it.

Nursing Homes Ireland wrote that while the majority of GPs provide a supportive and much needed service to nursing home residents, there are some areas of development required. These include the need for regular assessment visits to persons at end of life care, regular medication reviews, more communication with the multidisciplinary team, including discussions about place of care, resuscitation status and treatments provided.

At a public meeting a speaker expressed concern about the approach of some GPs to patient care "where very often they advise nursing home management to send terminally ill elderly patients to hospital rather than attend to them in their last hours in the nursing home".

Occupational Therapy Services

The importance of the Occupational Therapist's asessment of people with slow, progressive life-limiting illnesses or with short-term end of life care needs was stressed by a number of contributors. Following an evaluation of physical and mental abilities, the occupational therapist works with clients and families to determine how they want to spend their time and energy and what assistance they need. However, as one person wrote:

> *"Undoubtedly one of the most useful care-in-the-community services available at the present time is the occupational therapy service. Again, I am sure that you don't need me to rehearse its current limitations: patchy provision throughout the country, cuts in funding and delays in providing aids and equipment ..."*

The Association of Occupational Therapists in Ireland (AOTI) recommended that there should be more Primary Care occupational therapists so that clients can be seen promptly.

The Association recalled in its submission that the National Advisory Committee for Palliative Care (DOHC, 2001) report recommended that, "all specialist palliative care services should have an occupational therapy service"; to date this minimum standard has not been met.

Dietetic Services

Dietitians can make a valuable contribution in enhancing the quality of life of the palliative patient by offering expert advice, ongoing monitoring and continued support to the patient, carers and staff dealing with nutritional problems.

Currently the dietetic structure that supports palliative patients is limited in Ireland. Patients in the earlier stages of palliative care undergoing continued review in acute hospitals may

have access to clinical dietitians specialising in a number of areas including Oncology, Haematology, Dietetics, Neurology, Cardiology, ENT and Surgery. When care in the acute sector is completed there may be no further access to dietetic services. A proportion of palliative patients may be referred to Specialist Palliative Care (SPC). However within the SPC services there is often a void in dietetics service provision.

Aids and Appliances

The Association of Occupational Therapists of Ireland (AOTI) said in its submission that the availability of aids and appliances in the community is currently limited. This, it said, is particularly relevant to individuals requiring end of life care whose life expectancy may be limited to days or weeks, and for whom a delay in accessing aids and appliances would be inappropriate. The National Advisory Committee for Palliative Care (DOHC, 2001) recommended that each health board should have a sufficient bank of equipment to meet the needs of these individuals in the community. There should be an identified key holder to the community stores to enable access to equipment at weekends. In addition, all specialist palliative care units should have their own small bank of aids and appliances to facilitate rapid access to equipment. These aids and appliances would be rotated, as they may not be required for long periods of time in any particular household.

Community Care Services

Access to community care services, which can play an important role in supporting home care, was criticised by some, including the following:

> "Then there's the home help and allied services, none of them necessarily easy to access ...Then there's the bureaucracy that adheres to applying for anything ... If you are tired and unwell, the effort of finding your way through the morass (or even thinking about how to find your way through the morass) is too exhausting to contemplate, so people do without, and the end of life is far more bleak than it needs to be ..."

Access to appropriate and adequate home care packages should not be denied to those at end

of life who wish to continue to live at home.

National Eductional Psychologocal Services (NEPS)

The role of NEPS in helping schools prepare for and to respond to critical incidents was described to the Forum by a Senior Psychologist. Given the trauma experienced by schoolchildren as a result of deaths, particularly sudden deaths of other children following car accidents or suicide, or deaths of other people they know, the ability of the school and its teachers to respond appropriately is important to the promotion children's mental health and coping ability.

Funeral and Embalming Services

A number of funeral directors described their services at public meetings of the Forum. One of the main concerns for families is the care and preparation of the deceased once the funeral director takes over. The Irish Association of Funeral Directors (IAFD) also described embalming services, as follows:

> *"Modern embalming techniques allow for deceased persons to be viewed in a safe hygienic manner and improve greatly the presentation of the deceased. Funeral Directors throughout the country have access to or employ embalmers to carry out this function. Many members of the IAFD have invested heavily in providing suitable facilities for this difficult, unpleasant and yet essential preparation."*

The IAFD make a number of recommendations regarding collection procedures at public mortuaries and those approved to collect the remains of deceased persons. The Association also makes recommendations regarding the regulation of embalming services and the inspection of funeral homes and embalming facilities.

Cremation Services

One person who made an oral submission was critical of the standard of a cremation service she attended.

Voluntary Service Providers

The following is a sample of services relating to end of life provided by voluntary bodies who contributed to the Forum. The listing is neither exhaustive of the organisations involved in end of

life care nor of the services of those listed.

Anam Cara

Anam Cara is a national voluntary support organisation set up by bereaved parents for bereaved parents and siblings throughout Ireland. It organises informal meetings, formal, social and creative events, and other opportunities to meet other bereaved families.

ARC Cancer Support

ARC stands for Aftercare, Research and Rehabilitation Counselling and Complementary Care. It supports people over 18 throughout their cancer journey, particularly those with recurrent or advanced disease. It also supports the carers of those cancer sufferers and healthcare professionals working with them.

Irish Stillbirth and Neonatal Death Society (ISANDS)

ISANDS provides support for parents and families whose baby has died around the time of birth.

Jack and Jill Children's Foundation

The Jack and Jill Children's foundation provides early intervention home respite to families with children (up to the age of 4), with severe to profound developmental delay who require extended care and also children with life-limiting conditions requiring intensive medical and nuring care at home (non-oncology palliative care cases).

Living Links

Living Links provides a voluntary listening, support and outreach service to those bereaved by suicide.

Peamount Hospital

Peamount Hospital provides health and social care services to the community in partnership with the Health Service Executive to persons over the age of 18 years. It has a respiratory rehabilitation unit and an age-related rehabilitation unit. It also provides continuing care services for older people, people with intellectual disabilities and people with neurological disabilities.

Positive Action

Positive Action is a support group for women infected with Hepatitis C through contaminated Anti-D, a blood product manufactured by Blood Transfusion Services Board (BTSB).

Rainbows Ireland

Rainbows Ireland is a peer-support programme to assist children, adolescents and adults who are grieving a death, separation or other painful transition in their family.

The Children's Sunshine Home

The Children's Sunshine Home is for children medically diagnosed with life-limiting conditions.

The Irish Cancer Society Night Nursing Service

The Irish Cancer Society Night Nursing Service is a nursing service at home for the very ill. It is provided by the Irish Cancer Society and operates from 11.00pm to 7.00am. Bookings may be made two days in advance.

Fairness of Access to End of Life Care

At end of life in Ireland, the least we should be able to expect is equal access to basic end of life services. It should not matter where you live, what you are dying of, what age you are, indeed how assertive you are or others are on your behalf. Yet the evidence of the Forum is that, while progress has been made in recent years in the delivery of palliative care and services to other care groups such as children, the elderly, disabled persons and people with chronic illnesses, we are still quite unable to ensure equity of access and quality of end of life care. We must therefore regard ourselves as still at the beginning of the road of rethinking and reshaping our end of life services so that all of us will be assured of the access to the quality end of life care services we will need when our time comes.

Contributors to the Forum have made it clear that there is great disparity in hospice and palliative care services across the country. There is not ease of access to these services, even for those with cancer. We therefore need a system to determine eligibility for critical end of life care services. These services must be multidisciplinary to meet the particular needs of each

person as they arise.

The following are some of the additional priorities relating to access to end of life services, as identified by contributors to the Forum:

- Access to allied health professionals by incorporating them into existing palliative care/primary care teams. These professionals could then provide a dedicated service based on clinical need which concentrates on the management of specific symptoms such as agitation and chest/breathing problems, for example.

- Access to 24-hour medical cover, the expertise of nurse and pain control specialists and services of physiotherapy, occupational therapy, speech and language therapy and nutritionist if required.

- Availability of complementary therapies to improve end of life care such as aromatherapy, art therapy, reflexology, music therapy assisted activity programmes and homeopathy.

- Access to respite care

- Information on accessing services

- Access to practical aids to help nurse the patient at home

- Flexibility especially in home care and access to acute services, if required.

Partnership in Ensuring Access to End of Life Care for All

However, simply pressing for a minimum level of palliative care services and equality of access to them is not a sufficient response to meeting the needs of those at end of life. As we note elsewhere in this report, (Chapters 23 and 29) we need also to harness the resources of local communities and the voluntary sector to ensure appropriate support for people at end of life, particularly in the community and home settings.

This chapter not only makes it clear that our formal end of life services are patchy and inadequate, and need to be developed to provide equity of access for all who are dying, but it also demonstrates the wealth of voluntary enterprise in responding to the needs of people at end of life. These enterprises are expressions of a society and a community struggling to restore dying and death to the centre of its attention. For the future, if we are to bring end of life care into the twenty-first century, we must focus as much effort on encouraging and

developing these and similar initiatives as we do on the development of appropriate formal services and institutions. This will require a serious partnership between the voluntary and the statutory sectors in mapping, planning and promoting the range of services communities require to maximise the quality of life of their members at end of life.

Chapter 26
END OF LIFE CARE STANDARDS

"The quality of end of life care in a community is a measure of the social capital within it."
 - Professor David Clarke at the inaugural meeting of the Forum.

"If Zygmunt Bauman is right when he remarked (Soundings 35, p9) that "the quality of a society should be measured by the quality of life of its weakest members" we do well to remember that these are not simply and only the poor but also the world's dying."
 - Professor Allan Kellehear at a public meeting of the Forum.

Introduction

Many of the contributions to the Forum were in essence witness statements on the quality of life and the quality of care experienced by people at end of life in different settings and circumstances in modern Ireland. While there were frequent testimonies of very high quality care and service provision, there were also examples of unacceptable standards. A few, such as the following, compared standards in different facilities:

> *"(Name of son)'s mother was living in a nursing home, as she needed full-time care after suffering a series of strokes and falls. She was sharing a room with three other residents which was so small it was impossible to maintain any real privacy. When it was clear that she was dying, (name of son) and his family were struck by the lack of dignity surrounding her death. There was no facility for transferring her to a private room, which the family found very distressing. Staff did not seem to be qualified properly for the care that was required. (Name of son) was concerned about kicking up a fuss about care while she was dying in case his mother was treated negatively as a result. The guilt about this remains to this day. At the same time, another family member was dying in a different nursing home in very different circumstances. Her every wish was respected and her family had no regrets about how she died. The comparison for (Name of son) was unpalatable. He felt that the opposite happened in his mother's case and there should not have been such a lack of consistency in care between the two homes. It shouldn't be down to the luck of the draw."*

The following was another family's experience in a hospital immediately following a death:

> *"However, as soon as (name of deceased person) died, it was made clear that the nurses who were coming to the end of their shift wanted to have her washed and prepared for the undertakers before they went home, I also would imagine they needed to let the other patients back into their room. We were not given any time to spend with her after she had died, no one really sympathised with us or offered my Mom a cup of tea."*

Witness statements like these make it clear why it is so important to regulate and set standards and guidelines for end of life care, just as it is in relation to other aspects of care provision. Indeed, Forum contributors commented on a number of instruments which are driving improvements in end of life care provision, as follows:

- Quality Standards for End of Life Care in Hospitals, 2010 [Hospice Friendly Hospitals programme, Irish Hospice Foundation]

- Health Act 2007 (Registration of Designated Centres for Older People) Regulations 2009

- Health Act 2007 (Care & Welfare of Residents in Designated Centres for Older People) Regulations 2009

- National Quality Standards for Residential Care Settings for Older People in Ireland, 2009. [The Health Information and Quality Authority - HIQA]

- National Quality Standards: Residential Services for People with Disabilities [HIQA]

- Symptomatic Breast Disease Standards (See Standard 1)

- Code of Conduct for Nurses and Professional Guidance for Nurses Working with Older People [An Bord Altrainais]

- Pre-Hospital Emergency Care Council Clinical Practice Guidelines.

Quality Standards for End of Life Care in Hospitals

Several contributors alluded to the Hospice Friendly Hospitals Programme, which aims:

- to develop comprehensive standards for all hospitals in relation to end of life care
- to develop the capacity of acute and community hospitals to meet and exceed these standards
- to change the overall culture in hospitals & residential facilities in relation to all aspects of dying, death and bereavement.

The Irish Nurses Organisation expressed its support for these aims. Peamount Hospital reviewed deaths and the experience of dying in the hospital and established a committee, largely nursing based, to influence change in keeping with the aims of the programme.

The Hospice Friendly Hospitals' Quality Standards for End of Life in Hospitals outline what is required 'for the hospital system and for hospital staff to deliver effective end of life care'.[112]

Health Act 2007 (Registration of Designated Centres for Older People) Regulations 2009 and Health Act 2007 (Care & Welfare of Residents in Designated Centres for Older People) Regulations 2009.

On 1 July 2009 the Health Information and Quality Authority (HIQA) became responsible for the registration and inspection of all residential care services for older people in Ireland. A number of contributors spoke about the standards which are set out in legislation, including standards of accommodation and of care. The Care and Welfare Regulations include the following requirements regarding end of life care:

(1) The registered provider shall ensure that the designated centre has written operational policies and protocols for end of life care.

(2) The person in charge shall ensure that when a resident is approaching the end of their life:
  (a) appropriate care and comfort are given to the resident to address their physical, emotional, psychological and spiritual needs;
  (b) his or her religious and cultural practices, in so far as is reasonably practicable, are facilitated;

---

112 Draft Quality Standards for End of Life Care in Hospitals - A Consultation Document (2009), section 1.6. Dublin: The Irish Hospice Foundation.

(c) the resident's family and friends, in so far as is reasonably practicable, are facilitated to be with the resident when they are dying and overnight facilities are available for their use; and

(d) whenever possible, that each resident's choice as to the place of death, including the option of a single room or returning home, is identified and facilitated.

(3) The person in charge shall ensure, whenever possible, that in the event of the sudden death of a resident:

(a) the resident's death is managed/responded to with dignity and propriety;

(b) their religious and cultural practices, in so far as is reasonably practicable, are facilitated; and

(c) the needs of the resident's family, next-of-kin and friends, insofar as is reasonably practicable, are accommodated.

(4) The person in charge shall ensure respect for the remains of deceased persons and make arrangements, in consultation with the deceased resident's family, for the removal of remains. (S.I. No. 245 of 2009)

National Quality Standards for Residential Care Settings for Older People in Ireland

The Health Information and Quality Authority [HIQA] quality standards for residential care for older people came into effect on 1st July, 2009 at the same time as the Statutory Regulations. At a Forum workshop in September a HIQA spokesperson spoke about the Regulations, the Standards and the inspection process, which had commenced. She said that 'quality' is a multifaceted concept, without any single performance measure or metric. However, the international trend is to use the following key domains to define quality in healthcare:

- Patient Centred: Are health services respectful and responsive to patients needs?

- Access and Equity: Are services provided at a time, a place and in a format most appropriate to the needs of all service users and their families?

- Safety: Recognising all healthcare carries some risk, is care provided as safely as possible in a setting that anticipates and learns from errors or adverse incidents?

- Effectiveness: Are services providing the best possible care and outcomes for

service users and their families according to current evidence?

- Efficiency: Are services planned and provided to ensure the best possible health outcome for the resources used?

The National Quality Standards for Residential Care Settings for Older People are grouped into seven sections to reflect a quality service. A Standard on End of Life Care (No 16) is included in the section on Health and Social Care Needs. It states:

"Each resident continues to receive care at the end of his/her life which meets his her physical, emotional, social and spiritual needs and respects his/her dignity and autonomy."

Criteria 1 - 13 of Standard 16 address:

- Palliative care needs

- Dignity and respect

- Residents' wishes and choices

- Physical environment

- Staff training and education

- After-death care.

The Standards, and Standard 16 in particular, were welcomed by contributors to the Forum.

Inspection

The HIQA Inspector Manager who addressed the Forum said that the residential care provider must have written protocols on end of life care. She listed the following indicators of compliance with the end of life regulations and standard:

- Definition of End of Life
- Assessment and care planning
- Advance care planning
- Symptom management
- Place of death: single room, palliative care suite, home
- Family supports, facilities, meetings
- Procedure after death of resident

- Information to family after death ... practical issues, bereavement support services

- Procedure for return of personal possessions, documented & signed

- Support for other residents

- Notification of death of a resident

She also said that evidence of inappropriate transfer of dying to A & E would be picked up by inspectors by looking at the records of transfers to hospital and staff training levels.

Quality of Life at End of Life

An important report on improving quality of life for older people in long-stay care settings in Ireland was published by the National Council on Ageing and Older People shortly before the Standards were developed[113]. It was encouraging therefore that the National Quality Standards for Residential Care for Older people included standards addressing domains of quality of life of older people in long-stay settings identified in the report, including standards to promote autonomy and connectedness.

However, as the then Work Programme Co-ordination Manager with the National Council on Ageing and Older People said at a workshop, there are a number of other domains that are particularly important for the quality of life of older people at the end of their lives, including:

- life completion, which relates to a person's sense that he/she has achieved what they want to achieve e.g. saying important things to loved ones, being at peace

- the individual's relationships with the healthcare system, which includes a sense of control about treatment decisions, participating in care decisions and being treated as a person

- preparation/anticipatory concerns, which includes worries about being a burden, concerns about whether one's family is prepared for the future, fear of dying and regrets about life

- symptom impact, which has been identified as central in most end of life care studies and involves the control of symptoms to promote the comfort of the individual and ensure that their quality of life is as good as possible approaching death. Typical symptoms include pain, fatigue and nausea and patients have

---

113 Murphy, K., O'Shea, E., Cooney, A., Sheil, A., and Hodgins, M.,Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland (2006). Dublin: National Council on Ageing and Older People.

reported how these interfere with enjoyment of life and concerns about the future

- connectedness and effective social support, which relates to whether a person has a confidant to share their deepest thoughts and having time to spend with family/friends (Mularski et al., 2007 [114] cited in O'Shea et al., 2008[115]).

There is a growing appreciation that enhancing quality of life must be a central consideration in all care provision. Good end of life care too should be driven by the concern to enhance the quality of life of those at the end of their lives, not just the clinical duty to ensure high quality specialised medical and palliative care, though these are clearly very important to the quality of life of many at the end of their lives.

Regulation and standard setting will not, of themselves, ensure that service providers display the sensitivity and interpersonal skills needed to maximise the quality of life of those they care for at end of life. These are demanding skills implying an awareness and an understanding of the different dimensions of the human person and an appreciation of the importance of attending to the social, psychological and spiritual needs and preferences of the dying person, as well as to their physical needs and preferences. It requires an appreciation also that a person's pain may be psychological, social or spiritual, as much as it may be physical.

Above all, it is those with an ability to listen to the physical, emotional, social and spiritual needs of people at the end of their lives - whether these needs are spoken or unspoken - who will be most successful in alleviating their pain and enhancing their quality of life.

114 Mularski et al., 'A systematic review of measures of end of life care and its outcomes.' (2007) Health Services Research, 42 (5): 1848-1870

115 O'Shea, E., Murphy, K., Larkin, P.,Payne, S., Froggatt, K., Casey, D., Ni Leime, A., Keys, M. (2008) End of Life Care For Older People in Acute and Long-Stay Care Settings in Ireland. Dublin: National Council on Ageing and Older People and The Hospice Friendly Hospitals Programme

7

National Quality Standards: Residential Services for People with Disabilities [HIQA]

Standards for people with disabilities in residential care were launched by HIQA in May 2009 and a number of contributors commented favourably on them. One said that they "hold out hope that the quality of life for people with disabilities, in all care settings, will improve, particularly as they near the end of their lives".

Interestingly, in these Standards, end of life matters are provided for in the Section 1: Quality of Life, under Standard 2, Privacy and Dignity. They read as follows:

> "2.9 The individual receives support at times of illness and at the end of his/ her life which meets his/her physical, emotional, social and spiritual needs and respects his/her dignity, autonomy and wishes."

> "2.10 In so far as the individual wishes to do so his/her wishes and choices regarding end of life support are discussed and documented, and made known to staff and family members to ensure implementation."

It will be important to ensure that these standards are put on a statutory footing like the standards governing residential care for older people, and that the requisite funding is provided for their monitoring and inspection.

Symptomatic Breast Disease Standards and other Standards

In addition to the above mentioned standards, the Quality Assurance Manager, Healthcare Quality and Safety Directorate, HIQA, refered to the Authority's Symptomatic Breast Disease Standards. Standard 1 sets out the prerequisites for a functioning Specialist Breast Centre. This includes specialist palliative care staff and a Clinical Nurse Specialist in Breast Care who is able to recognise physical and psychological morbidity and the need to refer appropriately.

She also said that national quality and safety standards tailored to specific sectors such as acute care, primary care and ambulance care will be developed. They will cover all aspects of the patient journey including end of life care. They will be stratified to set out licensing requirements and to allow for continuous improvement.

Code of Conduct for Nurses and Professional Guidance for Nurses Working with Older People [An Bord Altranais]

In its submission, and in its presentation to a Forum workshop, An Bord Altranais referred to its professional guidance documents, including its Professional Guidance for Nurses Working with Older People, published in April 2009. The Chief Executive Officer wrote:

> *"An Bord Altranais believes that nursing care at the end of life should be based on the values inherent within The Code of Professional Conduct for each Nurse and Midwife (April 2000). The purpose of the code is to provide a framework to assist the nurse to make professional decisions, to carry out his/her responsibilities and to promote high standards of professional conduct. The nurse must at all times maintain the principle that every effort should be made to preserve human life and when death is imminent, care should be taken to ensure the patient dies with dignity."*

As we saw in Chapter 8 of this report, Standard 4: End of Life Care from An Bord Altranais' Professional Guidance for Nurses Working with Older People, states:

> *"The older person receives comprehensive, compassionate end of life care that is person-centred and responds to the older person's unique needs and respect for his/her wishes."*

An Bord Altranais presents its nursing standards as complementing other national standards and guidelines. In relation to this standard it states:

> *"When older people are at the end of their lives, nurses can make a difference to them and their families by creating and facilitating a therapeutic milieu that addresses their physical, psychological, social, cultural and spiritual needs. This includes collaboration with other healthcare professionals in providing evidence-based/best practice and establishing mechanisms for consultation regarding practice and referral. Older people may feel disempowered in their decision making at this time. In order to protect their rights, it is important to be guided by, and work within, a legal framework (Keys 2008)[116]. Providing relief from distress will*

---

116 Keys, M. (2008) The Legal Framework. In: O'Shea., Murphy K., Larkin P., Payne S., Froggart K., Casey D., Ni Leime A., Keys M. (2008) End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland. Hospice Friendly Hospitals Programme / National Council on Ageing and Older People. Dublin. Ireland

facilitate a comfortable death, and one that is remembered with peace and comfort by family and friends."[117]

Pre-Hospital Emergency Care Council Clinical Practice Guidelines

Dr Niamh Collins, Centre for Immediate Care Studies, UCD and Dr Geoff King, Director of the Pre-Hospital Emergency Care Council, addressed a Forum workshop on pre-hospital challenges and how they are being addressed. Following a recommendation of the Cardiovascular Health Strategy Group in 1999, the first Pre-Hospital Emergency Care Council Clinical Practice Guidelines were published in 2001 and have since been expanded to cover Clinical Practice Guidelines for emergency practitioners and responders, as listed in Chapter 25: "As research leads to evidence, and as practice evolves, guidelines are updated to offer the best available advice to those who care for the ill and injured in pre-hospital environment."

Regulation of Funeral Businesses

In its submission, The Irish Association of Funeral Directors (IAFD) raised a number of important issues about the registration and regulation of the 600 funeral businesses in the country. It said:

> *"Two thirds of the time the journey of a deceased person to (his/her) final resting place commences in a public hospital - one of the most regulated environments in the state, straight into the hands of the funeral profession, one of the most unregulated businesses in the state. Unbelievably, the collection of a deceased (person) that has known high-risk infection potential can be carried out by anyone, without proper equipment, health and safety training or protective clothing - and there is nothing the mortuary staff can do about it."*

In Chapter 15, on personhood and dignity, we listed challenges faced by a Clinical Services Manager. We repeat them here to emphasise the urgent need to regulate and set standards to ensure that such 'challenges' become a thing of the past:

- Funeral directors have put a child's remains in the boot of a car or have brought an adult coffin which has caused extreme distress for families.
- On occasions coffins have been too small.
- Children have been taken away in a body bag. When a child has to be taken to

---

117 Professional Guidance for Nurses Working with Older People, (April, 2009). Dublin: An Bord Altranais

hospital for post-mortem, taxi drivers find it difficult as have gardai when they have to identify a child.

- When a child presents with HIV it is impossible to find an undertaker.

The Association also raised issues relating to embalming. It said that while a small number of public hospitals allow trained embalmers into their mortuaries to embalm remains, many hospitals permit mortuary staff carry out this function on behalf of Funeral Directors regardless of the lack of facilities at the hospital and the lack of formal training they may have. This, the Association said, is a very 'grey' area.

The Association also said that there is no statutory inspection or monitoring of funeral homes from any source and as a result, it said:

> "There are some true 'hovels' that are put forward as funeral homes. Some embalming facilities have to be seen to be believed in their awfulness and would be shut down immediately if they were inspected by the HSA."

The Irish Association of Funeral Directors has a code of practice for its members, which they are required to display prominently in their premises. It covers professional conduct, advertising, information provision to clients, complaints, training and publicity. It recommends that all Funeral Directors should be signatories to a code of practice that reinforces the rights of client families, in terms of:

- provision of written, accurate estimate of expenses (funeral directors fees and disbursements)

- allow[ing] clients to give written consent to embalming

- agree[ing] to allow premises to be inspected for suitability by a competent authority.

Regulation of Domiciliary Care Services

The regulation of professional domiciliary care services was also raised by contributors. The lack of regulation of these services some believe is a serious deficit, which leaves people at the end stage of their lives in a very vulnerable position, particularly in view of difficulties accessing care services in the community, as already discussed. Contributors referred to the Law Reform Commission's Consultation paper, "Legal Aspects of Carers", published in July 2009, which proposed 21 provisional recommendations to govern the terms and quality of

the provision of professional domiciliary care services. It proposed that the remit of HIQA be extended to include the regulation and monitoring of such services. It raised the possibility of extending the "Fair Deal" to domiciliary care and it adverted to the fact that currently those who engage a domiciliary carer could be regarded as employers, subject to health and safety regulations, etc, unless the contract is through an intermediary.

Standards of Patient Care

One person wrote in a submission:

> "I rang the HSE for the Patient Charter, to give the right of dignity in death. They said it is nothing to do with us. I rang the hospital and they said I would have to talk to the HSE. When I said the HSE said I should talk to the hospital, the hospital said we know about it and if anyone asks we photocopy and send it to them.
>
> They said we do have a Mission Statement and you can download it. She said it was very general."

In her submission, the Ombudsman referred to a Statement of Good Practice for the Public Health Service in Dealing with Patients, published by the Office of the Ombudsman in 2006. The statement identified human rights and values in healthcare, and good practice with regard to information, consent, confidentiality and privacy, care and treatment, and safety. The statement is very relevant to the care and treatment received at end of life.

Mental Health Ireland wrote that there is a need to consider the development of a Quality Standard for End of Life care similar to the "gold standard framework in the UK". This would be applicable to all care groups in all care settings not already covered by regulations or standards.

The Irish Nephrology Nurses Association recommends that standards of best practice in conservative management of Chronic Kidney Disease (CKD) need to be in place to ensure a well-organised and efficient transition from supportive care to palliative care, thus assuring a 'people centred service' and access to palliative supportive services along the complete trajectory of Chronic Kidney Disease[118].

---

118 "The severe symptom burden of End Stage Renal Disease (ESRD) and a growing recognition that the provision of dialysis to elderly patients may not improve survival rates, while adversely affecting quality of life, led to the advent of what is called conservative management and supportive care without Renal Replacement Therapy (RRT)"

Bereavement Care Standards

In the absence of nationally agreed bereavement care standards, it is important to note the recommendations of the Review of General Bereavement Support and Specific Services Available Following Suicide Bereavement[119], published by the National Office for Suicide Prevention. This Review sets out a comprehensive service delivery model and the training, qualifications and standards required to ensure its delivery.

---

119 Petrus Consulting, Bates, U., Jordan, N., Malone, K., Monahan, E., O'Connor, S., & Tiernan, E. (2008). Review of General Bereavement Support and Specific Services Available Following Suicide Bereavement. Dublin: National Office for Suicide Prevention.

Chapter 27
THE CARE ENVIRONMENT

Introduction

Contributors spoke repeatedly about the physical environment of settings where people die. The comments of those who raised the issue in relation to hospitals and long-stay facilities were very similar: inadequate facilities, and particularly the lack of single rooms, prejudiced the privacy, dignity and closeness of the dying person with his/her family at a most precious time in their lives. There was dismay that the needs of the dying and their families did not seem to be taken into consideration in the design of public care facilities where people die. While they did not speculate on why this may be, there is a need to examine why this is so, if the situation is to be reversed in the future.

Hospitals

The mother of a terminally ill child wrote:

> "It is customary to move patients who are dying (12-24 hours left) to a two-bed room on their own. For all the rest of their stay/s they will have a room smaller than the cells in Mountjoy prison. Each time we were admitted to the specialist hospital I asked for a single room to minimise the children's exposure to infection. However, one was never available. One was always available however when my son was diagnosed with MRSA!!"

Another person wrote about the experience of a terminally ill person aged 99 with maximum VHI cover a few days before her death:

> "A few days before (name of person) died, an unconscious patient was brought into the ward. Her immediate and extended family all crowded around the very limited space around the bed; those who could not be accommodated gathered around the ward door and trailed out into the corridor. As they could not communicate with the unconscious patient, they availed of the opportunity to have a family reunion with all that entailed - excited greetings, loud laughter, mobile 'phone calls, mobile phones constantly bleeping and endless animated conversations; this was repeated each time another relative arrived. Added to this, a nurse was moving around with a trolley dispensing medication, the 'carer' was trying to calm one of his gregarious patients; you could sum up the situation in one word, bedlam."

The person who made this submission recommended:

> *"When a patient is terminally ill and the doctors advise the family accordingly, the patient should be moved to a private room; it would be very desirable if a reclining armchair or bed could be provided so that family members could take turns getting some rest. Tea/coffee facilities would also be very welcome during the long nights."*

> *"In a ward where there are other sick (and possibly dying) patients, a maximum of 2/3 people per patient should be allowed at each bedside."*

The following account of a family's contrasting experiences of death in a local county hospital and in a hospice in Northern Ireland illustrates a variability in environmental standards of services offered to Irish people at end of life:

> *"Our family's experience of the death of our mother in a local county hospital:*
> - *the ward had ten beds*
> - *loud, non-stop television*
> - *no or little restriction on visitors (on one occasion there were 17 visitors with a patient)*
> - *little if any privacy*
> - *pealing paint, torn curtains, general weariness of décor*
> - *inappropriate food - Mum was unable to feed herself - her tray was often returned untouched - no comment from staff if indeed they noticed*
> - *medication found among the sheets on more than one occasion*
> - *drilling was going on in the corridor outside her ward - this went on for about 2 hours - our complaints went unheard (no pun intended)*
> - *no easy access to consultant or registrar - on one occasion my brother and I waited all day to speak to the consultant only to be told, at 5.00pm that he had left the hospital two hours earlier.*
> - *eventually Mum was taken to the room designated as the 'hospice room' - it was quiet and large but obviously had not been in use for a considerable amount of time - it was very fusty and dull*
> - *poor interaction of staff with my mother, they spoke as if she was invisible, this did not apply to all members of staff*
> - *in the ward we were constantly asking for basics, eg clean sheets, commode,*

nappies (the latter cause great distress to Mum)

- *of course it wasn't all bad, but overall the experience was distressing for us all and in particular for my mother*

- *my mother was dying and in our opinion the inadequacies appeared glaringly obvious. Simple changes could have made such a difference.*

"My experience of the death of my aunt in a hospice in Nr. Ireland private room:

- *clean, bright and fresh room, no signs of wear and tear*

- *peaceful serene and quiet*

- *personal diet requirements, not elaborate, just appropriate*

- *holistic approach much in evidence*

- *massage available, simple things like hand massage were readily available*

- *reflexology available if appropriate*

- *visitors monitored and numbers curtailed when necessary*

- *there was a white board in each room, outlining daily activities of note and naming the medical personnel that day*

- *use of a kitchen was available to all visitors all day and night - a wonderful facility to have at our disposal*

- *spiritual support was readily available."*

Though we may not associate maternity hospitals with death or dying, some children are stillborn there, others do not survive birth, or are in intensive care because born prematurely or with congenital abnormalities or brain injuries at birth. Yet, a Neonatologist wrote:

"There are difficulties in the provision of end-of–life care in (name of hospital) as facilities are very restricted due to issues of space. The entrance to the neonatal unit is through the canteen. There is one small parent room, which cannot hold more than one double bed and does not allow rooming-in by the family. Many seriously ill infants remain in the open-plan neonatal unit in their final hours."

Morgues and Mortuaries

In his keynote address at the inaugural meeting of the Forum, Dr Maurice Manning asked why are our mortuaries generally appalling places to bring grieving relatives. This was echoed at the meeting by the President of the Institute of Architects who said that there was a lack of thought in the design of morgues. The issue was also raised at a Forum workshop where it was said that mortuaries are not designed as special places and in fact often share space with hospital waste and disposal. This is an important issue which needs to be taken up with the Department of the Environment and the Local Authorities, one speaker said. At another workshop a speaker said that mortuaries need to have welcoming quiet and comfortable facilities adjacent. In its submission, the Irish Association of Funeral Directors said that one large Dublin Public Hospital does not provide mortuary chapel services and recommends that all such hospitals should do so if their facilities will allow it.

Long-Stay Care Facilities

In his keynote address Dr Maurice Manning also said:

> *"After we have praised the many dedicated and caring staff of our long-stay facilities let us ask some hard questions about why these, the oldest children of our nation, are cherished so unequally - sometimes in beds no more than 13 inches apart."*

This is a question that has been asked umpteen times in recent decades by many agencies and by the media. The private 'business-ification' and sequestration of the most vulnerable older people, who have suffered life- threatening and life-limiting conditions, is only in very recent times being counterbalanced by measures such as the introduction of the National Quality Standards for Residential Care Settings for Older People in Ireland. As already said, these Standards have been very much welcomed by contributors to the Forum. The standard governing the physical environment states:

> *"The location, design and layout of the residential care setting are suitable for its stated purpose. It is accessible, safe, hygienic, spacious and well maintained and meets residents' individual and collective needs in a comfortable and homely way."* *(Standard 24)*[120] [121]

---

120   National Quality Standards for Resiidential Care Settings for Older People in Ireland (2009). Cork; Health Information and Quality Authority

121 The standard stipulates criteria applying to all designated centres, criteria for existing centres and criteria for newly built designated centres, new extensions and first time registrations, which will see the useable bedroom floor space increase in time or with new centres/builds

Whether the word 'homely' above is interpreted as rhetorical or not will take time to determine. However, from contributions made to the Forum, it is clear that there are already some hopeful signs of change: changes in thinking about residential care homes and how they are configured and actual changes in design and décor to make the 'homes' more homely.

At a Forum workshop, a Health Service Planning Specialist for Older People described different models of residential care settings as follows:

- the hospital model where 'medical' is the default setting

- the hotel model: more likely in the private sector, and

- the household, or 'teaghlach' model, which is now being championed in the HSE

Teaghlach means 'hearth'. The kitchen is the centre of these type of homes. The Teaghlach model is not just concerned about the design of residential care settings; it is also concerned about the culture of a facility, including how residents and staff relate. This approach is well established in other countries such as the Netherlands, where a quarter of all facilities are now built according to the household model.

Scientific studies have shown that the use of appropriate combinations of colours increases the well-being of those in different environments, including those being cared for in hospitals and nursing homes. Specially chosen colours in hospitals for the mentally ill have had dramatic effects. Another example of an initiative to address environmental standards comes from the testimony of an Acute Psychiatric Unit, where a refurbishment was undertaken by a colour consultant who addressed a Forum workshop:

> *"Since the ward has been completed, clients, staff and visitors are delighted with the exquisite colours, the increased lightness, everyone has expressed positive feelings when asked to comment on the physical environment. Staff now enjoy working in a brighter, more relaxed in a happier environment."*

For very little money, a sick building can be transformed into a more therapeutic and pleasant environment for those with chronic and life-limiting illnesses.

Cemeteries and Monuments

Desmond Fitzgerald, who designed the Omagh monument with the artist Sean Hillen, addressed a Forum workshop about commemorative monuments and the layout of cemeteries in multicultural Ireland. He said that Ireland has accommodated minorities well in the past - as

testified by the Jewish, Huguenot and Quaker burial grounds that are still a feature of our urban landscapes. But he asked if we should not now be thinking of following the model of the Mariebjerg cemetery in Copenhagen, because of the growing cultural diversity of the country. He said:

> *"The Danish cemetery layout provides a system of some 40 open spaces enclosed by hedges. They are connected by grass walks and allow for different types of burial in each space. The possibilities can be set out in several ways - for example most Danes are Lutherans or nonbelievers but the set-up allows for religious communities such as Jews and Roman Catholics to have their own dedicated plots. It also allows for spaces to be set out for cremations, conventional interments and anonymous burials (something which is not uncommon in Scandinavia). Most importantly of all, it allows for different aesthetic preferences - eg interment with conventional headstones, interment with horizontal headstones flush with grass, forest burial and various other approaches such as family plots within a matrix of formal hedges."*

On monuments, he said that they are for the living, not the dead. The Omagh Memorial Garden recognises the significance of the (bombing) event and reflects the support, love and healing which came from all over the world, and particularly from throughout Ireland, north and south, in the weeks and months which followed the bombing, while also providing space and atmosphere for reflection.

On a contrasting note, one contributor wrote:

> *"A couple of weeks after the burial, my mother and I went to visit the grave and were horrified to see the way the grave diggers had left it. Everything was strewn all over the place, as they had to remove the surround stone. The grave had already begun to sink, and it was my brothers who had to go down with extra soil to make sure the grave was filled in properly."*

The Home Environment

In a presentation to the Forum representatives of the Royal Institute of Architects said:

> "When given the choice, people prefer to spend the end of their lives at home, because it offers:
>
> • dignity and sanctuary
>
> • familiar environment
>
> • person autonomy
>
> • communication with family and loved ones."

People at different stages of their lives need different things in their houses. However, a well designed house will take account of all the life cycle, including the dying phase. Designing lifetime adaptable housing is important for the welfare of older people and people at the end of their lives. Particular environments are healthier and make us feel better. This applies to every age group. Good housing design from the point of view of the dying person will be good design for all. Good design is good economics. Rodd Bond of the Netwell Centre, a collaborative demonstration project aimed at developing innovative service models to support older people to age-in-place in their own homes, said that lack of home care services is not the only challenge to dying at home. There are also the ergonomic problems (difficulty in implementing AJ metric handbook dimensions or Part M of the Disability Guidelines). There are then also economic or affordability problems to be overcome.

Speakers emphasised the importance of using co-ordinated architectural, interior, and landscape design principles when planning a lifetime adaptable home. This is equally true when designing nursing homes and hospital rooms. This was illustrated by speakers using the following evidence based design wheel:

EDB Wheel: Murray O'Laoire, Architects
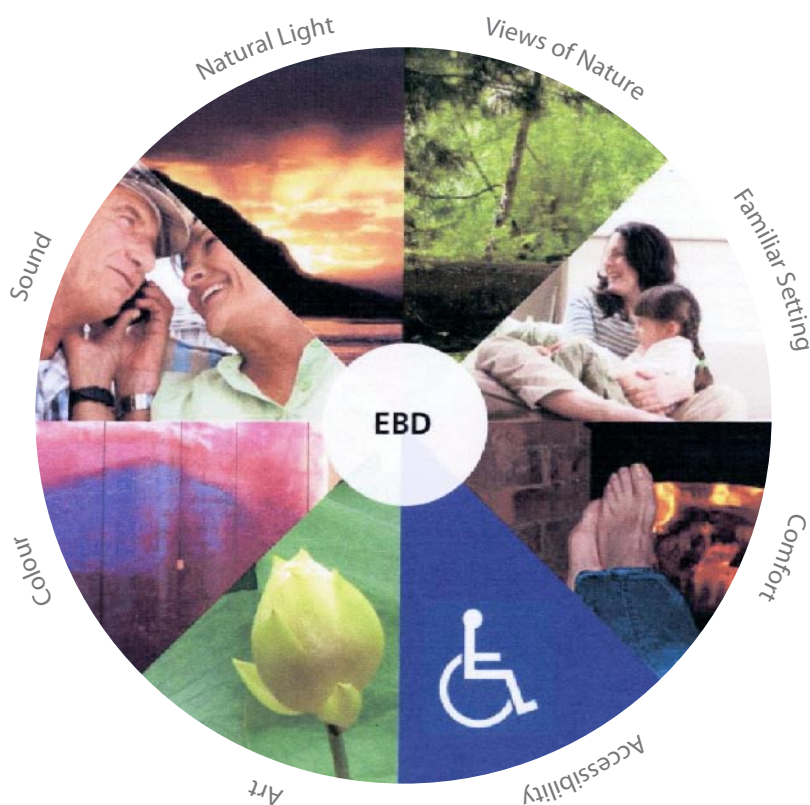
Conclusions

While the majority of people die with dignity, recent studies[122,] into end of life or palliative care in acute and long-stay settings have consistently highlighted that the availability of single rooms at time of death is low in acute hospitals with those available prioritised for infection control (MRSA etc). In addition facilities for families and friends are generally poor.

The All Ireland Gerontological Nurses Association said in its submission:

> *"The importance of a suitable environment and dying with dignity is central to quality end of life care."*

It identified changes required, as follows:

- Improvement in the physical environment where people die, such as comfortable

---

122   Irish Hospice Foundation, A Baseline Study on the provision of Hospice/Specialist Palliative Care Services in Ireland. 2006: Dublin; O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ní Léime, A. and Keys, M., 2008. End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland. Dublin: NCAOP/IHF.

single rooms, en-suites, facilities for families and accessible attractive sensory gardens and courtyards.

- Access to capital funding and design consultants in planning new buildings or reconfiguration of existing buildings.

The Irish Association of Palliative Care recommended in its submission:

> "For all modifications to existing care settings and for new developments, reference should be made to the relevant publications and standards documents dealing with evidenced based design of hospices, nursing homes and hospitals. This will support the provision of good end of life care in Ireland. [123, 124]"

The National Disability Authority said that it welcomed "the recent publication of the Design and Dignity Guidelines by the Irish Hospice Foundation. Should the Irish Hospice Foundation wish to develop more detailed, technical guidance on hospice design the National Disability Authority and the Centre for Excellence in Universal Design at the National Disability Authority in particular would be happy to provide advice or partner."

The President of the Institute of Architects said:

> "design and the environment for the dying should be structured into policy" and "the Institute of Architects is happy to act as a conduit in this process".

When considering new policies, we need to recognise that "the unit of accommodation in hospitals should be a room, rather than a bed, and that sharing a room with others at end of life should, in so far as is possible be a matter of choice for all concerned[125]." We would also do well to bear in mind that it has been calculated that the lifetime ratio of hospital costs is roughly as follows 1:5:100-200 capital/running/staff. Increasing the percentage of single beds in a hospital from 50% to 100% would increase the initial building costs by only 4%.[126]

---

123 Marymount Hospice, International Expert Advisory Group Report on Palliative Care. 2005.

124   HfH, Guidelines for Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End of Life Care 2008, Irish Hospice Foundation: Dublin. p. 44.

125 TRIBAL, Design & Dignity Baseline Review, Hospice friendly Hospitals Programme (2007), Dublin: Irish Hospice Foundation.

126 Notes of an address by Dr Roger Ulrich, Professor of Architecture at Texas A&M University and a faculty fellow of the Center for Health Systems & Design, at Conference, Hope and Opportunity: Hospice Principles and Hospitals Practice, Clontarf Castle, November 2007

Also, according to the same source, Dr Roger Ulrich, Professor of Architecture at Texas A&M University, the evidenced positive outcomes of single bedded rooms are:

- reduction in infections and therefore costs

- reduction in nurse travelling and time taken in moving around

- reduction in noise and therefore in blood pressure and negative outcomes

- improvement in communication, which is inhibited in multi-bedded rooms because of self-censorship for privacy reasons

- facilitation of family stays through the use of Murphy beds

- elimination of the stress of roommates

- improvement in opportunity for views to the outside world of nature. [127]

Finally, it would seem clear that a national evidence based strategy to encourage and support people to age and die in place is needed as part of an overall strategy for the ageing of the Irish population that is so much talked about.

---

127 Ibid

Chapter 28
MANAGEMENT OF END OF LIFE CARE

Introduction

End of life care management issues were raised by a number of contributors to the Forum. These invariably related to management in institutions, particularly acute hospitals. There was little comment on the management of end of life care in the community. The treatment of the remains after death was raised as a significant management issue, however.

In the report, End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland, O'Shea et al.[128] identify the barriers to end of life care as: continuity of care between settings; organisation of care in a setting; education and training of staff; cultural awareness among staff of the needs of the dying; staffing levels; physical resources; spiritual and psychological support; and communication. While older people were the subjects of this report, the list gives an indication of the range of management issues which must be addressed by those in leadership positions where people die.

Management of End of Life Care Services

While it is not possible to manage end of life care perfectly in the absence of adequate policy direction or resources, neither is it possible to postpone dying until these deficiencies are rectified. Contributions to the Forum have identified a number of management issues, which, if they were addressed, would considerably limit risks of inappropriate, wrongful or negligent treatment, or indeed, administrative failures, leading to unnecessary suffering for people at end of life and for their families and friends.

The Death, Dying and Bereavement Committee (DDB), Our Lady's Hospital for Sick Children ((OLCHC) wrote:

> "The inherent tension between the needs of an acute hospital and the needs of
> people dying and their families is a day to day reality. Planning for dying in hospital
> is inadequate in terms of space, physical environment and staff skills."

At one workshop there was a discussion about the mission and purposes of our acute

---

128 O'Shea, E., Murphy, K., Larkin, P.,Payne, S., Froggatt, K., Casey, D., Ni Leime, A., Keys, M. (2008) End of Life Care For Older People in Acute and Long-Stay Care Settings in Ireland. Pp. 48-53. Dublin: National Council on Ageing and Older People and The Hospice Friendly Hospitals Programme.

hospitals. If the mission of a hospital is to cure or rehabilitate, does this make it inherently unsuited to the care of the dying? It was suggested that this was not necessarily the case. However, it may only be when care of the dying is identified as a core function of a hospital on a par with its other functions that end of life care will become a core activity within it, and that the risk of inappropriate treatment of the dying and of their families will be eliminated.

Where there is no focus on end of life care in hospital Mission Statements, strategies, plans, budgets, then end of life will not be incorporated into care pathways; end of life care processes and procedures will be inadequate; and there will be a greater likelihood of inappropriate or negligent treatment of the dying. The following is an excerpt from the submission from the Ombudsman which illustrates the risks:

> "Some of the cases I have examined relate to people with advanced terminal illness being admitted to an acute hospital through a busy and extremely unpleasant A&E Department. They were forced to remain there for hours in a very sick condition, with what they perceived to be total disregard for their dignity, physical, psychological or spiritual well-being. I do not underestimate the challenge hospitals face with limited space and resources, but if we continue to tolerate this treatment of people, especially people who have already been diagnosed with terminal illness, we will not bring about change as quickly as is needed. It is a function of hospital management to husband resources in such a way as to avoid the type of major distress caused in the above instances. "

Reducing Risk in End of Life Care

Contributors spoke of organisational breakdowns which prejudiced or might have prejudiced the welfare of people at end of life or bereaved persons. They serve as illustrations of potential risk rather than a review of end of life care risks. Those who have management or administrative responsibilities relating to the care of people at end of life need to undertake assessments to establish the risks and the measures they must put in place in their areas of responsibility to obviate those identified. The following are some examples of avoidable mistreatments, again provided by the Ombudsman:

> "A person was not fed adequately because her admission had not been planned properly, a referral to another service had not been prioritised and the family had not been communicated with. A person developed pressure sores because there was a failure to follow guidelines on positioning and turning, managing diet and provision of fluids. A person did not receive oxygen as intended because it

*had not been described adequately in the medical chart. A person was unable to
communicate clearly before her death because a writing error resulted in the wrong
amount of medication being prescribed. In all these cases, the benignly worded
'administrative errors' had serious clinical outcomes."*

Another person wrote:

*"I understand completely that the service has to be paid for but surely it is possible
to ensure that records are updated to note that the patient DIED and that the bill
should be sent to next of kin."*

All the effort to ensure that an elderly man who is dying is prescribed the right medication
may be wasted if he is living on his own and is unable to get scripts to the chemists. The Irish
Pharmacy Union wrote:

*"A ... study by Lucey and McQuillan (2008)[129] ... performed a systems analysis of the
process by which patients under the care of specialist palliative home care obtained
medications and highlighted factors that delay this process ...This study found the
main factors causing delay to be medications not being in stock in pharmacies,
medications not being available on state reimbursed schemes and the inability of
patients and carers to courier medications."*

It is not just healthcare personnel who must be alive to the risk of poor treatment of those at
end of life or the bereaved, as these statements indicate:

*"Parents have to register their children's deaths in the same location as the birth
registry."*

*"... IBEC acknowledges that in many workplaces and in wider society there are gaps
in the way that bereavement and grief are dealt with."*

Contributors also offered ideas on how risks identified might be addressed. IBEC, for example,
said in its submission that it would be pleased to get involved in a discussion about how grief
and bereavement issues in the workplace might be resolved. It added that many employers
now provide Employee Assistance Programmes (EAPs) to support employees with a variety of

---

129   Reference not provided

problems and concerns of a personal and sensitive nature.

> "EAPs offer independent, confidential counselling and support to staff and play
> a key role in helping good practice employers manage stress and emotional
> pressure in the workplace. They have an obvious role to play in helping manage
> bereavement and grief, not just at the time of death, but in the period afterwards.
> EAPs also have the advantage of being available to employees who have lost
> friends and colleagues other than close relatives."

Other examples given of how certain risks are managed include the following:

> "In palliative care, medication is prescribed with the aim of removal or alleviation
> of symptoms and to improve quality of life with minimum adverse side-effects. The
> thorough knowledge of community pharmacists of drug incompatibilities, dose
> changes and dose titrations plays an effective role in minimising risk. Prescriptions
> are cross-checked to minimise the risk of adverse drug interactions and reviewed to
> ensure correct dosage and identify any potential omissions."

> "Patient-held records lead to improved services and empower the patient to
> demand better services."

From contributions it would seem that in managing end of life care risks there is sometimes a
fine line between effective record management and intrusive bureaucracy:

> "Patients requiring palliative care should have access to all necessary medication
> as and when required ... Simplifying the bureaucracy surrounding unlicensed
> medication and reimbursement issues needs to be addressed in order to improve
> prompt access to such medication in the community."

> "The diligent and accurate documenting of events, progress, interventions and
> communications, is a basic requirement of all healthcare professionals, yet far too
> often I (the Ombudsman) come across substandard practice. These failures impair
> the proper and safe sharing of information with other healthcare professionals
> and, if required, with the patient or family. Comprehensive and accurate medical,
> nursing and allied health records are critical to ensure best practice is delivered.
> Sound record management practices are vital to the maintenance of records for
> future audit, information and/or examination."

Another example of managing competing risks is that raised by members of the Irish Haemophilia Society and of Positive Action - the Hepatitis C/ Anti-D Support Group. When someone dies with an infectious disease, the body is placed in a black body bag. This practice of most hospitals is a major concern for the members of the two organisations.. The issue is one of reconciling the public health infection concerns of hospitals with sensitivity to the needs and feelings of familiies of sufferers.

Management of Staff

The greatest threat to high standards of end of life care is poor treatment by healthcare staff. "My Office," the Ombudsman wrote, "constantly reinforces the message to Healthcare Management that sloppy, insensitive treatment of patients or families is completely unacceptable, regardless of circumstances".

Another threat to effective end of life care provision is lack of clarity about who is responsible for each aspect of its delivery, including medical, nursing, spiritual, social and psychological care. The Directors of Nursing, Specialist Palliative Care Network, for example, say clear identification of who is responsible and accountable for the delivery of end of life care is essential in order to avoid confusion and breakdown in communication when it comes to decision making. The Irish Nurses Organisation adds:

> "Irish nurses are at the forefront of the provision of end of life care. In order to deliver quality end of life care, those that manage the services must appreciate the less tangibles aspects of care such as journeying with the patient, and providing spiritual and emotional care."

A further threat to standards of end of life care delivery is lack of competence on the part of staff. A contributor wrote:

> "As a Service, we are struggling to provide appropriate support and guidance for our staff."

This is because

> "Often staff feel very challenged by the decisions they have to make regarding pain management and medication, artificial nutrition and the whole area of resuscitation and allowing people to die in their own beds with dignity and respect."

Confidence of staff in providing end of life care can determine whether someone can continue to live where they are used to living, for example in a nursing home. It is therefore imperative that management ensures that staff who look after people at end of life are both competent and sensitive in their work. The Irish Nurses Organisation suggests that management must be supportive of change at both individual and organisational levels. This means providing the resources to facilitate practice development initiatives and to enable staff to participate in education.

The DDB Committee, Our Lady's Hospital for Sick Children wrote:

> "Staff need to be supported by the knowledge that they are working within a
> carefully designed, well managed, high quality service. In addition, it is essential
> that all those who care for and support dying and bereaved people, regardless
> of their role, should be provided with support for themselves. Coupled with this
> it is also essential that staff involved in caring for people who are dying and for
> people who are bereaved are well informed so they feel confident about the care
> and support they give. They should have adequate opportunities to develop their
> knowledge, understanding, self awareness and skills."

Public Accountability

Bearing in mind that end of life is a public health matter, affecting everybody without exception, openness about how end of life care is delivered is a matter of public interest. While the responsibility for certain decisions may be reserved to particular service providers, the basis on which decisions are made must be publicly available. One contributor recommended:

> "There should be a State requirement that ALL hospitals should be monitoring
> through regular self review (based on structured governance procedures), audit
> and even external peer review all processes involved in its End of Life Care and full
> transparent reporting of its results should be made available in the public arena."

Conclusion

The following rules of end of life care management in healthcare institutions have been condensed from contributions to the Forum:

- Establish whether deaths take place in the facility or not

- Identify how people die in the facility

- Determine not to be taken by surprise when deaths do occur in the future. Do this by:

  - establishing that the provision of end of life care is a core function of the facility

  - establishing that it has equal status with other functions

  - refocusing services where required

  - planning, being prepared, identifying risks

  - supporting and enabling staff

  - leading from the front, being open, broadcasting the ethos of the facility .

Chapter 29
ORGANISATION OF END OF LIFE CARE

Perspectives of Practitioners on Models of Care

At a workshop, Dr Brian Maurer of the Irish Heart Foundation said that from the perspective of a cardiologist "treating patients with inevitably advancing cardiac failure, but with the time taken to progress from diagnosis to death varying from days to years," the following issues need to be addressed:

- Patient and family expectation, false hope, belief in medical science
- Difficulty in accepting treatment as essentially palliative rather than curative
- Care systems orientated towards providers, professionals and systems (processes), rather than towards patients
- Patronizing systems of care leading to loss of dignity and autonomy
- Coercing, perhaps unintentionally, patients to adapt to particular solutions
- The orientation of the modern scientific medicine towards diagnosis and cure
- Loss of interest due to defeat when "nothing further can be done". The death of the physician at the hands of the medical scientist
- The buck does not stop anywhere
- Getting the balance right between team care, individual responsibility and personal relationship between the provider and patient
- De-medicalizing the process of dying
- The tragedy of death in hospital
- Inappropriate therapeutic enthusiasm.

At a public meeting, a hospital doctor described the "medical model" that was in existence when he was training 45 years ago. He outlined how in the case of cancers, when treatment was not successful, the doctor believed that he or she had no further role in the care of a patient. During hospital ward rounds certain patients would be passed by on the basis that nothing more could be done. A short note was written on the chart for pain relief and it was left to the nurses to provide further care which they did with courage and humanity.

Looking at today's practice, he said the Hospice Movement had moved away from the "medical

model" of care and now sought to provide a service which addressed the needs of the whole person. At the same time the hospital medical model evolved to a team based approach to the care and management of a sick patient. This involved the coming together of surgeons, physicians, anaesthetists, pathologists, radiologists, oncologists and palliative care specialists linking up with GPs and the Hospice Home Care Teams.

Painting a vision of how things might be in the future, he welcomed the Hospice Friendly Hospital programme, which aims to provide those who die in hospitals or in nursing homes the same benefits they might expect if cared for at home.

These experienced practitioners give us a glimpse of how end of life care in hospitals has been evolving and of the issues that need to be addressed to overcome the failings of current end of life care models. Many people have been grappling with these issues and have been articulating alternative approaches to end of life care, and organisational frameworks to facilitate their implementation. The All Ireland Gerontological Nurses Association, for example, advocates:

- The development of person centred models of care to ensure that the unique values, individual perspectives and choices of the dying person guide care delivery.
- Further development and testing of care pathways and models to improve integrated end of life care.
- More research and development of disease specific frameworks for people with non-malignant disease such as dementia, motor neurone disease and heart failure.

Contributors frequently spoke about how end of life care might be better organised. They made observations and recommendations about:

- co-ordination of end of life care across organisational boundaries
- interdisciplinary collaboration
- integrated team working
- care pathways and frameworks
- integrating palliative care into disease management frameworks
- exploring new end of life care models.

Co-ordinated Care Across Organisational Boundaries

The following is a contributor's account of bringing a person home from hospital at end of life. It illustrates the precarious situations people find themselves in when end of life home care back-up services are not properly co-ordinated:

> *"We made the decision to bring (name of person) home where she would be cared for by myself and my father. We were told by a hospital social worker that all of the support for (name of person) to be at home, eg hospice visits, home care assistant. District nurses, etc had been put in place and that this had been fully co-ordinated in order for these to begin within hours of her returning home. Shortly after (name of person) arrived home on a Friday morning I received a phone call telling me that everything was in place for home care to begin on Monday. I was shocked and deeply concerned by this as there is no way in which I would have agreed to (name of person) being at home for three days before any support began ..."*

Mental Health Ireland said that there is a need for more integrated hospital, community and continuing care services "as too often services in the present system operate in isolation and this can lead to very unsatisfactory outcomes for the carers and the person needing care".

The Respiratory Nurses Association said that the need to address the primary/secondary interface in palliative care for COPD is documented in the recent IHF report on extending palliative care for all.

In its presentation to a workshop, the Irish Pharmacy Union said:

> *"Patients expect services to be of high quality and to be well co-ordinated. They wish to be enabled to die in the place of their own choice, often their own home. Adequate notification of discharge is essential to ensure that a seamless transition occurs and that continuity of care is maintained."*

In a presentation to a Forum workshop, The Directors of Nursing, Specialist Palliative Care Network Group said:

> *"A service follows the patient regardless of the place of care, while ensuring integration with the primary carers in each setting, i.e. acute hospital, residential unit and community. Reflecting on the developments within palliative care services, the DoN's are aware of an emerging fragmentation, which could ultimately compromise standards of care being delivered to patients and families."*

Fragmentation of end of life care services needs to be researched, investigated and discussed by the key providers with a view to identifying solutions for problems identified, and to establishing best practice in different senarios. For example, organisation of services, such as palliative care, on the basis of client group will always be problematic, both in terms of access to services and to their co-ordination once access is achieved.

Interdisciplinary Collaboration

Important suggestions about interdisciplinary collaboration were made by contributors to the Forum. Experts and specialists in different fields emphasised the dangers and limitations of a single-discipline approach to the delivery of person-centred end of life care. The following are representative of suggestions made:

> *"Emerging service models for people with scleroderma must take account of the palliative care approach required. Collaboration between rheumatologists, respiratory specialists, gastroenterologists, nephrologists and palliative care specialists will assist in the development of treatment protocols required to ensure that interventions focus on holistic and co-ordinated approaches that consider palliative needs throughout the disease trajectory, with a focus on quality of life and support for families." (From the Irish Raynaud's and Scleroderma Society)*

> *"Shared care at end of life involving respiratory and palliative care teams needs to be actively supported."*

> *"There should be a named specialist respiratory nurse available to advise any community-based nurse with a patient (COPD) at end of life. Specialist palliative support should become available on an as needed basis." (HRB Clinical Nursing and & Midwifery Research Fellow)*

> *"End of life care needs to incorporate palliation as a during-life component of elderly healthcare, starting at a low base, and rising to eventually become the predominant theme.[130] Because of the unpredictable and long-term trajectories of non-malignant diseases, geriatricians are faced with the difficult task of negotiating the juncture between being gravely ill and dying.[131] For such diseases it is often appropriate that non-specialist or specialist palliative care should be*

---

130   Lynn J, Adamson DM. Living well at the end of life: adapting healthcare to serious chronic illness in old age. Arlington, VA, Rand Health, 2003

131   Finucane TE. How gravely ill becomes dying: a key to end of life care.JAMA. 1999 Nov 3;282(17):1670.

provided alongside disease modifying and life-prolonging interventions ...[132]

Dialogue and collaborative work should continue between palliative care, geriatric medicine, old age psychiatry and general practice as to optimal models of palliative care for older people;...Palliative care should also be integrated into all chronic and life-limiting disease management programmes." (Irish Medical Organisation)

"I suggest ... expansion of the role of Geriatricians in particular in the area of community liaison with GPs so that end of life status can be accurately recognised early and appropriate care planning done to avoid the misery of abrupt acute hospitalizations and inappropriate investigation where these will be of no real benefit to the end of life person or her/his family. Community Geriatricians would fit very well into the new Primary Care Centres now under construction/ development up and down the country." (Consultant Geriatrician & Senior Lecturer in Medicine)

"Developments at the international level point to the need for a more co-operative relationship between the disciplines of paediatrics and special education in order to optimise the educational experience for students with specialized medical and educational needs[133]

One of the most significant challenges to face health and education policy-makers and personnel who seek to meet the physical, intellectual, psychosocial, emotional and spiritual needs of these children (with life-limiting conditions), therefore, is how to fully embrace the conceptual, relational and action driven work necessary to develop a 'partnership' approach to community based, paediatric palliative care and inclusive education provision - and ensure collaborative effort ... Outcomes which have resulted in overlooking the health and education needs of children with LLC reflect social, economic and political actions and decision making processes which contribute to 'exclusionary' practice and often create new forms of segregation ...

As the provision of palliative care support (of children with LLCs) implies the involvement of a variety of professionals who come from diverse professional and institutional backgrounds[134] we also need to identify key factors which are

---

132 HSE and IHF, Palliative Care for All - Integrating palliative care into disease management frameworks, 2008 p15

133 Sexson, S.B., and Madan-Swain, A. (2001): School reentry for the child with chronic illness. Journal of Learning Disabilities. Vol 26 (2) Feb 1993, pp 115-125.

134 Ebersold, S., (2003): Inclusion and cooperation in mainstream education. European Journal of Special Needs Education, Vol 18, No 1, pp 89-107.

consistent with the development of a 'collaborative culture' which foster cohesive practice among professionals, including:

- *Identifying the rationale for the development of a 'partnership' model for the provision of palliative care support to students with LLC;*

- *Identifying the impact of partnership ... on child and family outcomes*

- *Identifying specific roles and responsibilities of professionals having regard to the differing professional contexts in which individuals work;*

- *Identifying the need for agreed protocols between professionals in the health and education sectors in relation to support provision to students with LLC and their families;*

- *Identifying the means of facilitating timely and appropriate responses and effective provision of services and supports to students with LLC;*

- *Identifying the ways in which findings and recommendations to policyholders and stakeholders in the fields of education, health and disability can be effectively produced and disseminated*

- *Identifying the means of developing the existing education and palliative care knowledge base to improve the position of children with LLC and their families." (Special Education Teacher).*

"Collaborative working remains the key to effective end of life care, between intellectual disability services and palliative care teams ..." (Clinical Nurse Manager)

"An End Stage Renal Disease (ESRD) working group, a sub-group of the Robert Wood Johnson Foundation (RWJF programme, 'Promoting Excellence in end of life care' concluded that there was an urgent need to recognise that palliative care and EOLC is an integral component of comprehensive care, not an adjunct." [135]

"There must be effective communication and collaboration between professional groups and clinical specialities to eliminate failure in providing a service to patients where they choose how and where they wish to die." (Irish Nephrology Nurses Association).

---

135 Swartz, R.D., and Perry, E. (2003) Advance directives are associated with 'good deaths' in chronic dialysis patients. Journal of the American Society of Nephrology, 3 pp 1623 - 1630

"Some neurologists are not linking into palliative care from the time of diagnosis (the pre-terminal phase). Sometimes they wait until the terminal phase." (Motor Neurone Disease Nurse Specialists).

Integrated Team Working

Contributors emphasised the multifaceted nature of end of life care provision and of the consequent need for a comprehensive team approach to its delivery. At a workshop, a social worker with the Cystic Fibrosis Association of Ireland said that given the need there is for multidisciplinary involvement at end of life, regular team meetings are necessary to allow all staff the time and space to discuss the psychosocial issues as they arise, as well as the medical treatment of physical deterioration.

Drawing on his experience as a chaplain in Canadian oncology hospital a Clinical Pastoral Education Supervisor said that chaplains need to be integrated into the palliative care team at all levels ... contributing to patient care by fuller charting and direct involvement at rounds and team meetings.

The integration of chaplains into palliative care teams was also raised at workshops and public meetings. Every hospital and hospice needs to have trained and accredited chaplains and the chaplaincy team needs to be integrated into the multidisciplinary team, given the importance of holistic care at end of life. Chaplains need to be seen as professionals alongside other disciplines. Communication and co-operation with members of other disciplines is essential.

The Irish Society of Chartered Physiotherapists special interest group in oncology and palliative care emphasised in their submission that a team approach is essential in end of life care:

> *"As Physiotherapists we have our part to play within the multidisciplinary team both in Specialist Palliative Care settings and also within General Palliative Care.... Development of care plans, care pathways and better co-ordination of care and communication are of utmost importance if teamwork is to be a success."*

The parent of two deceased children said that

> *"parents of terminally ill children need to be involved in their care. They need to be an integral part of (the) team when it comes to decisions."*

Care Pathways and Frameworks

A number of other contributors advocated the development or introduction of care pathways to improve care provision at end of life:

> *"We don't have a care pathway in the acute sector in Ireland unlike in the UK or Australia. The Liverpool Care Pathway keeps everyone in the loop."*

The Neurological Alliance of Ireland said in its submission that a number of initiatives developed in the UK in relation to palliative care for cancer have been incorporated in the design of specialist palliative care programmes for people with neurological conditions and their families in the later stages of their illness. These models include:

- The Gold Standards Framework[136],
- The Liverpool Care Pathway for the Dying Patient[137],
- The Preferred Place of Care[138].

The Irish Nephrology Nurses Association recommended the development of an integrated individualized patient care pathway "utilizing tools such as the Liverpool Care Pathway, the Gold Standards Framework and Preferred Place of Dying."

---

136   "GSF is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every patient. It helps clinicians identify patients in the last years of life, assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of patients and their families and encourages inter-professional teams to work together. GSF can help co-ordinate better care provided by generalists across different settings. The 5 goals of the GSF are to provide for patients with any final illness:

  1.   Consistent high quality care
  2.   More home based, less hospital based care
  3.   Alignment with patients' preferences
  4.   Pre-planning and anticipation of needs
  5.   Improved staff confidence and teamwork"

- taken from website www.goldstandardsframework.nhs.uk

137 "The Liverpool Care Pathway for the dying patient (LCP) was developed to transfer the hospice model of care into other care settings. It is a multiprofessional document that provides an evidence-based framework for the dying phase. It provides guidance on the different aspects of care required including comfort measures, anticipatory prescribing of medication, and discontinuation of inappropriate interventions. Additionally, psychological and spiritual care and family support is included." Quotation taken from abstract of Jack BA, Gambles M, Murphy D, Ellershaw JE. (2003) Nurses' perceptions of the Liverpool Care Pathway for the dying patient in the acute hospital setting.   Int J Palliat Nurs.2003 Sept; 9 (9):375-81.

138 "The Preferred Priorities for Care (PPC) is a document that individuals hold themselves and take with them if they receive care in different places. It has space for the individual's thoughts about their care and the choices they would like to make, including saying where, if possible, they would want to be when they die. Preferred Priorities for Care (PPC, formerly known as Preferred Place of Care) is an Advance Care Plan (ACP), in which individuals can write down their preferences and priorities for care at the end of life in order to help prepare for the future. This document is intended to encourage and assist people to think and talk about their priorities." Taken from www.endoflifecare.nhs.uk/eolc/CS310.htm

The All Ireland Gerontological Nurses Association said that "care standards such as the Liverpool Care Pathway, Gold Standards Framework and the Preferred Priorities for Care Initiative have been shown to improve symptom management in palliative care. However, their application and validity in care of older adult settings requires further research."

Integrating Palliative Care into Disease Management Frameworks

Contributors referred frequently to the publication, Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks, published by the Health Service Executive and the Irish Hospice Foundation in 2008. This recommended, inter alia, that

> "All health staff who care for patients with life-limiting non-malignant diseases, including those in SPC (Specialist Palliative Care), disease specific specialities and primary care, should work in a collaborative manner so that patients' palliative care needs are met in appropriate settings." [p.53]

This was echoed by contributors speaking for people with various diseases other than cancer:

> "It is very appropriate now that the Irish Hospice Foundation build on the previous work of 'Palliative Care for All' and in essence working to address the full cycle of life and generate a discussion on End of Life (EOL) issues that will hopefully create a service model and an all-encompassing framework for the holistic treatment of persons with End Stage Renal Disease [ESRD]."

> "Palliative Care for individuals with life-limiting diseases ... may be needed alongside disease modifying interventions, eg neurology and specialist pain management".

> "Emerging service models for people with scleroderma must take account of the palliative approach required."

> "The Alzheimer Society of Ireland believes that there is a need to implement palliative care interventions for people in the very advanced stages of dementia. This is currently happening with the IHF taking the lead on a small scale exploratory study in conjunction with the Alzheimer Society. The Alzheimer Society of Ireland believes that such an approach should allow care practices to be developed. These initiatives will take into account the reality of living through the

end stages of dementia, both for the person and their family and serve further to inform policy and practice in the area."

"Equally important, is that palliative care services should be available and developed not only in institutional settings but also in community based settings."

"There is a need to ensure that that end of life palliative care is incorporated in all disease specific care pathways."

On the delivery side, specialists illustrated the rationale for the new concept of palliative care in graphics, such as the following:

A. Traditional Model

Active Treatment

Palliative/ Terminal Care

↑ Diagnosis

↑ Death

B. Current View

Active treatments

Palliative Care

Grief

↑ Diagnosis

↑ Death
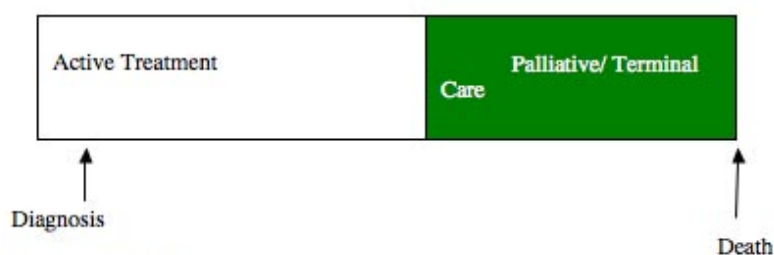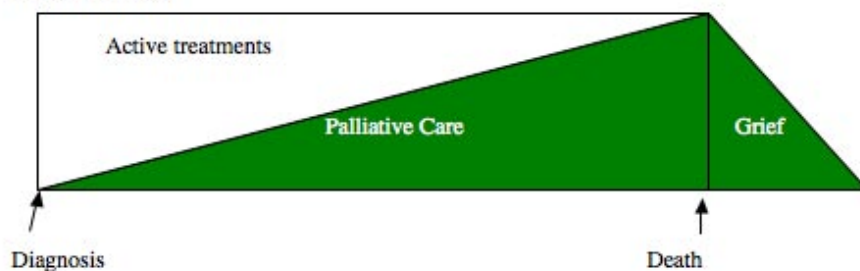
Finlay I (2001). UK strategies for palliative care. Journal of the Royal Society of Medicine 94:437-441.

A in the diagram above represents traditional palliative care services. B in the diagram represents proposed palliative care services.

Exploring New Models of End of Life Care Provision for Older People

Age and Opportunity emphasised the importance of testing "new models and approaches that bring about a greater fusion between end of life care and gerontological care within all long-stay settings in Ireland".

Reference was also made to the model of end of life care for older people proposed in the report, End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland. This model envisages four levels of end of life care for older people: fundamental, enhanced, advanced and complex.

> *"While to some extent this model reflects familiar notions of nursing 'dependency', it is more complex than this. This is because levels of care need to be assessed holistically in relation to four domains - physical, psychological, social and spiritual- as well as in relation to the extent of distress reported by the older person and/or family, or observed by others. This model of service need is based on complexity of need rather than a diagnostic category such as cancer or heart failure. It is also not dependent on prognostication of 'dying' that is known to be unreliable and difficult for professionals, and widely resisted by patients themselves. It is a model based upon the recognition of need - defined as 'distress' (aspects of patient's experience that they or their families report as distressing for whatever reason)."* [139]

Exploring New Models - The Compassionate Community Model

As already mentioned, a number of contributors, notably Professor Allan Kellehear, emphasised the importance of a public health focus on death, dying, loss, disposal and care. One of the reasons for this is that reliance on more health professionals and services as the only means to improve quality of life at end of life limits reform. In any event, the one approach, - more and better services, professionals and institutions - without the other - community involvement - will be much less effective.

> *"Without a community that is aware of how it can provide practical help with a life lived with a terminal illness or with lifelong grief, there is little alternative*

---

139   O'Shea et al (2008). End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland pp 173-4. Dublin: National Council on Ageing and Older People and Hospice Friendly Hospitals programme (IHF)

to institutional or direct service responses. Without a community that is educated to understand not simply basic nutrition, or the uses of sun block creams, but also the social dangers and hazards of ageing, cancer or bereavement, there are few alternatives to professional or institutional care. Is this all we want for our end of life care?"

One contributor recommended:

"A Compassionate Community model that is based on the WHO Healthy Cities Model[140] but emphasising the public health focus on death, dying, loss, disposal and care. Such work would help change attitudes and behavior towards death, dying and bereavement and promote the 'normalising' of death as an important part of the life cycle."

The defining characteristics of a Compassionate Community are identified as follows:

- Has local health policies that recognise compassion as an ethical imperative
- Meets the special needs of its aged, those living with life-threatening illness and those living with loss
- Has a strong commitment to social and cultural difference
- Involves the grief and palliative care services in local government policy and planning
- Offers its inhabitants access to a wide variety of supportive experience, interactions and communication
- Promotes and celebrates reconciliation with indigenous peoples and the memory of other important community losses
- Provides easy access to grief and palliative care services
- Has a recognition of and plans to accommodate those disadvantaged by the economy, including rural and remote populations, indigenous people and the homeless
- Preserves and promotes a community's spiritual traditions and storytellers.

---

140   Kellehear, A. (2005). Compassionate Cities. Oxfordshire: Routledge

Kellehear is challenging when he says that

> "Someone surely MUST have a national policy looking at death education in the context of creating communities that care for the dying, the bereaved and those who care for both. But if you believe that you would be wrong."

However, he is not despairing. He says that there can be another string to our bow, another way to develop the best end of life care. "The choice is not simply between institutionalisation, suicide, or hoping for the best (dying in your sleep in the peak of rude but ageing health)." With leadership and a public health approach we can begin to incorporate end of life in the overall effort to develop compassionate communities willing to get involved in promoting a good death for their members".

Framework for Developing Bereavement Care, Training and Services

The Bereavement section of the Irish Hospice Foundation says:

> "It is increasingly accepted that bereavement care should be organised according to a continuum which respects and supports natural coping (NICE 2004, Centre for Advancement of Health 2004[141], Schut and Stroebe 2005[142]). The service continuum is often described according to three levels ranging from pre-death care, information and natural support (level one), to volunteer bereavement support services (level two), through to professional and specialist bereavement services (level three).

> Effective provision of these levels of support involves investment in accurate and accessible information about grief which should be readily accessible to people and those who care for them and work with them. It also includes nurturing notions of the 'good death' and making sure that people receive the care they need and want towards the end of their life."

---

141   National Institute for Clinical Excellence (2004) Supportive and palliative care for cancer with adults [Online] Available from: http://www.nice.org.uk/page.aspx?o=csgsp (Accessed January 17th 2007)

142   Schut H and Stroebe M (2005) interventions to enhance adaptation to bereavement Journal of Palliative Medicine 8 (supplement 1) S140-S147

The Irish Hospice Foundation endorses the 'Pyramid of Bereavement Care' model as an evidence-based and non-pathological approach to grief support at a national level. This is reproduced below, sourced from the Petrus review of bereavement services[143].

Service Delivery Model
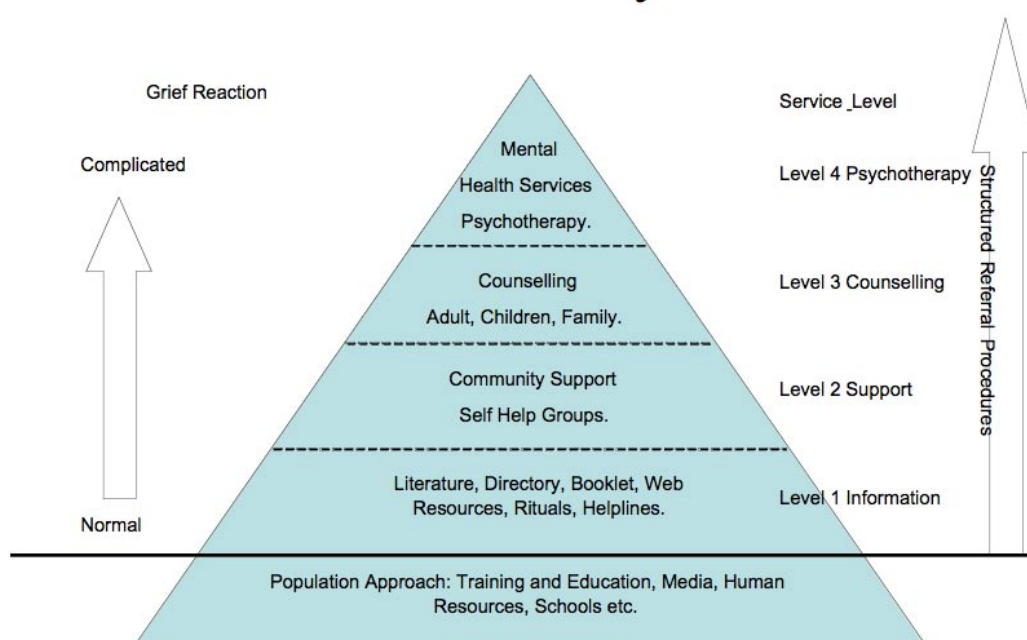
Conclusion

Contributions to the Forum therefore indicate that in order to be effective and fit for the purpose of meeting people's needs and aspirations, end of life care requires:

- co-ordination across organisational and sectoral boundaries

- interdisciplinary collaboration,

- integrated team working

- the development of care pathways and frameworks

---

143 Petrus Consulting, Bates, U., Jordan, N., Malone, K., Monahan, E., O'Connor, S., & Tiernan, E. (2008). Review of General Bereavement Support and Specific Services Available Following Suicide Bereavement. Dublin: National Office for Suicide Prevention

- implementation of the recommendations of Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (2008)

- exploration of new end of life care models.

These requirements are in keeping with the direction set by the OECD report on an integrated Public Service in Ireland, which says in its introduction:

> "In a changing, more complex, diverse, outward looking, dynamic and educated society, greater focus needs to be placed by the Irish Public Service on citizens and their expectations, and on targeting delivery of services from their perspective so as to achieve broader societal goals. In essence, the Irish Public Service now needs to become more outward focused by better integrating and utilising the systems and processes it has developed, so that it is best placed to more effectively contribute, alongside the broader society (citizens, business, unions and other actors), to the identification and attainment of overall societal goals."[44]

---

144   OECD, (2008). Ireland - Towards an Integrated Public Service. Paris: OECD

Responses to the Needs and Rights of People at End of Life - Policy and Action

8

Chapter 30
NATIONAL POLICY ON PALLIATIVE AND END OF LIFE CARE

Introduction

Contributors spoke frequently about policies governing end of life in Ireland. They referred to national government policies and sectoral, or agency based policies. While the main focus was on health policy, and hospice and palliative care policy in particular, other policy domains were also raised. In his keynote address at the inaugural meeting of the Forum, Dr Maurice Manning said:

> *"Public policy in Ireland, which seeks to plan for and address social needs based on a 'life events' approach, does not, at the moment, adequately address the wider experience of end of life. It focuses on birth and childcare, education and training, employment, marriage, illness and/or disability, retirement and older age. Bereavement sometimes gets a look in, but dying and death are usually missing from the frame. Perhaps in our desire to emphasise the positive aspects of older age we may be in danger of forgetting that dying and death are the end point in the process of ageing. Perhaps we know that all too well and are simply trying to avoid the fate which for some older people precedes death – confined to a bed in an open ward in an old building eating our dinner on one side of a curtain while on the other side a person uses a commode."*

Speaking from the perspective of caring for children with life-limiting conditions another contributor said:

> *"The development of policies and practices appropriate to people in the dying state is an ongoing challenge. This requires full recognition of the dying state as a legitimate diagnosis. The palliative care approach, while seen as a most positive development, is still not an integral part of the hospital system."*

The purposes and functions of our heath system must be kept under continuous review to ensure that it addresses the continuum of health and social care needs of the population, rather than just the needs of those who can benefit from curative interventions. This must be underpinned by national healthcare policy which must ensure that end of life care enjoys parity of esteem and purpose with curative, rehabilitative and other care in settings where people die, including in acute hospitals, and that funding is adequate to meet the needs of people at end of life.

Policies Relating to Palliative Care

In a presentation to the Forum, the Chairperson of the of the Irish Association of Palliative Care (IAPC) set out the main developments in policy on palliative care in this country in the decade, as follows:

In 1999, a National Advisory Committee on Palliative Care was established to prepare a report on palliative care in Ireland. Its report was published in 2001 and adopted as official policy for the development of palliative care services in the country. However, though endorsed by the National Health Strategy, *Quality and Fairness*, in the same year, its recommendations have not yet been fully implemented and significant inequalities in palliative care provision exist throughout the country. On the other hand, in a European evaluation of palliative care in 27 member states, Ireland came second after the UK.

A Palliative Care Needs Assessment for Children (DoHC/IHF 2005):

- Found inequities in the provision of palliative care services for children with life-limiting conditions
- Called for more comprehensive data on children with life-limiting conditions, more support for parents caring for children at home and more paediatric trained staff to help parents provide home based care
- Identified the need to develop SPC paediatric posts to spearhead the development of services and education.

Baseline Study of the provision of hospice/specialist palliative care services in Ireland (IHF 2006):

- Examined the recommenations of the National Advisory Committee and what had been achieved
- Completed a series of national needs assessments
- Highlighted the gaps in services provision and explored the implementation challenges.
- The study recommended an "accelerated palliative care implementation programme" in areas where services were least developed as well as multi-annual funding to meet the core running costs of all specialist palliative care services.

A Strategy for Cancer Control in Ireland, (National Cancer Forum 2006):

- Recommended the development of four managed cancer control networks with two cancer centres and a comprehensive specialist palliative care service in each.

Towards 2016 (Department of the Taoiseach, 2006):

- Indicated that a total resource fund of €150m should be allocated to Services for Older People and Palliative Care under the Partnership Agreement.

2007 Programme for Government (Dept of the Taoiseach): Made commitments:

- to meet the needs of all people who require palliative care at home, in the community or in a specialised hospice

- to remove regional disparaties in the provision and funding of palliative care in the next five years

- to work with organisations such as the IAPC.

In 2008, the Health Service Executive and the Irish Hospice Foundation published the report of the 'Extending Access' study, PALLIATIVE CARE FOR ALL Integrating Palliative Care into Disease Management Frameworks. The overarching policy recommendations of this report were:

1. Current government health policy that refers to people with life-limiting non-malignant diseases does not make reference to the need for palliative care. All policy documents that refer to life-limiting diseases are to include plans for access to appropriate non-specialist and specialist palliative care.

2. Although the HSE currently funds the majority of SPC services in Ireland, and Government policy states that SPC services should be available to all patients, a small number of SPC services restrict their services to people with malignant disease, MND, HIV and AIDS

   a) The recommendations of the 2001 report of the NACPC are (to be) fully implemented.

   b) Governance and monitoring systems to be introduced to ensure that SPC is provided on the basis of need rather than diagnosis to all patients with life-limiting illness.

3. As palliative care seeks to focus on quality of life and adopts a holistic approach to patient care which encompasses both the person diagnosed with a life-limiting disease and those that matter to them, it can be helpful to embrace these principles in a variety of end of life programmes within a population health approach.

The introduction of an end of life strategy[145] to support and guide all health service staff who work with people who are near end of life, in order that all people can maximise quality of life and die with dignity and comfort.

In July 2009 the Health Service Executive published, *Palliative Care Services - F ive Year/Medium Term Development Framework.* Based on a 2007 audit, the resultant overview of palliative care provision nationally indicated significant variations in the levels of specialist palliative care service provision across each service category, as follows:

SPECIALIST PALLIATIVE CARE IN-PATIENT UNITS

- There are eight dedicated specialist palliative care in-patient units across the four HSE Areas.

- There is a wide regional and intraregional variation in the availability of specialist palliative care in a specialist in-patient unit.

- Three geographic areas have no specialist in-patient units and no access to specialist in-patient beds for those patients most in need.

- Some specialist in-patient units have varying levels of the multidisciplinary team providing the specialist palliative care service.

- Waiting lists currently exist for admission to some specialist palliative care in-patient units.

SPECIALIST PALLIATIVE DAY CARE CENTRES

- There are six specialist palliative day care services nationally across the four HSE Areas.

- The total number of patients accessing these services in 2006 was approximately 2,600.

---

145   End of life strategies have been developed in other countries as a mechanism to deliver increased choice to all patients, regardless of their disease, about where they live and die. Such strategies seek to provide patients with the support to make this possible, and enhance co-ordination between all relevant service providers in this area.

- Currently, the majority of specialist palliative day care centres operate Monday to Friday, 9am – 5pm.

- There is a wide intraregional variation in the availability of specialist palliative day care services.

- Three geographic areas have no specialist palliative day care centres. These are the same areas with no Specialist Palliative Care In-Patient Units.

SPECIALIST PALLIATIVE CARE IN THE COMMUNITY

- Almost all LHO Areas had access to Specialist Palliative Care / Home Care Teams in the community.

- Many of these services are a consultant-led multidisciplinary service. However, in some areas there continues to be a number of nurse-led services.

Implementation of Policy

Contributors referred to, or spoke about, many other policies relevant to end of life care in Ireland. Most have already been mentioned in the course of this report, including policies and strategies governing primary care, disability, mental health, mental capacity, residential care, home care, carers, quality standards, equality and organisational reform, to name but some.

Often the main concern was simply the implementation of current policy, particularly the 2001 report of the National Advisory Committee on Palliative Care and the report, *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks* (2008)

Resources for End of Life Care

The key to policy implementation for many was the adequacy of the funding made available for end of life care services. The following are some of the views expressed on the matter:

> "*The further development of specialist palliative care requires an ongoing investment in capital projects i.e. in-patient specialist palliative care units and in personnel to meet the increasing needs of an ageing population. The predicted increase in demand over the next twenty years requires investment now to prevent existing services becoming overwhelmed and unable to maintain the high standards of quality care deserved by patients and families during this time.*"

"The difficulty in making hospice service available to all those who need it is, I think, probably partly due to lack of funding; however it can also happen that the will to provide such services is not always present from certain quarters."

"It is obvious from the under-funding of both hospice/palliative and geriatric care and lack of support for home carers that public policy is inadequate. If we are choosing to fund other areas before the needs of the elderly, who worked to make our country what it is today, the needs of our disabled children and the needs of our friends and relatives with terminal conditions, it is a measure for how little policy makers respect and value these people and the people who care for them, love them and will be affected by their illness."

"The IMO is concerned that current initiatives to improve palliative care in acute hospital and long-stay care facilities are under-resourced."

A doctor spoke of under-resourcing in the community as a serious issue: the home must be recognised officially as a 'place of care' for the dying and there must be teamwork (doctors, other professionals, patient and family) in its provision. A consultant geriatrician asked, "what needs to be done to correct the increasing problem of lack of appropriate care for end of life people in Ireland? I suggest the following: Focus resources on Community Hospitals, i.e. provision of designated end of life/palliative beds closer to home."

Other contributors spoke of healthcare budget cuts, ward closures, chaplaincy posts being lost and a claim that 50% of the funds allocated to the development of palliative care in 2006 and 2007 were diverted. One person wrote in a submission:

"*Action is ... required from a large number of stakeholders, including government departments, voluntary groups, general public, educational institutions, frontline staff and clinical personnel to ensure appropriate end of life care for those whose need is not affected by the current health service cuts."*

Provision and Access to Services - the Policy Dimension

While we have already reported views and observations on provision and access to palliative care and end of life services, we return briefly to the subject here given the importance attached to it by contributors when speaking about end of life care policy. For instance, the Irish Association of Palliative Care says that one of its primary objectives is provision and access to palliative care services "through the shaping of policy in the island of Ireland".

Alluding to the disparity in hospice and palliative care services across the country, the Hospice CEOs group said:

> "There isn't ease of access to these services, even for those with cancer. We therefore need a system to determine eligibility for critical end of life care services. These services must be multidisciplinary to meet the particular needs of each person as they arise."

In response to the lack of a statutory framework underpinning access to health and personal social services within a stated time frame, the National Health Strategy, Quality and Fairness (2001)[146], promised to clearly define eligibility to such services in legislation. In light of the fact that people continue to die without adequate end of life support services, the need to introduce the promised legislation, which would provide a clear entitlement to palliative care services for all, was emphasised as urgent.

As it is, the evidence indicates that where there is a shortfall in hospice and specialist palliative care services or where they are underdeveloped, more people die in acute general hospitals. Where services are more developed, there appears to be an increased incidence of death occurring in a hospice/palliative care in-patient unit or home setting. [147]

A Comprehensive Palliative Care for All Policy

Representatives of people with particular conditions emphasised the importance of developing policy frameworks to ensure the availability of an appropriate range of palliative care services to them when needed.

Reference was made, for example, to quality requirement 9 of the UK National Service Framework for Long Term (Neurological) Conditions which states that people with those

---

146 Department of Health and Children, Quality and Fairness. A health system for you. (2001), pp 74 - 75. Dublin: The Stationery Office

147   Irish Hospice Foundation, A Baseline Study on the provision of Hospice/Specialist Palliative Care Services in Ireland. 2006: Dublin.

conditions receive a "comprehensive range of palliative care services when they need them …
and that these services should meet their needs for personal, social psychological and spiritual
support, in line with the principles of palliative care".

Reference was also made to the National Service Framework for Renal Services – Part Two -
End of Life Module (2005), which contains a number of key quality requirements for end of life
care (EOLC) to support people with renal failure to live out their lives as fully as possible and to
die with dignity. This document, includes "a specific section on EOLC and refers to the need to
combine palliative care and renal skills in the development and provision of services to those
with terminal renal failure."

While supporting the recommendations of *Palliative Care for All: Integrating Palliative Care into
Disease Management Frameworks*, the Alzheimer Society of Ireland said:

> "The end of life issues for people with dementia have, to date, largely been ignored
> in the policy arena. The absence of a policy and services in this area is noteworthy,
> leaving people with dementia, their families and carers in a difficult position with
> very little or no choice about the type of care at the end of the person's life."

These sentiments broadly echoed those of representatives of people with other conditions
facing the end of life. Policy must ensure that end of life/palliative care is incorporated all
disease specific care pathways.

Development of an End of Life Strategy

In the course of the Forum, contributors understandably placed a great deal of emphasis on
palliative care policy and its implementation. However, there was also an awareness of the
need to understand end of life as a public health matter relevant to everyone in all walks of
life and in all settings. There was strong recognition that this should be translated into public
policy development in a diverse range of areas relevant to the welfare of people at end of life
and to their survivors. Areas of public policy needing development which were mentioned,
included: housing (lifetime adaptable, for example); legal (mental capacity legislation);
employment (support provisions for bereaved persons), to name but a few.

However, the *sine qua non* for sustainable progress in addressing the needs of people at end of
life is widespread personal commitment to reform, and public engagement in the processes of
reform.

Chapter 30   NATIONAL POLICY ON PALLIATIVE & END OF LIFE CARE

In his address to a public meeting of the Forum, Professor Allan Kellehear painted a bleak picture of possible consequences of failure to acknowledge the public health dimension of end of life and a failure to develop a public health policy to match, when he said.

> *"Unless, there is a major change of political attitude toward end of life care policy in industrial societies – just like this one, and globally, - among our social critics, commentators, supporters of hospice, academics, policymakers, and politicians - we will see a return to the widespread social neglect of the dying we first witnessed in our hospitals after world war two ... In the patterns of social justice that we repeat the world over, we will more or less serve the ill but neglect the dying because the dying, by definition, have no voice to speak for them when they are gone."*

Even if this may sound theatrical to some ears, particularly in the light of advances made in recent years in this country, there is no guarantee that progress will be sustained in what seems to some a socially rudderless society.

In his Keynote Address at the Inaugural Meeting of the Forum, Dr Manning said:

> *"In an increasing number of developed countries the end of life is ... seen as part of the public health agenda and governments are formulating end of life strategies. These have at their core a need for greater engagement with society on issues related to dying, death and bereavement. This is a great opportunity for Ireland to provide leadership because, regardless of the gravity of our economic situation, we cannot abandon the development of policy and strategy. If anything, we should be engaging more with people precisely because there are less resources available and because 'necessity is the mother of invention'."*

The National Health Service introduced an End of Life Care Strategy in England in July 2008.[148] The aims of the strategy are:

- "To bring about a step change in access to high quality care for all people approaching the end of life.

- This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status.

---

148 Department of Health, End of Life Care Strategy- promoting high quality care for all adults at the end of life (July 2008) London: DOH

- High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

- Implementation of this strategy should enhance choice, quality, equality and value for money."

These aims are very much in keeping with much of what the contributors to the Forum have been saying about universal access to high quality end of life care in whatever setting a person may end his/her life. Clearly, as recommended by *Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks*, (p. 52), an end of life strategy should be introduced in this country too. In the light of the Forum's deliberations, however, its aim should not be limited to 'supporting and guiding all healthcare staff who work with people at end of life'.

It should have a wider public health brief with a view to developing a national engagement with end of life and community based solidarity with with those at end of life. As indicated in the introduction to this report, the National Council on Ageing and Older People and the Irish Hospice Foundation recommended in a joint statement[149] that the advocacy base for the reform of end of life care in this country should be broadened to include all those agencies with a stake in promoting quality of life at end of life in Ireland. In view, however, of the potential for an even wider interest and participation by the general public in end of life care reform (as demonstrated by the extent of individual participation in the Forum), an Irish End of Life Strategy must have as one of its aims to take end of life care into public ownership by

- promoting public engagement in reducing premature deaths

- by identifying and promoting ways of increasing public, and particularly local community, interest and participation in end of life policy and services development.

What people have been saying through the Forum is that as a society we must plan and provide much better for end of life than we do at present, such that together, as a society, we accord as much importance to improving the quality of life of those at the end of their lives as we do to curing and to saving lives. To do this we must have a more sustained focus on end of life:

- by being more conscious and aware of our citizens who coming towards the end of their lives

- by identifying their physical, social, psychological and spiritual needs, and

---

149 End of life Care for Older People in Acute and Long-Stay Care Settings in Ireland. Joint Statement, Hospice Friendly Hospitals Programme and National Council on Ageing and Older People (2008)Dublin: NCAOP & IHF

- by estimating and providing the human and economic resources required to meet these needs and to ensure the best possible quality of life for them.

Without public and private reassurances of solidarity and evidence of the availability of physical, social, psychological and spiritual support, the fear of a painful and undignified death will increase, (particularly among older people and those suffering chronic illnesses), the risk of depression and suicidal tendencies will continue to grow and there will be an increased acceptance of assisted suicide and euthanasia.

Information for Policy-making and Service Planning

Good policy and strategic planning must be founded on reliable information. Frequently Forum participants alluded to the need for better information, and the need for research to provide it. One said, for example:

> *"Accurate information is required to ensure the provision of planned renal services in the future. Unless there is systematic information gathering on referral patterns on the decision process not to treat End Stage Renal Disease, it is impossible to ensure responsive and planned appropriate care."*

At a workshop it was agreed that for the purposes of planning and funding, there was a need to collect more information on the levels of dying children's needs and of their families.

At another workshop, the Development Manager of the Neurological Alliance of Ireland emphasised that there was insufficient neurological information for planning purposes or the development of pathways.

It was said too that an organisation was reluctant to advertise an important end of life service it provided for fear of not being able to meet demand. Clearly levels of unmet need for critical end of life services should be quantified. Such an audit should establish the services required, whether specialist or general, and where they should sit organisationally.

The fact that two-thirds of Irish people would wish to die at home (Weafer/TNS MRBI 2004) and that currently only 25% of people die at home presents significant challenges for Irish society. Research to establish how much the percentage of those dying at home would increase were community and home care, including palliative care, available on the basis of need, would seem an important priority. There also needs to be an economic analysis of the financial costs and the financial and human benefits of a comprehensive, integrated end of life care service nationally.

Contributors to the Forum identified a number of important deficits in data available for end of life policy development and service planning, including data on the following:

- the level of gerontological nursing expertise within long-term care

- quality of life for people with end stage neurological disease

- the benefits of conservative management of patients with terminal chronic kidney disease

- the bereavement experience of parents

- end of life care for people with dementia

- subjective experience of palliative patients, including palliative oncology

- the implementation status of the recommendations of key policy reports.

Chapter 31
TOWARDS AN ACTION PLAN

Introduction

While the Forum was a consultative process, and not a systematic or comprehensive examination of particular issues or themes, contributors expressed their personal and professional views, beliefs and understandings on a wide range of issues. Though there were many common concerns, sometimes considerable divergence of view was evident, confirming the complexity of the matters discussed. While many problems relating to the experience of end of life in this country were identified, contributors were not always directive about how those problems should be addressed. And, while some individuals were prescriptive, consensus about solutions proposed was more problematic, given divergent views expressed by other contributors. The Forum therefore raised as many questions as it answered.

The value of the report of the proceedings of the Forum then is as a point of reference for those developing an Action Plan on end of life in Ireland. It provides an illustrated guide to those navigating complex issues in changing times, rather than a black-and-white map of one-way streets. The following, however, are some of the prominent themes and issues raised in the Forum which might inform the Action Plan.

Death is Part of the Life Cycle

In this country we have adoped a life cycle approach in national policy and planning:

- in the Social Partnership Agreement, Towards 2016

- in the National Development Plan 2007 - 2013, Transforming Ireland - A Better Quality of Life for All, and

- in the National Action Plan for Social Inclusion, Building an Inclusive Society.

This approach, which accords with the direction set by the OECD report on an integrated public sevice for Ireland,[150]   should ensure:

- that no population group - children, younger and older adults of working age,

---

150 OECD, (2008). Ireland - Towards an Integrated Public Service. Paris: OECD

older people, or people with disabilities - is overlooked by society

- that an integrated approach obtains across policy areas

- that the citizen rather than the provider is at the heart of public services planning and provision.

Death is, of course, part of the life cycle - the last part in this world so far as the individual is concerned. However, death can occur at any age and therefore must be taken into account in policies governing all of the above mentioned groups. End of life, death and bereavement must be integrated in planning initiatives for all age groups and that planning must be informed, first and foremost, by the lived experiences of end of life: of infants and children; of their families; of younger and older adults, (whether of working age or otherwise); and of people with disabilities. It is hoped that the report of the Forum's proceedings, which expressly seeks to give equal voice to citizens as to service providers, will prove useful to those responsible for service planning and development in all fields and for all groups.

It is recommended that the Action Plan include provision to monitor the development and implementation of national social policy in Ireland to ensure that dying, death and bereavement are appropriately provided for. In this regard, for example, the Government is committed to the development of a Positive Ageing Strategy. Given that three-quarters of those who die in Ireland are over 65 years of age, it will be important that the strategy addresses the critical end of life issues which particularly apply to older people, as identified by the Forum and by others.

End of Life is Everybody's Business

End of life is everybody's business, not just the business of the caring professions. It is the business of lawyers, bankers, architects, town planners, teachers, public representatives, journalists, public and private sector employers and managers, just as it is the business of medical, social and pastoral care providers. This was clear from contributions to the Forum, which identified a wide range of financial, legal, environmental, administrative, cultural and educational measures which might be taken to improve the quality of life of those at end of life and of bereaved persons. Drawing on the baseline report of the Forum's proceedings, separate agendas for action might be drafted for the attention of particular groups of people working in different sectors, such as those mentioned above.

Chapter 31 TOWARDS AN ACTION PLAN

End of Life is a Public Health Matter

By their contributions to the Forum, people from all walks of life and people representing organisations with very different responsibilities also demonstrated that the responsibility for articulating and responding to end of life questions, including questions about end of life care, should not be left only to those who provide hospice and palliative care services. How end of life services are organised, and how people at end of life are provided for, are matters of public interest, for open discussion by society as a whole. An International Work Group (IWG) on death, dying and bereavement proposed a "charter for the normalisation of dying, death and loss"[151], with this in mind, rather than hiding them away or giving responsibility for them to a few.

We must see and treat dying, death and loss as public health matters; they must be anticipated, and any harm that they cause the individual must be minimised by building our capacity to show solidarity with the dying and the bereaved. This, the IWG says, requires "community development, education, participatory healthcare approaches, legislative and policy change." It identified the following as essential elements of a public health approach to end of life care:[152]

- recognition of the inevitability of death and the inevitability of loss
- cultural sensitivity and adaptability
- a culture/settings approach
- social justice, by promoting equal access for all
- a population health approach
- sustainability.

The Action Plan must adopt a similar public health approach and include provision for initiatives in the above areas identified by the IWG, which are very much in keeping with views expressed by contributors to the Forum.

Broaden the Advocacy Base for the Reform of End of Life Care in Ireland

It is important to maintain and develop the interest shown by Forum participants in working together to reform end of life care and welfare in Ireland. The following are some of the ways

---

151 International Work Group on Dying Death and Bereavement, Charter for the normalisation of death, dying and loss. Mortality, May 2005; 10(2) 157 -161, Routledge Taylor and Francis group

152   Ibid

in which this might be done:

- Explore and promote community development approaches to addressing end of life issues at the local level

- Welcome the offers of organisations such as the Citizens Information Board (CIB) and the Money Advice and Budgeting and Service (MABS) to work together to further develop public information on end of life matters

- Support the organisation of End of Life Fora for groups who may wish to explore further end of life issues as they affect their client group

- Resource and jointly organise workshops for organisations whose members or staff lack confidence to address the end of life issues of their members

- Make common cause with organisations which seek to prevent premature death; support the work of accident and suicide prevention groups, for example.

Develop Public Awareness about End of Life Issues and Change Attitudes to Death, Dying and Bereavement

The End of Life Care Strategy for England sets out the intention of that government to make end of life care a priority. However, as it says, "government action alone cannot change attitudes towards death and dying, nor raise awareness of the issues involved".[153] The Strategy therefore made provision for the establishment of a broad based national coalition of organisations, building on the involvement and commitment of the wide range of stakeholders who contributed to this strategy, in promoting greater public discussion and awareness of issues involved with death and dying. This has since been established and is called *Dying Matters*. It is recommended that the Action Plan seek to involve all those who contributed to the Forum in 2009 in the development of a similar public education and awareness raising initiative in Ireland.

Develop an End of Life Strategy

There is a need too to develop an End of Life Strategy in its own right in Ireland. Perhaps recognising the danger of neglect of the dying, other countries are increasingly placing end of life on their public health agendas and developing strategies to address end of life issues, such

---

153 End of Life Care Strategy - Promoting high quality care for all adults at end of life. (2008), p. 38 London: Department of Heath

as those raised by Forum participants.

The report, *Palliative Care for All - Integrating Palliative Care into Disease Management Frameworks* recommended that an end of life strategy should be introduced. In the light of the Forum's deliberations, however, its aim should not be limited to 'supporting and guiding all healthcare staff who work with people at end of life'. It should have a wider brief with a view to developing a national engagement with end of life and community based solidarity with those at end of life. It is recommended that the Action Plan include a provision to develop an End of Life Strategy which addresses the issues raised by the Forum.

Strengthen the Information Base for End of Life Planning and Services Development

As indicated by the National Council on Ageing and Older People in its presentation to the Forum, "The World Health Organisation in its report, Better Palliative Care for Older People (WHO, 2004), noted that 'needs during the last years of life have not been a research priority … and in general much more money is spent on research into potentially curative treatment.'"

Contributors to the Forum frequently alluded to deficits in information for end of life planning and services development purposes. The Action Plan should therefore include provisions:

- for a review of data deficits identified by contributors to the Forum

- for a review of the adequacy of the data available for the planning of end of life care provision nationally in all care settings, and

- for the development of an end of life research strategy.

An All Ireland Institute of Hospice and Palliative Care, should it be established as proposed, might take responsibility for some of this work.

Strengthen Regulation and Standard Setting

Regulation and standard setting will not, of themselves, ensure that service providers display the sensitivity and interpersonal skills needed to maximise the quality of life of those they care for at end of life. However, it is clear from the Forum there are a number of regulation and standard setting measures which might be considered for inclusion in the Forum's Action Plan, as follows:

- regulation of the funeral industry

- regulation of domiciliary care services, particularly end of life care services, and development of quality standards for end of life care at home

- implementation of the Quality Standards for End of Life Care in Hospitals launched by the Irish Hospice Foundation in May 2010

- review and promote the development of bereavement care training, structures and standards in the voluntary and statutory sectors

- campaign for the widespread introduction of household or "teaglach" model of residential care

- campaign for the provision of single rooms to enable those at end of life who want one to die in privacy and with dignity to do so

- develop mortuary standards, including standards for the treatment of remains after death; following clarification of policy on the use of body bags and embalming practices, standards governing these practices in particular need to be developed

- review and promote improved standards to meet psychosocial care and service needs at end of life in Ireland

- review and promote improved standards to meet spiritual care needs at end of life in Ireland.

Chapter 31   TOWARDS AN ACTION PLAN

Implement National Policy on Palliative Care

It is proposed that the Action Plan include a campaign for adequate resourcing and full implementation of:

- The Report of the National Advisory Committee on Palliative Care (Dept of Health & Children, 2001)

- Commitments on palliative care in the 2007 *Programme for Government*

- *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks* (HSE & IHF, 2008)

- *Palliative Care Services - Five Year/Medium Term Development Framework* (HSE, 2009).

- *Palliative Care for Children with Life Limiting Conditions in Ireland - A National Policy* (Department of Health and Children, December 2009)

The campaign should be designed to promote greater access to palliative care and should take account of the following recommendations proposed by contributors to the Forum:

- Ensure equity of paediatric with adult palliative care

- Resource Community Hospitals to provide more palliative and end of life accommodation and services closer to people's homes

- Provide access to consultant led palliative care for those in continuing care

- Monitor HIQA reports detailing end of life care services and staff competences in continuing care facilities where people die

- Provide palliative care for all at home on the basis of need, through the provision of integrated services on a 24/7 basis

- Treat and work with family carers as partners in the provision of end of life care at home. Identify and provide supports to them in a timely manner, including respite care and Home Care Packages. Provide them with training as required

- Incorporate end of life care in guidelines and pathways for all life-threatening diseases and conditions

- Introduce the legislation promised in the National Health Strategy, Quality and

Fairness (2001)[154], which would provide a clear entitlement to palliative care services for all.

Explore the Possibility of developing a distinctly Irish Dimension to End of Life Care and Welfare

As noted in Chapter 4 of this report, in other cultures end of life care has characteristics distinctive to those cultures, with benefits beyond end of life care provision itself. Care at end of life can be an indicator of the performance of the whole care system and a catalyst for its reform. It is clear that if certain of the problems in end of life care in Ireland documented in this report were comprehensively addressed, the whole healthcare system would stand to benefit. Likewise, the Forum should seek to act as a catalyst to preserve and promote what is best in the Irish approach to dying and death, including sympathy and solidarity with the bereaved following a death. It is proposed that provision be made in the Action Plan to explore the possibility of adopting a theme for a number of years to give a particular focus and character to end of life care and welfare in this country.

It is further proposed that the theme selected should have relevance for the healthcare system as a whole. This is in order that it may enhance the possibility of the initiative serving as a model with a wider application. Examples of possible themes include:

- interpersonal communication in end of life care
- partnership working in end of life care
- valuing carers in end of life care
- promoting the art of healing in end of life care

Promote Transparency of Decision Making at End of Life

It is proposed that the Action Plan should include support for a campaign for openness and transparency in the way end of life decisions are taken. The campaign might focus particularly on:

- good practice in communication by healthcare providers with patients on the range of options open to them, explaining each in terms of the expected quality of life, the emotional and other costs, the likelihood of success and the effect on length of life

---

154. Department of Health and Children, Quality and Fairness. A health system for you. (2001), pp 74 - 75. Dublin: The Stationery Office

- good practice in establishing with the person at end of life whether family carers or others should be included in decision making processes

- the development of evidence based guidelines for end of life decision making where they do not exist

- the preparation and observation of nationally agreed procedures and guidelines for Do Not Resuscitate (DNR) orders

- ensuring that the procedures and guidelines for DNR orders used in different hospitals and ambulance services are freely available, preferably in one place or on one site, pending the introduction of national procedures.

Promote Discussion of proposed Code of Practice on Advance Care Directives

The report on the proceedings of the Forum sets out views expressed by participants on Advance Care Directives (ACDs). While there are differences of opinion on ACDs, from the terminology used to the need to provide a legal framework for them, the initiatives taken to address the matter by the Irish Council for Bioethics and the Law Reform Commission, among others, have raised further questions, which require discussion. In its workshop presentation, the Law Reform Commission suggested that these issues be taken up by the Forum. They are set out most succinctly in the Code of Practice on Advance Care Directives, which the Law Reform Commission proposes should be developed by the Office of Public Guardian[155]. The Action Plan might therefore seek to promote discussion on the following:

- treatment that constitutes basic care,

- treatment that constitutes palliative care,

- treatment that constitutes life-sustaining treatment,

- the circumstances in which artificial nutrition and hydration may be considered to be basic care and, as the case may be, life-sustaining treatment,

- the process of putting in place a Do Not Resuscitate Order,

- including the need for a prior consultative process, that this is documented on a person's medical chart and that it is made by the most senior available member

---

155 See: Law Reform Commission (2009) Report. Bioethics: Advance Care Directives, Appendix: DRAFT MENTAL CAPACITY (ADVANCE CARE DIRECTIVES) BILL 2009.

of the healthcare team.

The Hospice Friendly Hospitals Programme of the Irish Hospice Foundation has published an Ethical Framework for End of Life Care, which will be of assistance, if the Action Plan includes the promotion of discussion on the above issues.

Develop Information Provision

Individual people and families need to have sufficient information to allow them:

- to prepare for end of life,

- to maximise living in the time left following a diagnosis of a life-limiting illness/ condition

- to make informed choices and to act as equal partners in their own treatment and care

- to cope with bereavement.

The Action Plan should include joint initiatives with the Citizens Information Board and others to explore how their information content and delivery might be enhanced in the light of the deliberations and outcomes of the Forum. It should also review standards of information provision by those who provide end of life care services in the community, in continuing care, in hospitals and in hospices. The Action Plan should be proactive in fostering the development of comparative information on end of life and bereavement care services provision in all settings.

Enhance End of Life Education and Training

The importance of end of life education and training was a constant theme of the Forum and many emphasised inadequacies in education and training received. There was notable diffidence on the part of some, particularly people in the private nursing homes and intellectual disabilities sectors. Training and education around death, dying and bereavement should be comprehensive and tailored at different levels – for the public, for volunteers, for health professionals and for specialists. Professional education and training for all those who care for people at, and following, end of life must be an important focus of the Action Plan. It should include:

- public education on end of life and bereavement

- support for the development of the Palliative Care Education Framework at all levels

- engagement with specific sectors to determine more precisely their education and training needs

- advocacy on behalf of those sectors most in need of resources and opportunities for end of life education and training.

Address Financial Concerns at End of Life

A constant theme of the Forum was the contrast between people's preferred place of death (at home, for the majority) and their actual place of death, usually in a hospital or other institutional setting. There are different reasons for this, including the availability and affordability of community and palliative homecare services. Pending the introduction of an entitlement to palliative care, it is recommended that the Action Plan include provision to campaign for a medical card for everyone with an advanced incurable illness and/or for a Palliative Home Care Package, or its monetary equivalent, for those being cared for at home. The Irish Hospice Foundation has already called for an entitlement to a medical card[156], saying that people with advanced incurable illnesses should have access to a full range of free medical and health services, including basic supports at home, such as oxygen supplies, a hospital bed at home and access to the services offered by a community-based, multidisciplinary team.

Consideration should be given to including in the Action Plan support for a campaign encouraging people to avoid dying intestate by making a will. The campaign should also promote separate legal representation for those making wills and those benefiting from them. It should further promote greater use of Enduring Power of Attorney. The Action Plan might also support the establishment of a register of wills.

Improve the Organisation of End of Life and Bereavement Care

It is clear from the contributions to the Forum that good end of life and bereavement care requires:

- co-ordination across organisational and sectoral boundaries

- interdisciplinary collaboration, and

---

156 Call for a Statutory Entitlement to a Medical Card for People with Advanced Incurable Illnesses. Irish Hospice Foundation Press Release, 28 November 2008

- integrated team working.

It is recommended that the Action Plan include measures to foster good practice in co-ordinated, collaborative and integrated end of life care by promoting:

- the development of care pathways and frameworks where such are needed

- the introduction of new end of life care models where current models are inadequate.

Ensure that the Action Plan is balanced

Through the Forum on End of Life in Ireland we have been able to get a glimpse of how end of life is perceived in this country, of what matters most to people when they think about their death and the death of people close to them. While end of life constructs are far from uniform, some themes have emerged from this national conversation. Taken together rather than singly, these themes facilitate the development of a shared vision of how contemporary Ireland can address the challenges of dying, death and bereavement. The Action Plan can contribute to the realisation of that vision, providing it too does not allow one of these themes to dominate to the exclusion of others.

As we have already seen, in this country, in common with people in other Western societies, we place a great emphasis on individual autonomy at end of life, perhaps because we fear increasing dependence on others at that time. On the other hand, the Forum also revealed an equally strong emphasis on positive interpersonal communication at end of life, perhaps because we do understand our social nature, our interdependence with others. The Action Plan should therefore seek to ensure that its programme of work balances efforts to promote greater autonomy at end of life with efforts to enhance the manner in which we communicate with and treat each other at this most sensitive of times.

Bob Carroll,

April, 2010.

Appendices

• •

Appendix 1 Chairpersons Panellists and Presenters who contributed to End of Life Forum Workshops in 2009

Workshop 1 - Hospice and Palliative Care, 25 March 2009

Chair: Tim Dalton

Panellist: Patsy McGarry

Presenters: Mo Flynn,   Hospice CEOs Group

                       Dr Miriam Colleran,   Irish Palliative Care Consultants
                                                          Association,

                       Maura McDonnell,   Director of Nursing, SPC Network,

                       Dr Joan Cunningham,   Irish Association of Palliative Care,

                       Jim Rhatigan,   Milford Care Centre, Limerick.

                       Kathleen McLoughlin,   Milford Care Centre, Limerick.

Workshop 2 - Specific Illnesses and Disability (A), 6 April 2009

Chair: Dr Tom Carey

Panellist: Doireann Ni Bhriain

Presenters   Dr Brian Maurer,   Irish Heart Foundation,

                       Joe Bollard,   National Council for the Blind of
                                                          Ireland

                       Mairin O'Shea,   Cystic Fibrosis Association of
                                                          Ireland

                       Mary Ferns,   Irish Cancer Society.

Workshop 3 - Specific Illnesses and Disability (B), 22 April 2009

Chair:	Emily O'Reilly	
Panellist:	Senator Ronan Mullen	
Presenters	Sandra Moloney and Fidelma Rutledge,	Irish Motor Neurone Disease Association
	Karen Pickering,	Muscular Dystrophy Ireland
	Aidan Larkin, and Margaret Maguire,	MS Society of Ireland,
	Mags Rogers,	Neurological Alliance of Ireland.

Workshop 4 - Specific Illnesses and Disability (C), 5 May 2009

Chair:	Jim Power	
Panellist:	Eileen Pearson	
Presenters	Joan O'Donnell,	Disability Federation of Ireland
	Ann Tyrell Kennedy,	Irish Raynaud's and Scleroderma Society
	Anna Clarke,	Diabetes Federation of Ireland
	Anne Duffy,	Irish Haemophilia Society
	Annie Dillon,	The Alzheimer Society of Ireland

● ●

Appendix 1 Chairpersons Panellists and Presenters who contributed to
End of Life Forum Workshops in 2009

Workshop 5 - Health Statutory Agencies, 13 May 2009

Chair:	Prof Eamon O'Dwyer	
Panellist:	Eamon Timmins	
Presenters	Siobhan Barron,	National Disability Authority
	Anne Callinan,	National Office for Suicide Prevention
	James Conway,	Health Services Executive
	Margaret Cahill,	Health Information and Quality Authority.

Workshop 6 - Gay and Lesbian Groups, 20 May 2009

Chair:	Paul Murray	
Presenters:	Ailbhe Smyth,	National Lesbian and Gay Federation
	Odhran Allen,	Gay and Lesbian Network
	Dr Agnes Higgins,	School of Nursing & Midwifery, TCD
	Dr Michele Glacken,	Dept Nursing & Health Studies, St Angela's College, Sligo

- -

Appendix 1   Chairpersons Panellists and Presenters who contributed to End of Life Forum Workshops in 2009

Workshop 7 - Medical and Nursing Specialist Agencies, 3 June '09

Chair:	Mrs Justice Catherine McGuinness	
Presenters:	Liz Hoctor MPSI,	Irish Pharmacy Union
	Kathleen Walsh,	An Bord Altranais
	Aisling Culhane,	Psychiatric Nurses Association
	Ursula Courtney,	ARC Cancer Support Centre
	Prof Sean Tierney,	Vice President, Irish Medical Organisation

Workshop 8 - Children and End of Life, 10 June 2009

Chair:	John Lonergan	
Presenters:	Gwen Bowen,	Bowen and Co. Solicitors.
	Sharon Hayden,	DDB Committee. Our Lady's Hospital, Crumlin
	Anne Reilly,	The Jack and Jill Foundation.
	Dr Joan Lawlor,	School of Nursing and Midwifery, TCD
	Dr Eleanor Molloy,	Holles St., OLCH Crumlin and UCD
	Anne Marie Carroll,	Children's Sunshine Home

Workshop 9 - Bereavement Groups, 8 July 2009

Chair: Dr Jane Wilde

Presenters: Ron Smith-Murphy,   ISANDS (Irish Stillbirth and Neonatal Society)

                Joan Conlan,   Rainbows Ireland

                Peter Hanlon,   Health Service Executive, Bereavement Therapist

                Sharon Vard,   Anam Cara

                Michael Egan,   Living Links

Workshop 10 - Older People (A), 15 July 2009

Chair: Anna Nolan

Presenters: Eamon Timmins,   Age Action Ireland

                Gabrielle Jacob,   National Council on Ageing and Older People

                Linda Desmond,   Carelocal

                Eilis Murray,   Friends of the Elderly

Workshop 11 - Older People (B), 16 July 2009

Chair: Paul Murray

Presenters: Ciaran McKinney and   Age and Opportunity
                Ann Leahy,

                Ena O'Mahoney,   Irish Senior Citizens Parliament

Appendix 1 Chairpersons Panellists and Presenters who contributed to End of Life Forum Workshops in 2009

Workshop 12 - Religious, Spiritual and Faith Groups, 22 July 2009

Chair: Dr Ann Lavan

Presenters:		
	Dr Rory Corbett,	Church of Ireland
	Helen Haughton,	Society of Friends
	Prof Desmond O'Neill,	Catholic Bishops Consultative Group on Bioethics
	Carolyn O'Laoire, Carmel Molloy and Marie Gribbon	National Association of Healthcare Chaplains

Workshop 13 - Carers Groups, 30 July 2009

Chair: Fr Fergus O'Donoghue S.J.

Presenters:		
	Tony O'Donovan,	Home Instead
	Brigid Barron,	Caring for Carers
	Patricia Hallahan,	Dementia Services Information & Development Centre, St. James's Hospital
	Clare Duffy,	The Carers Association
	Sandra Fagan,	Family Carer

Workshop 14 - Housing and Environmental Groups, 9 September 2009

Chair: Bill Darlison

Presenters: Melissa MacGillicuddy,   Colour Consultant

                Desmond FitzGerald,   Irish Landscape Institute

                Rodd Bond,   Dundalk Institute of Technology
                                             Netwell Centre

                James Doyle,   Emergency Response Ltd.

                Sean Ó Laoire &   Murray Ó Laoire Architects/Royal
                Nikki O'Donnell,   Institute of Architects in Ireland

                Bernadette Ryan,   Association of Occupational
                                             Therapists of Ireland

Workshop 15 - Marginalised Groups, 10 September 2009

Chair: Tom O'Higgins

Presenters: Nancy Power,   MABS Traveller Group

                Alice Leahy,   TRUST

                Lesley-Ann Kavanagh,   Waterford Brothers of Charity.

                Biddy Connors,   Irish Traveller Movement

                Mary O'Shea,   Executive Director, Dublin Aids
                                             Alliance Ltd.

• •

Appendix 1   Chairpersons Panellists and Presenters who contributed to End of Life Forum Workshops in 2009

Workshop 16 - Nursing and Community Homes, 17 September 2009

Chair: Andy Pollack

Presenters: Mary O'Donnell,   Health Information and Quality Authority

                  Ann Coyle,   Health Service Executive

                  Darci Meyers,   Dechen Shying Spiritual Care Centre

                  Elaine Keane,   Peamount Hospital

                  Dr Siobhan Kennelly,   Connolly Hospital Liaison Team for Older Persons.

                  Sinead Fitzpatrick,   Nursing Homes Ireland

Workshop 17 - Emergency Services, 23 September 2009

Chair: Paul Murray

Presenters: Jerry Kelliher,   Office of Emergency Planning, Dept. of Defence

                  Dr Niamh Collins,   Course Director for Advanced Paramedics, UCD

                  Dr Geoff King,   Pre-Hospital Emergency Care Council (PHECC)

                  Mark Wilson,   Station Officer, Dublin Fire Brigade

                  Kieran Henry,   Advanced Paramedic, Cork

                  Supt. Karl Heller,   Garda Community Relations

• •

Appendix 1 Chairpersons Panellists and Presenters who contributed to End of Life Forum Workshops in 2009

Workshop 18 - Education and Dying, 30 September 2009

Chair:	Joe Little	
Presenters:	Sharon Eustace,	National Educational Psychological Services
	Pádraig McMorow,	Kilkenny Bereavement Support
	Jennifer Moran Stritch,	Limerick Inistiute of Technology
	Clodagh Cooley,	IHF and Palliative Care Education Task Force
	Deborah Hayden,	Our Lady's Hospice Education & Research Centre
	Ally Cassidy,	Rigpa's Spiritual Care Education Programme
	Mary Godfrey,	Centre of Children's Nurse Education, Our Lady's Children's Hospital Crumlin

Workshop 19 - Human Rights, Advocacy and Legal, 7 October 2009

Chair:	Paul Murray	
Presenters:	Raymond Byrne,	Law Reform Commission
	Jackie Buckley,	Solicitor, Hayes Solicitors
	Egide Dhala,	Education & Integration of Migrants Centre, SPIRASI

Appendices

Appendix 1 Chairpersons Panellists and Presenters who contributed to End of Life Forum Workshops in 2009

Workshop 20 - Patient and Family Groups, 14 October 2009

Chair:	Aubrey Flegg	
Presenters:	Cathriona Molloy,	Patient Focus
	Detta Warnock,	Positive Action
	Ursula Gilrane-McGarry and Tom O'Grady,	St Angela's College, Sligo
	Phyllis Grothier,	Mothers' Union

Workshop 21 - EU and International, 21 October 2009

Chair:	Professor Mary McCarron,	
Presenters:	Rev. Dr Michael Wright,	International Observatory on End of Life Care, Lancaster University, England
	Tessa Ing,	End of Life Care Strategy, Department of Health, London

Workshop 22 - Ethics, 11 November 2009

Chair:	Catriona Crowe	
Presenters:	Dr. Dónal O'Mathúna,	School of Nursing, DCU
	Professor David Smith,	Royal College of Surgeons in Ireland
	Ruth Maher,	Our Lady's Childrens Hospital
	Dr Dermot Phelan,	Mater Hospital, Dublin

Workshop 23 - Eclectic, 18 November 2009

Chair: Lee Dunne

Presenters: Lelia Doolan,   Irish Society of Homeopaths

                    Ann James,   Humanist Association of Ireland

                    Ellen Fitzpatrick,   Baha'i Faith

• •

Appendix 2 Chairpersons and Panellists at Public Meetings of the End of Life Forum in 2009

Public Meeting 1 Dublin   25 June 2009

Chair: Michéal ÓMuircheartaigh

Panellists   Gus Nichols, Irish Funeral Directors Association

                       Eamon Donnelly, Retirement Planning Council

                       Michael Finucane, Solicitor

                       Tadgh Daly, Nursing Homes Ireland

                       George McCullough, Dublin Cemeteries

                       Philip Smith, Arthur Cox Solicitors

                       Des Stone, Comminity Welfare Officer

Public Meeting 2 Galway   30 June 2009

Chair: Pádraig Ó Céidigh

Pannelists: Dr Ita Harnett, Palliative Care Consultant

                       Robert Conneely, Funeral Director

                       Éadaoin O'Brien, Irish Centre for Human Rights

                       Michael Egan, Living Links

                       Raymond Gately, Chaplain, Merlin Park Hospital

                       Dr Helen Greally, Psychologist, Cancer Care West

. . . .

Appendix 2 Chairpersons and Panellists at Public Meetings of the End of
Life Forum in 2009

Public Meeting 3 Limerick   1 July 2009

Chair: Frank Prendergast

Panellists: Dr Gareth Quinn, Consultant in Emergency Medicine

                    Gwen Bowen, Solicitor

                    Jim Rhatigan, Milford Hospice

                    Gerry Griffin, Funeral Director

                    Mary O'Dwyer, District Public Health Nurse

                    Alice McAuliffe, Social Housing for the Elderly

                    Marie Carey, Ashlawn Nursing Home

                    Carmel Toohey, Living Links.

Public Meeting 4 Cork   2 July 2009

Chair: Dr Deirdre Madden

Panellists: Dr Gerard McCarthy, Consultant in Emergency Medicine

                    Sr Nan O'Mahoney, Chaplain, Marymount Hospice

                    Dr Seamus O'Tuama, College of Business/Law

                    Dr Mary Boyd, Director of Nursing, Cork University Hospital

                    Gwen Bowen, Solicitor

                    Kevin O'Connor, Funeral Director

                    Orla Jennings, Social Worker, Cork University Hospital

                    Michael Egan, Living Links

Appendix 2 Chairpersons and Panellists at Public Meetings of the End of Life Forum in 2009

Public Meeting 5   Dublin   16 September 2009

Chair: Mary Davis

Guest Speaker: Dr Allan Kellehear, Professor of Sociology, Centre for Death and Society, University of Bath

Public Meeting 6   Dundalk   29 September 2009

Chair: Gerry Kelly

Panellists: Fr John Okwui Anih, St Patrick's Parish

                    Katie Callaghan, Louth County Hospital

                    Dr Kieran Hannan, Renal Consultant

                    Rosetta Herr, Nursing Homes Ireland

                    Miriam Murran, Solicitor

                    Tony Shevlin, Funeral Director

                    Eamon Woulfe, Chief Fire Officer

Public Meeting 7   Sligo 8 October 2009

Chair: Dermot Healy

Panellists: Sharon Brennan, CNS Support Team, North West Hospice

                    Fr John Carroll, Chaplain, Sligo General Hospital

                    Gerard Clarke, Funeral Director

                    John Griffin, Retired Director of Nursing

                    Patricia Hannon, HSE Bereavement Therapist

                    Dr Diarmuid Hegarty, Medical Director NOW Doc & Acting Coroner.

Appendix 2 Chairpersons and Panellists at Public Meetings of the End of Life Forum in 2009

Public Meeting 8 Waterford   27 October 2009

Chair: TV Honan

Panellists: Dr Abdul Bulbulia, Retired General Practitioner

Frank Hutchinson, Solicitor

Fr Art McCoy, Chaplain

John Thompson, Funeral Director

Dr Emmet Walls, Consultant in Palliative Medicine

Pat Wilson, Bereavement Counsellor

Public Meeting 9 Tullamore   28 October 2009

Chair: P.J. Fitzpatrick

Panellists: Michael Byrne, Solicitor

Pauline Carbery, Bereavement Counsellor

Dr Michael Cushen, Consultant in Palliative Medicine

Fr Shane Crombie, Chaplain

Phil O'Reilly, Funeral Director

Paula Phelan, Director of Nursing

Appendix 3 Organisations and Persons who made Written or Oral Submissions to the Forum on End of Life

Brendan Connolly

Bowen and Co, Solicitors

Carers Development Unit, HSE South

Marriagequality

An Bord Altranais

Irish Translators and Interpreters Association

The Cystic Fibrosis Association of Ireland

Irish Nutrition and Dietetic Institute

Rainbows Ireland

Irish Association of Funeral Directors

Irish Society of Homeopaths

Irish Nurses Organisation

Jennifer Moran Stritch

Irish Pharmacy Union

ARC Cancer Support Centre

Midlands Bereavement Liaison Project

Huntington's Disease Association of Ireland

Marie Keating Foundation

Cashel and Ossery Mothers' Union

Kathleen McLoughlin

Kathy Sinnott MEP

Money, Advice and Budgeting Service (MABS)

Citizens Information Board

Irish Practice Nurses Association

Geralyn Hynes

Bruce Pierce

Gay & Lesbian Equality Network

The Ombudsman

Nursing Homes Ireland

Cairdeas, Brothers of Charity, South East

Irish Red Cross

Home Instead

TRUST

Emer Campbell

Mental Health Ireland

Irish Council for Bioethics

Irish Palliative Consultants Association

Irish Medical Organisation

Age and Opportunity

Marie O'Mullane

Muriel Dolan

Anne Bardon

Phil O'Callaghan

Prisca Mc Nally (2)

Declan Foley

Derek Whelan

W. Terence Liston

Larry Kelly

Anon

Niall O'Donoghue

Appendix 3 Organisations and Persons who made Written or Oral Submissions to the Forum on End of Life

Judith Ashton

Mary Tim Crowley

Kate Somerville

Susanne Marshall

Anonymous

Dr Laurence Cox

David Gibson

Marie Hickey

Anne Akamnonu

Sr Aine Costello

Ethel Deacon

Carmel Kilbride

Joann Cantrell

Joanne Carr

Sr Jean Kelly

Sylvia Wigham

Pat McCourt

Maureen Gilbert

Chartered Physiotherapists in Oncology and Palliative Care

Miriam Kingston

Claire Crehan Dowdall

Deirdre Carr

Trina Lyons-Rahilly

Ann Kingsley

Nasrin O'Kelly

Siobhan Henley

Patricia Cullen

Margaret Namirye

Mary McCahill

Mary F. McAteer

Catherine Timoney

Mrs Gerry Sheehy

Colette McCann

David Gibson

Deirdre Linder

Vanessa Burke

Lelia O'Flaherty

Shirley Devitt

Neurological Alliance of Ireland

Age Action Ireland

Caroline Moore

Marie Cody

Rhonda Forsythe

Anonymous

Mary P. Gallagher

Sheila Geoghegan

Claire Cahill

Marin Byrne

Mike Garde

Moira Staines

Jane McKenna

Irish Nephrology Nurses Association

Graham Parkes

Anna Deveney

Carol Caffrey

Irish Business & Employeers Confederation

Irish Water Safety

Anonymous

SW Submittal

Moya Loughnane

Anonymous

Anonymous

Anonymous

Michael O'Connor

DDB Commmittee, Our Lady's Children's Hospital Crumlin

Anne Keating

Dr Carl Cannon

Marion Browne

Proinnsias O'Keeffe

Joyce Marie Sheldon

Mary Whelan

Mrs Lally

Leo Leyden

Celine Henry

Imelda King-Kennedy

Margaret Murphy

Noel McCullagh

Lisa Slattery

Anonymous

Dr Gerard J. Burke

Eithne Cotter

The Bar Council

Patricia Silke

The Humanist Association of Ireland

Sile McNeill

Bridie Connolly

All Ireland Gerontological Nurses Association

Anne Nolan

Irish Catholic Bishops Bioethics Group

Helen Kelly

Wendy Donaghy

Anne Buckley

Bernie Corr

Catherine Paradise

Colin Hayes

Dr Denis O'Mahony

Anonymous

National Maternity Hospital

Emma Doyle

Fidelma Kelly

Gráinne Hill

James & Anne Maher

Anam Cara

Louise Kinsella

Sarah Devitt

Sharon Vard

UCD School of Nursing

Irish Association of Palliative Care

Irish Thoracic Society

Anonymous

Anonymous

The Association of Occupational Therapists of Ireland

Irish Wheelchair Association

Irish Hospice Foundation Bereavement Section

Marie Lynch, IHF

Staff:

Mervyn Taylor, Forum Project Manager

Paul Murray, Forum Co-ordinator

Linda Collins, Forum Administrator

• •

Appendix 3 Organisations and Persons who made Written or Oral Submissions to the Forum on End of Life

Appendices

• •

Appendix 3 Organisations and Persons who made Written or Oral Submissions to the Forum on End of Life