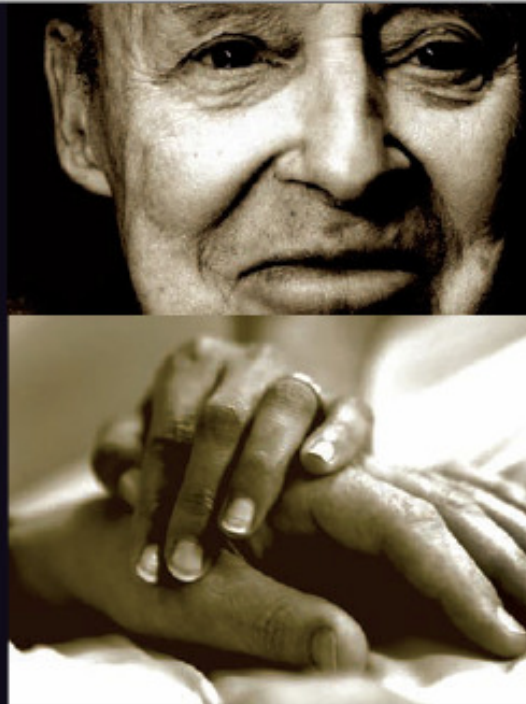# End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland

Hospice *friendly* Hospitals PROGRAMME

National Council on Ageing and Older People
An Chomhairle Náisiúnta um Aosú agus Daoine Aosta

End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland

Seminar Proceedings

Seminar organised by
The Hospice Friendly Hospitals Programme and the
National Council on Ageing and Older People

Yvonne McGivern (Editor)

Foreword

As Chairpersons of the National Council on Ageing and Older People and the Irish Hospice Foundation, we are pleased to present the Proceedings from the Seminar, *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland.*

The Seminar took place on April 17, 2008 in Croke Park Seminar Centre, Dublin. It attracted over 100 delegates from across the statutory, voluntary and private sectors. Delegates included policy-makers in the fields of health and in particular in the area of palliative care; planners and providers of services for older people; planners and providers of health at a national and regional level; older people, representatives of older people and carers; and researchers with an interest in ageing, service planning and quality of life issues.

The report launched at the Seminar, *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland*, is a very important report indeed. Jointly commissioned by the National Council on Ageing and Older People and the Irish Hospice Foundation, it is the first ever research study carried out in Ireland into quality of life and quality of care issues for older people at the End-of-Life. Conducted by a research team based at the Irish Centre for Social Gerontology, NUI Galway, the study includes a detailed survey of end-of-life care in over 300 acute care and other long-stay facilities throughout the country. It also sets out the views and feelings of older people who are currently in receipt of end-of-life care, as well as the opinions and observations of key direct care staff working in these settings.

The study raises many important issues for policy-makers and for service planners and providers. Most fundamentally of all it raises the question of the value placed by Irish society on how its older members are supported and cared for at the end of their lives. The process of dying is reflective of broader social values and the study findings suggest that neglect of end-of-life care for older people is indicative of ageist attitudes in our society. Ageism promotes the notion that older people are a burden on society, leading to their neglect and social exclusion. It limits their participation in society and restricts the types and quality of services available to them. Clearly, the eradication of ageist attitudes and behaviour that tolerate the neglect of end-of-life care for older people must be a primary concern for leaders in society and for those charged with promoting equality of treatment for all.

Death is a profound event in the lives of an individual and their families. But it is also a social event - people need the solidarity of others in order to enjoy a dignified and comfortable death. Our focus must be on identifying and embracing a compassionate approach to care which supports older people in life and death. Our service planning and provision must maximise the quality of life for older people at the end of the lives and meet their physical, psychological, social and spiritual needs. People should always take precedence over paperwork. All residential care facilities for the chronically ill should provide comprehensive end-of-life care services. This requires private space for patients and their loved ones, appropriately trained staff and access to all of the necessary expertise. It also means allowing time for staff to spend with patients in providing essential informal care or relationships of friendship and companionship.

On behalf of the National Council and the Irish Hospice Foundation we would like to thank all of those who took part in the research – the older people and the healthcare staff. We would like to thank the report's authors, Professor Eamon O'Shea and Professor Kathy Murphy, both of NUI Galway, and Dr Katherine Froggatt of the University of Lancaster, for their presentations of the research findings to the Seminar.

We would also like to offer our thanks to Marian Finucane, Shelagh Twomey, Ann Coyle and Julie Ling for their presentations. Thanks are also due to the session chairs Noel Usher and Dermot McCarthy and to the workshop chairs: John Brennan, Bill O'Herlihy, Sr Mary Threadgold, Rodd Bond and Dr Doiminic O Brannagain. We would also like to thank the workshop speakers: Professor Des O'Neill, Dr Max Watson, Carmel Molloy, Daphne Doran and Patricia T. Rickard-Clarke. Thanks also to the Seminar delegates for their valuable contribution to discussions.

Thanks are also due to workshop rapporteurs Angela Edghill and Marie Lynch from the Irish Hospice Foundation and Olga McDaid, Patricia Conboy and Sinead Quill from the National Council on ageing and Older People. We would also like to thank Ms Yvonne McGivern for her presentations summarising the output from the workshops and for preparing the Seminar Proceedings.

Dr Ciarán Donegan
Chair of the National Council on Ageing and Older People

Denis Doherty

Chair of the Irish Hospice Foundation

Contents

Final Session: Quality of Life at the End-of-Life: Issues for Society, for Service Providers and Policy

Promoting Quality of Life at the End-of-Life: Issues for Irish Society

Marian Finucane

Report of Issues for Society Arising from the Workshops   *Yvonne McGivern*

End-of-Life Care in Acute Hospitals and Long-Stay Care Settings: Issues for Service Providers   *Shelagh Twomey*
Ann Coyle

Report of Issues for Society Arising from the Workshops   *Yvonne McGivern*

End-of-Life Care for Older People: Policy Priorities   *Julie Ling*
Report of Issues for Society Arising from the Workshops   *Yvonne McGivern*

Closing Remarks   *Denis Doherty*

Introduction to seminar proceedings

Yvonne McGivern

Editor

Introduction

The purpose of this report on seminar proceedings is to provide a focused and accurate summary of the deliberations of the seminar.

The main aim of the seminar was to provide a forum in which to consider the determinants of quality of life of older people at the end-of-life and to identify priority measures and policies to ensure the highest standards of end-of-life care for older people in acute and long-stay settings in Ireland.

The goals of seminar were as follows:

- To present and to consider the findings of the joint National Council on Ageing and Older People and Irish Hospice Foundation study*, End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland.*
- To assist understanding of the environmental, clinical, palliative, psycho-spiritual, legal and ethical aspects of care and support needed by older people at the end of their lives.
- To consider the implications of the study findings
  - o for Irish society;
  - o for policy on older people and end-of-life care;
  - o for the promotion of best end-of-life care for older people in acute and long-stay facilities.
- To exchange information and experiences of policies, initiatives, services and practices that enhance the quality of life of older people at the end of their lives in different settings.
- To influence current and future standard setting governing end-of-life care services and services for older people generally.
- To assist the development of public policy and service planning in the interests of quality of life for older people at the end of their lives.

The report is divided into three sections following the structure of the seminar:

Opening Session

Presentation Of The Findings Of The Research Study

Chair: Noel Usher, Director, Office for Older People, Department of Health and Children

Opening Remarks

Ciaran Donegan, Chair, National Council on Ageing and Older People

On behalf of the National Council on Ageing and Older People and the Irish Hospice Foundation and its Hospice Friendly Hospitals Programme, I am delighted to welcome you to the Seminar, *End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland.* We are delighted to welcome speakers and participants alike.

The Seminar marks the publication of the report, *End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland*, undertaken by the Centre for Social Gerontology at NUI Galway. The report is the focus of the opening session. Professor Eamon O'Shea presents the context of the report and a summary of the main quantitative findings. Professor Kathy Murphy presents the main findings from the qualitative research stage of the study, encompassing the views and experiences of older people and their carers. Finally in this session we hear from Dr Katherine Froggatt about ways of thinking about new frameworks for end-of-life care.

The parallel workshop sessions focus on the end-of-life care needs of older people and good practice in response to those needs in both acute and long-stay care settings. Following short presentations by workshop speakers, each workshop will discuss the issues arising for society, for service providers and for policy.

In the final session, Quality of Life at End-of-Life, Marian Finucane looks at the issues for Irish society in promoting quality of life at the end-of-life and we hear the findings from the workshops in relation to society. Next we hear from Shelagh Twomey and Ann Coyle about the issues from the service providers' perspective and again we hear what workshop participants had to say about this. Finally, before Denis Doherty's closing remarks, we hear from Julie Ling about the issues for policy makers and we learn what workshop participants had to say on this.

We are very grateful indeed for your participation in the seminar. We hope that you find it informative and worthwhile.

End-of-Life Care for Older People in Acute and Long-Stay Settings: Context and Quantitative Findings

Professor Eamon O'Shea, Director, Irish Centre for Social Gerontology, NUI Galway

Introduction

The research conducted for this study had two parts: a postal survey of acute and long-stay facilities; and qualitative interviews with a sample of staff and patients/residents. Professor Kathy Murphy looks at some of the findings from the qualitative work in the next paper. My purpose here is to give you some background to and an overview of the survey findings.

Background to the survey

The aim of the survey was to gain insight into the likely impact of physical, environmental and staffing issues on end-of-life care for older people in acute and long-stay settings. It extends and develops previous work done by the National Council on Ageing and Older People in 2006 on quality of life in residential care settings in Ireland (Murphy and colleagues, 2006).

The population of interest

We identified 675 long-stay facilities that we believed were suitable for the study. These included public, private and voluntary settings, acute hospitals and psychiatric hospitals. We had some difficulty identifying this population as not all long-stay facilities, for example, are included on the Department of Health and Children's database, particularly those in the private sector, and in the voluntary sector, facilities were sometimes included in both public and private databases.

The questionnaire

The survey questionnaire (see Appendix 1 of the study report) was based on a previous study into end-of-life care in nursing homes in the United Kingdom (Froggatt and Payne, 2006). It was modified to accommodate the broader nature of the Irish study population (in particular, inclusion of acute and psychiatric hospitals) and some of the questions were adjusted to make sure they were suitable for the Irish context.

The questionnaire included questions on beds and patients/residents, dependency, deaths, services and facilities, staffing, education and training, communication and

liaison with other services, bereavement support, and policy and guidelines. It also included three open-ended questions on understanding of end-of-life care, elements of good quality end-of-life care and barriers to care.

We made some changes to the questionnaire following a pilot survey before sending it by post with a covering letter to the Director of Nursing/Person in Charge at each of the 675 facilities. We telephoned and sent a reminder letter to those who had not replied by the completion date. Where we found that a questionnaire had not been received we sent a replacement. From follow-up phone calls we discovered that some facilities were no longer in operation or did not have long-stay beds; removing them left our sample population at 592. We got replies from 326 of them, giving a response rate of 55 per cent, which is excellent for a postal survey.

The context of the study
Before looking at some of the findings from the survey I first of all want to draw your attention to some of the issues that you will hear more about throughout the day as well as in Kathy Murphy's and in Katherine Froggatt's presentations. You will be able to read more about these in the study report.

Quality of life domains
We know from the literature on end-of life care (Mularski and colleagues, 2007) that there are several areas important in assessing quality of life:
- *Life completion:* This is concerned with the person's sense that they have achieved what they want to achieve. It includes being able to help others, saying important things to loved ones, having a sense of meaning, being at peace, having time with family.
- *Relationships with the health care system:* This emphasises the person's relationship with the health care system – it includes a sense of control about treatment decisions, knowing where to get information, participating in care decisions, knowing what to expect about the illness, and being treated as a person.
- *Preparation/anticipatory concerns:* This includes worry about being a burden, about whether their family is prepared for the future, fear of dying, financial strain and regrets about life.

- *Symptom impact*: This has been identified as central in most studies of end-of-life care. Control of symptoms is crucial in promoting the comfort of the patient and ensuring that their quality of life is as good as possible approaching death.
- *Connectedness and affective social support:* This is about whether the person has a confidant to share their deepest thoughts and how much and how frequently they spend time with family/friends.

All of were relevant for our study. It is interesting to note that the things that are important to us in life are important to us in death, wherever it is that we are about to die, be it an acute hospital or a long-stay unit or at home.

A good death

This brings us to the notion of 'a good death'. What is a good death? Is there such a thing? Can you have any sort of a good death? In many countries, including the UK and Ireland, the idea of what constitutes a good death has been articulated primarily by the Palliative Care or Hospice movement. Issues that come up in relation to a good death are autonomy, pain relief, symptom control, information and issues to do with denial of death and acceptance of death.

It is difficult in practice to reproduce the model of a good death as advocated by adherents of palliative care in settings other than hospices. The physical environment may be incompatible with reflective care; people may die in crowded circumstances without the support of family and friends. In such circumstances, staff must strive to meet criteria such as symptom control and maintaining the dignity of the person who is dying within the limitations of their physical surroundings.

A good death, therefore, is always a bounded concept, influenced by time, space and resource constraints. This is one of the things that we need to address in policy deliberations. We need to consider what it is we can influence in the public sphere - we can influence some aspects that make up a good death in the private sphere but what can public policy influence or have an impact on? That is the real challenge.

Barriers to end-of-life care

Finally, before we look at some of the survey findings, it is important to keep in mind the main issues that can undermine the delivery of effective care for people at end-of-life. These include the following:

- Continuity of care
- Organisation of care
- Education and training
- Cultural awareness
- Staffing
- Physical resources
- Spiritual and psychological support
- Communication.

Survey findings

Location at time of death

Nearly all residents who die in private nursing homes do so in single rooms; dying on a multi-bedded ward was more common in acute hospitals and psychiatric hospitals (56 per cent and 57 per cent respectively). Almost three quarters of HSE extended care units said that their patients are usually cared for in a single room at the time of death. This contradicts recent evidence on the lack of single rooms for people dying in hospitals in Ireland (Tribal Consulting, 2007). The difficulty may be that the survey question asks for information on generic usual location at time of death rather than actual location for named patients/residents, which may have led to some overestimation by nurse managers of single room placement. Data from the qualitative part of the study - analysis of practice and process in six selected sites – also suggests that single room placement may be less common than the survey findings show. The survey results may reflect the aspirations of nurse managers in terms of their preferred location for their patients rather than the multi-bedded ward reality, particularly within public long-stay facilities and acute hospitals.

Palliative care beds

In general, the number of designated palliative care beds in the system is extremely low at 0.5 of all beds. The survey shows that HSE extended care units have the highest number of designated palliative care beds at 49, followed by the private nursing home sector at 41. There are no designated palliative care beds in the acute hospitals that responded to the survey.

Staffing issues

Overall, acute hospitals have the best staff ratios while public long-stay facilities have better ratios than private nursing homes. Acute hospitals have a qualified nurse to

patient/resident ratio of 1:0.6 compared to a similar ratio for private nursing homes of 1:5.3. The ratio for HSE extended care units is 1:2.1. Differences in registered nurse staffing levels across facilities may have implications for the quality of care provided to patients/residents at end-of-life.

Less than a third of all facilities and only a quarter of long-stay facilities reported that their qualified nurses hold a post-registration qualification in palliative care. This proportion ranges from only nine per cent of voluntary welfare homes to 42 per cent of voluntary homes/hospitals. In contrast, three quarters of respondents from the acute sector report that some of their nurses have post-registration qualification in palliative care. In relation to other staff, only one third of all respondents responded that their care/support staff had attended short courses in end-of-life care and only 12 per cent replied that doctors/consultants in their facility had received any form of specialised training in palliative care/medicine. Despite performing well in relation to nurse awareness of palliative care, only one third of acute hospital respondents reported that their care/support staff had attended training in end-of-life care. Moreover, only 43 per cent of acute hospitals reported that their doctors/consultants had received specialised training in end-of-life care.

Clearly much remains to be done across all facilities to improve education and training among staff in relation to end-of-life care.

Communication and liaison with other services
There are generally low levels of access to consultant-led palliative care teams, especially within long-stay facilities, where only two fifths of respondents indicated that they are connected to the service. Access is especially low among HSE extended care units, which is surprising given the public nature of the facility. Access is also low for voluntary welfare homes where only 20 per cent of facilities indicated that they have direct access to consultant-led palliative care teams. There are generally higher levels of access across all facilities to 24-hour advice on resident/patient care from specialist palliative care services, as might be expected. About two thirds of all long-stay facilities report access to advice, ranging from 27 per cent in voluntary welfare homes to 74 per cent in HSE extended care units.

Respondents were also asked about the extent to which a range of external service providers, including consultants in palliative care, clinical nurse specialists in palliative care and other health professionals, visit older people receiving end-of-life

care in their facility. More than half of all facilities (57 per cent) never receive any visits from consultants in palliative care. The proportion of respondents reporting no visits is lowest for acute hospitals and highest for voluntary welfare homes.

There is a greater level of visiting/provision by clinical nurse specialist in palliative care across all facilities, suggesting that they may play a more significant role than consultants in the provision of palliative care services in Ireland. One third of private nursing homes report that the clinical nurse specialist makes regular visits and/or provides services - slightly higher than the corresponding figure for HSE extended care units at just under 30 per cent. However, most of the involvement of the clinical nurse specialist occurs by request; for example, 53 per cent of private nursing homes, 68 per cent of voluntary homes/hospitals and 55 per cent of HSE welfare homes report visits only when asked. This may be an efficient use of available resources, but it does little to promote the culture of end-of-life care within the various settings.

Bereavement support
Overall, there is a low provision of formal bereavement support structures available before and after death within the acute and psychiatric sector. Two fifths of acute hospitals do not have a private space for engaging in confidential consultations with relatives and friends.

There are few facilities available within the acute and psychiatric hospital sectors for family and friends wishing to stay overnight with their loved-ones when death is imminent. Tea/coffee/snack-making facilities are available in less than one third of acute hospitals and in only 50 per cent of psychiatric hospitals. Less than one third of acute hospitals (31 per cent) and psychiatric hospitals (29 per cent) have a bereavement officer/family liaison nurse in place to engage with families following bereavement. Only one third of acute hospitals have formal support structures to support relatives, friends and fellow patients following the death of a resident/patient; however, 71 per cent of psychiatric hospitals do have such support structures in place.

Private facilities generally perform better in respect of the availability of facilities for families and friends visiting residents/patients who are dying. In contrast to the acute hospital sector, the majority of long-stay facilities across the three sectors have private rooms available for confidential consultations with family and friends of the

person dying. Quiet rooms are also generally available, although more so in the private sector than in the public sector. In contrast, sleeping facilities for relatives, both in private rooms and on the wards, are in short supply. Public facilities outperform private facilities in the provision of mortuary services, which might be expected given relative size differences.

In general, bereavement support structures for families following death are weak in the long-stay sector and, in some areas, such as the availability of formal support services, weaker than the acute hospital sector. In particular, very few public HSE care facilities report having formal bereavement support structures in place to support the family and friends of the deceased. Similarly, the data shows a general absence of bereavement officers/family liaison nurses within the long-stay sector.

Policies and guidelines
While written policies on end-of-life care are available in most facilities (80 per cent), they are not uniformly available within the long-stay care sector. In addition, we have no information on procedures and practices within the facilities (20 per cent) without written guidelines. Availability of guidelines ranges from 85 per cent in acute hospitals to 40 per cent in voluntary welfare homes. Written guidelines are more available in the private long-stay sector than in the public or voluntary long-stay sector.

Care in the last hours of life, last offices and contacting a patients' priest/minister/spiritual adviser are generally well catered for within written guidelines, achieving 80 per cent coverage or above in public, private and voluntary facilities. Symptom control and informing other patients of the deaths of residents achieve or exceed 60 per cent coverage, although there is scope for improvement in relation to each of these policies.

Informing other patients about a fellow-patients death only achieves 40 per cent coverage in public long-stay facilities. Coverage does not exceed 40 per cent in relation to written policies/guidelines on the needs of residents from ethnic minority groups. The poorest performers in relation to ethnic guidelines are HSE welfare homes and voluntary welfare homes, where only a quarter of respondents in each setting indicated they had guidelines in this area.

The existence of written policies on advance directives is low overall, but particularly so in public long-stay facilities. Similarly, integrated care pathway coverage does not exceed 20 per cent in any of the sectors.

Barriers to delivering good quality care
Respondents were asked to identify the key barriers/constraints that currently prevent their facility from delivering the best possible care to older people who are nearing the end of their life.

For everyone lack of funding is a major issue as without the appropriate financial resources no improvements can be made. All sectors indicate a lack of funding as an impediment to the provision of optimal care in their facilities.

Lack of trained staff was a key issue for all facilities. For example, respondents from the private nursing homes sector expressed concern that some of their staff had no previous experience with death. Without common training it was difficult to establish an ethos of care that put the patient first.

Infrastructural deficiencies are a barrier to providing optimal end-of-life care. Lack of space is a problem, especially in public care settings. Respondents from acute hospitals, psychiatric hospitals and voluntary homes/hospitals refer particularly to the lack of availability of single rooms and dedicated space for older people who are dying in their facilities.

Respondents also expressed concern about the lack of hospice beds and/or community support to enable the transfer of patients to a more suitable environment where they could experience a more peaceful and dignified death. Transfer issues were also raised, with some suggestion that patient care is undermined when people have to be transferred to an acute hospital to continue their care, as the appropriate care cannot be provided in existing long-stay settings. Lack of privacy for families and friends of patients is also a problem, as there are limited facilities available to allow them to stay over with patients or to have a private space to grieve for their loved ones following their death.

The presence of family and friends at the time of death may also create problems. Some respondents referred to the lack of respect shown to health professionals by family members visiting the patient. Others highlight the problem of overcrowding

when there are too many people visiting a patient. Uninformed relatives, family disharmony and lack of respect for patients' wishes also appear to be problems that can interfere with the caring process at end-of-life.

Institutional barriers are particularly evident in the private sector where many facilities do not have established links with external specialist service providers. Private nursing homes appear to be particularly affected; respondents report that patients have to be transferred to a hospital even though they would prefer to be able to provide the appropriate care for them in their facility. This concern is also expressed by respondents from voluntary welfare homes. The need to broaden the availability of palliative care services is also evident, particularly within acute hospitals. Because these services are in such short supply, they are only currently available to cancer patients. The inability to provide pain control and prescribe drugs without the presence of the GP is a problem for some respondents. Greater support from external services such as GPs and specialist palliative care services can help improve the care provided to patients dying in all facilities.

In conclusion

While all issues to do with end-of-life care cannot be captured in a survey, we now, at least, have a benchmark against which future progress can be measured. For example, we know that there is a need for more information and better communication to improve the quality of end-of-life care - these are critical components. If we don't know what people want then how do we provide what they need? We know now that there are significant gaps in provision and services and facilities are poorly provided in some settings. There are issues to be addressed in terms of the physical infrastructure; practice development, education and training; and in the integration of palliative and gerontological care. While much work remains, there is a willingness to engage with best practice in end-of-life care. This makes it more likely that we will see improvements over time, provided that new initiatives and resources can be agreed.

We must keep in mind that entry into a nursing home or a long-stay facility tends to be a transition from active engagement in life to potentially passive mode, with the older person thinking that perhaps they are never going to get back to where and how they used to live. We need to be aware of this transition and that thoughts of loss and death may be uppermost on people's minds. We need to think about how we can enable older people to live complete lives in both acute and long-stay

settings. How do we facilitate a lived life in places when death and dying are in people's minds? If we were to get that right we would be along way to improving quality of life for older people at the end-of-life. The Hospice Friendly Hospitals Programme is doing much to improve things. I leave you with the thought that we need a lot more innovation in the care of older people, and in the care of older people who are dying.

What Older People at the End of Their Lives Are Saying
Professor Kathy Murphy, NUI Galway

Introduction

One of the challenges of this study was to find ways to elicit the views of older people on death and dying. Ethical constraints meant that we had to approach the older person indirectly. Below we describe our method of approach. We then move on to present some of what the older people we interviewed told us.

Talking to older people about death and dying: how we did it

The sample

We conducted interviews with thirty older people, the recipients of end-of-life care, in six facilities across the country. We chose a range of places to represent the sort of places of care in which older people die:

- An acute hospital typical with more than 500 but less than 1,000 beds
- Two Health Service Executive (HSE) extended care units with not less than 100 beds, one in an urban and one in a rural setting
- Two private nursing homes, one urban and one rural, one with fifty to 75 beds and one with more than one hundred beds
- A long-stay unit attached to a palliative care centre.

Gaining access

We contacted each place by telephone and invited them to take part in the study. We gave them an overview of the research and assurances that their facility would remain anonymous. All but one agreed to take part. Where permission was refused we approached the next facility in that same category. Gaining access to the two private nursing homes was more time-consuming than was gaining access to the public health facilities - we had to get consent from the owner as well as from the direct care staff.

Once consent was given, we sent an information pack to the sites. Each pack contained the following:

- A copy of a letter from NUI Galway Research Ethics Committee confirming that the study had received ethical approval.
- An Agent Nomination form (in accordance with Data Protection Acts, 1998 and 2003)

- A detailed information briefing sheet clarifying the role of the research assistant who would visit the site, the type of questions to be asked and materials to be obtained.

We gave the site contact numbers of the research team to allow them to raise any concerns or issues they might have. We made one further telephone call to each place to confirm that it would act as a research site and we received from them a signed consent form.

The research assistant role

We assigned a research assistant to each study site. The role of the research assistant was to prepare a profile of the site including a description of the environment and a sketch map of the setting showing layout of rooms, distance to nursing office and so on and to get verbal and written consent from the direct care staff and patients to take part in an interview that would be conducted by a qualitative researcher. The research assistant typically visited the site two days before the interviewers.

We ran training for the research assistants and the interviewers. The training introduced them to the study and to the data collection tools that would be used during the site visit and instructed them on the nature of the interviews. The interviewers – one to interview staff, the other patients – were experienced qualitative researchers competent in interviewing frail, older people and/or vulnerable people.

Documentation, data and measurement

At each site the research assistant obtained photocopies of documentation, policies and guidelines related to end-of-life care for older people. This included the following:
- Dependency levels of people in the unit
- Nursing assessment records, including any tools used for such assessments
- Off-duty rota for the assessment of staffing levels across a 24-hour period
- Medication charts of those to be interviewed
- Clinical records, both medical and nursing, of those to be interviewed.

The patient data we examined was limited to data collected up to thirty days prior to the visit. We used the KATZ scale and the Karnofsky Performance Status (KPS) scale to work out dependency levels of those patients taking part in the study. The

KATZ scale is used as an assessment tool and a self-report measure of function (Reijneveld and colleagures, 2007). The KPS scale is seen as a 'gold standard' measurement of performance in debilitating illness and offers a three-dimensional assessment of health status (activity, work and self-care). It can be administered by any healthcare professional and has been adapted for use in palliative care (Abernethy and colleagues, 2005).

Choosing individual older people to talk to

We received a list from the senior nurse at the site of up to ten patients thought suitable for interview. We had agreed criteria for choosing patients that were based on previous work interviewing patients in end-of-life studies (Payne and colleagues, 2007; Seymour and colleagues, 2005). These included:

• Those over 65 years of age, orientated and able to discuss their experiences

• A diagnosis suggestive of chronic life-limiting illness (e.g. cancer, chronic obstructive airways disease and so on)

• Those with complex health issues requiring regular medical attention

• Those whom the senior nurse would not be surprised were they to die within six to nine months of the interview, given their overall state of health

• A gender balance reflective of older person demographics (60 per cent female, 40 per cent male).

The research assistant and senior nurse agreed the list of patients. Patients who could not take part for physical or mental health reasons were subsequently excluded. Where a patient did not want to take part, another was chosen from the agreed list.

The interview

The length of time that those interviewed had been in the care setting varied from a few weeks in the case of acute hospitals to a number of years in long–stay care settings. Some had mild cognitive impairment but were able to understand and respond to questions. Interviews lasted between 15 and 65 minutes.

We designed an interview guide based on previous work reported in the literature and in consultation with partners in the research team (Payne and colleagues, 2007; Hawker and colleagues, 2006). We modified it to be culturally sensitive to the Irish context. We tested it in a pilot study before the main data collection stage and as a

result we made minor changes. The interview guide included questions about the patient's understanding of the reasons for admission, their experience of care received and their physical environment. Issues around death and dying were introduced indirectly in terms of their concerns and/or worries over their future.

We recorded the interviews with the patient's permission and these recordings were transcribed word for word. We used a data analysis package called Atlas Ti to manage the data and we took a grounded theory approach to analyzing the data (Glaser and Strauss, 1967). We present the data by theme (living, dying and relationships; transitions into dying; and organisation and ethos of care) rather than case-by-case basis to, among other things, protect the anonymity of sites and participants (Large and colleagues, 2005).

The findings
The views we show here come from across the continuum - first realisations of deteriorating health through reality of the dying experience to personal expectations of a good death. Many of the patients interviewed were aware of their poor health but not that it necessarily indicated their dying since they had 'bounced back' on previous occasions.

Living, dying and relationships within acute and long-stay settings
The degree of frailty experienced by those we interviewed varied - some retained greater independence than others. Most described frailty as a decline or recognition that improvement in response to treatment and care was slower or less than expected. Those who had experienced urgent and unplanned deterioration in their health - a fall, stroke or unresolved infection - were very conscious of a major change in their health status. Some likened frailty and decline to the dependency of childhood:

> Of course, I mean I'd love to be able to walk around the room and to the loo on my own, but I need help everywhere you see. But I can't dress myself now and I can't undress so there are a lot of restrictions, but I can do nothing about it. (GRT5, Patient 03, Voluntary Home)
> Yes, I got a stroke there in October, I was in bed one night, I went up to bed as a 77 year old man, got up the following morning a two year old. Only had one leg, one hand. (BLT6, Patient 01, Extended Care Unit)

Patients also equated their age with the inevitability of illness and, although they still remained focused on possibilities for the future, they realised that their frailty had significantly altered their future long-term care options:

> Well, I'd be in bed and out of bed. I feel weak, I have been so long in bed that I feel fairly weak. It's a similar, since I came here, well, I have improved a bit but not as much as I thought I would have, you know. (BLW4, Patient 02, Extended Care Unit)
> I am, I feel, a little bit better now but I'll go home but I don't think I'd be really able to manage on my own. (SAZ12, Patient03, Acute Hospital)

Some were unhappy being seen as frail and dependent. One woman described how she felt constantly pressured by staff to go into town in her wheelchair, even though it made her uncomfortable:

> I felt a bit obvious in a wheelchair, when everyone was shouting over to you: 'What happened to you?' You know what I mean, that kind of way. (BLW4, Patient 03, Extended Care Unit)

There were those who were not always resigned to frailty as an inevitable consequence of ageing. One woman with a dense hemiplegia – a paralysis of the left half of her body - remarked how staff would enlarge a copy of the crossword so that she could see it to complete as part of her cognitive and motor skills maintenance programme.

Patients (and staff) from all care settings considered activity and occupation an important enhancement to quality of life. However, the range of activities available varied between settings and overall staff expressed concern about a lack of opportunities for patients. It was noted that those without families or those who were immobile were particularly disadvantaged.

The value of creating and sustaining relationships was important to understanding the end-of-life experience from the patient perspective as well as from the care-giver's. Patients appreciated common courtesies such as being greeted by name:

> They say to you, 'Look, I'm so-and-so. I'm looking after you today…' I think it's a good point – we've a relationship. (SAZ12, Patient 02, Acute Hospital)

Patients did not specifically identify staff members as being particularly close to them but described relationships with staff in warm, if somewhat general, terms:

They keep a close eye… they are all very attentive – give them their due – they are fond of me, you see. (GR5, Patient 02, Voluntary Home)

In some care settings, there was a sense among the patients that the facility was a 'home away from home', particularly if they lived there for many years. However, not everyone shared this view - some patients longed to be at home. They did not feel that their current accommodation was 'home-like' and suggested that their care was focused on the routine of the staff rather than their personal wishes. For example, it was perceived by one patient that if staff wanted to leave early, she would have to go to bed early. Others just wanted to be in their own home and it was this desire to be at home rather than anything particularly lacking in the care setting that prevented them from feeling at home. For example, one patient said he just wanted to be at home sitting in his own chair. A staff member suggested that some people never settle in residential care – their sense of loss of freedom stops them from entering fully into life there. It is notable that this specific problem was only described by patients resident in private nursing homes and not in the other care settings of the study:

It's not homely here in the nursing home. (PIX33, Patient 04, Private Nursing Home)
I'm dying to go home - there's no freedom (here). It's not like home. I miss the bit of land.
(PIX48, Patient 19, Private Nursing Home)

Sometimes the sense of belonging stemmed from relationships between patients. One woman who had initially been reluctant to become a resident in the nursing home described her feelings of support from her fellow patients prior to a planned home visit:

All the girls from my table came down and gave me a hug to come back. They made me feel at home. (GRT5, Patient 01, Voluntary Hospital)

Many patients experienced personal losses on admission to long-stay care. Relationships changed or were lost altogether. In one case a patient was admitted on the day of her husband's death and attended his funeral from there. She never returned to her own home again:

I had a kind of a tentative booking here then, so the day he died I came in here. I was caring for him for about seven years at home… . Well, there was, because there was a room booked and I mean I might have lost it if I didn't come here. We all have to make hard decisions in our lives and I couldn't ever live at home again anyway because I had to sell my home and my car and I

have, my peripheral vision is non-existent and my other eye isn't too great either, but I would
never be able to drive a car again, and I couldn't live on my own. I had a lot of control over it in
so far as my family just, we are a very close family so there was no, there was no concern
about it overall. It was just that I went to my husband's funeral from here. (GRT5, Patient 03,
Voluntary Hospital)

Some had lived alone for many years or had lived with other family members prior to
moving to the care setting. This sometimes translated into a desire to be reunited
after death with partners and/or relatives who had already died:

A great comfort altogether. You learn things from that. So I'm going to meet them all above. So
there'll be the two of us and she saying, 'Why did you do this and that?' (laughing). I always
quote the words of St Paul. He was a great man. And he would say, 'No eye has seen nor ear
heard nor mind conceived the things God has prepared for those who love me.' It's grand to
know and believe it with your heart and soul there's something wonderful waiting for you. It
makes the whole process easier. (GRT5, Patient 05, Voluntary Hospital)

Transitions into dying

Some of the older people we interviewed seemed to recognise certain signals that
somebody else was about to die but only a very small number discussed their own
impending death. Where this was explicitly acknowledged, being able to achieve a
sense of closure over their life was important. Patients often rationalised their deaths
through a belief in God – it was God who would decide on the time and manner of
death. They spoke about death as a normal and inevitable part of the life cycle, over
which they had little influence. Some said that they not only accepted death but
looked forward to it as a way of meeting with family members who had pre-deceased
them. This belief appeared to sustain them in the face of death. In most cases, death
was perceived to be beyond their control:

Oh yes, yes. God has his own wise ways. We go the way he wants us to go. (BLW6, Patient
02, Extended Care Unit)
You take it day to day – all you know is you're going to go sometime anyway – we all have to
do it. (BLW4, Patient 05, Extended Care Unit)

Patients' first exposure to the dying process was when another patient was moved
when close to death:

I seen them go upstairs. And he went upstairs and I was told he died….If you go upstairs,
anyone that went upstairs they died... that's the way, you get sick and you go. A lot of them
went upstairs and died up there. They went away, that's the way to look at it you know. A lot of

men went upstairs in a wheelchair and you are gone the next morning. (BLT6, Patient 03, Extended Care Unit)

Down in the Unit that a patient died and one said it was so hard because she was dying right next to me, and she was actually feeling sick for a while afterwards, sort of, that they feel it. (BLW4, Staff 01, Extended Care Unit)

Patients shared their feelings about the impact of the death of other patients to whom they had become close:

One of the nurses called me and she said, she caught me by the hand and she took me into the office and she said (name) sit down there now. I have something to tell you… your little pal passed away last night. I could cry this minute, that's how I feel about her, I miss her so much. (BLW6, Patient 04, Extended Care Unit)

A 'good' death was described as one which was neither protracted nor painful. Death did not always imbue fear. This was often related to the belief that they would be reunited with someone already dead:

I said, 'Are you afraid of that?' 'Afraid,' she said. 'I'm not,' she says 'Of what?' she says, 'Because I know my son will be there to meet me,' and she really opened her eye. (BLT6, Staff 01, Extended Care Unit)

We examined patients' (and staff) experiences of the management of complex symptoms at the end-of-life. Patients generally found a responsive approach to their symptoms. Sometimes, however, a patient's description of pain management was suggestive of gaps in knowledge regarding principles of pain management, such as explanation about medication and the avoidance of sub-therapeutic doses. The generalised descriptions given by patients were indicative of limited involvement in and understanding of the clinical aspects of their care.:

No, I haven't been in pain at all. They're very good for giving you tablets, painkillers. They'd get a doctor if you were in pain. The first night I came in I was in very severe pain with the breathing and they got a doctor immediately for me and he diagnosed what he thought might help and I found them very helpful. (SAZ12, Patient 01, Acute Hospital)

I'm getting some, what a tablet or, I'm getting something. I don't know what it is. It's not doing no harm anyway. (PIX48, Patient10, Private Nursing Home)

Sometimes I get loaded in the water, you see, and I get Panadol sometimes and that's as near as they can go. (PIX48, Patient 04, Private Nursing Home)

Patient interviews confirmed that by and large they were treated with respect. This was particularly so where the institution responded to what the patients themselves wanted in terms of treatment and of opportunities to talk about dying.

Organisation and ethos of care

In general, there was limited criticism of care provided overall and the end-of-life care experienced by patients would appear to be a positive when taken as a whole. Overall, the philosophy of care mirrored best principles for end-of-life care. However, there were deficits in terms of work practices and poor consultation with patients regarding their wishes and desires as end-of-life approached.

Patients were concerned that staff did not have enough time to deal with all the care issues that arose and felt that this affected the capacity of staff to give the attention they needed:

> They could do with more staff. They are run off their feet at times. Especially in the mornings when there's a lot of old people or Alzheimer's and those they all have to be dressed and that you know…and washed. (GR5, Patient 01, Voluntary Hospital)

Recommendations

In our report, *End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland,* we make six recommendations. All of them are pertinent in the light of what older people at the end of their lives are saying:

• There should be greater consultation with older people so that we can establish their needs and preferences with respect to end-of-life care.
• There needs to be improvement in the physical environment where people die, particularly with respect to the availability of single rooms and facilities for families and friends.
• Greater cultural awareness and understanding of dying and death is needed
• We need policy reform to ensure that end-of-life care is recognised as an important public health issue.
• We must develop practice to ensure that end-of-life care for older people is integrated into the everyday life and work of acute hospitals and long-stay facilities.
• We need to test new approaches that bring about a greater fusion between end-of-life care and gerontological care within all long-stay settings in Ireland.

Conceptualising New Frameworks for Understanding End-of-Life Care

Dr Katherine Froggatt, Senior Lecturer, International Observatory on End-of-Life Care, Lancaster University

Introduction

In the study report, *End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland*, we propose an approach for developing good practice in end-of-life care for older people living and dying in various care settings in Ireland. This approach is informed by the research undertaken for the study. My aim here is to give you an overview of it.

Mapping the transition from life to death for older people

Underlying the approach are the following premises or principles:

- Older people in acute and community hospitals and nursing homes have needs for care and support
- There is often uncertainty about the passage from life to death for individual older people
- Many domains are encompassed in ensuring a good quality of life and death towards the end-of-life including: physical, psychological, cognitive, spiritual, social and economic dimensions
- Older people and their families live in complex social networks of mutual interdependency.

We found that older people and their families in the context of hospitals and long-stay care settings encounter four 'zones'. We have called these zones:

- Living with losses
- Living and dying
- Dying and death
- Bereavements.

They are illustrated in Figure 1 below and we look at each in more detail below.

Living with losses

If quality of life of long-stay residents is to be preserved then there must be an enduring emphasis on living and life. At the same time there must be an awareness

that the older person is living with change, including loss of function (physical, psychological, cognitive), status and identity. Some residents/patients may be more aware of the transitions than others but most older people recognise admission to care as a major life-event.

Living and dying

Changes in a person's physical functioning and a decline in cognitive abilities may raise questions about the nature of future support and care provided. A lack of recognition of the potential meaning of this zone can lead to instances of over and under-intervention of care, depending upon how the future is perceived – is it one of living or of dying?

Dying and death

Awareness in older people and their families and/or staff, that the older person is 'actively' dying is associated with implicit or explicit acknowledgement of the 'dying' status of the person. Entry to this point may be gradual or it may be clear cut following an acute illness episode such as a stroke.

Bereavements

Anticipatory and actual losses may be experienced concurrently within the *Living with Losses* zone for older people, their families and staff. These will become more prominent during the *Living and Dying* and *Dying and Death* zones. Following the death of the older person, bereavement may be experienced by families, friends, co-residents, co-patients and staff. Care for older people's families needs to continue after the death, as they face the future without the deceased.

Figure 1: An Individual's Life – Death Trajectory
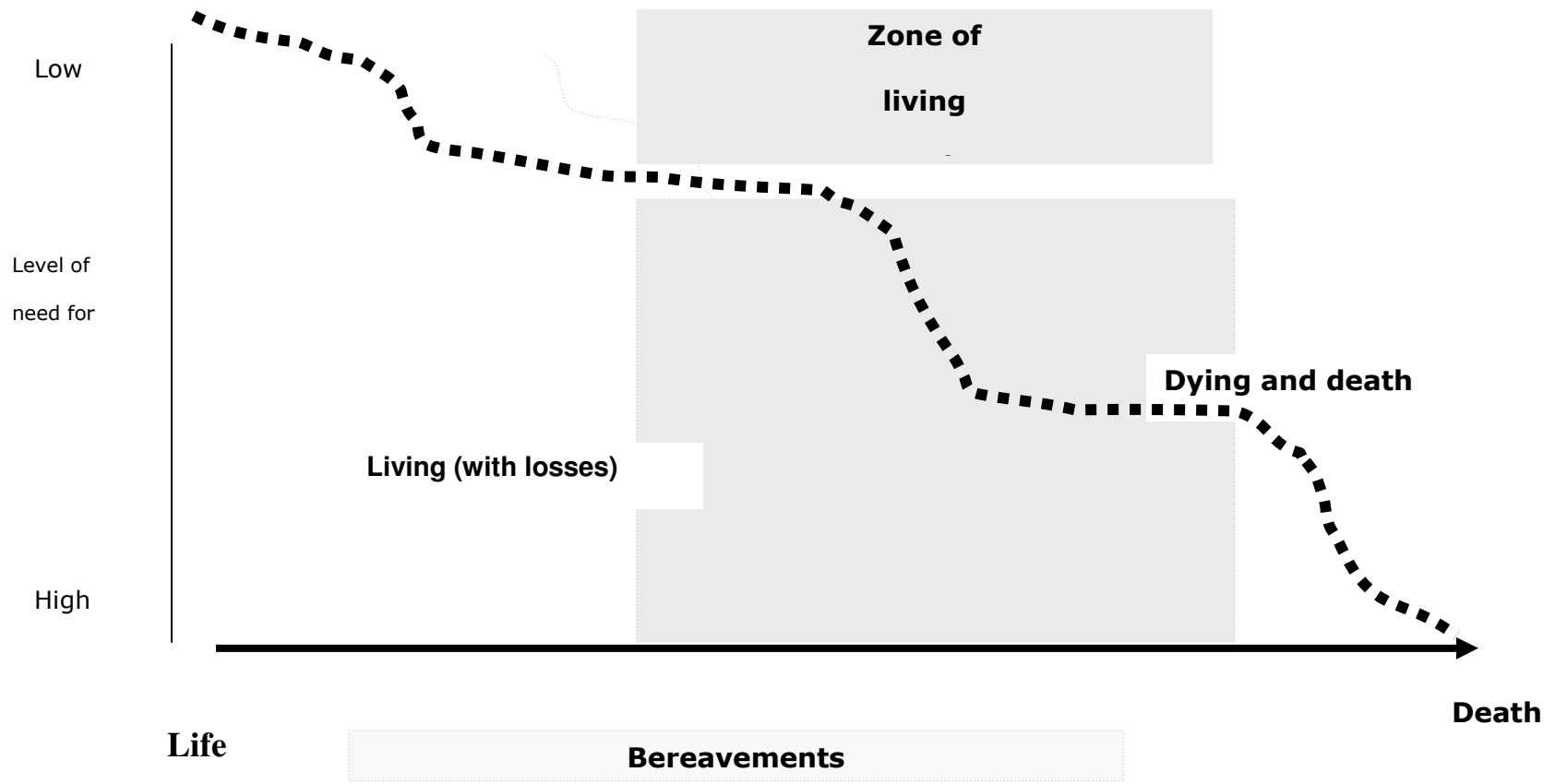
While we see these zones as mainly sequential, the uncertainty of dying trajectories or pathways in late old age and the phenomenon of 'bounce back' mean that a person may experience a number of episodes where they may be perceived to be in the *Living and Dying* zone. There may be 'fuzzy boundaries' between *Living with Losses*, *Living and Dying* and *Dying and Death* zones.

Focus for and dimensions of the framework for end-of-life care

End-of-life care provision should be:
• Respectful of the older person and promote of their dignity
• Supportive of families (the term families will include friends and significant others) who are central to the experience of the dying person and have their own needs
• Supportive of staff and acknowledge the impact of loss and that bereavement may be experienced by them
• Facilitated by co-ordination between providers that acknowledges the movement of older people between care settings.

While the focus is on the care of older people in particular settings, we recognise that the wider social and cultural context shapes the values and practices in these settings. Good end-of-life care for older people must include individual level and social level responses and must take into account the rights and responsibilities of all parties.

We have therefore identified five areas of focus and four dimensions of care. The five areas of focus are as follows:
• The older person
• The family
• The staff within the care setting
• The organisation
• Wider society.

The four dimensions of care are as follows:
• Knowing and revealing needs
• Expressing values and preferences
• Interacting with others
• Developing knowledge.

Table 1: Framework Required to Ensure Good End-of-Life Care for Older People

Focus	Dimensions **Knowing and Revealing Needs**	Dimensions **Expressing values and preferences**	Dimensions **Interacting with others**	Dimensions **Developing Knowledge**
Older person	Recognition of changes for self. Willingness to reveal changes to others	Expressing values and decisions to others	Helping others understand what is needed to feel safe, comfortable, supported in distress. Respect for staff.	Confidence and 'language' to express things.
Family	Recognition of changes for self and older family members. Willingness to reveal these to others.	Ability to understand and express own values and decisions. Recognise values of older person and family members.	Helping older people in getting care/support compatible with wishes. Helping others understand what is needed to feel safe, comfortable and supported.	Confidence, knowledge and ability to engage with health/social care system.
Staff	Recognition of changes and losses for older person and family and of own needs in context of dying and bereavement work.	Seeking to understand values and preferences of older person and family members. Need awareness of own values.	Facilitating and eliciting experiences and views of older person and family members. Expectation of respect from older person and family.	Listening skills. Confidence to engage in difficult conversations. Models of loss and change. Ageing and dying.
Organisation	Recognition that older people and their families are facing loss and change and that staff are affected by deaths of older people and by distress of family members.	Agreed mission statement expressing organisational values and culture. Written protocols for end-of-life care, including support systems for staff.	Facilitating communication and information provision respectful of patient and family styles and preferences. Acknowledging support needs of staff at all levels.	Supportive organisational culture. Leadership and knowledge in seeking to improve end-of-life care. Facilitating change, innovation and excellence.
Society	Recognition of the value of talking about death. Valuing and listening to older people and their advocates.	Articulating differing cultural values re end-of-life issues and care.	Identification of places where interactions can occur e.g. schools, libraries. Prevention of ageism and other forms of discrimination.	Dying, death and society. Place of dying in ageing. Loss and change.

Knowing and revealing requires an explicit recognition of bodily, emotional, social and spiritual changes for patients, families and staff. Organisations must be able to recognise and respond to the fact that older people and their families are facing losses and life changes. At the level of society, death must be talked about with reference to cultural and religious norms and values. Older people must be allowed to express values and decisions to others. For that to happen, staff must recognise the primacy of patient and family values and preferences. They must be aware of their own values and the impact these might have on the caring process. Organisations have values too and they must be stated so that there is no ambiguity with respect to the approach to care at end-of-life. At a practical level this would involve written protocols for end-of-life care, including support systems for staff.

Interaction and communication about end-of-life are required at all levels, between patients and staff, between families and staff and within families and organisations. We recognise that for people with dementia or other conditions that affect the ability to communicate, there is a responsibility on the people around them - family or staff - to get to know the person and how they convey their wishes. The development of a life-long, inter-generational understanding of dying and death is also necessary for good quality care to emerge at the end-of-life. Ageism needs to be tackled to ensure that there is no discrimination against older people at end-of-life.

Without self and professional recognition of the changing needs of older people in hospitals and long-stay settings, it is hard for older people and their family to have their needs met. That is why ***developing knowledge*** is so important. Patients need confidence and language to express preferences. Likewise, families require knowledge to engage with the health and social care system on behalf of themselves and in partnership with the older person. Staff need listening skills and the confidence to engage in difficult conversations with people who are dying. A supportive organisational culture is needed to facilitate open communication about dying and death between staff and patients.

Levels of care and service provision
A tiered model of service provision is required to meet the varying needs of people at end-of-life in different care settings. We envisage four levels within this tiered model:
- Fundamental
- Enhanced

- Advanced
- Complex.

This model of service provision is based on complexity of need rather than a diagnostic category such as cancer or heart failure. It is based on the recognition of need, defined as 'distress', and on the ability of patients and family to report or display distress and/or of staff to recognise this. We see the levels of care in this tiered model as building blocks - as complexity increases so does the need for *additional* service provision rather than *alternative and separate* service provision.

We suggest that all older people in hospitals and in nursing homes need good quality **fundamental** care: attention to their comfort, dignity, safety and respect for their wishes. As their needs become greater and their level of distress becomes more difficult to address, some may need **enhanced, advanced** and ultimately **complex** care. The level of care must be assessed holistically in relation to four domains – physical, psychological, social and spiritual needs – as well as in relation to the extent of distress reported by the older person and/or family, or observed by others.

We realise that there is more to do here in defining the environments of care and the resources required for each level of care, which will require further research. The following description, however, offers a starting point.

Level 1: Fundamental
All care workers need to recognise that the older person and their family are facing changes in all domains of their lives on admission to the institution and as their condition deteriorates. They need to provide competent, compassionate care and communicate and provide information in relation to their level of expertise in a way that maximises safety and dignity in all care interventions (e.g. bed baths, serving meals). They should have appropriate skills in the provision of fundamental care, listening and communication and know when and how to refer to staff with greater experience and skills. Training should include an understanding of the basics of care provision, ageing and loss and change.

Level 2: Enhanced
An end-of-life care 'champion' should be identified from amongst the regular staff in each ward or long-stay facility. This person will need additional training and expertise but will have high credibility and a good understanding of cultural and organisational

practices. S/he will need skills in assessment of need across all domains and an ability to elicit the concerns of older people and their families. This person needs to have organisational backing to ensure they can release resources to support the older person and their family at specific points of distress and need during end-of-life care. S/he will need training to know the limits of his or her abilities and when to refer on.

Level 3: Advanced

Staff will be practising at a highly skilled level and may be part of a team covering a number of institutions or part of a specialist palliative care service. Typically, this care provider will attend the older person in their normal institution and/or provide advice and support to the care staff. This person will need advanced and specialist assessment skills (e.g. in pain management, symptom control, psychological screening) and will be able to advise on management strategies and deliver interventions. S/he will be able to support other staff in delivering elements of the specialist care planned. S/he will need regular supervision and opportunities to update his or her skills.

Level 4: Complex

This requires the input of a multi-disciplinary team with intensive input in the institution where the older person is or, if this is not possible, in a more appropriate care environment such as a hospice. Team members will need skills in assessment, monitoring and intervention delivery, including opportunities to update and extend their skills. They will need opportunities for supervision and critical reflection.

In each location, there will need to be educational input to develop staff skills and competencies in each of these areas. A potential educational framework could be provided through the *Senses Framework* (Nolan and colleagues, 2006) developed in the UK care home context. This would need further work for use in the Irish context and for end-of-life care.

Next steps

We would recommend a number of steps. First of all, the approach I have set out here needs to be tested in the field. Second, there is some overlap between this approach and that of the Irish Hospice Foundation's Hospice Friendly Hospitals

(HfH)[1] Programme; we believe that there is potential to learn from the HfH programme. Finally, we would encourage the integration of end-of-life care and gerontological practice.

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[1] The HfH Programme seeks to change the culture of care and organisation with regard to dying, death and bereavement. It focuses on four key themes: integrated care; communication; design and dignity; and patient autonomy.

Parallel Workshop Session:

End-of-Life Care Needs Of Older People
And
Good Practices In Response To Those Needs
In Acute And Long-Stay Settings

Workshop 1
End-of-Life Care
Clinical Needs And Practices

Chair: John Brennan

END-OF-LIFE care: Clinical Needs and Practices. In My End is My Beginning? Gerontological or/and Palliative Care in Healthcare: Can a focus on end-of-life care improve during life care?

Professor Desmond O'Neill, Consultant Physician in Geriatric and Stroke Medicine, Adelaide and Meath Hospital, Tallaght and President of the Irish Gerontological Society

Introduction

End-of-life care is an important issue. It raises two very important questions which we will consider here:

- Can a focus on end-of-life care improve during life care? To quote Mary, Queen of Scots, 'In my end is my beginning?'
- Where does the provision of gerontological care fit in with palliative care and end-of-life care when most older people will not die of cancer?

I welcome the report, *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland,* and its many insights into perceptions of end-of-life care. I would, however, point out that it does not report or comment on gerontological training of staff in these settings, and this is a major flaw which compromises the value of an otherwise excellent report for those who work with older people. It is really astonishing that the focus on training and education for end-of life care in the report concentrated on palliative care only, and not on gerontological nursing – considering that nursing is the core health profession involved with end-of-life care, and that gerontological nursing courses provides many of the elements of holistic palliative care. However, whether it is for nurses, doctors, psychiatrists or GPs, gerontological training contains within it the elements of good care for the complex care of older people. To talk about end-of-life care without this is, in my view, building without a good foundation. Gerontologically trained care staff and gerontologically trained nursing staff are the core of good care for older people.

Concern over care standards during life: Nursing homes

There are major concerns over care standards during life. The most recent Nursing Homes Report by Nursing Homes Ireland (2008) showed a level of funding that is incompatible with the delivery of complex nursing home care, if all residents truly

need nursing home care . It may be that many of the clients of these homes are residential clients rather than people needing nursing care: this is the only explanation for such a low level of funding. By the calculations of the Joseph Rowntree Foundation (http://www.jrf.org.uk/knowledge/findings/foundations/0186.asp), no less than at the time of the Leas Cross Report (2006) it is impossible to see how all of the needs of complex nursing home care could be met. Indeed, the fact that it is stipulated in the Health (Nursing Homes) Act 1990 that nursing homes should provide palliative care highlights the disconnect between the level of funding and that aspiration - and indeed, the legal requirement to do so.

We know – and we heard it from the report authors in their presentations – that there are inadequate numbers of adequately trained staff in palliative care skills. There is a lack of clarity over training, support and responsibilities of medical officers, in just the same way that this has not been articulated for overall care of older people in long term care. This is a key issue, and one that I have signalled to the Irish College of General Practitioners. The medical officer to a nursing home, looking after, say 90 older people, needs to reflect on what skills are needed? Equally, the practitioner needs to reflect on the support needed, and to clarify precisely between the HSE and nursing home as to who is to provide these? There is also a lack of specialist support for the medical officers. There has been talk of funding for increased geriatrician and old age psychiatry to support care in nursing homes but it has not yet materialised.

Main diagnoses

We need to remind ourselves why people are in nursing homes. It is predominantly due to neurological disease: 38 per cent of residents have dementia; 25 per cent have had stroke; others have Parkinsonism, neurological trauma or multiple sclerosis (MS). Most are going to die of the complications of stroke and dementia. Therein lies the challenge – in particular, that of swallow failure, one of the most intractable problems faced in neurological disease and for which neither geriatricians nor palliative care physicians have particularly good control over at the moment.

Services during life care

We now know that those discharged to nursing home care are neglected in terms of the care provided for therapy and specialist support. The table below, from Noone and colleagues (2001), 'What happens to stroke patients after hospital discharge?'

shows that 59 per cent of people in the community will be seen by an occupational therapist compared to 29 per cent of those in a nursing home; 15 per cent of those in hospital get the services of a speech and language therapist (SLT) compared to seven per cent of those in a nursing home. These findings are similar to those of the Irish National Audit of Stroke Care (2008).

Table 1. Services for patients with acute stroke (Noone and colleagues, 2001)

	Community	**Hospital**	NH
Physiotherapy	72%	70%	48%
OT	59%	60%	29%
SLT		15%	7%
Day Services	48%	5%	5%

The level of provision of services to people in nursing homes during life – before we start to consider end-of-life – is dismal.

Concern over care standards during life: Hospital
There is a systematic failure to recognize functional loss in hospitals. Identifying functional loss is key: it determines whether you are going to die or go to a nursing home, and it determines your length of stay in hospital. There is also a systematic failure to adapt services to the needs of older people.

It is important, however, not to paint an unremittingly bleak picture: things have developed and moved on. I was the ninth geriatrician in Ireland; there are now 53. One third of people over the age of 65 in our hospital as medical emergencies come under the care of geriatrician. We do need, however, to concern ourselves with the two thirds who do not: acute geriatric medical services have been shown to reduce death and disability by 25 per cent (Ellis and Langhorne, 2005)

The report presents nursing staffing ratios for hospitals (1:0.6), for public facilities (1: 2.1) and for private facilities (1: 5.3). There are those who might say that, in OECD terms (Simoens, Villeneuve and Hurst, 2005), the staff ratio for public settings is relatively high; the ratio for private settings on the hand must raise questions as to whether or not you can deliver good care during life and good end-of-life care with such a staffing ratio - unless a large proportion of patients are residential rather than nursing care patients.

The data on nurse to patient ratios would be more useful if we knew what the nursing staffing ratio is for hospices. In one hospice I know of there is 86 per cent occupancy; a bed is left vacant for 24 hours after a death in deference to the other people in the hospice and in deference to the staff. To many in a public sector running at over 100 per cent capacity, this is Shangri-la, a utopian ideal. Nevertheless we should be thinking about how we can start to develop that degree of sensitivity in our units. It does presents a challenge – but rather than get irritated by it, and say that we cannot do it, we must work out how we can incorporate aspects of that element of care within what we have. It is not that we do not want it, it is that we do not know how to go about getting it - and that is something we may learn. The approach of the hospice sector also serves to highlight the important role of the voluntary sector: it is only a strong voluntary sector that can pose such challenges to the HSE and the Department of Health and Children and say, this is how we run things.

Changing paradigms
One of the reasons I enjoy working in gerontology is that we have turned the World Health Organization box on its side.

Prevention	Health gain	Health Maintenance	Palliation

The box portrays how we input into care: first of all, there is prevention, then health gain, health maintenance and lastly, palliation. But this is not what is happening. What is happening is that we experience all of these stages throughout life to a greater or lesser extent – from the palliation provided by a spoonful of Calpol in early life to the preventative 'flu injections in later life. This raises an important issue for the terminology we use in relation to palliative care and end-of-life care: the need to acknowledge that while palliation becomes increasingly important at the end-ofllife, it forms part of our armamentarium, part of our philosophy of care, *throughout life*.

Effectiveness of palliative care in dementia
Dementia must be the key area of interest. In a recent review of 40 published articles on the subject of effectiveness of palliative care in dementia, Sampson and colleagues (2005) found that there was no evidence of care benefit – no clear indication of effect. (Of the 40 articles only four of the studies reported were eligible and only two were judged to be of sufficient quality.) This finding should be taken with

some caution: the absence of evidence is not evidence of absence. My sense is that if there is a good level of gerontological care administered by staff with a high level of training then the input of specialist palliative care becomes much less of a core concern. While I was Visiting Professor at the University of Louisville, Kentucky - where Medicare (the US federal government health insurance for older people) mandates some time in palliative care for people with dementia - I visited a voluntary run nursing home where there was a high level of nurse and physician training and a comprehensive programme of diversion activities, including art and music therapies. The palliative care physician who visits once a week said that he had little to do at this nursing home whereas in those nursing homes where there is not this level of training and attention he reported spending most of his time doing the job of a geratrician or a psychogeratrician.

The recommendations of the report, End-of-Life Care in Acute and Long-Stay Care Settings in Ireland

If I had to review the six recommendations set out in the report I would first of all re-order them, putting the last one – testing new models – first. I would also add to them (in *italics*) as follows:

- Testing of new models and approaches that bring about a greater fusion (*understanding of commonalities*) between end-of-life care and gerontological care within all long-stay settings in Ireland.
- Greater consultation with older people in order to establish needs and preferences with respect to *(during life and)* end-of-life care
- An improvement in the physical environment where people *(live and)* die, particularly with respect to the availability of single rooms and facilities for families and friends.
- Greater cultural awareness and understanding of dying and death, including consideration of the current disparity of esteem between younger and older *(lives and)* deaths within the health and social care system.
- Policy reform to ensure that end-of-life care is recognised as an important public health issue, separate to palliative care but inclusive of many of its key elements.
- Develop practice to ensure that *(gerontologically informed during life)* and end-of-life care for older people is integrated into the everyday life and work of acute hospitals and long-stay facilities.

The challenge in all of this is an inexorable move throughout health systems to de-professionalization and genericization. We need to make sure that we have a balance between generic skills and training, and specific skills and training. The professions, and those who are sub-specialists within their profession - including gerontologists - need to be both honest and tough: honest to recognize that this battle between genericization and specialization is occurring, and tough and honest to find our role within it.

To conclude

We must capitalize on the current attention on, and interest in, end-of-life care. Now is the time to say that better end-of life, and during life, care can be provided for older people. We must look at the resources that are seen as norms for end-of-life care and we must claim them corresponding needs-related care for during life care.

The role for the voluntary sector is hugely important. When my patients leave extended care there is a clear preference for voluntary institutions over public and private institutions. How to build that sector is a key challenge, as it has been one of the successes of the hospice movement.

Finally, what we need now is investment in gerontological nursing, medicine and therapies. It is my view that there should be at least one nurse on every ward in every hospital with a Postgraduate Diploma in Gerontological Nursing. We need to recognize that the care of older people is complex and we need to front-load it with knowledge that saves everyone time, effort and money. The question is this: is palliative care nested within that?

Recommended reading: some recent articles

I would draw your attention to some recent publications that are of particular relevance here:

- Rozzini and colleagues (2007) ask the question, do we really need palliative care for patients with severe dementia? The answer is yes, we do - but we need someone to decide when it is that the person is moving from predominantly health maintenance to end-of-life care. Geriatric medicine and gerontologically informed care are probably the skills that we need to work that out.

- R. Rozzini, T. Sabatini, A. Ranhoff, and M. Trabucchi. 'Do we really need palliative care for severe dementia patients?' Age and Ageing Advance Access published on September 1, 2007, DOI 10.1093/ageing/afm035. *Age Ageing* **36**: *584-587.*

- Dylan Harris's paper (2006) is probably at the aspirational end of things: he suggests that we are not paying enough attention about what can be incorporated in terms of palliative care in gerontological nursing.

- D. Harris. 'Forget me not: palliative care for people with dementia.' *Postgraduate Medical Journal 2007*; **83**:*362-366*; doi:10.1136/pgmj.2006.052936

- We have the Mini Mental State Examination (MMSE) - Aminoff and Adunsky (2004) argue for use of the Mini Suffering State Examination (MSSE).

- Bechor Zvi Aminoff and Abraham Adunsky. 'Dying dementia patients: Too much suffering, too little palliation.' *American Journal of Hospice and Palliative Medicine, Sep 2005;* **22**:*344 - 348.*

- An excellent overview of ageing and in a way the best textbook of gerontology is the October 2007 *Annals of the Journal of the New York Academy of Science* on healthy ageing and longevity. Contained here is Small's paper, 'Living well until you die: Quality of care and quality of life in palliative and dementia care.' It points out the commonalities between geriatric medicine and gerontological nursing care, and palliative care.

- N. Small. 'Living well until you die: Quality of care and quality of life in palliative and dementia care.' *Annals of the New York Academy of Science.* **1114:** 194–203 (2007).

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Workshop 2
Communicating About End-of-Life Issues

Chair: Bill O'Herlihy

Communicating About End-of-Life Issues

Dr Max Watson, Consultant in Palliative Medicine, Northern Ireland Hospice

Introduction

My aim here is to examine what is meant by end-of-life issues, to look at staff perception's of these issues as they relate to communication and to examine communication issues within each of the four dimensions of care - knowing and revealing needs; expressing values and preferences; interacting with others; and developing knowledge - described in the report, *End-of-Life Care in Acute and Long-Stay Settings in Ireland*, and in Katherine Froggatt's seminar presentation.

First of all, it is important that we realise that this report, *End-of-Life Care in Acute and Long-Stay Settings in Ireland*, is about *us* – it is not about '*them*'. End-of-life care in these settings is a service *for us*. It is also important to keep in mind that the reason the report examines end-of-life care in both long-stay and acute settings is because it is in these places that most older people, most of us, will die – from all types of illnesses.

What are end-of-life issues?

There is a perception that end-of-life care for older people is the same as or the equivalent of palliative care in a hospice. It is not. It is something very different from standard palliative care. It is linked to quality of life issues: the dying, after all, are the living. As set out in the HIQA Draft National Standards for Residential Care Settings for Older People in Ireland (2008), it is about 'an explicit end-of-life care standard which embraces a holistic, person-centred approach to the care of the dying.'

The report encourages us to think beyond our comfort zone: it is saying to us, 'Your background isn't big enough; you don't know enough; you need to step outside of your circle of comfort into the bigger area that is end-of-life care.'

Focus internationally is shifting to a broader understanding that goes beyond palliative care provision for cancer patients to embrace a compassionate approach that supports people who are living with, or dying from, progressive or chronic life-threatening conditions. We know – and the report shows - that older people's

trajectories or pathways towards death are uncertain. We therefore need to have in place systems and structures that allow us to handle this uncertainty. While it may not be possible to know exactly when a person is going to die it may be possible to locate them on a pathway to death. Being able to do this allows us to know when it is that they might need the sort of care that draws on the care of traditional palliative care. The approach allows a longer lead-time to death. It also takes into account the potential uncertainty surrounding dying and death, including the possibility that some people follow complex and non-linear pathways to death.

Staff perceptions of end-of-life care and communication
What did staff feel was important to end-of-life care and communication? The report notes that they talked about the importance of open – 'good' - communication with the patient and with the patient's family. But what do we mean by good communication? It is time spent talking; it is sensitive; it involves privacy and dignity and respect; it involves active listening. We need time if we are to listen actively. The chief skill of communication is not being able to talk but in being able to listen. We are not good at it. It is not one of those things that is measured or assessed as part of our job appraisal. Nevertheless, as the report states, the need to develop good relationships is fundamental in communication at end-of-life. At the end of your life you need relationships that will sustain you, therapeutic relationships with a doctor and/or a nurse you can trust. We need to empower these sorts of relationships because at present they are not articulated as a part of the job description. The barriers identified in the report to good communication at end-of life are lack of space, lack of time, lack of training, cultural differences and lack of support for patients and staff. We can – and we must - learn from bad practice.

Dimensions of care

Knowing and revealing needs
There is no evidence that being older makes it easier for us to communicate our needs and wishes around death or to take part in a discussion about death. The researchers note in the report that they could not establish whether the reluctance of patients to talk about death was a self-deception or self-protection process.

Many staff members do not feel comfortable raising the issue of death and dying with patients. Why is that? Is it because it makes staff feel uncomfortable or is it because they do not believe that it is in the patient's best interest? We need to tease these

issues out. Staff say that there is a lack of knowledge and skill, that it is hard to find the right time to raise the issue, that they themselves may not have experienced the situation before, that there are cross-cultural issues because of multicultural staff, and that they believe that it is unsettling for patients. All of these contribute to inhibiting open communication. The common strategies used to deal with these feelings are to say things such as, 'You have to keep cheerful', 'Don't worry', 'Keep going', and 'Always look on the bright side'. In other words, distraction – but for whose benefit? As for staff from different cultures, we have to take responsibility for training and preparing them *before* they come into our culture so that they are ready when they arrive and do not have to think on their feet.

Expressing values and preferences
We worry a lot about choice because we live in an autonomous world. Yet if you have never had choice in your life how will you be able to take advantage of it in death? Emphasizing choice and autonomy is of little value if people find it difficult to talk about death and dying; choice at the end-of-life is of little value if you have not had choice from the moment of arriving in the acute setting or the hospice setting or the long-stay setting. In other words, we need to ask, is choice part and parcel of our culture or is it a tick-box exercise?

I believe that the palliative care approach needs to be adapted to fit the needs of older people. When it comes to expressing values and preferences the report shows that patients are largely positive about the care they receive. But in interpreting this you must remember that there is a power relationship between resident and staff: what resident is going to complain to a staff member about the care they received from another? It might not be sensible to do so.

Interacting with others
The bottom line is that you cannot *not* communicate. We communicate through our structures – for example, the curtain between beds. We communicate when we do not use words. Interactivity is a crucial part of life. It is about relationships. It is important to remember that the older people we meet in acute and long-stay setting are *us;* they are not different to us.

Developing knowledge
Most staff, if asked, will say that they want more training. What we need, however, is not more training courses but rather adult learning systems – systems that monitor

what we do and give us feedback so that we know how we are doing and what we need to do to improve. How do you achieve this when the HSE is not going to pay for it or provide it? We need to think of ways in which we can provide it that are practicable.

To conclude

Each of the report's six recommendations has a communications aspect to it – from the need for greater consultation with older people to investment in the physical infrastructure to remove inhibitions to communication to increasing cultural awareness to policy reform. We know that how many cases are taken out against doctors and nurses that relate to communication issues but yet we do not spend any money improving communication skills.

To finish, I would quote first of all McNamara (2004), who is cited in the report:

> '*There is such a variety of world-views in post-industrial society, from secularist to a wide variety of diverse religious/ spiritualist approaches, that the concept of a 'good enough death', where people are helped, insofar as possible, to be symptom-free and enabled to have control over how they die, is perhaps the most that can be achieved.*'

And, finally, to quote a member of the Sioux Nation, 'Western medicine is taking dying away from us and hiding it in hospitals.'

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Workshop 3
Personal, Pastoral And Spiritual Supports

Chair: Sr Mary Threadgold

Personal, Pastoral and Spiritual Supports

Carmel Molloy, Pastoral Care Worker, Louth Specialist Palliative Care Services

'You matter because you are, and you matter all the days of your life.'

Dame Cicely Saunders

Introduction

Three different ways of viewing ageing have been suggested (MacKinlay and Trevitt, 2007):

- Ageing as a period of physical decline that includes illness and disability and emphasize the 'burden' aspect of the ageing population
- Successful ageing - ageing which promotes continued engagement with the wider community and the pursuit of physical and psychosocial activities
- Ageing as a spiritual journey, one that involves a search to find meaning in one's life, and therefore reason for continued life and hope.

According to Touhy (2001), the nurturing of the body, mind and spirit is part of holistic care. As he notes, however, it is not often the primary focus in nursing homes - the focus there is on physical needs. He believes that 'limiting care to the physical needs denies elders the opportunity to live out their life with meaning, purpose, and hope.'

Pastoral care, spirituality and religion

Spirituality is about one's sense of one's inner self. It is about the meaning of life. It is about the principles and values one lives by and about what one treasures and values. It is also about one's deepest relationships with the self, with others, with the earth and with the transcendent – with God or however that is understood and experienced. Religion is about the outward expression of spirituality. It is a framework, a system of beliefs, values norms and rituals. It is supported by a community of people who believe in and are guided by the same story. Pastoral Care seeks to pay attention and respond to both spiritual and religious needs.

Spiritual needs

Spiritual needs are as follows:

- To be loved and to give love
- To believe in oneself

- To have hope
- To have peace
- To find meaning in life, loss, suffering and death
- To be involved and to contribute
- To forgive
- To connect
- To belong
- To grieve.

Spiritual needs can be particularly acute at different times – for example at times of change, on recognition of ageing, at time of illness, with terminal illness, in bereavement and as death approaches. Spiritual distress can be manifest as fear, anger, guilt, denial, hopelessness, restlessness and depression. Spiritual care is about helping people find meaning, hope and wholeness in their life and in relationships and it is about responding to spiritual pain. Responding to spiritual needs involves giving people the opportunity to talk and reflect, asking questions such as 'How are you doing?' and 'How are you within yourself?' There are activities which can touch a person's spirit or sense of themselves. These include reading, the expressive arts, music, walking, gardening, plant or pet therapy and intergenerational work. Storytelling can be important. As Sue Monk Kidd (2006) says,

> '*Discovering our personal stories is a spiritual quest. Without such stories we cannot be fully human. For without them we are unable to articulate or even understand our deepest experiences.*'

MacKinlay and Trevitt (2007) define spiritual reminiscence as a focus 'on the meaning of life through the life story, including connectedness, and the faith context… and on what has given joy or brought sadness.' They note that spiritual reminiscence 'may identify events that caused anger, guilt or regret.'

Primarily, we respond to spiritual needs by the quality of our presence, by accompaniment, by companionship. Dame Cicely Saunders (2003) says that,

> '*Our most important foundation … is the hope that in watching we should learn not only how to free the patient from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen and how just to be there.*'

Religious needs

Religious needs include being able to connect with a faith community and to celebrate with the faith community. They also involve having access to local religious leaders, having access to a quiet place or space, and having customs and rituals respected. Responding to religious needs means enabling celebration of religious services, prayers, feasts and so on and helping the person to maintain contact with his/her local faith community as well as providing facilities for the observance of rituals and customs. The UK National Institute for Health and Clinical Excellence (NICE) sets out standards for provision of spiritual support services.

Implications for service providers and for society

There are implications for staff in terms of providing personal, pastoral and spiritual supports. Staff must be at ease talking with patients and families about religious and spiritual needs and must be able to make an assessment of a patient's spiritual needs. They must also be comfortable with the idea of accompanying a patient/ family member. They need to be aware of their own beliefs and to have an ease when listening to and talking to someone with a different set of beliefs or way of expressing faith. They must be culturally aware. They must be at ease talking about dying and death. They need to be aware of any possible personal bereavement issues and to be able to deal with personal unresolved issues around death and dying. Thus there is a need for training and education in the spiritual care of older people and a need for training in cultural awareness. Appropriate support needs to be in place to enable staff to grieve the loss of a patient and the relationships they may have established with patients' families.

Implications for funders and managers include the need to provide both space and personnel so that appropriate spiritual care can be available for patients and family members and the need for training in spiritual accompaniment.

There are also implications in terms of society. Public attitudes towards ageing, dying and death need to be developed and challenged through public education and information campaigns. As to the implications for church representatives, they must be aware of the importance of keeping in touch with members of their faith communities, and that pastoral care involves spiritual as well as religious care.

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Workshop 4
Designing For Dignity

Chair: Rodd Bond

Designing for Dignity

Daphne Doran, Standards Development Manager, Hospice Friendly Hospitals Programme

Introduction

Dignity is hard to define. It is a concept that is related to respect and honour. It is easier to identify indignities than it is to define dignity. According to the Irish Council of Bioethics (2007) competent adults have the right to self-determination and related rights to bodily integrity, privacy and dignity.

The Hospice Friendly Hospitals (HfH) Programme has dignity as one of the principles underpinning the HfH *Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care* (2008), and states that:

> *'Dignity refers to the state or quality of being worthy of respect, and the healthcare environment can contribute to or detract from a person's sense of self respect and the respect of others. People strive for and are entitled to dignity in dying and in death. Healthcare systems should ensure that patients are cared for and die with dignity and that all care and treatment is provided in environments that safeguard and promote respect for the individual and a sense of self worth. Healthcare design should therefore actively seek to prevent indignities arising from inappropriate environments. People wishing for a dignified death fear one where their intimate and personal needs will be exposed and they will be subjected to demeaning environments which cannot support provision of compassionate care. Good hospital design must promote the dignity of and respect for the dying patient, grieving relatives and fellow patients.'*

The importance of the physical environment

The physical environment plays a major role in the management of death, dying and bereavement in hospital and long-stay settings and there needs to be investment and improvement in our hospitals so that they better facilitate quality end-of-life care.   .

Where people die

According to the Central Statistics Office (CSO, 2006), 30,000 people die each year in Ireland. Just over 75 per cent of these deaths are people aged 65 years and over.

Of these, according to the report, *End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland*, 40 per cent occur in acute hospitals; 40 per cent in private nursing homes and public long-stay care facilities; and 20 per cent at home.

Definition of a good death

In 1997 The US Institute of Medicine defined a good death as:

> *'… one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.'*

Factors involved in good end-of-life care

Environmental factors identified in the report, *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland* that can contribute to good end-of-life care as are:

- A relaxed, friendly, comfortable, peaceful supportive environment
- The availability/provision of single rooms
- Facilities that provide privacy and enable family and friends to visit
- Facilities for relatives.

Barriers

The report (p.127) also states that it can be difficult to create the ideal environment for people to die:

> '*Infrastructural deficiencies are a barrier to providing optimal end-of-life care. Lack of space is a problem, especially in public care settings. Respondents from acute hospitals, psychiatric hospitals and voluntary homes/hospitals refer particularly to the lack of single rooms and dedicated space for older people who are dying in their facilities. This problem is sometimes more pronounced in acute hospitals where patients may have to be moved around due to the lack of available space. The busy and noisy environment of a large hospital with adiverse patient mix further impedes the delivery of good quality end-of-life care.*'

Effects on patients and staff

The physical environment was highlighted by staff participants (p.159) in the study as a particular issue in delivering quality end-of-life care. Most believe that a single room

is the best place for a patient to die, providing privacy and dignity for patients and families, while not disturbing other patients.

> 'We haven't got any sort of a dying room... What we do is sort of put them into a corner... If a person is dying we usually put them into a corner … .'
> 'But I find it awful to be honest ... Because there is no privacy ... So many people flying in and out that the curtain ends up just at one end and the patient is just exposed.'

Enhancing the dignity of patient at the end-of-life

The Centre for Health Policy and Management at Trinity College, University of Dublin, identified from a literature review (2007) the main areas that can enhance the dignity of patients as they approach the end of their life. These are:

- The external environment
- The internal environment
- Single rooms
- Working environments for staff
- Facilities and services for relatives.

The Design and Dignity Baseline Review (2007) produced by Tribal Consulting for the HfH Programme identified concerns about the areas referred to in this literature review. In particular it identified a lack of the following:

- Attention to external and natural surroundingsSingle room accommodation (six per cent of the total available beds) and how that limited single room accommodation is used mainly for infection control purposes Facilities for one-to-one consultations
- Optimum working conditions for staffFacilities for families in hospitals and mortuariesProvision for different cultures and beliefs.

The HIQA *Draft National Quality Standards for Residential Care Settings for Older People in Ireland* (2008) are a key document to ensure quality residential care for older people. The standards cover areas such as rights, protection, health and social care needs, quality of life, staffing, the care environment and governance and management and significantly include a standard for end-of-life care.

The End-of-Life Care Standard states that:

'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.'

Other criteria within the HIQA Standards relevant to dignity and end-of-life care are as follows:

16.5   The residential care setting has facilities in place to support end-of-life care so that the resident is not unnecessarily transferred to an acute setting except for specific medical reasons, and in accordance with his/her wishes.

16.6   Every effort is made to ensure that the resident's choice as to the place of death, including *the option of a single room* or returning home, is identified and respected.

16.7   The resident's family and friends are facilitated to be with the resident when he/she is very ill or dying and *overnight facilities* are available for their use. Upon the death of the resident, time and privacy are allowed for his/her family, friends and carers. An atmosphere of peace and calm is maintained at all times.

25.10   The residential care setting provides a light and tranquil environment through the use of appropriate colours and furnishings.

25.54   There is a minimum of 80 per cent of residents accommodated in single rooms.

25.40   In existing residential care setting [shared] bedrooms currently shared have at least 7.4 m² per resident. By 2014 there are no more than two residents/room except in a high dependency room - up to six highly dependent residents can be accommodated together.

25.22   Screening is provided in rooms with more than one occupant to ensure privacy for personal care.

HfH Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care

The design of a hospital and the hospital environment affects the patient's death and their relative's memories of the death. Matters that promote and sustain patients' dignity at end-of-life must be central to the design of hospital and long-stay setting environments of the future. The HfH *Design and Dignity Guidelines for Physical*

Environments of Hospitals Supporting End-of-Life Care (2008) provide the necessary guidance for the design and planning of hospitals so that the buildings can support quality end-of-life care. The Guidelines are also appropriate for community hospitals and other long-stay settings, enhancing the HIQA *National Quality Standards for Residential Care Settings for Older People in Ireland*.   It is anticipated that the *Guidelines* will primarily be used in the development of project briefs for new hospital buildings. They are also relevant for refurbishment projects, and can be used to assess existing facilities and guide improvements.

The *Guidelines* are underpinned by the promotion and protection of the following principles:
•   Dignity
•   Privacy
•   Sanctuary
•   Choice and control
•   Safety
•   Universal access.

Evidence-based design (EBD) considers the links between the building design, the environment and patient and staff outcomes.   Evidence-based design in healthcare can support the creation of safe, therapeutic environments for patients, promote effective delivery of care, and improve working conditions for staff.   The HfH Guidelines develop several EBD issues for application to physical environments for dying, death and bereavement including wayfinding, single rooms, the visual and sensory environment, art in healthcare environments and staff issues.

The *Guidelines* promote the **option** of a separate single unit of accommodation with individual en-suite facilities for all patients approaching end-of-life. For patients who wish for privacy at end-of-life, that option is very important. With additional benefits of:
•   Facilitating treatment and delivery of intimate personal care without impacting on the dignity of the patient or other patientsProviding less stressful conditions for patients, by minimising disturbance from other people Offering more control over the immediate environmentProviding people with more choice in activities of daily life

- Providing optimum conditions for protecting patient confidentiality Facilitating good communication by doctors and nurses
- Supporting minimal contact with other patients' illness or death
- Providing best protection from hospital acquired infection
- Facilitating the short-term repose of the patient immediately after death and prior to removal to the mortuary, with minimum impact on other patients.

Advice is provided within the *Guidelines* on design of areas used by patients and relatives such as arrival areas, entrance and reception areas, circulation spaces, a multi-faith area and gardens, patios and courtyards. Advice is also included on relatives' rest rooms, relatives' accommodation, catering facilities for relatives, sitting rooms and sanctuaries. Staff needs are also considered and design guidance is provided for key areas for staff involved in the provision of end-of-life care. Finally guidance is provided on design of mortuaries to meet the needs of bereaved relatives.

Summary
The study, *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland,* promotes a framework for good end-of-life care. This framework should be:
- Respectful for the dying person and promote their dignity
- Supportive of families who are central to the experience of the dying person and have their own needs
- Supportive of staff and acknowledge the impact of loss and that bereavement may be experienced by them.

These issues are addressed in the HfH *Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care* and the HfH Programme will strongly encourage all involved in future developments of hospitals and long stay care settings to adopt them so that the environments where end-of-life care is provided can ensure the dignity of the patients and support their relatives and the staff providing care.

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Workshop 5
Decision Making And Advance Care Planning

Chair: Dr Doiminic Ó Brannágain

Decision Making and Advance Care Planning

Patricia T. Rickard-Clarke, Full-Time Commissioner, Law Reform Commission

Introduction

The first thing is to identify the work that the Law Reform Commission (LRC) has been doing on the area of decision-making. We produced a consultation paper in 2003 on *Law and the Elderly*; in 2005 we produced a further consultation paper on capacity and decision making, *Vulnerable Adults and the Law: Capacity*; in 2006 we produced a final report, *Vulnerable Adults and the Law* in which we proposed a new structure for decision making for adults taking into account constitutional law, rights and the Human Rights Convention and the important part of the participation of the individual in decision making. That legislation is now being drafted and we hope that the Government will publish the Bill this year as part of its legislative programme.

During this work on decision-making the issue of Advance Care Directives did arise. We felt that we should postpone this and do a separate study on it. We felt that since Ireland is so far behind in terms of a proper structure for decision making that it would be best to identify this structure first before dealing with other issues. We hope to publish a consultation paper on advance care directives in July 2008 and we plan to devote the LRC annual conference in October 2008 to the topic.

In this presentation I will cover the current Irish position and give you some examples of provision elsewhere.

What are advance care directives?

Generally what we mean when we talk about an advance care directive is this: an individual making a decision or series of decisions on future medical treatment which is designed to take effect should the person lack the requisite capacity to make the relevant decision at a future date.

With advances in medical science and medical technology, life can be and is prolonged. People make decisions to prolong life at all costs legally or ethically when the person concerned may not wish for this. It is important that the individual's decision is recognised.

Euthanasia is illegal in Ireland; it is important to note that any advance care directive cannot be against the law.

Form of a directive

There are three forms of directive:

- Instructional directives: in effect, a checklist. These can be inflexible and prescriptive and at the same time they can lack sufficient detail and definition to be directive.

- Proxy directives: a directive that asks someone else to stand in the person's shoes and make a decision. The main issue here is that the proxy may have his or her own view and may therefore not make the decision that the individual concerned would make.

- Combination directives: a combination of the above.

There are what are known as negative advance care directives: in effect, advance refusals of treatment. In the case *Re A Ward of Court (No.2)* in 1995 Mr Justice O'Flaherty noted that, *'There is an absolute right in a competent person to refuse medical treatment even if it leads to death.'* He based this on common law and on constitutional law. Denham J backed this view, saying that medical treatment given without consent maybe 'a trespass, a battery and an abuse of constitutional rights.'

The English *Mental Capacity Act 2005* deals only with advance directives to refuse treatment (even if it leads to death) and not to compel treatment. Under the Act, advance care directives are referred to as advance decisions. It is worth noting that you can refuse treatment but you cannot refuse basic care, that is, the offer of oral food and water and hygiene measures.

Positive advance care directives are advance requests for treatment. Here you are asking to be treated in certain ways. A person has a constitutional right in Irish law to refuse treatment but not a positive right to ask for treatment (except children, who have a right to immunisation).

Origins and development

It was a Chicago attorney, Luis Kutner, who first devised a living will in 1967, a directive in which a person stated what treatment they wanted in their final days. There are benefits to such directives. They relieve the family of the burden to make

decisions, if indeed they have that right. In other jurisdictions there is a developed health proxy regime. Advance directives allow incompetent patients to participate in decisions; and they help promote awareness of end-of-life decisions.

The Irish legal position

There is no legislation which addresses the case of advance directives in Ireland. There are no ethical guidelines set down by the Irish Medical Council. The English *Mental Capacity Act 2005* does give statutory recognition to advance decisions to refuse treatment. An enduring power of attorney (EPA) is a legal mechanism established by the *Powers of Attorney Act 1996* for granting certain decision-making powers to a nominated attorney in the event that the person loses capacity.At present, EPAs can only give attorneys the power to make property, financial and business affairs, and personal care decisions on behalf of the donor. The Commission has recommended that an enduring power of attorney (EPA) should be capable of permitting an attorney to make certain healthcare decisions on behalf of the donor where the donor lacks capacity to make the decision.

During our research we came across the widely held and entrenched view that next of kin could make decisions on behalf of their next of kin who are ill. This is completely divergent from the legal situation in Ireland. There is no legal basis for next-of-kin to consent to medical treatment on behalf of an incapacitated patient. Madden (*Medicine, Ethics and the Law* (Tottel Publishing 2002) at paragraph 11.57.) states that a court would uphold the validity of an advance directive if first, the individual was competent and informed when they made the decision set out in the directive, and second, that it was clear and specific to the patient's current situation. She argues that this is in keeping with the court's development of the unenumerated constitutional right to refuse medical treatment (Re a Ward of Court (No.2).

Formalities

Under the English *Mental Capacity Act 2005*, an advance directive can be written or oral. However, the more serious the decision, the more formality is required. For example, those directives in relation to life-sustaining treatment, as we note below, must be formal. An advance care directive (or decision as it is referred to in the English Act) can be made by a person aged 18 and over. It can be set out in layman's terms. It must be valid – in other words, it must be ascertained that the person has not withdrawn the decision set out in it, that he or she had the capacity to

make the decision when they made it. Also, a decision is considered to be no longer valid if the person subsequently made a lasting power of attorney, with the decision given to a proxy. It is also considered no longer valid if the person has done something that indicates that he or she has changed their mind (see the case of *HE v A Hospital NHS Trust*). The advance directive or decision must also be applicable: it must apply to the proposed treatment – in other words, it is a decision in relation to a particular treatment.

In the case of decisions to refuse life-sustaining treatment a greater level of formality is required, as we noted above: the decision must be verified by the maker that it is to apply to the treatment even if this puts his or her life at risk. It must be in writing and it must be witnessed. The Code of Practice that accompanies the *Mental Capacity Act* 2005 recommends that it is good practice to have the benefit of the advice of a healthcare professional thus enabling the individual to understand the implications of the decision.

In Ireland a person over 18 has the power to make decisions. In Section 23 of the *Non Fatal Offences Against the Person Act*, a person over age 16 can make decisions in relation to any surgical, medical or dental treatment. This Act does not provide for the refusal of treatment and this needs clarification in law. As we noted above in the UK an advance directive can be made by a person aged 18 and over; the age varies in other jurisdictions, for example in Denmark it is age 15 and over.

The issue of informed consent

Informed consent is an important consideration. If a treatment is to be carried out then the question arises, does the individual really understand what s/he is doing? This is important under human rights law, constitutional law and in the law of torts. There is no requirement in the English *Mental Capacity Act 2005* that it be an informed decision, that the person should have up to date information. However, we feel that this is important in our jurisdiction. Should we propose a statutory regime to say that informed consent is required? How could that be achieved? It means in reality getting professional advice. The British Medical Association guidelines recommend that this should be so; the Irish Council for Bioethics notes that it is important to be specific in outlining preferences for particular treatments and scenarios and therefore it is important that counselling is required.

Reviewing an advance care directive

There is also the issue that if a decision has been made many years before, should it be updated? How often should it be updated? Under the English *Mental Capacity Act* there is no time limit on the date of a directive and the date of its execution. As time passes questions of validity, relevance and applicability arise. There is no provision for review of a directive under the English *Mental Capacity Act*. The Irish Council for Bioethics recommends that there should be a review, as does the Scottish Executive in its Guide to Advance Statements.

Revocation

The English *Mental Capacity Act 2005* provides that an advance decision can be withdrawn at any time when the person has the capacity to do so. The withdrawal need not be in writing, it can be an informal revocation unless the directive was in relation to life-sustaining treatment. For our jurisdiction it is important that we have clarity on this point.

Storing an advance care directive

There is no guarantee that an advance care directive will reach the appropriate physician at the appropriate time. Some countries have registries, for example the US Living Will Registry and Livstestamenteregistret in Denmark. In order that it be brought to the attention of the appropriate person it is important that a formal system be initiated.

Reform options

We have no case law and no legislation in Ireland. The challenge for the LRC is to decide whether we set down in prescriptive, statutory form provisions for directives or decisions or whether we set down guidelines backed by a statutory code in relation to general principles. We must make decisions about what we call these directives; we must decide if they are to be positive or negative; we must decide on age and so on. As to examples from elsewhere, the Hong Kong Law Reform Commission chose a non-legislative approach with a Model Form Advance Directive, publicity programmes and a review; the Manitoba Law Reform Commission introduced Non-Statutory Guidelines.

Final Session:

Quality of Life at the End-of-Life: Issues for Society, for Service Providers and for Policy

Chair: Dermot McCarthy

Promoting Quality of Life at the End-of-Life Issues for Irish Society

Marian Finucane, Journalist and broadcaster, RTE

It strikes me, whether you look at what we have achieved, the Peace Process in Northern Ireland or the IFSC, for example, that we are a country full of people with intelligence, skill, compassion and commonsense. We have all of these qualities in abundance. Yet when it comes to the question of care at the end-of-life we behave as if we are stupid, uncaring, dismissive, insensitive and, broadly speaking, cruel. Not in all circumstances but in some. I do not understand why we cannot, with the collective intelligence we exhibit in other areas, apply these qualities to the event that is going to happen in every one of our lives.

We may not want to die but when we are dying there are some things we want: we would like to be listened to; we would like our wishes about certain matters to be respected; we would like to be in a physical environment that is not depressing; we would like to avail of the best skills available, from simple kindness to pain control.

It seems to me, however, that we do not do end-of-life care very well, except in some instances where we do it brilliantly. Why is that we cannot look at those situations, take the learning from there and apply it to other settings? That we cannot do this is beyond belief. All it requires is a decision and an act of will. It is a decision and an act of will essentially on the part of the government to drive it but it is also a decision and an act of will, a commitment, from all of you practitioners. If we decide that we are going to do it, then we can do it.

Sixty per cent of us are going to die in an acute hospital. I do not want to die in an acute hospital but it may very well happen - it may be that I will not have any control over it. I was at a meeting in an acute hospital about these issues. Everyone was there - from consultants to administrators to domestic staff. The domestic staff were shy and not confident about speaking up in front of the 'head honchos'. Eventually one woman spoke up. She said that from her experience of working in the hospital it was the last place that anyone should go to die. She told about bringing tea and biscuits and talking to a man who been in the hospital for several years. No-one took much notice of him. His wife was dead and when he was in hospital the last of his daughters died. He had no grandchildren; he was on his own. He had some kind of

medical event and people rushed to his bedside to resuscitate him. The woman was appalled. The man had told her many times that what he wanted more than anything else was to slip away. He was a man of faith and he wanted to go to meet his wife and daughters and the rest of his family. The woman thought that what had been done by the hospital to this man was bordering on cruelty. I agreed with her.

Where are the listening skills? We need to have listening skills in order to know what it is that people at the end of their lives want. Of course, if we get sick we want to be cured, if we have a heart attack we want to be made better. We want the best care that is available and we want it for all of those we love. But it is a sad, unavoidable fact that we are going to die; it is part of our life that we are going to die. We are born, there is the bit in the middle and we die. We put a huge amount of emphasis on the quality of life for that bit in the middle and we do not address the quality of life for the end-of-life.

If change is really to happen, I would suggest that acute hospitals make the provision of end-of-life care a key part of their annual service planning so that they must address annually.

The hospice movement has wonderful skills that are available to people with terminal illness. When my own mother was dying and in a very distressed state I rang St Francis's Hospital, a wonderful place, and they said, no they could not take her because they only dealt with people who had cancer. I said fine. They were very helpful, very supportive and kind. It took a few years for me to get a red, roaring rage about this. Someone said to me recently, if we were to provide hospice care on the grounds of religion, or if we discriminated on the grounds of gender or race, there would be an outcry – it would not be acceptable. The skills and the environment provided by the hospice movement should be available to every single person in the country: they should get this sort of care not on the basis of their diagnosis but on the basis of their needs. And the person with the greatest need should be the first in line. That seems to me to be the most reasonable, logical thing in the world.

Quality of life at end-of-life is hard to provide in acute hospitals: they were built when we did not think about these things. But consider a very old person in such a hospital who needs to use a commode – the next bed is two feet away. The person's family come to visit to say goodbye – which have the right to do. But consider how distressing this might be for the person in the next bed who is perhaps recovering

and will live – that person has a completely different set of needs. This is why the Hospice Friendly Hospitals Programme is very important.

What you need when you are dying are dignity, peace, space and all of the basic things that you would not dream of doing without in your life. Why should you do without them at the end of your life? You need a room, your own toilet. You may want silence or music, friends, a party even - and why not? We have the skills to deliver this sort of care. Why have we not done it?

I would recommend that you listen to that tea lady from the acute hospital. She had more wisdom in her little finger about that man's life and death than all the skilled people that were available in that fine, large hospital. It is about time, too, that the people with different skills – the gerontologists, the palliative care specialists – talk to one another and work together. It is important that care at the end-of-life should be done in concert. Knowledge should be shared and should be delivered with dignity and respect. There should be the skills within nursing homes, private and public, to listen to the older person and to find out what his or her individual needs are. It is appalling how some people talk to older people. My 89-year-old uncle is frequently offended by people talking about him and his life rather than to him, treating him as though he were deaf – he is not- or as though he has lost his intelligence – he has not. They should instead be asking him what he does or does not want to do. We do not treat younger people this way – why should we treat older people this way?

We need to think about whether it is the best thing for an older person who has something wrong with them - and which may get worse - to be taken out of a nursing home or a small community hospital and sent to an A&E, to a large acute hospital. I think if you were to ask them you would find that many would say that they do not want to be moved, that they are happy where they are, near family and friends, in a place that the person may now regard as home. What we are talking about here is replicating the quality of life we would have in our own home. I do not want to get sick and I do not want to die but if and it does happen I would like to be in my own home with views that are familiar to me, with the photographs of my family around me, with the familiarity of my own space. It would seem to me that to provide services to those who can and those who want to remain at home is not rocket science. Since everything comes back to money, this approach would probably save money in the long term. These are important things to think about.

I know as a human being, as someone who has read the research and from my own experiences interviewing people, you must find a way to allow the person who is dying to tell you what it is that they want and you must find a way to hear that. Recruitment of staff with these qualities and training of staff to engender these very important qualities are essential. People must be allowed the respect of articulating what it is that would give them the comfort they need and that they deserve.

We know that all these things can be done. We just need to make the decision to do them and we need to do them.

Report of Issues Arising for Society from the Workshops

Yvonne McGivern

Many of the same issues in regard to society arose in each of the workshop sessions.

It was recommended that a dialogue on end-of-life care be instigated, a national debate about death and dying. It was felt that there is a need to get people thinking and talking about the issues involved. Opening up the topic for discussion and debate, it was felt, should serve to make everyone more comfortable talking about death dying and should help to lessen the fear - if not of death and dying then perhaps at least the fear of raising the issue, talking about it and listening to older people who are ill and/or dying.

It was proposed that this national debate should consider what end-of-life is – is it the last hours, the last days, the last weeks? And, allied to that, that it should consider what end-of-life care should involve. It was mentioned that some decisions about actions taken at end-of-life were driven more by a fear of litigation than by the needs and wishes of the dying person.

It is the older person who has the right to make decisions about his or her own healthcare - family members do not have the legal right to make such decisions. It was noted, however, how widely held the perception is – among the general public and among healthcare professions – that family members do have this legal right. There is a need to overturn this perception and to make it known that it is the older person's right to make these decisions. Ireland is at present far behind other states in issuing guidance and/or regulation on the form, use and standing of Advanced Care Directives, that is, plans or decisions made by a person about his or her care or treatment at the end-of-life. It was made known that the Law Reform Commission, which has done much work on this, will be issuing a consultative document in July 2008. The general public and healthcare professionals among others should be encouraged to make submissions.

It was felt that a national debate or discussion on death and dying and end-of-life care should help to address ageism and ageist attitudes in society and in the healthcare system. It should not only contribute to a cultural shift in our thinking

about death and dying and end-of-life care but also to a shift in thinking about how we think about ageing and older people, how we see life and living in older age, how we treat older people and so the nature of end-of-life care, and the manner and the environment in which we provide it. There is a need to increase awareness of the need for supportive, compassionate environments for people at the end-of-life and the need for holistic end-of-life care.

It was suggested that the annual NCAOP/Equality Authority/HSE 'Say No To Ageism' campaign should in 2009 focus on end-of-life issues.

It was recognised that Ireland in the last decade has undergone not only economic change but social and cultural change: the population is more diverse in its cultural and religious make-up; religious observance has declined among parts of the population; the nature of family relationships and living arrangements has changed. All of these changes, it was noted, have and will continue to have impact on how we care for older people at the end of their lives. For example, these changes mean that we need to build greater cultural awareness among staff in healthcare settings, including a greater awareness of religious and spiritual needs of older people who are ill and/or dying; we need to provide appropriate pastoral and spiritual care to the diverse population of older people; we need to provide a room for family members who may have travelled a distance to be with their loved one; and we need to provide end-of-life care facilities that are connected to the communities in which older people – in which we – have lived their lives, facilities that promote the inclusion of family and friends.

End-of-Life Care – Issues for Service Providers

Shelagh Twomey, Deputy Programme Manager, Hospice Friendly Hospitals Programme

Introduction

Before we look at some of the issues for service providers – those in acute hospitals – it is worth stepping back to look again at what end-of-life care is.

In an acute hospital end-of-life care encompasses all deaths that occur in that environment – which may range from sudden or traumatic death to death that is reasonably well predicted.

The meaning of the term 'end-of-life care' itself is somewhat unclear. Lorenz and colleagues (2004) define it as 'a chronologically indefinite part of life when patients and caregivers are struggling with the implications of an advanced chronic illness.' The UK's National Institute for Health and Clinical Excellence (NICE) in its *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer* (2004) notes that end-of-life care begins when it is possible to know someone is actually dying. It is a continuum rather than a point in time.

End-of-life care in an acute hospital

End-of-life care in an acute hospital is about many things. It is about creating space; it is about ensuring that the person feels protected, valued and accompanied on the final journey. It is also about helping families to take part in the provision of dignity and respect and to communicate effectively with the older person, the team and each other. End-of-Life care in an acute hospital is merely what we would want for our loved one or for ourselves.

Meeting the needs of those facing end-of-life

We know that people want to be pain-free. We know they want to be surrounded by family. We know they want to retain their dignity. We know they want to feel valued. We know they need privacy. We know they need effective communication. If we know all of these important things why is it that we often struggle with end-of-life issues in our hospitals? Let us look at the issues for service providers in acute hospitals in relation to the provision of end-of-life care.

Issues for Service Providers

In order to provide quality end-of-life care a focus on staff and systems is as important as a focus on patients and families - otherwise care will be 'hit and miss' and dependent on the individual.

In relation to the provision of care at end-of-life in acute hospitals, the outcome needed is that of a consistently high standard of care regarding all aspects of dying, death and bereavement within a quality improvement approach. It is acknowledged that a comprehensive framework of standards to guide the management of dying, death and bereavement is required against which performance can be measured. The Hospice-friendly Hospitals Programme is undertaking this work currently.

There is much that an acute hospital can do to support the delivery of quality end-of-life care even in the absence of such standards. Much of this is about effective communication within and among teams and between patients, families and service providers. Open case conferences, 'shared care' approaches, effective multidisciplinary team working are good examples of seamless service provision and of how integration can work within a hospital system and across services and settings.

Management support and resources

It is important that hospital management are explicitly supportive of quality end-of-life care, especially in terms of providing the resources it needs, and in measuring performance. Guidelines, procedures and standards must be in place to guide end-of-life care across all cultures. This is not the case currently but many hospitals are currently reviewing or developing these documents and seeking ways to ensure that the necessary education, training and systems are in place to support this.

The physical environment

The physical environment is an issue for service providers as much as it is for patients and their families. It is important to provide physical surroundings that are supportive of dignity and privacy for patients and families – private communication; privacy in accommodation; family space. We know that the environment has an impact on the well-being and recovery time for patients. Hospital staff also need supportive spaces.

The culture of the hospital

The culture of an acute hospital also has an impact on staff. People facing the end of their lives need time, comfort and to feel protected and safe. This is not a time to feel rushed. There are difficult and painful decisions to make. There are difficult conversations to be had. All of this has to happen in the mayhem that is often the norm in an acute hospital.

Training and education

There is a lack of training, confidence and awareness in initiating discussions about people's concerns and preferences for end-of-life. This has culminated in inadequate assessment and review of people's preferences and needs. Application of palliative philosophy and principles to the level of palliative care approach enhances end-of-life care. Staff need regular and appropriate educational updates and training opportunities so as to build confidence leading to improved outcomes for all. They need access to and knowledge in relation to when to refer to specialist palliative care services.

Conclusion

Acute hospitals need to become places where staff can live and work with dying, death and bereavement with confidence, compassion and skill, places where patients and families are truly at the centre of the focus of care.

There are many issues facing those who provide services at end-of-life in hospitals. This is an area of healthcare that has not traditionally been well-planned. The Hospice-friendly Hospitals Programme is seeking to rectify that by helping hospital staff to put hospice principles into practice and achieve a consistently high standard. When a person is dying we only get one chance to get it right for that person and their family. The services we provide and the manner and circumstances in which they are provided can make such a difference to all involved. A good death is possible in an acute hospital. So, let's get it right all of the time.

For further information see www.hospicefriendlyhospitals.net

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Teaghlach: A New Model of Residential Care

Ann Coyle, National Planning Specialist, Office of the CEO, Health Service Executive

Introduction

This presentation is about a new initiative in residential care that we are calling 'Teagleach', an Irish word that has many connotations: it means a family group, living comfortably together, cosily warm around a glowing fire, engaged in all inclusive conversation, each person protective of the others. It suggests a respect and familiarity and a happy and helpful ambience of share experiences.

The notion of home is central to this new model. Everyone has a basic right to home. Unfortunately, however, some older people in need of long-term care have to relinquish that right in exchange for care.

Why change is needed

It could be argued that we have arrived at residential care from the old workhouse system via the acute hospital. While this has brought some very good practices in pain relief, infection control and palliative care somewhere along the way we have lost sight of the fact that people actually live here. The average length of stay in a long-term care facility is two and half years – that is a long time to live in a hospital type environment that is not home or even home-like. While the emphasis is on good physical care, it could be argued that there is little emphasis on autonomy emotional well-being or maintaining relationships. This is no-one's fault – it is just the way it is. But it does need to change.

Work done to date

Much work has been done over the last few years on patient-centred care. This has included programmes such as *Ten Steps to Healthy Ageing*, *Essence of Care*, and recently the *Hospice Friendly Hospitals.* There has also been accreditation, the setting up of person-centred care pilots projects and other individual projects such as those in Clonakilty, County Cork where a dementia ward has been converted to a small scale living environment for specialized dementia care and in County Louth where a review of quality led by Brighide Lynch, Area Coordinator of Services for Older People, resulted in the development of a culture change programme in the residential units in Louth. Changes have also been made in the design of facilities -

among the new residential units built recently (much better than what we had before) are those with single rooms and beautiful gardens. The Draft HIQA Standards (2008) have also been important in driving change – they are rights-based and person-centred; they support self-determination, choice, privacy and dignity and they should enable residents to maintain contact with families and friends.

Moving forward

There is a huge willingness among those working in long-term care to make things better, to improve facilities and to change the culture. We need to harness all of this and work together in order to make progress.

Vision

What we in the HSE are now trying to do is to drive this change. Our vision is to create a new model of residential care, one that supports older people's ongoing right to home with continued meaningful connectedness to their family and friends right up to the end of their lives. The aim is to drive a change in culture from a task-orientated institutional model to one which supports older people to continue to direct their own lives supported by consistent and valued teams.

What has to happen

To achieve this, a lot has to happen. The facilities must become home in all respects - not home-like or home-from-home or homely but home. This means creating small-scale living environments or households which support six to ten people with all the elements of home while providing all the required care in an atmosphere that staff want to work in. The aim is to be able to allow people to choose to live as privately or as much within the community that is the household as they want.

The principles that underpin this model are as follows:
• The household is each person's home
• The people who live there direct their lives individually and collectively
• The people who live there are served by highly valued, de-centralised teams that have responsibility and authority
• The physical building is designed to be a true home.

There are many examples of this model in action for many years, particularly in the United States – the Eden Alternative (http://www.edenalt.org/), the Green House

Project, the Household Model and the overarching organisation, the Pioneer Network (http://www.pioneernetwork.net/) which is dedicated to supporting facilities engaged in changing the culture of residential care – and in northern Europe for example in the The Netherlands – Daelhoven (www.daelhoven.nl), Weikslag, Ter Reede - and in Sweden - Ros Angers.

The idea behind this new model is that we move away from the institutional look and feel of traditional residential care settings. The key features of this 'true home' are as follows:

- the kitchen becomes the central focus of the household;
- there is a front door;
- there are single rooms and semi-private hallways (so that strangers are not walking past residents' doors);
- there are no nurses' stations;
- there are no medication rounds;
- residents have a choice in relation to what they want to do, what activities they take part in, what meals they eat and so on; and
- there are dedicated staff who work there all the time.

Benefits

There are many benefits to this approach although there is little published research evidence on it at present. Evidence from a longitudinal study in the Green House Project in the US shows that residents score better on quality of life; quality of care at least equalled and, for changes in functional status, exceeded the comparison nursing homes (Kane and colleagues, 2007). There was evidence of improved diet and weight gain and a reduction in medication errors. In terms of staff, there were improved recruitment and retention rates – people like working this way (Farrell, 2005).

People often ask how can we achieve this new way of working with the staffing levels we have? What others who have successfully implemented this model have found is that it does not require an increase in staff numbers – it is more a matter of working in a different way. Another frequently asked question is how can you have an open plan kitchen when there are issues of health and safety including infection control and risk management? Experience in other countries has been that these layouts can be and have been achieved by working with the regulators involved.

Opportunity

Our aim is to embed these principles into how we do our business in the HSE and to develop the Teaglach concept. We now have an opportunity to make the changes needed to move towards this model of residential care with the commitment by government to develop new residential care beds, some within the Fast Track beds scheme, others are coming through the National Development Plan. The Draft HIQA Standards are driving changes in existing facilities.

Challenges

There are also many challenges. It is not just about changing the physical infrastructure, it is also about changing the culture - bringing in new ways of working. To achieve this we need bring all stakeholders along with us, not just those within the HSE and the private sector but those outside of it, older people's groups, families of older people, the community - everyone who is interested in working towards this common goal. We also need to work to sustain the momentum for change so that real transformation can take place, and we need the resources to achieve the change.

Resources and references

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For further information, please contact Ann Coyle, Ann.coyle@hse.ie

Report of Issues Arising for Service Providers from the Workshops

Yvonne McGivern

Clinical practice

In terms of clinical practice, it was suggested that the following issues be addressed:

- That the role of medical officers in nursing homes be clarified in terms of the responsibilities of the medical officer, the support available to the medical office and the training needed for the role
- That the role of ward managers in driving change be recognised and supported
- That Advanced Care Planning (that is, Advanced Care Directives) be carefully structured and introduced and that training and support be put in place in relation to its introduction and to the invocation of such directives
- That staff training be embedded within a continuing professional development (CPD) framework and that it be designed to address among other things the ability to recognise the transitions made by a person entering long-stay care (including the transition to dying and death), the skills and abilities to deliver complex care including care for those people with dementia, the ability to recognise and deal with cultural differences between staff and patients
- Recognising that collaboration is the key to person-centred care
- Promoting and implementing the concept of integrated pathways of care in a context of specialists and a lack of collaborative working practices
- The need to address instances of conflicting policies – for example, enabling independence and access and conforming to health and safety policy
- Recognising that the physical environment matters and that small changes make big differences
- Supporting innovation and creativity.

Communicating about end-of-life issues

In terms of communicating about end-of-life issues, the following recommendations arose:

- The need to recognise the importance of the role of the ward manager
- The need to give the ward manager the freedom to empower staff to act in line with best practice in order that it becomes embedded throughout the facility
- The need to recognise, acknowledge and value the experience of all staff members

- The need to have in place the framework or structure needed to be responsive to the needs of patients and to be supportive of staff
- The need to instil and embed palliative care principles in all care settings and for all needs.

Issues of personal, pastoral and spiritual supports

The following issues were identified for service providers in relation to personal, pastoral and spiritual supports:

- It was highlighted that, where resources are constrained, it becomes increasingly important to be creative and innovative in meeting older people's religious and spiritual needs. It was also noted that sometimes, even when resources are constrained, money can be found for innovative ideas. One innovative idea that was mentioned was the availability of 'multi-faith lockers' which were mobile and acted as sacred spaces at end-of-life.
- Increased recognition of the service, in the form of money, personnel and space, was seen as being critical. It was highlighted that it is difficult to persuade management of the need for policies and procedures around the provision of personal, spiritual and pastoral care as it is often seen as non-essential care. It was proposed that pastoral care should be seen as a critical part of a multi-disciplinary team.
- It was felt that there was a need for a dedicated champion for the provision of personal, spiritual and pastoral care and that it should not be a 'bolt-on' to existing roles, which are typically over-stretched already.
- It was also felt that there was a need to change attitudes in relation to who can administer pastoral care services.
- It was felt that there is a critical need to persuade management to make acute/long-stay facilities, which are often seen as souless, into more human spaces. This requires a more innovative and holistic approach away from an over-reliance on medication, to one that includes, art, music, touch and feeling, massage, acupuncture and reflexology. This holistic care can often fill the space between medical intervention and end-of-life care.
- The issue of spiritual pain was raised and it was felt that more recognition needed to be paid to the possibility and reality of its existence at end-of-life, in the first instance, and to the heterogeneity of the experience of spiritual pain, in the second.

- It was proposed that training and education around the provision of personal, spiritual and pastoral supports should be substantially improved with increased availability of specific training for staff at all levels. It was felt that training was particularly important when relating with older people who were not at peace at the end of their lives in order to help alleviate distress and anger.

Designing for dignity

In relation to designing for dignity, the following issues for service providers were mentioned:

- The difficulties in adapting existing buildings and spaces to be suitable for the provision of end-of-life care were acknowledged. It was noted, however, that small changes can make big differences. In designing and re-designing the space in which end-of-life care is provided the importance and value of innovative and creative thinking about design and layout and appearance should not be encouraged.
- It was noted that attention needs to be paid to the integration of the wide range of policies that affect service provision, in particular the need to address the issues thrown up where one policy conflicts with or impedes the implementation of another: for example, health and safety policy is often at odds with other policies.

It was noted that service providers are key stakeholders in end-of-life care and so have a responsibility not only to identify the issues but also to speak out for change.

End-of-Life Care for Older People: Policy Priorities

Julie Ling, Nurse Advisor, Services for Older People and Palliative Care, Department of Health and Children

Introduction

My aim with this short presentation is to give you an overview of health policy on older people and an overview of palliative care policy and where the two meet.

Older people

The Years Ahead Report 1986

The *Years Ahead Report* set out a policy for older people that stated (p.134) that:

'*Community hospitals … will support caring relatives by providing respite care for dependent elderly people and … provide sensitive and sympathetic continuing nursing care and terminal care.*'

The National Health Strategy 2001 – Quality and Fairness –
A Health System For You

The National Health Strategy in relation to older people stated the following as its aims:

• Better health for everyone

• Fair access

• Funding of long-term care

• Responsive and appropriate care delivery

• Programme of investment in services

• High performance

• National standards

• SSI extended to residential care of older people.

The Report of Inter-Departmental Working Group on Long-Term Care 2008

In 2005 the Tanaiste Mary Harney and the Minister for Social and Family Affairs, Séamus Brennan, established the Inter-Departmental Working Group on Long-Term Care. The Group was chaired by Department of the Taoiseach and comprised senior officials from the Departments of Finance, Health and Children and Social and Family

Affairs. Its report was published in 2008. It stated that the 'central principle of policy going forward should be to support older people to remain in the community.' Its recommendations included the following:

- The expansion of Home Support Packages
- Increased funding for the Home Help Service
- Revised Nursing Home Subvention Eligibility Thresholds
- Increased Respite Care Grants
- Improvements in Carer's Allowance and Carer's Benefit Schemes.

Department of Health and Children funding for older people

In the 2006 Budget an additional €150 million was set aside for services for older people in addition to the core base funding. In 2007 the Revenue allocated funding of €255 million. The 2008 Budget provided an additional €135 million to the core base funding. The total spend in last three years has therefore been €540 million.

Policy direction for older people

In terms of policy, the aim is to further develop care in the community with the set up of, for example, primary care teams and the use of home care packages and home help services. The Office for Older People has now been established. There are plans for the development of a National Positive Ageing Strategy. Much work has been done in relation to nursing home standards and regulation with the publication in 2008 of the HIQA Draft National Quality Standards for Residential Care Settings for Older People in Ireland. These Quality Standards include a standard on end-of-life care, Standard 16. This Standard sets 13 criteria to ensure that, '*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.*'

Towards 2016

The policy priorities in relation to older people set out in *Towards 2016*, the Ten-Year Framework Social Partnership Agreement 2006-2015, are to ensure that older people have access to a joined-up, user-friendly, customer focused service consistent with individual needs; that standards for residential care are developed; that there is standardised inspection of both public and private care settings for older people; and that additional resources are made available for community care for older people.

Palliative care policy

Cancer Services in Ireland: A National Strategy 1996

In terms of palliative care policy, this strategy sets out that there should be '…palliative care for all patients with active and progressive disease, which is no longer responsive to curative treatment.' (p.59)

The Health Strategy 2001

The Health Strategy notes that in relation to palliative care there should be structured planning and delivery of services; that specialist palliative care services are be provided in each health board area; that there should be access to palliative care for people with non-malignant disease; and that the palliative care approach should be an integral part of all clinical practice.

The Report of the National Advisory Committee on Palliative Care 2001

This Report notes that quality of life is the key aim of palliative care and so should be incorporated early, in some cases at the time of diagnosis; that all three levels of palliative care – a palliative care approach (level one); general palliative care (level two) and specialist palliative care (level three) - should be available; that care should be appropriate and led by patient need. It stated that there should be an in-patient specialist unit in every health board (now HSE area) as well as community hospital beds for the provision of intermediate level in-patient care. It noted too that bereavement support should be available whenever and wherever needed.

A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services2006

This study shows that palliative care is currently available in every county in Ireland, although access to a specialist in-patient unit, to medical support and to a multidisciplinary team does vary. The study also shows that palliative care support beds are available in residential care settings for older people.

Towards 2016

Towards 2016 states that there is a need for 'further developing palliative care throughout Ireland, with particular reference to the baseline study on the provision of hospice/specialist palliative care services.' (p.53)

The World Health Organisation Better Palliative Care for Older People (2004)

This report pointed out that, '*Palliative care must not be something that only specialized palliative care teams and palliative care services or hospices offer when other treatment has been withdrawn. It should be an integral part of care and take place in any setting.*'

Summary

To sum up, our priorities for action are as follows:

- To progress the implementation of palliative care policy
- To ensure that appropriate outcomes for the core and additional funding provided for older people and palliative care are achieved, together with the ongoing monitoring of funding and activity.

Report of Issues for Policy Makers Arising from the Workshops

Yvonne McGivern

Staffing numbers, skills and dependency levels

There is a concern about the disparity in staffing ratios across different care settings. It was agreed that it is important to know the relationship between staff numbers and the dependency level of those within the setting and to know the type and level of staff qualifications.

Education

It was agreed that there is a need for ongoing education and training of all staff involved in the care of older people. It was suggested that this could be addressed through continuous professional development (CPD) education and training. However, with the pace of change and development in various fields of care, it was noted that CPD education and training should be regulated.

Collaborative working

It was recgonised that there is a need for a debate in relation to collaborative working practices among those specialists involved in end-of-life care of older people. It was agreed that while collaborative working is essential it must operate in a way ensures that specialists do not lose their role. It was noted that there is a need to embed the palliative care approach but at the same to time to avoid or to overcome any split between palliative care specialists and other specialists.

Availability of the right care in the right place

It was agreed that there should be no need for an older person to leave the long-term care setting in order to receive full multidisciplinary team care. It was agreed that when an older person at the end-of-life needs acute services that these should travel to the older person rather than the older person having to move to an acute setting.

The need to recognise the importance of personal, spiritial and pastoral care at end-of-life and to develop and implement policies for such care was acknowledged. It was suggested that guidelines published by the UK's National Institute for Health and Clinical Excellence be put to use in Ireland.

It was agreed that there is a need to develop policy to support the principles of dignity, sanctuary, choice/control, confidentiality and privacy within the design of facilities for end-of-life care.

Implementation of standards

It was agreed that the HIQA standards for residential care, including the standard that related to end-of-life care, should be implemented with immediate effect.

While the role of the HIQA standards in driving appropriate design for end-of-life care was welcomed, the challenge in applying these to older facilities in contract to new build was recognised.

Resources

It was agreed that there is a need to develop and implement policies that will draw funding for both the space and the staff needed to deliver appropriate care.

Advance care planning

It was noted that doctors sometimes ask next of kin to sign consent forms but that there is no legal basis for this. Similarly, issues surrounding 'Do Not Resuscitate' orders are frequently addressed to families and not to patients. The legal reality is that doctors should take medical decisions in the best interests of patients who are incapacitated and advise the family accordingly. The need for education of both the public and healthcare professionals regarding the current legal situation was highlighted, as was the need for the relevant professional bodies 'to come on board' and proactively address the issues raised by the provision of healthcare to people who are incapacitated and by Advance Care Directives.

Ms. Rickard-Clarke stated that the dignity and wishes of the individual are paramount in the resolution of the issues raised by Advance Care Directives. Dr. O Brannagain highlighted the need to advertise among healthcare professionals the legal rights of ill and incapacitated people and to ensure that patients are central in decision-making about their own care.

It was stated that the area of death and dying is now 'more grey' than it used to be. Patients with neuro-degenerative disorders and heart disease may experience loss of brain function and of swallowing and other reflexes at a later stage in their illness.

Those patients may have peg tubes inserted while they are fit and well and before they are needed. At later stages in patients' lives, differences emerge between doctors and families as to when to continue to use peg tube feeding and when to discontinue use. There are also differences between the professional bodies, the Irish Medical Council and An Bord Altranais, regarding the same issue. Dr. O'Brannagain highlighted the lack of policies on peg feeding in most hospitals.

The Law Reform Commission is examining the issue of informed consent in the context of Advance Care Directives. Relevant questions here are: does the person really know what he/she is consenting to; and is he/she up to date in terms of information on the issues, for example, has professional advice and information been sought?

A question was posed about the feasibility of seeking assessment of needs of people at end-of-life under the Disability Act. It was stated that an assessment of needs may be possible but this would not necessarily result in provision of a service. The issue of wanting treatment was identified as more difficult than that of refusing treatment. Ms. Rickard-Clarke pointed out that the same debate about entitlement to treatment had underpinned the disability debate previously and was now at issue in relation to the Fair Deal Scheme. There are economic issues involved in the debate and the decisions are typically regarded as being for the executive (government).

Failure to invoke Advance Care Directives has been an issue in other jurisdictions (up to a proportion of thirty to sixty per cent) and age, sex and timing have all been factors in this experience. The Law Reform Commission is considering how best to guard against non-invocation and non-implementation of patients' wishes by doctors. It was stated that the Guardianship Board would be able to exercise some responsibilities in this regard.

Concluding Remarks

Eugene Murray, Irish Hospice Foundation

We can measure the consequences (of ageism) in a very real way. The dimensions of ageism are as follows: a 22-bedded female nightingale ward, 73 feet 3 inches by 23 feet 4 inches with one side room 8 feet 1 inch x 8 feet 2 inches; wash-hand basins to facilitate infection control measures; four toilets; and space between beds ranging from 13 inches to 42 inches with an average of about 31 inches. This is the not untypical situation recently revealed in one community hospital.

The Hospice Friendly Hospitals Programme was initiated by the Irish Hospice Foundation in 2007 in partnership with the Health Service Executive. It aims to put hospice principles into hospital practice and to ensure that a systematic quality approach exists within the public health services to facilitate, in so far as is humanly possible, a good death when it is expected, or can be predicted, and supportive systems when death occurs unexpectedly. Through this Programme the Foundation will continue to engage with people who are broadly interested in end-of-life care and policy issues in an acute hospital and residential setting. Our Chairman, Denis Doherty, who is also Chairman of Nursing Homes Ireland sees the potential for this Programme to expand and address many of the issues raised today - possibly developing a strand focusing on the particular needs of community hospitals and nursing homes.

I would like to thank all who have contributed to the success of this seminar and I look forward to further collaboration with the National Council on Ageing and Older People as we jointly develop a policy statement based on today's deliberations.

Appendix A

Biographies:

Speakers and Chairs

Rodd Bond

Rodd is an architect with a unique blend of experience in the development and application of technology applied to environments and processes that support people's health and wellness. He has worked on a range of international healthcare projects including the Sana'a Medical Faculty in the Yemen and on the master plan for the Shifa International Hospital in Islamabad, Pakistan. He is currently director of the Netwell Centre in Dundalk Institute of Technology (DkIT). The Centre hosts the Nestling Project, a collaborative initiative between the local authority, the HSE and DkIT. Over the past year Rodd has also managed Dundalk's participation in the WHO Age-Friendly Cities Project.

Denis Doherty

Denis chairs the Board of Directors of the Irish Hospice Foundation. He is a Fellow of the Chartered Institute of Personnel and Development. Between 1971 and 2005 he worked in the health services, initially as head of Human Resources in the North Western and Midland Health Boards. Between 1975 and 1980 he was Programme Manager (Assistant CEO) in the North Western Health Board. From 1980 to 2002 he was CEO of the Midland Health Board and from 1988 to 1997 he was CEO of the Mid Western Health Board

Dr Ciarán Donegan

Ciarán is Consultant Physician in General and Geriatric Medicine at Beaumont Hospital and is Chairperson of the National Council on Ageing and Older People. He chaired the Consultative Committee that supported the development of the report, End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland.

Daphne Doran

Daphne is the Hospice Friendly Hospitals Programme's Standards Development Project Manager. Her career has been in residential care, working in both the statutory and voluntary sectors. For the past 15 years she has worked in the regulation of registered services in Northern Ireland where she was a member of the Task Group in the Department of Health, Social Services and Public Safety responsible for drafting minimum standards for a range of services. Her work has involved promoting the best possible outcomes for service users. She has a great deal of experience in multi-disciplinary and partnership working procedures to develop service user-focused standards.

Ann Coyle

Ann trained as an occupational therapist in 1981 and worked for several years as a practitioner in mental health and as a manager of a large occupational therapy team in Northern Ireland. She became a community care administrator in 1992 and a general manager (Louth Community Services) in 1998. In 2003 she became the Director of Services for Older people in the North East and in 2007 moved to the newly established role of National Planning Specialist (Older People) in the Office of the CEO.

Marian Finucane

Marian joined R.T.E. in 1974 as a TV/radio announcer. She began working in programmes in 1976 as a presenter of a books/media review programme. Since then, on both radio and television, she has worked in current affairs, religious affairs, women's issues, light entertainment, documentaries, books and media. Having presented The Marian Finucane Show on RTE radio from 1998 to 2005 on weekdays, she now hosts the programme on weekend mornings. In 2005 she received an honorary degree from NUI Galway. Apart from her media work this degree was in recognition of her work raising funds towards the building of an AIDS hospice and orphanage in Cape Town, South Africa. She has served on a number of Government Committees for the Departments of the Taoiseach; Agriculture; Arts & Culture; and Justice. She is a Director of the Irish Hospice Foundation, a Commissioner on the Commission for Victims of Crime, and Chairperson of Friends in Ireland.

Katherine Froggatt

Katherine qualified as a registered nurse following a geography degree at Durham University. She worked in radiotherapy and the care of older people before moving into research in university and hospital settings, undertaking research and practice development in the areas of oncology and palliative care. She has been involved in several projects concerned with care homes. She recently completed a three year research fellowship to develop end-of-life care in care homes. She currently works at the International Observatory on End-of-Life Care at the Institute for Health Research, Lancaster University. She co-leads a programme of research concerned with older adults and palliative and supportive care as part of the Cancer Experiences Collaborative.

Julie Ling

Julie is Nurse Advisor, Services for Older People and Palliative Care in the Department of Health and Children. She is a member of the National Council for Specialist Palliative Care and sits on several national steering committees and working groups. She was involved in the development of draft national standards for residential care settings for older people. Since 2007 she has been working on the development of a national policy on palliative care for children with life limiting conditions. She has written on various aspects of palliative care, is co-editor of 'Palliative Care in Ireland', and is on the editorial board of the International Journal of Palliative Nursing. She worked in cancer and palliative nursing at the Royal Marsden Hospital, London before moving to Dublin in 1997. In 2002, following work as a clinical nurse specialist in palliative care at St Luke's Hospital and later as Assistant Director of Nursing at Our Lady's Hospice, she joined the Department of Health and Children.

Carmel Molloy

Carmel is Pastoral Care Worker with Louth Specialist Palliative Care Service. She is a member of The Little Sisters of the Assumption. For many years she managed the Home Help Service in Dublin's inner city Liberties and Rialto area. Her work there brought her into contact with older people as they became more frail and dependent. In 2003 she was certified as a Health Care Chaplain by the Health Care Chaplaincy Board. She has has a Graduate Diploma in Bereavement Studies from the Irish Hospice Foundation and the Royal College of Surgeons in Ireland.

Yvonne McGivern

Yvonne is a research specialist and author of the bestselling textbook, *The Practice of Market Research*. She has edited reports on age-related topics for the National Council for many years and for other organisations including Age Action Ireland and the Irish Gerontological Society. She was report writer for the Working Group on Elder Abuse and has recently finished writing a training manual on elder abuse awareness for the HSE.

Professor Kathy Murphy

Kathy is Professor of Nursing at NUI, Galway. She is a registered general nurse and has a Masters degree from Kings College London and a PhD from NUI Galway. Her clinical background is in older people's services and accident and emergency nursing. She has held ward manager posts in both. She has worked in nursing

education for the last 16 years, and in NUI Galway for the last eleven years. Her doctoral work focused on quality of care for older people in Ireland and she has been involved in a number of national studies focused on quality of life and older people.

Dr. Doiminic Ó Brannagáin

Doiminic is a graduate of the NUI at University College Dublin. He completed Vocational Training in General Practice in 1995, followed by Higher Specialist Training in Palliative Medicine in 2001 through the Royal College of Physicians in Ireland. He was appointed Consultant in Palliative Medicine at the North Eastern Health Board in 2002. Between 1991 and 1996 as a member and latterly chair of the National Non-Consultant Hospital Doctors Committee of the Irish Medical Organisation he was involved in contract and medical indemnity negotiations nationally. He was a member of the Permanent Working Group (PWG) of Junior Hospital Doctors in Europe and worked on taskforces for Medical Manpower Planning and the Working Time Directive in Europe. He was the PWG delegate to the European Union of General Practitioners and sat on the CPME (the Standing Committee of European Doctors).

Bill O'Herlihy

Bill founded Public Relations of Ireland Limited in 1973, which now trades O'Herlihy Communications (OHC). Bill has brought his current affairs, features and sports broadcasting experience to bear in establishing OHC as one of Ireland's premier public relations agencies. In addition to his public relations role, Bill has been involved with RTÉ for 40 years. He worked as a presenter with RTÉ Current Affairs on the award winning *7 Days* programme and has anchored the Olympics, World Cup Finals in soccer and rugby, the European Championships and the European and World Track and Field Championships. In 2003 he received Irish Sports Journalist of the Year Award.

Professor Desmond O'Neill

As a medical undergraduate of Trinity College Dublin, Des spent a year in Marseilles as a volunteer with an NGO working with older people. He subsequently trained as a geriatrician in St James's Hospital Dublin and at the University of Bristol. Following an appointment as consultant geriatrician in Selly Oak Hospital, Birmingham he returned to Dublin and currently is the senior academic in Medical Gerontology at the TCD campus at the Adelaide and Meath Hospital in Tallaght. His focus of research is

rooted in gerontology and the neurosciences, with a strong emphasis on liaison with the humanities.

Professor Eamon O'Shea

Eamon is a personal Professor in the Department of Economics and Director of the Irish Centre for Social Gerontology (ICSG) at the National University of Ireland, Galway. He holds an MA from University College Dublin, an MSc from University of York and a PhD from University of Leicester. Including the report being launched today, he has authored/co-authored 15 books and monographs, mainly in the field of ageing and social policy and is responsible for 16 commissioned policy reports from national and international agencies. He has contributed 22 chapters to various books, mainly on ageing and inequality issues. He was chair of the National Economic and Social Forum Expert Group on *Care of the Elderly* in 2005 to 2006. His work has been influential in setting the agenda for the ongoing reform of the long-stay sector in Ireland. He is currently a member of the National Council on Ageing and Older People.

Patricia Rickard-Clarke

Since 2001 Patricia has been the full time Commissioner with the Law Reform Commission, having been a part-time Commissioner since 1997. Up until 2002 she was a partner in the Private Client Department of McCann FitzGerald, specialising in taxation and trusts. Over the years she has contributed to a number of publications on trusts, settlements and succession law and has contributed to the publication, *Older People in Modern Ireland: Essays on Law and Policy* (First Law) published in 2005.

Sr Mary Threadgold

Sr Mary Threadgold, MSc, MRCSLT, is a Sister of Charity and a Speech and Language Therapist. In 1990 she devised Sonas, a therapeutic communication activity for older people whose communication is impaired because of dementia or other cognitive deficits. The aim of group and individual sessions is to activate each participant's potential for communication. Sr Mary set up Sonas aPc to train healthcare staff and carers in the use of the Sonas approach. The organisation became a limited company and registered charity. It receives annual funding from the HSE. Sr Mary is presently working on a spirituality project entitled Dóchas, the

aim of which is to help older people to find joy and peace through a broad range of spiritual experiences.

Shelagh Twomey

Shelagh Twomey is Deputy Programme Manager of the Hospice Friendly Hospitals Programme, Irish Hospice Foundation. She was a Clinical Nurse Specialist in Palliative Care in Wexford General Hospital for three years. For the previous five years she worked with the County Wexford Hospice Homecare Team. She has a Higher Diploma in Palliative Nursing from UCD and Our Lady's Hospice, and a Masters in Nursing Clinical Practice from UCD. She has been a member of the executive committee of the Irish Association for Palliative Care since 2004.

Noel Usher

Noel has worked in the Department of Health and Children (DoHC) since the early 1970s. He has been a member of the Department's Management Advisory Committee since 2002 during which time he held responsibility for the Child Welfare and Protection, Health Promotion, Environmental Health, Public Health, Social Inclusion and Primary Care functions. Earlier this year the Government established the new Office for Older People and Noel was appointed its first Director. As well as continuing as a member of the Management Advisory Committee in the DoHC, as a Director of the new Office Noel will be invited to attend meetings of MAC of the Departments of Social and Family Affairs and Environment, Heritage and Local Government where issues relating to the new Office are on their agenda. Noel is also a member of the Government's Senior Officials Group on Social Inclusion.

Dr Max Watson

Max trained in theology, medicine and general practice. He worked in Nepal for eight years setting up a general practice training programme. He returned to the UK to complete training in palliative care in London and Belfast. He is currently a lecturer in Palliative Medicine in the University of Ulster, Consultant at the Northern Ireland Hospice and Honorary Consultant in Palliative Medicine at the Princess Alice Hospice, Esher. He is special adviser to the Hospice Friendly Hospitals Programme. He is author of the *Oxford Handbook of Palliative Care*, *Oncology*, *The Oxford GP Library Pain and Palliation*, London and Belfast *Palliative Care Guidelines* and series editor of the Oxford specialist end-of-life handbooks. He is the originator of the Princess Alice Certificate in Essential Palliative Care which has trained over one

thousand doctors and nurses since it began in 2001 and is now running in Nepal, India, Kyrgystan and in three centres across the UK every six months.