



HospiceFriendly  
**HOSPITALS**

Putting Hospice Principles into Hospital Practice.

# Quality Standards for End-of-Life Care in Hospitals

Making end-of-life care central to hospital care



*The*  
**ATLANTIC**  
*Philanthropies*





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# The Four Standards

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## 1 The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients

## 2 The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

## 3 The Patient

Each patient receives high quality end-of-life care that is appropriate to his/her needs and wishes.

## 4 The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during, and after the patient's death.

# A Message from President McAleese



In May 2007 I launched the Hospice Friendly Hospitals Programme. I am particularly aware of the importance of the publication of the *Quality Standards for End-of-Life Care in Hospitals*.

Dying, death and bereavement can be the most troubling aspects of our human existence. They can also be sources of wisdom, fortitude and, indeed, peace. For those who care for and support us as we leave this life, and for those who live on, the end of life is something deeply profound but it is also something with very practical consequences. These Standards reflect this unity of the profound and the practical. They encourage us as individuals to reflect carefully on how we can honour the sacredness of every human life through responding with equal honour to the issues and experiences that are an essential part of being an individual.

All of us will face the end of our life and, sadly, some will meet it sooner than others. Not everyone, however, is faced with the task of caring for or planning for those whose lives will end in hospitals. In introducing these Standards we must be mindful not just of seeing the person in the patient but also of seeing the person, and the future patient, in the professional. The focus of the Standards around the needs of patient, family, staff and the hospital as a system is hugely important and reflects the interweaving of the little details of life stories into the big picture of complex hospital systems.

Ar scath a chéile a mhairimid ... We live in each other's shadow. We also die in each other's shadow. As citizens first, and patients or providers second, we should welcome these Standards because they are, ultimately, for all of us.

A handwritten signature in black ink that reads "Mary McAleese". The signature is fluid and cursive.

MARY McALEESE

PRESIDENT OF IRELAND

# Introduction

COMPETENCE, COMPASSION, COMMUNICATION, CO-ORDINATION

## Care at the End of Life: From the Margins to the Mainstream

Each year almost 30,000 people die in Ireland.<sup>1</sup> While surveys suggest that the great majority of people would like to die at home the reality is that the great majority currently die outside the home. Three-quarters (75%) of all deaths now take place in hospitals and long-stay facilities and almost half (48%) of deaths occur in acute hospitals.<sup>2</sup> End-of-life care in our hospitals is therefore everybody's business.

While there is a clear need to explore options for supporting more people to die at home, or in a community setting, the reality is that for the foreseeable future, a significant proportion of deaths will occur in hospital. The **Department of Health (England) End of Life Care Strategy** (June 2008) states that *"hospitals will continue to be major providers of end-of-life care for the foreseeable future"* and that *"Boards of provider organisations should therefore take responsibility for ensuring they provide high quality end-of-life care"*.<sup>3</sup> A consensus is slowly emerging, nationally and internationally, that care at the end of life should become an indicator of the performance of healthcare systems.<sup>4</sup>

While there are many instances where people receive high quality end-of-life care in a hospital setting and while the quality of end-of-life care in Ireland compares favourably with that reported by hospitals elsewhere<sup>5</sup>, there continue to be problems with the end-of-life care provided to patients. These problems are of concern to all of us.

Thanks to advances in public health and medicine, people are now living longer than ever before and for that very reason more people live with chronic and possibly life limiting and/or life threatening disease and increasing co-morbidity. Given that ill-health increases with old age, older people are significant users of healthcare and the bulk of expenditure on healthcare

1 Central Statistics Office(CSO) Available at:[www.cso.ie/statistics/births,deaths and marriages/principal statistics](http://www.cso.ie/statistics/births,deaths and marriages/principal statistics)

2 McKeown,K., Haase T.,and Twomey S.,2010a.Resources and Facilities for End-of-Life Care in Hospitals, National Audit Report 1,Dublin:Irish Hospice Foundation.

3 Department Of Health, 2008. 'End of Life Care Strategy: Promoting high quality care for all adults at the end of life'. London: Department of Health. Available at: <http://www.dh.gov.uk/en/publications/publications and statistics/publications and policy guidance/End of Life Care Strategy: Promoting high quality care for all adults at the end of life..>

4 Hospice Friendly Hospitals, 2006.'Grant Proposal to The Atlantic Philanthropies'. Dublin: The Irish Hospice Foundation.

5 For example, in a study of palliative care (PC) in the EU, Ireland was placed second, after the UK, out of the EU-27. This was on the basis of resources(such as PC staff, beds, units, etc) and vitality(such as the number of activists and professionals involved in PC)(Martin-Moreno,Harris,Gorgojo,Clark,Normand,Centeno,2008).More recently, Ireland was positioned 13th out of 33 European countries in the 2009 European Healthcare Consumer Survey Index(Bjornberg, Cebola Garrofe and Lindlaid,2009).This is up two positions on the previous year.

# Introduction

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will be required for the last year of life. This equally applies to healthcare expenditure for the final year of life preceded by illness for all age groups. Issues of quality of life versus quantity of life increasingly arise and Clark (2002) makes the point that even though a palliative care perspective tries to encourage medical professionals to be more comfortable in their acceptance of death, other developments in the medical system have pulled efforts in the opposite direction. He cites, for example, an assumption in society *"that every cause of death can be resisted, postponed or avoided"*<sup>6</sup>

Despite, or perhaps because of, the significant advances in medicine generally, end-of-life care is not fully reflected in hospital cultures, systems and structures. It is frequently not seen as a core activity of hospitals and is not normally included in hospital service plans. The lack of a comprehensive approach to end-of-life care gives rise to a concern that we may not be guaranteed a good quality of life in our declining years or a good death at the end. Such concerns lie behind the increasing demand for end-of-life care to become compulsory on all relevant undergraduate education courses.

*The Quality Standards for End-of-Life Care in Hospitals* have been developed in partnership with healthcare staff and interested parties including bereaved relatives. They set out a shared vision of the end-of-life care each person should have and what each hospital should aim to provide. The Standards identify what hospitals should strive for and how they can ensure that the essential elements of a consistent quality approach to end-of-life care are in place in all parts of the hospital whether death is unexpected or expected. The Standards take into account the fact that delivery of end-of-life care is governed not only by people's identified needs but also by their expressed preferences as well as their cultural and spiritual values. The underlying message of the Standards is that time is of the essence and that provision of high quality care is paramount.

The Standards have been developed as part of the Hospice Friendly Hospitals (HFH) Programme, a five-year national programme initiated by the Irish Hospice Foundation in May 2007 in partnership with the HSE and supported by The Atlantic Philanthropies, The Dormant Accounts Fund and the Health Services National Partnership Forum. Because there is evidence to show that applying palliative care/hospice principles at end of life results in better outcomes for patients, families and staff, the mission of the HFH Programme is to put hospice principles into hospital practice. The key aims of the programme are:

<sup>6</sup> Clark D, 2002. 'Between hope and acceptance: the medicalisation of dying'. British Medical Journal. BMJ; 324:905-907.

# Introduction

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- **To develop Standards for end-of-life care in hospitals**
- **To develop the capacity of hospitals to meet these Standards**
- **To improve the overall culture of care and organisation in hospitals regarding all aspects of end of life, dying, death and bereavement**

The development of these Standards is an important stimulus to promote ongoing improvement of end-of-life care in hospitals and there can be no doubting the commitment of many hospitals to this process. In 2008-2009, 24 acute hospitals and 19 community hospitals participated in a baseline *National Audit of End-of-Life Care in Hospitals*<sup>7</sup>. This audit is among the most innovative and ambitious audits of end-of-life care undertaken internationally and all those hospital staff and bereaved relatives who participated, and indeed the whole health service in Ireland, have reason to be proud of this achievement. These Standards, together with the results of the audit, and the earlier *Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End of Life Care (2008)*, will enable hospitals to draw up Development Plans for End-of-Life Care which will guide them as they implement the Standards over the coming years. These development plans will also enable progress to be monitored both at hospital and national levels.

The Standards have been developed to ensure positive outcomes for patients, families and staff and will result in better support systems where sudden or traumatic death occurs. In cases where death is expected, or the possibility that it might occur is suspected, then it is not unreasonable to say that the outcome ought to be ‘*a good death*’ and, at the very least, an ‘*acceptable death*’. The Standards take as their starting point the fact that, in practice, hospitals have to deal with the many different scenarios associated with end of life – miscarriage; intra-uterine death; stillbirth; death of a baby, child, or teenager; serious illness; diagnosis of a life-limiting or life-threatening disease; loss of independence; transition to long-term care; multiple and complex illnesses; traumatic death such as murder, suicide, road traffic accident or a sudden critical illness. The Standards also acknowledge that end of life can involve

<sup>7</sup> The results of the national audit are published in five reports and are all available at: <http://www.hospicefriendlyhospitals.net> The reports are:

(i) Mc Keown, K., Haase, T., and Twomey, S., 2010a. Resources and facilities for End-of-Life Care in Irish Hospitals, National Audit Report 1, Dublin: Irish Hospice Foundation

(ii) Mc Keown, K., Haase, T., and Twomey, S., 2010b. Dying in Hospital in Ireland: Nurse and Doctor Perspectives, National Audit Report 2, Dublin: Irish Hospice Foundation

(iii) Mc Keown, K., Haase, T., and Twomey, S., 2010c. Dying in Hospital in Ireland: Family Perspectives, National Audit Report 3, Dublin: Irish Hospice Foundation

(iv) Mc Keown, K., Haase, T., and Twomey, S., 2010d. The Culture of End-of-Life Care in Ireland, National Audit Report 4, Dublin: Irish Hospice Foundation

(v) Mc Keown, K., Haase, T., Pratschke, J., Twomey, S., Donovan H., and Engling, F., 2010. ‘Dying in Hospital in Ireland: An Assessment of the Quality of Care, Report 5, Final Synthesis Report, Dublin: Irish Hospice Foundation

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complex questions, sometimes of an ethical nature, and challenging issues such as advance care planning and preferred place of care/death, organ donation, post-mortems, funeral arrangements, wills, and legal and financial concerns. The need to respond fully to people's bereavement support needs is also acknowledged as is the need to ensure that the physical environment of hospitals is designed and organised to facilitate sensitive end-of-life care, privacy, choice, and dying with dignity. Four words emerged as being significant in the course of developing the Standards: **Competence, Compassion, Communication, Co-ordination.**

In developing the Standards, the Hospice Friendly Hospitals Programme has consulted with the Health Information and Quality Authority (HIQA). HIQA has a number of statutory responsibilities under the Health Act 2007, including the responsibility for setting Standards in health and social services and monitoring healthcare quality. HIQA is currently developing the *National Standards for Quality and Safety* which will enhance the environment for delivering quality end-of-life care. Implementing these Standards is the first step in a two to three year programme that will culminate in a mandatory licensing system for public and private healthcare providers which has been recommended by the Commission on Patient Safety and Quality Assurance and endorsed by the Government in February 2009.

HIQA has endorsed the work of the HFH Programme in relation to the development of Standards for end-of-life care in hospitals. The HFH Programme envisages that its Standards will be referenced within the *National Standards for Quality and Safety*, and will inform future reviews carried out by HIQA. HIQA has consistently demonstrated a strong commitment to ensuring provision of high quality end-of-life care. In particular, the *National Quality Standards for Residential Care Settings for Older People* addresses the provision of end-of-life care and the *National Quality Standards for Residential Care Settings for People with Disabilities* contain specific Standards criteria in relation to end-of-life care. The *Quality Standards for End-of-life Care in Hospitals* both complement and build on these achievements.

In the development of these *Quality Standards for End-of-Life Care in Hospitals* Ireland has learned from the experience of similar Standards and quality initiatives in other countries. The development of the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9* has also involved learning from the experiences of others and the results show that we have much still to learn. There is now, however, a unique opportunity for Ireland to show leadership within the health services of Europe as we commence the challenging task of bringing end-of-life care in hospitals from the margins to the mainstream.



Part 1

# Cycle of Life & Death



# Cycle of Life & Death

## The Lifecycle Approach

Hospitals and healthcare are part of a much wider network of service provision for the public. National policy and planning regarding the future of public services uses a lifecycle approach to address issues that people are likely to face at each stage of their lives, from birth through to old age<sup>8</sup>. This lifecycle approach has been reinforced by the OECD report on an integrated public service for Ireland which suggests:

- **That no population group – children, younger and older adults of working age, older people or people with disabilities – is overlooked by society**
- **That an integrated approach is applied across all policy areas**
- **That the citizen rather than the service provider is at the centre of public service planning and provision**

This approach is guided by an inclusive vision of public services as being developed ‘with the public’ rather than simply ‘for the public’.

Death is part of the cycle of life, and is therefore central to public service provision. The end of life occurs most commonly in old age but it can also occur at other stages of the life cycle: miscarriage, at the very start of life; accident; suicide; onset of disease, or a complex range of diseases in older age. Addressing end of life can mean addressing issues of a legal, financial, legislative, ethical, existential, spiritual, environmental and administrative nature as well as issues related to population health and to personal, clinical and palliative care.

The terms ‘end-of-life care’, ‘dying’ and ‘death’ are used throughout the document to refer to the various aspects and stages at the end of life. The term ‘end-of-life’ (see Glossary) is used when there is advanced life-limiting or life-threatening disease or where a life-limiting / life-threatening disease becomes unstable. The term ‘dying’ (see Glossary) is used when a diagnosis of dying has been made using specific clinical criteria. It is usually used to describe a time period when death is imminent, and life expectancy is limited to a short number of days, hours or less. The term ‘death’ refers to the state or condition of being without life, animation or activity.<sup>9</sup>

<sup>8</sup> See, for example, Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2015; National Development Plan 2007-2013: Transforming Ireland.

<sup>9</sup> Shorter Oxford English Dictionary. Volume 1. 2002. 5<sup>th</sup> Edition. Oxford. Oxford University Press.

# Cycle of Life & Death

Within this document, hospice refers to a philosophy of care that includes but is not solely reflected in a medical speciality. The philosophy goes beyond palliation and is characterised by a holistic (physical, psychosocial and spiritual) attention to illness. The focus of a hospice philosophy is not exclusively on dying and death but rather on providing holistic care and symptom control as soon as possible in the disease trajectory in order to improve all aspects of care, as distinct from focusing exclusively on end-of-life care, dying and death.<sup>10</sup>

## End-of-Life Care in the context of the Hospice Friendly Hospitals Programme

The HFH Programme adopts a broad systems approach to improving the organisation and culture of care within hospitals, across hospitals, and between hospitals and community care. It acknowledges the central role of those who provide clinical care and works to ensure that end-of-life care is central to the mission and everyday business of the hospital.

In the context of the HFH Programme, end-of-life care relates to all care – clinical, administrative and support - provided by hospital staff on all aspects of end of life, dying, death and bereavement regardless of age or diagnosis, or whether death is anticipated or unexpected. It includes:

- death in the womb and in infancy
- death in accidents and traumatic events
- people living with advanced life-limiting conditions (for whom death within a period of one-two years is a distinct possibility)
- people in the terminal phase of illness
- the care and support required by families and friends and by the staff who care for them
- care for the body of the deceased and for the bereaved

<sup>10</sup> O'Shea, D., Keegan, O. and McGee, H., 2002. 'End-of-life care in general hospitals. Developing a quality approach for the Irish setting'. A Statement of The Irish Hospice Foundation. Page 11 & 12. Dublin: The Irish Hospice Foundation.

# Cycle of Life & Death

A Hospice Friendly Hospital respects the curative modal of care but ensures the hospital is also a place where staff can 'live and work with dying'. It is a patient and family centred system. It supports staff in supporting others through illness and the possibility or likelihood of death. A Hospice Friendly Hospital is a hospital where end-of-life care is 'everybody's business'; it is identifiable by the widespread organisational culture that demands the provision of a high quality of caring at the end of life.

## Patterns of Dying

Each person's journey towards the end of life is different. Some die suddenly, some die prematurely, some at birth and some before they are born. Others die relatively quickly as a natural conclusion to a very long life and some linger for a while – somewhere between life and death – before eventually dying.

### **Start of Life and Childhood<sup>11</sup>**

#### **Miscarriage, Intra-uterine Death, Stillbirth and Neonatal Deaths**

The loss of a child through miscarriage, intra-uterine, stillbirth or neonatal death is a difficult and challenging life event for parents and families. Careful consideration and thought is required by hospital staff when communicating with, and supporting, parents at these times. More than one in five pregnancies ends in miscarriage – around 14,000 women in Ireland each year have a miscarriage.<sup>12</sup> It can be presumed, by people who have no experience of miscarriage or loss, that parents and families may only grieve for a baby who has been born alive and whom they have got to know, if only for a short while. However, many parents find that people around them, at home, at work or in their circle of friends, who have no experience of miscarriage, do not understand the depth of feeling a person has for a baby who was barely formed.

The treatment of women who experience stillbirth has improved over the past ten years but this is dependent on how communication and support provision are managed by healthcare

<sup>11</sup> The Quality Standards for Babies and Children at End of Life(See Appendix 1) represent an adaptation of the Quality Standards for End-of-Life Care in Hospitals to respond to identified needs specific to a baby, child and his/her family regarding end of life.

<sup>12</sup> The Miscarriage Association of Ireland. Available at: [www.miscarriage.ie/About/miscarriage](http://www.miscarriage.ie/About/miscarriage)

# Cycle of Life & Death

professionals. For babies who are born with congenital conditions that are incompatible with life, the beginning of life is also the end of life and this has a profound effect on families. Good communication is fundamental to providing good patient care and is essential when telling parents that their baby will die before or after birth, or telling them that their baby has died.

## **Babies and Toddlers**

The death of a baby or toddler has a profound effect on families. It is important that parents and families are supported and encouraged to create memories in the short time they have with their baby or child.

## **Children**

Even when a child's death may be anticipated, s/he continues to develop physically, emotionally and cognitively throughout the course of the condition and this may affect both his/her health and social needs, in addition to his/her understanding of disease and death.

Children may know when they are dying because they have attended hospital for many months and years and are very informed about their illnesses. They may have encountered others in their peer group who have died. Even young children can be aware of physiological changes in their bodies and intuitively sense the loss of function and a reduction in energy and enthusiasm. In addition, children may be aware of the feelings and actions of others around them, including their fears and anxieties.<sup>13</sup>

## **Teenagers**

The time span of children's illnesses can mean that a child lives through teenage years to young adulthood with an illness that is life-limiting. As well as the challenge of coping with puberty and all that being a teenager entails, there is the additional challenge of coping with a life-limiting illness which may become more progressive and lead to death.

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<sup>13</sup> Oncology Unit, Our Lady's Hospital For Sick Children, Crumlin, 2004. 'Precious Times, a handbook on palliative care for parents of children with cancer'. Dublin: The Irish Cancer Society.

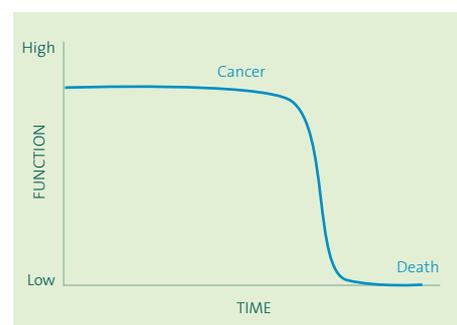
# Cycle of Life & Death

## Adults

In adulthood, the end-of-life period could extend to days, weeks, months or years. Three distinct trajectories of illness or patterns of illness have been identified for people with progressive chronic illnesses.

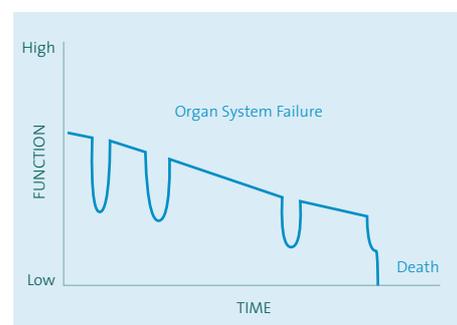
### Pattern 1: Short period of reasonably predictable and evident decline in physical health, typically cancer

Patients experience a decline in physical health which may occur over weeks, months or years. Psychological, emotional and spiritual distress peaks at diagnosis, again at recurrence, and then again at the terminal phase.



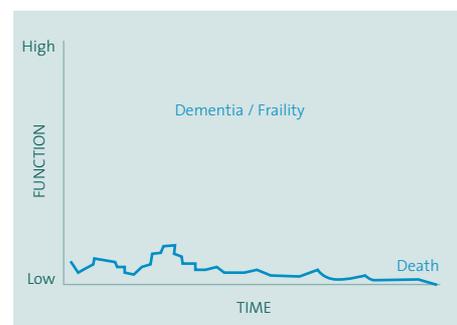
### Pattern 2: Long-term limitations with intermittent serious episodes, typically heart failure and chronic obstructive pulmonary disease

Patients are usually ill for many months or years with occasional acute (often severe) exacerbations. Psychological, emotional and spiritual distress may be evident, reflecting the gradual loss of identity and increasing dependence. Deteriorations are generally associated with admissions to hospital and intensive treatment. In such situations, where death does occur, it can be interpreted as a sudden death, particularly by family members. In reality, many of these patients survive several exacerbations but experience a gradual deterioration in health and functional status.



### Pattern 3: Prolonged deterioration typically associated with brain failure due to Alzheimer's or other dementia or generalised frailty of multiple body systems.

Patients experience progressive deterioration from an already low baseline of cognitive or physical functioning. Loss of cognitive function may cause parallel loss in activities of daily living, social withdrawal and emotional distress.



# Cycle of Life & Death

## People with Disabilities

Disability is diverse and complex and can have a significant impact on a person's quality of life and, by extension, on how they may view dying and death. People's disability status is not fixed and the incidence of disability increases with age.<sup>14</sup> The gradual or sudden onset of disability may trigger an engagement with issues relating to dying and death. Some people with a longer-term disability and their families have to deal with issues relating to dying and death in a manner or at particular points in their lives that is quite different for those without a disability.

A person with a disability and his/her family may sometimes approach dying with concerns that people that do not have a disability do not have to face. For example, a parent of an adult with an intellectual disability may approach the end of life more concerned with what his/her death will mean for the future care of a son or daughter than with his/her own death. Awareness of such concerns by those involved in the provision of end-of-life care may be a significant factor in helping someone deal with the reality of approaching death. Also, the death of a parent or primary carer of a person with an intellectual disability may have a significant impact on the way s/he is supported in the future (e.g., having to leave home and move into a group home setting). People with intellectual disabilities may, therefore, need additional bereavement supports.

When it comes to end-of-life care, the needs of people with disabilities and their families are clearly no different to those the general population. This means that the person has choices, receives end-of-life care that is appropriate to his/her needs and wishes, and that every effort is made to optimise his/her quality of life by providing the best possible care to the end.

The Standards seek to ensure that there is equality of access to quality end-of-life care in hospitals, that staff have the skills to communicate and deal sensitively with people with different types of disabilities and that the information, physical environment, communications and services infrastructure for end-of-life care in the hospital is fully accessible to people with disabilities regardless of the nature of the disability. An important consideration in this regard is that services are amenable to direction and shaping by people with disabilities.

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<sup>14</sup> The 2006 Census reports that 393,785 people (9% of the population) have a disability.



Part 2

# About the Standards



“The changes  
being sought are in  
awareness, attitude,  
skills, practice and  
organisation.”

# About the Standards

## Purpose of the Standards

Hospice principles should inform all end-of-life care, regardless of location. Whether in home, hospice or hospital, the necessity for a holistic approach of tending to the physical, psychological, emotional, spiritual and social needs of a person, in the wider context of family and community, remains constant. The purpose of the *Quality Standards for End-of-Life Care in Hospitals* is, therefore, to assist with putting hospice principles into hospital practice.

The *Quality Standards for End-of-Life Care in Hospitals* have been developed to guide hospital staff who have responsibility for providing end-of-life care and to ensure that end-of-life care becomes central to the organisation and management of hospital activities. It is hoped that they will deepen appreciation of the role of specialist palliative care providers while focusing on the potential of all other staff to deal confidently with end-of-life issues and develop their own palliative care skills.

The *Quality Standards for End-of-Life Care in Hospitals* envisaged as resulting in a hospital culture of compassionate care that will be beneficial to all patients, families and staff and not just those approaching, or at, end of life. The Standards seek to achieve in all hospitals:

- **An acknowledgement of end-of-life care as a core quality service delivery component**
- **A hospital culture of compassionate end-of-life care**
- **Effective pain and symptom management**<sup>15 16</sup>
- **Ongoing capacity development to ensure that the hospital can deal adequately with the different end-of-life scenarios that may arise**

<sup>15</sup> Pain is described as an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. Pain can be described as acute, chronic and /or recurrent. Acute pain is associated with acute injury or disease. Chronic pain is defined as pain that has persisted longer than three months or past the expected time of healing following injury or disease. Pain that comes and goes is called recurrent pain. Depending on his/her underlying illness, a patient may be affected by one or a combination of two or three different types of pain.

Pain is a subjective experience and is influenced by circumstances, only the person in pain can really say how painful something is, therefore pain is what the person feeling it says it is. Patients at end of life may also experience other symptoms related to the disease process or treatments or may require support to address the psychosocial, spiritual, and cultural issues associated with end of life and dying.

Pain and its relief must be assessed and documented regularly. Pain intensity should be regarded as a vital sign and along with the response to treatment and side effects should be recorded as regularly as other vital signs such as pulse or blood pressure. The prescription of analgesic (pain relieving medication), should be reviewed regularly to ensure that the pain medication is effective and appropriate to the level of pain experienced by the patient.

<sup>16</sup> Symptoms refer to common symptoms that may occur at end of life: pain, nausea, breathing difficulties, increased secretions, restlessness and anxiety.

# About the Standards

- **Co-ordination and integration of care teams including out of hours and across various settings**
- **A hospital environment that supports personal dignity, privacy and confidentiality**
- **Education, training and supports for healthcare staff to enable them to be both competent and confident in dealing with the professional and personal challenges involved in delivering high quality care at end of life.**

## Focus of Standards

The work of the Hospice Friendly Hospitals Programme focuses on the needs of patients, families, staff, and hospitals as systems. To date it has addressed four key themes: Integrated Care; Communications; Design & Dignity and Patient Autonomy. These themes emphasise strategic issues which impinge, in differing ways, on patients, families, staff and hospital management. These strategic issues include: co-ordination within and between care providers and between home, hospice and hospital; interpersonal and clinical skills, the physical environment and facilities for privacy, prayer, personal hygiene and refreshments; ensuring an ethical approach in which the wishes of the patient are respected, while taking into account the views of families and the clinical responsibilities of staff.

The *Quality Standards for End-of-Life Care in Hospitals* focus on adult patients in acute hospitals. In Appendix 1 these Standards have been adapted to provide *Quality Standards for Babies and Children at End of Life*. This section also includes miscarriage, intra-uterine death, still birth and neonatal death.

The *Quality Standards for End-of-Life Care* are focused on hospitals and responsibility for their implementation lies firmly with hospitals and their staff. It is envisaged that the Standards will also facilitate and support care in the home, in hospices and in long-stay settings such as nursing homes. However, this will require determined and ongoing focus on resourcing, organisation and integration if primary and community care services are to play their necessarily significant role in ensuring that a majority of people can die in the place of their choice.

These Standards alone will not bring about change; they are, however, a foundation on which change will be built. The changes being sought are in awareness, attitude, skills, practice and organisation. Taken together they amount to a change in culture; in simple terms, *'the way we do things around here'*.

# About the Standards

## The Link between Standards and Audit

The National Audit of End-of-Life Care in Hospitals in Ireland was carried out in 2008/9. It was based on a sample of 1,000 deaths with data collected from nurses, doctors and relatives who spent the most time with the patient during the last week of life. As a proportion of total deaths in Ireland in 2008, the audit is a representative sample of 10% of acute hospital deaths and 29% of community hospital deaths.

The audit was completed in 24 acute hospitals which constitute three quarters of the acute hospital sector in Ireland in terms of patients (72%), deaths (71%), staff (73%), and bed-capacity (74%). In that sense, it is truly a national audit, and its findings are relevant to the entire acute hospital sector. The audit was also completed in 19 community hospitals which represents 20% of community hospital beds in the country; these hospitals tend to have a higher average number of beds (110) compared to the average community hospital (68).

The findings of the audit were given careful consideration in the course of preparing these Standards and influenced its final drafting. Overall, the audit suggests the quality of care for people who die in an Irish hospital compares favourably to hospitals in other countries, and this is consistent with other international comparisons. At the same time, the audit revealed that, for those who die in an Irish hospital, there are significant and substantial weaknesses at every stage of the patient's journey from admission to discharge at death. These weaknesses are also opportunities to correct them and the audit provides a menu of different ways to improve the quality of hospital care for patients at the end of life.

The audit identified 18 separate influences on end-of-life care. In order to demonstrate the link between these findings and implementation of the Standards, we present them thematically as 18 ways to improve end-of-life care under each of the four standards.

# About the Standards

## Standard 1. The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.

### 1.1 Put End-of-Life Objectives in the Hospital's Service Plan

The audit revealed that hospitals which have end-of-life objectives in their service or business plans have better care outcomes compared to those who do not. This provides solid grounds for recommending that all hospitals should have end-of-life objectives in their service plans. It also highlights the leadership role of hospital management in setting goals for end-of-life care and the practical impact this can have on clinical care.

### 1.2 Move from Emergency to Planned Admissions

Most patients who die in acute hospital are admitted through A&E, even though many would have been patients of the hospital already, with already-diagnosed conditions. Admissions through A&E have a negative impact on care outcomes; this is mainly perceived by nurses and doctors and underlines a perception from inside the hospital that A&E is not an appropriate route of admission for many patients. Improvements could be made to care outcomes, in cases which are not truly accidents or emergencies, by simply changing to a more planned and hospitable route of admission. Conversely, a more planned approach to discharge might also reduce unplanned and emergency admissions.

### 1.3 Improve the Hospital's Physical Environment and Usage of Single Rooms

Single rooms are consistently associated with better care outcomes. In addition, wards which lack dignity or which have poor environmental quality are associated with poorer outcomes. This is solid evidence that substantial improvements in care outcomes could be achieved by simply increasing the number and/or usage of single rooms for end-of-life care, and by improving the physical environment of multi-bedded wards.

# About the Standards

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## 1.4 Improve Documentation in the Healthcare Record

The audit revealed that the quality of patient documentation in the healthcare record is uneven. Documentation about selected aspects of care – notably diagnosis of dying, decisions about palliative care, wishes of relatives to be kept informed - had no effect on any of the care outcomes. Given that documentation is essential to supporting a consistent approach to patient care across the hospital team – and other studies have found it to be a good indicator of quality of care - this result merits further reflection on how healthcare records are maintained. Documentation is markedly better in some wards (oncology) and specialties (cancer) – both associated with better care outcomes – which suggests that it is more affected by work practices than by patient needs.

## 1.5 Ensure Sufficient Ward Staff

The ward environment can be a demanding place of work and staffing levels are of primary importance. Wards that have inadequate staffing levels have a significant negative effect on care outcomes. This is an issue that merits attention by hospital management, and requires detailed and transparent assessments of workloads taking into account ward type, work processes, and the composition of ward staff.

## 1.6 Improve Hospital Information Systems

The overall quality of information about various aspects of end of life in Irish hospitals is poor. This draws attention to the need for a national minimum dataset on deaths in hospital – and other out-of-home places of care - so that the HSE can produce a more accurate national picture of deaths across the spectrum of care settings, and address any governance issues that might arise from the analysis of that data.

## 1.7 Facilitate Patients to Die at Home

The audit suggests that a substantial minority of patients (20-25%) could have died at home if appropriate supports were available. This issue merits further examination from the perspective of meeting patient needs and preferences.

# About the Standards

## Standard 2. The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

### 2.1 Develop Skills to Diagnose End-of-Life and Dying

The diagnosis that a person may be approaching the end of life or dying is recognised to be a clinical challenge and the audit confirms this since we could find no relationship between the diagnosis of dying and care outcomes. Given the importance of assessing patient needs through proper diagnosis, this result merits further training on this aspect of caring for patients at the end of life.

### 2.2 Improve End-of-Life Care Decision-Making

The extent to which end-of-life care decisions are taken about dying patients in Irish hospitals is significantly less compared to patients on the Liverpool Care Pathway (LCP) in English hospitals. The audit found that doctors and nurses were reluctant to make decisions to stop invasive treatments when patients were dying. Apart from the decision to move patients into a single room, which could be regarded as an end-of-life care decision, there was no relationship between end-of-life care decisions and care outcomes. This finding merits reflection and discussion on how decisions are made and implemented about patients in their last week.

### 2.3 Hold Team Meetings

Team meetings, especially between nurses and doctors, have a positive impact on symptom management and patient care. These meetings – including after death review meetings - are recommended good practice in end-of-life care settings, and should endeavour to involve patients and/or relatives, if that is their wish. However, the audit revealed that holding of team meetings seems to be less influenced by patient needs than by the work practices of different wards (being more frequent in oncology and geriatric wards) and specialties (being more frequent for cancer patients).

# About the Standards

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## **2.4 Provide Training in End-of-Life Care**

Nurses who have done a formal training course on end-of-life or palliative care, since qualifying, generate better care outcomes compared to nurses who do not. This is a definitive endorsement of the value of training. Ideally, basic training on end-of-life issues should be provided for all professional, support and administrative staff who come in contact with patients and relatives; more intense training is needed for clinical staff in areas such as breaking bad news, end-of-life discussions, diagnosing dying, managing symptoms, understanding bereavement and loss, and dealing with death at a personal level.

## **2.5 Prepare Staff for the Death of Patients**

Care outcomes are improved significantly when a nurse feels prepared for dealing with the death of a patient. While this may appear obvious, the fact that most hospital staff receive little or no preparation for different aspects of care at the end of life suggests that this insight is rarely acted upon. Feeling prepared for the death of a patient is enhanced by experience and training but it is also strongly associated with feeling comfortable talking about death and talking to people who have been recently bereaved. This is important because we know that hospital staff are broadly similar to the people of Ireland in that a majority of them are not very comfortable talking about dying, death and bereavement.

## **2.6 Build on the Experience of Staff**

The audit found that a nurse's years of experience working in a hospital and ward has a positive effect on care outcomes. This result gives substance to the idea that a hospital's greatest resource is its staff but adds to it by showing that the resource improves as staff mature. The finding underlines the importance of retaining experienced nurses within the hospital and ward, and ensuring that they have a direct role in patient care. It is likely that the benefits of staff experience are mediated through ward managers who, by their example, set and maintain standards of clinical care that produce better outcomes. In addition, the finding invites hospitals to think creatively about the processes that need to be in place to help staff distil their years of experience into wells of experience by developing a more mature understanding of the simple essence of care.

# About the Standards

## Standard 3. The Patient

Each patient receives high quality end-of-life care that is appropriate to his / her needs and wishes.

### 3.1 Extend to All Patients the Quality of Care for Cancer Patients

The audit revealed that a hierarchy exists in the quality of dying in Irish hospitals, based on the patient's disease. The range, from best to worst, is: cancer, circulatory diseases, respiratory diseases, dementia/frailty. The quality of care in the specialty of cancer – which is not confined to patients in oncology wards but affects all cancer patients, the majority of whom are not in oncology wards - offers an example of how better end-of-life care can be provided in a hospital. It is true that the disease trajectory of cancer patients is more predictable than for other patients but the audit suggests that the reasons for their better outcomes are not specific to cancer, but attributable to other factors such as more planned admissions, greater likelihood of dying in a single room, better communication, more team meetings, and more support for families to stay overnight and be present at the moment of death. This finding also opens up the possibility that the cancer specialty could take a lead role in terms of improving the overall standard of end-of-life care across each hospital.

### 3.2 Improve the Quality of Communication with Patients

Care outcomes are influenced by the quality of discussion with patients and relatives, not by the amount of discussion. Equally significant is the fact that care outcomes are influenced more by the quality of discussion with relatives than with patients. This may be due to the way we measured communication which focused exclusively on verbal communication – the quality of discussion – since that may be less important than non-verbal communication as patients in their last week of life begin to show signs of withdrawing from the world and, in these circumstances, relatives usually become patient proxies. At the same time, the findings raise questions as to whether care and communication is as patient-centred as it could or should be. Whatever the reason, the audit provides grounds for suggesting that further reflection and discussion is merited about the way nurses and doctors communicate verbally and non-verbally with patients during their final weeks and days. The findings also provide grounds for suggesting that nurses and doctors – but possibly other hospital staff – may benefit from some basic training in communication skills.

# About the Standards

## 3.3 Strengthen the Role of Specialist Palliative Care

Specialist palliative care is known to be effective and the audit suggests that its effectiveness is mediated through other variables which are known to have a positive and direct impact on care outcomes such as cancer patients, single rooms, team meetings, and support for families. The audit also identified a lack of clarity about the role of specialist palliative care services in acute hospitals and this points to a need to strengthen its role while also expanding that role to meet the needs of all patients who need it.

## Standard 4. The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during and after the patient's death.

### 4.1 General Support for Families

The audit reveals that one of the strengths of the hospital system is its relationship with families, both in terms of the quality of communication and facilitating them to be with the patient as much as possible, including at the moment of death. This has a positive influence on care outcomes. It endorses and encourages the widespread practice in Irish hospitals of facilitating relatives to be with the patient during his/her final journey.

### 4.2 Support for Families Following Sudden Deaths

Just as cancer is associated with more positive care outcomes, sudden deaths are associated with more negative ones. Sudden deaths are more likely to result in a post-mortem and, understandably, this can be difficult for relatives since the sense of loss at death may be compounded by the shock of its suddenness, and by the fact that funeral arrangements may have to be delayed as a result of the post-mortem. The audit shows that a third of relatives do not seem to have been properly informed about the reasons for a post-mortem and were less than satisfied with the information provided by the hospital. In light of this, hospitals may wish to look at their systems for responding to the more intense needs of relatives in the event of a sudden death and/or post-mortem.



Part 3

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# The Standards



# The Four Standards

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## 1 The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.

## 2 The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

## 3 The Patient

Each patient receives high quality end-of-life care that is appropriate to his/her needs and wishes.

## 4 The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during, and after the patient's death.

# Standard 1

## The Hospital

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The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.



*“A member of the management team is responsible for end-of-life issues.”*

# Standard 1 The Hospital

## Standard 1 The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.

- 1.1 A CULTURE OF COMPASSIONATE END-OF-LIFE CARE
- 1.2 GENERAL GOVERNANCE POLICIES AND GUIDELINES
- 1.3 EFFECTIVE COMMUNICATION
- 1.4 THE HEALTHCARE RECORD
- 1.5 THE HOSPITAL ENVIRONMENT
- 1.6 MONITORING AND EVALUATING END-OF-LIFE CARE
- 1.7 ASSESSING AND RESPONDING TO THE END-OF-LIFE CARE NEEDS OF PATIENTS
- 1.8 CLINICAL RESPONSIBILITY AND MULTIDISCIPLINARY WORKING
- 1.9 PAIN AND SYMPTOM MANAGEMENT
- 1.10 CLINICAL ETHICS SUPPORT
- 1.11 CARE AFTER DEATH
- 1.12 POST-MORTEMs
- 1.13 BEREAVEMENT CARE

# Standard 1 The Hospital

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## 1.1 A CULTURE OF COMPASSIONATE END-OF-LIFE CARE

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The Hospital Service Plan<sup>17</sup> contains a clear statement on the hospital's ethos of end-of-life care.

### How do we know that we are meeting this Standard?

- The Hospital Service Plan reflects a clear and transparent hospital ethos of end-of-life care and includes a statement of intent accordingly.
- A named senior member of the management team is allocated responsibility for ensuring that all hospital departments self-assess against the *Quality Standards for End-of-Life Care in Hospitals*.
- The Annual Report includes a section on Provision of End-of-Life Care.
- The hospital has a Standing Committee on End-of-Life Care with multi-perspective representation.

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<sup>17</sup> The Hospital Service Plan may be an individual hospital plan or hospital network plan.

# Standard 1 The Hospital

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## 1.2 GENERAL GOVERNANCE POLICIES AND GUIDELINES

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Governance policies and guidelines are in place in the hospital to ensure best practice in the implementation of the Quality Standards.

### How do we know that we are meeting this Standard?

- Hospital policies and guidelines for end-of-life care are set within the currently prevailing legal and ethical framework<sup>18</sup> and are based on best national and international practice.
- Policy and guidelines on end-of-life care in the hospital are available and are easily accessible to all staff in the hospital.
- All staff use and are trained to use these guidelines in accordance with their roles.
- Guidelines on advance care planning are available to support a culture of identifying patients' wishes and preferences.
- There is a system in place for regularly reviewing and updating all policies and guidelines relating to end-of-life care.

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<sup>18</sup> Health Service Executive (HSE), 2008. 'HSE Procedure for Developing, Policies, Procedures, Protocols and Guidelines'. Dublin: Health Service Executive (HSE). "Each health professional/HSE employee is accountable for their practice... This means being answerable for decisions he/she makes and being prepared to make explicit the rationale for those decisions and justify them in the context of legislation, case law, professional standards and guidelines, evidence based practice, professional and ethical conduct. It should be recognised that policies, procedures and guidelines represent a statement reflecting an expected standard of care and be introduced in law as evidence of the standard of care expected". Page 4.

# Standard 1 The Hospital

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## 1.3 EFFECTIVE COMMUNICATION

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There is timely, clear and sensitive communication with each patient and his/her family as appropriate on matters relating to end-of-life care.

### How do we know that we are meeting this Standard?

- All communication between hospital staff and patients and/or family members is governed by the wishes of the patient.
- Policy and guidelines are available for communicating with patients diagnosed as requiring end-of-life care. (Standard 1.2)
- The hospital communications policy includes evidence-based protocols for communicating prognostic information to patients.<sup>19</sup>
- The hospital communications policy includes direction on communication-related complaint practices for patients, family and staff.
- Advance care directives and patient preferences are clearly recorded in the Healthcare Record (Standard 1.4) and communicated to relevant staff.
- There is an acknowledgement across the hospital that staff other than clinicians and nurses may have an important role to play in ensuring effective communication with patients and families in respect of end-of-life care.

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<sup>19</sup> Clayton, J, M., Hancock, K, M., Butow, P., N., Tattersall M., H., N., Currow D., C., 2007. 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers'. The Medical Journal of Australia. MJA; 186 :( 12 Suppl) S77-S108.

# Standard 1 The Hospital

## Accessible Information<sup>20</sup>

- The information is presented in a range of formats to ensure that it is accessible to individuals with hearing difficulties, visual impairment and those with language or literacy difficulties and those who have an intellectual disability.
- Information is provided both verbally and in written form as required.
- Braille, sign language, symbols/ pictures, professional interpreters are used as appropriate.
- *Reference should also be made to Standards 3.1, 3.2, 4.1, 4.2 and 4.3.*

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<sup>20</sup> For guidance on accessible information, reference should be made to:  
National Disability Authority, 2006. 'Code of Practice on Accessibility of Public Services and Information provided by Public Bodies': Plain English Edition. Dublin: National Disability Authority.  
Citizens Information Board, 'Access to Information for All'. Available at: [www.citizensinformationboard.ie/Publications/Access to Information for All](http://www.citizensinformationboard.ie/Publications/Access%20to%20Information%20for%20All)  
National Adult Literacy Association Health Literacy Programmes. Available at: <http://www.nala.ie/>

# Standard 1 The Hospital

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## 1.4 THE HEALTHCARE RECORD

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The Healthcare Record<sup>21</sup> supports and enhances governance and communication in respect of end-of-life care.

### How do we know that we are meeting this Standard?

- The Healthcare Record is retrievable by all departments on a 24/7 basis.
- The Healthcare Record provides an accurate chronology of events and records all significant consultations, assessments, observations, discussions, patient preferences, decisions, interventions and outcomes.
- Members of the multidisciplinary team consult each others notes within the Healthcare Record on a regular and systematic basis.

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<sup>21</sup> Health Services Executive, 2007. National Hospitals Office. Code of Practice for Healthcare Records Management. Version 2.0. Available at:[http://www.hse.ie/About the HSE/Publications about HSE Services/National Hospitals Office Code of Practice for Healthcare Records Management Version 2.0](http://www.hse.ie/About%20the%20HSE/Publications%20about%20HSE%20Services/National%20Hospitals%20Office%20Code%20of%20Practice%20for%20Healthcare%20Records%20Management%20Version%202.0)

# Standard 1 The Hospital

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## 1.5 THE HOSPITAL ENVIRONMENT

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The physical environment where end-of-life care is provided supports high quality care and facilitates dignity and privacy.

### How do we know that we are meeting this Standard?

- Key areas of the hospital environment related to end-of-life care are assessed against the Hospice Friendly Hospitals Programme *Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*.<sup>22</sup> The annual service plan identifies and prioritises funding to refurbish these key hospital areas as required.
- The *Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care* are promoted throughout all relevant hospital departments and copies are widely available throughout the hospital and are easily accessible to all staff.
- All refurbishments and new hospital buildings take into account the *Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*.
- End-of-life care patients are offered the choice of being accommodated in a single room.
- The hospital facilitates access to rooms and spaces where discussions between patients, staff and family members can take place in a quiet, comfortable environment where privacy is ensured.
- The hospital facilitates family members with overnight rest and refreshment facilities.

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<sup>22</sup> Hospice Friendly Hospital's Programme, 2008. 'Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care'. Dublin: The Irish Hospice Foundation.

# Standard 1 The Hospital

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## 1.6 MONITORING AND EVALUATING END-OF-LIFE CARE

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End-of-life care in the hospital is continuously evaluated.

### How do we know that we are meeting this Standard?

- All hospital departments self-assess against the *Quality Standards for End-of-Life Care in Hospitals*. (Standard 1.1)
- Where appropriate, the hospital utilises the individual hospital data arising from the National Audit to benchmark nationally and identify priorities for improvement.
- The hospital collects data on end-of-life care throughout the hospital. This information is recorded and reported electronically and published annually.
- Each hospital department identifies key performance indicators for end-of-life care relevant to the patient population it serves.

# Standard 1 The Hospital

## 1.7 ASSESSING AND RESPONDING TO THE END-OF-LIFE CARE NEEDS OF PATIENTS

All patients who are at a stage where they may be approaching end of life are identified and provision for their individual care is made accordingly.

**How do we know that we are meeting this Standard?**

### Advance Care Planning

- End-of-life care for each patient is guided by the principle of advance care planning and advance care directives (where they exist) are included as part of an individual care plan.<sup>23</sup>

### Assessment

- There are effective mechanisms in place to identify patients who may be approaching or at the end of life.<sup>24</sup>
- The needs of a patient identified as approaching or at end of life are assessed in a holistic manner, with particular emphasis on pain and symptom assessment, and documented in the care plan within the Healthcare Record.

<sup>23</sup> Care plan: A care plan is based on information gathered during patient assessment. It identifies the patient's care needs, lists the strategy to meet those needs, documents treatment goals and objectives, outlines the criteria for ending interventions, and documents the individual's progress in meeting specified goals and objectives. The care plan must be related to the patient's identified care needs and patient care processes are planned to achieve optimal outcomes for the patient. The care plan may include prevention, care, treatment and rehabilitation as components.

The care plan forms part of the Healthcare Record. As the patient's needs change, the care plan also changes. Changes are documented in the Healthcare Record as notes to the initial plan and/or as revised or new care goals. In some instances a new care plan may be required. The format of the plan in some organizations may be guided by specific policies and procedures, protocols, practice guidelines, clinical paths or a combination of these.

<sup>24</sup> The concept of the 'Surprise' Question has been put forward by, among others, the National Gold Standards Framework (available at: <http://www.goldstandardsframework.nhs.uk/TheGSFToolkit/Identify/TheThreeTriggers>). The 'Surprise' Question: 'Would you be surprised if this person died within the next 6-12 months?' is described as an intuitive question to assist clinicians in recognizing patients who may be near the end of life. The 'Surprise' Question can be applied to years/months/weeks/days and trigger the appropriate actions. It is suggested that the 'Surprise' Question facilitates earlier recognition of people nearing the end of their life which leads to earlier planning and better care.

# Standard 1 The Hospital

- Staff establish if patients have an Advance Care Directive in place and, where relevant, this is discussed, reviewed and updated with the patient or relevant third party.
- The outcome of the assessment of need is communicated in a format and language suitable for the patient and his/her family. (Standard 3.1 and Standard 3.2).
- There is ongoing consultation with the patient and with his/her family, the latter if the patient wishes, with regard to outcomes of treatment and progress.
- Policy and guidelines identify and address any additional or special needs a patient may have, e.g. intellectual disability, reduced capacity, mental health difficulties, ongoing difficulties in coping.

## The Care Plan

- The patient's care plan, including pain and symptom management and preferred place of care, is reviewed and updated regularly in accordance with his/her clinical condition, needs and preferences.
- The care plan is accessible to all relevant healthcare staff and implemented by each person/team in carrying out their respective roles.
- Guidelines for "Diagnosing Dying" are available to assist staff to identify when a patient may be dying and are referred to as part of care planning.

# Standard 1 The Hospital

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## 1.8 CLINICAL RESPONSIBILITY & MULTIDISCIPLINARY WORKING

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All patients who are approaching end of life are supported by a named lead clinician(s) working in consultation/partnership with the multidisciplinary team.<sup>25</sup>

### How do we know that we are meeting this Standard?

- The lead clinician and/or the clinician responsible for the patient's care is identified and documented in the Healthcare Record.
- The patient is facilitated to discuss his/her care with the lead clinician.
- Policy and guidelines are in place for communication between disciplines, teams and service providers whether hospital-based or community-based in order to facilitate a planned approach to the patient's admission, care, and discharge/transfer out of the hospital. (See standard 1.2).
- There is clear allocation and documentation of responsibility within and between clinical teams involved in the care of the patient, regarding the patient's admission, care, and discharge/transfer out of the hospital.
- When the patient moves to a different clinical environment within the hospital and the responsible lead clinician changes for a period of the patient's care, there is formal handover of information and accountability for the overall care of the patient.
- The multidisciplinary team meets on a regular basis and these meetings include consideration of the views of the patient and family members, the latter if relevant.
- The patient and/or family are accommodated to be present at a multidisciplinary team meeting, if appropriate.

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<sup>25</sup> Department of Health and Children, 2008. 'Building a Culture of Patient Safety'. Report of the Commission on Patient Safety and Quality Assurance. Recommendation 5.9, page 22. Dublin: The Stationery Office.

# Standard 1 The Hospital

## 1.9 PAIN AND SYMPTOM MANAGEMENT

Effective pain<sup>26</sup> and symptom management is provided as a key component of end-of-life care and staff education in the hospital.<sup>27 28</sup> (See also 3.4).

### How do we know that we are meeting this Standard?

- There is a written hospital/departmental ethos regarding pain and symptom management that is evident through attitude, action and documentation. (Standard 3.4)
- Evidence-based guidelines for pain and symptom management at end of life are easily accessible to all clinical staff and adhered to at all times.
- The hospital/department has Guidelines for use during initial assessments and reassessments that assist staff in identifying patients who are experiencing pain.
- There is documentation within the Healthcare Record of regular assessment, timely response, monitoring and review of pain and symptoms according to need and the patient's expressed experience of the pain/symptom(s) and intervention measures.<sup>29 30 31</sup>
- The patient is referred to specialist palliative care services as soon as patient needs, symptoms and other care factors indicate a need for such expertise.

26 The British Pain Society, 2004. 'Understanding and Managing Pain: Information for Patients'. London: The British Pain Society.

27 Department of Health & Children, 2001. 'Report of the National Advisory Committee on Palliative Care'. Dublin: The Stationery Office.

28 The Royal College of Anaesthetists. The Pain Society, 2003. 'Pain Management Services. Good Practice'. London: The Royal College of Anaesthetists. The Pain Society.

29 Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine, 2005. 'Acute Pain Management: Scientific Evidence'. Second edition. Victoria: Australian and New Zealand College of Anaesthetists.

30 Australian and New Zealand College of Anaesthetists, Faculty of Pain Medicine and Joint Faculty of Intensive Care Medicine. 2008, 'Statement On Patient's Rights to Pain Management and Associated Responsibilities'. Available at: <http://www.anzca.edu.au/resources/professional-documents/professional-standards/pdfs/PS45-2008.pdf>

31 The Royal College of Anaesthetists. The Pain Society, 2003. 'Pain Management Services. Good Practice'. London: The Royal College of Anaesthetists. The Pain Society.

# Standard 1 The Hospital

## 1.10 CLINICAL ETHICS SUPPORT<sup>32</sup>

Hospital management ensures that each staff member has access to Clinical Ethics Support as appropriate to his/her role.

### How do we know that we are meeting this Standard?

- All staff providing end-of-life care to patients adhere to the mission, vision and values of the hospital (Standard 1.1)
- Each staff member ensures that s/he is familiar with and guided by the Professional Ethical Code of Conduct appropriate to his/her role.<sup>33 34 35</sup>
- Hospital management promotes a positive ethical climate within the organisation in which all employees feel comfortable raising and discussing ethical concerns.
- Transparent and equitable processes and mechanisms for ethical decision-making are in place and may be used to resolve disagreements about the interpretation of policies or to address potentially difficult or contentious ethical issues that may arise in relation to end of life.
- Mistakes are acknowledged and there is ongoing evaluation and review to ensure that ethical challenges are accurately identified and resolved.

<sup>32</sup> Hospice Friendly Hospitals Programme, 2010. 'An Ethical Framework for End-of-Life Care'. Dublin: The Irish Hospice Foundation.

<sup>33</sup> The Medical Council, 2009. 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners'. 7<sup>th</sup> Edition. Dublin: The Medical Council.

<sup>34</sup> An Bord Altranais, 2000. 'Code of Professional Conduct for each Nurse and Midwife'. Available at: <http://www.aib.ie/Professional Practice & Education/Policies and Guidelines>

<sup>35</sup> An Bord Altranais, 2007. 'Guidelines to Nurses and Midwives Regarding Ethical Conduct of Nursing and Midwifery Research'. Dublin. Available at: <http://www.aib.ie/Professional Practice & Education/Policies and Guidelines>

# Standard 1 The Hospital

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## 1.11 CARE AFTER DEATH

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*Policies and Guidelines for care after death are respectful of the deceased person and his or her wishes and beliefs.*

### How do we know that we are meeting this Standard?

- Policy and guidelines are in place for 'care of the deceased person's body after death'. All relevant staff use and are trained in the use of these.
- A universal symbol, which is recognised by all staff and by the public as indicating that a death has occurred, is clearly visible in the ward/ department.
- Where appropriate, hospital staff consult the family members to ensure that the wishes, if known, of the deceased person, are respected.
- Information is provided to family members on matters associated with post-mortems where relevant.
- If the person's death is not referred to the Coroner, the hospital has a clear procedure for notification of death within three working days of the death occurring.
- The hospital notifies the deceased person's GP and other relevant primary and secondary care services as soon as possible, ideally on the first working day following the patient's death.
- A letter/sympathy card is sent to the patient's family within two weeks of the person's death.
- Any requests for payment of hospital bills are scheduled to ensure that they arrive after the sympathy letter/card.

# Standard 1 The Hospital

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## 1.12 POST-MORTEMS

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The hospital manages all aspects of post-mortems in a transparent, timely and sensitive manner.

### How do we know that we are meeting this Standard?

- The loss being experienced by the family is recognised and acknowledged, and staff are sensitive to avoiding the potential for further distress when communicating information about the post-mortem.
- Families are provided with verbal and written information regarding hospital post-mortems and coroner post-mortems.
- Policy and guidelines address:
  - Requesting informed consent for non-coroner's post-mortem
  - Dealing with questions relating to the role of the coroner and the formal identification of the deceased person
- A member of staff is available to speak with bereaved families where a post-mortem is to be carried out.
- Records are kept of all contact with the family regarding post-mortems.

# Standard 1 The Hospital

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## 1.13 BEREAVEMENT CARE

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The hospital provides assistance and supports to families in dealing with loss during the period approaching and following a death.

### How do we know that we are meeting this Standard?

- End-of-life care is managed in a multidisciplinary manner to ensure that all needs can be responded to effectively.
- Where there is clear indication that death may be imminent, family members are alerted as appropriate.
- Where families have differences of opinion, these are acknowledged and addressed sensitively.
- Families who are experiencing significant difficulty, for example, a high level of distress, are referred to the appropriate member of the multidisciplinary team.
- If requested, the patient's family can obtain further information or discuss concerns about the care and treatment of the patient with a member of the multidisciplinary team.
- Families are offered timely bereavement supports- beginning with information, identification of any risk factors and referral if appropriate.
- All supports and services consider and respond to individual, cultural and spiritual requirements. (Standard 4.6).

### Identifying and responding to bereavement support needs

- Staff have an understanding of the range of responses to bereavement.
- Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. This information may be offered on more than one occasion. (Standard 4.6)

# Standard 1 The Hospital

- Staff have an understanding of the types of risk factors, (e.g. personal attributes, the nature of the relationship with the deceased, whether death was perceived as sudden or expected, traumatic or peaceful), which may result in complicated bereavement and refer to relevant professional support as appropriate.
- Staff have information on and access to appropriate professional support to address different types of risk factors and possible complicated grief responses.
- The bereavement support needs of children and teenagers are assessed and responded to appropriately.

## Bereavement Services

- Formal bereavement support is offered by the hospital and with reference to other community and professional providers.
- Bereavement services are guided by a standardised assessment process<sup>36</sup> and families' bereavement needs are kept under review.
- Families are assured of confidentiality and privacy when using bereavement services, in accordance with current legal and ethical legislation.
- The bereavement service organises events that facilitate the grieving process such as remembrance services and public talks.
- Families are offered the opportunity to provide feedback to the service – this feedback informs service development and provision.

<sup>36</sup> 'A standardised assessment process refers to a protocol adopted by the hospital which ensures that staff consider the same issues in assessing bereavement needs – e.g. personal strengths and risks; interpersonal resources or stresses; situational aspects concerning the death.'

See: Stroebe, M. S., S. Folkman, et al. 2006. 'The prediction of bereavement outcome: development of an integrative risk factor framework'. *Social Science & Medicine* 63(9): 2440 and Agnew, A., R. Manktelow, et al., 2010. 'Bereavement needs assessment in specialist palliative care: a review of the literature'. *Palliative Medicine*; 24(1): 46-59.

# Standard 2 The Staff

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Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.



*“Each one of us knows what happens next.”*

# Standard 2 **The Staff**

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## Standard 2 **The Staff**

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Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

- 2.1 CULTIVATING A CULTURE OF COMPASSIONATE END-OF-LIFE CARE
- 2.2 STAFF INDUCTION
- 2.3 STAFF EDUCATION AND DEVELOPMENT NEEDS
- 2.4 STAFF EDUCATION AND TRAINING PROGRAMMES
- 2.5 STAFF SUPPORT

# Standard 2 The Staff

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## 2.1 CULTIVATING A CULTURE OF COMPASSIONATE END-OF-LIFE CARE AMONG STAFF

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All hospital staff have access to education and training opportunities in the delivery of compassionate end-of-life care in accordance with their roles and responsibilities.

How do we know that we are meeting this Standard?

- The Hospital Manager ensures that there are education, training and staff mentorship programmes in end-of-life care for hospital staff in accordance with the size, complexity and specialties of the hospital.
- The design of staff education and training programmes involves key stakeholders with relevant experience and knowledge.
- A core group of clinical and non-clinical hospital staff with the required expertise in end-of-life care are facilitated and supported to deliver end-of-life care education and training to hospital staff.
- The hospital facilitates staff, as appropriate, to undertake additional formal education and training in end-of-life care.

# Standard 2 The Staff

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## 2.2 STAFF INDUCTION

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All newly recruited staff are inducted on the general principles and components of end-of-life care in the hospital.

How do we know that we are meeting this Standard?

- The hospital's general induction programme includes a component on end-of-life care.
- The *Quality Standards for End of Life Care in Hospitals* are introduced and explained.

# Standard 2 The Staff

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## 2.3 STAFF EDUCATION AND DEVELOPMENT NEEDS

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The education and development needs of staff are assessed relative to their roles in end-of-life care and according to emerging national consensus on competencies and standards.

### How do we know that we are meeting this Standard?

- Hospital staff are competent to deliver high quality end-of-life care in accordance with best practice.
- Competency statements are developed for different categories of staff in accordance with their individual roles, and performance management systems are used to measure this aspect of care.
- An audit of education and training needs in end-of-life care is conducted every two years.

# Standard 2 The Staff

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## 2.4 STAFF EDUCATION AND TRAINING PROGRAMMES

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Staff education and training programmes have defined objectives that reflect evidence-based best practice and legislation.

### How do we know that we are meeting this Standard?

- Staff education and training programmes cover the key elements of the *Quality Standards for End-of-Life Care in Hospitals*, and specifically address pain and symptom management and how to support patient preferences and values.
- The hospital provides and maintains resources and facilities for education, training and continuous professional development in coordination with the regional education and training services of the HSE.
- Education and development programmes relating to end-of-life care are revised annually by a team that includes the hospital manager and other disciplines directly involved in end-of-life care.
- Priority groups of staff members who would benefit from specialised education in end-of-life care are identified every two years and their participation in standard and accredited education programmes on an ongoing basis is facilitated by the hospital.
- If the hospital implements an Integrated Care Pathway in respect of End-of-Life Care, appropriate support and training is provided in accordance with specific guidance from the relevant experts.

# Standard 2 The Staff

## 2.5 STAFF SUPPORT

Staff support services relating to end-of-life care reflect the need for peer support<sup>37</sup> and professional support<sup>38</sup> systems.

### How do we know that we are meeting this Standard?

- The Hospital Management Team facilitates the provision of formal and informal structures and support systems for practical and emotional support to each member of staff. These supports address both the professional and personal needs of the individual involved in the provision of end-of-life care.
- Written information is provided to each staff member on:
  - Skills and techniques for effective self-care<sup>39</sup>
  - Opportunities for reflective practice
  - Supervision
  - Recognition of burnout and compassion fatigue
  - Support services available and how to access these support services
- Each staff member takes personal responsibility for his/her self-care.<sup>40</sup>

<sup>37</sup> Peer support is usually contained within the team and can be informal and/or formal support. Informal support refers to expressed recognition, understanding and acknowledgement of the potential issues relating to end-of-life care. Formal support refers to structured support that is offered according to specific criteria such as individual or team support, timeframe of support, meeting place, issues to be addressed.

<sup>38</sup> Professional support systems refer to supporting the individual regarding life events not directly involving workplace issues.

<sup>39</sup> 'Staff review the four main aspects of self care, physical, emotional/cognitive, relational and spiritual'. Hill Jones, S., 2005. 'A self-care plan for hospice workers'. American Journal Hospice and Palliative Care; 22; 125-128.

<sup>40</sup> 'Physicians working with patients at end-of-life frequently have to respond to overwhelming human suffering in the absence of adequate institutional support or resources. In this context, the idea of "self-care" may seem a selfish irrelevance and an unjustifiable luxury. In fact, self-care is an essential part of the therapeutic mandate. Self care enables physicians to care for their patients in a sustainable way with greater compassion, sensitivity, effectiveness and empathy'. Kearney M.K., Weininger R.B., Vachon M.L.S., 2009. 'Self-care of Physicians Caring for Patients at the End of Life: Being Connected...A Key to My Survival'. Journal of the American Medical Association JAMA; 301(11):1155-1164.

# Standard 2 The Staff

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- Each staff member has access to Clinical Ethics Support as appropriate to his/her role (Standard 1.10).
- Policy and Guidelines are in place to support staff involved in dealing with trauma or sudden deaths..
- Issues and challenges for staff arising from the delivery of end-of-life care, care of the dying patient and care of the deceased patient, form part of team discussions and are addressed in reviews of end-of-life care.
- Private space is available to enable staff to discuss and address issues that may arise when providing end-of-life care and dealing with death.
- Staff who use support services to address issues that may arise during provision of end-of-life care are facilitated to provide feedback on their appropriateness and value.

# Standard 3 The Patient

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Each patient receives high quality end-of-life care that is appropriate to his/her needs and wishes.



*“Ask me what I want.”*

# Standard 3 The Patient

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## Standard 3 The Patient

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Each patient receives high quality end-of-life care that is appropriate to his/her needs and wishes.

- 3.1 COMMUNICATING DIAGNOSIS OF THE POSSIBILITY OF A NEED FOR END-OF-LIFE CARE
- 3.2 CLEAR AND ACCURATE INFORMATION
- 3.3 PATIENT PREFERENCES
- 3.4 PAIN AND SYMPTOM MANAGEMENT
- 3.5 DISCHARGE FROM HOSPITAL
- 3.6 THE DYING PATIENT

# Standard 3 The Patient

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## 3.1 COMMUNICATING A DIAGNOSIS OF A NEED FOR END-OF-LIFE CARE

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There is timely, clear and sensitive communication with each person, as appropriate, in respect of a diagnosis that s/he may be approaching or at the end of life.

### How do we know that we are meeting this Standard?

- The patient, unless s/he states otherwise, is always responded to directly and confidentially in respect of any matters relating to his/her possible need for end-of-life care.
- The communication to the patient of a clinical decision that s/he may be near the end of life is recorded in the Healthcare Record.
- The manner and style of communication takes account of the person's capacity for understanding and his/her religious, cultural and ethnic preferences.
- When the patient lacks capacity/is deemed not competent to give consent, this is noted and monitored on an ongoing basis.
- Where a patient has additional communication needs arising from a disability or from language or literacy difficulties, these needs are identified, documented and responded to individually.
- The patient is actively involved in discussions and decisions regarding admission, discharge home, or transfer to another setting for end-of-life care.

# Standard 3 The Patient

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## 3.2 CLEAR AND ACCURATE INFORMATION

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Clear and accurate information is provided as appropriate to the patient about his/her condition, treatment options, prognosis and care plan in a timely and culturally appropriate manner and in accordance with the patient's needs and preferences.

### How do we know that we are meeting this Standard?

- Information is shared sensitively with the patient and, if the patient wishes, with his/her family members.
- Any unexpected changes to the patient's condition or care plan are communicated to the patient, or to family members if appropriate, in a timely manner.
- Details of the information provided to the patient are documented in the Healthcare Record.
- Information on end-of-life care and supports is provided both verbally and in written form and in a format and language suitable for the patient and his/her family (See Standards Criterion 1.3).

# Standard 3 The Patient

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## 3.3 PATIENT PREFERENCES

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*The patient receives care in a manner and care setting of choice.*

### How do we know that we are meeting this Standard?

- Discussions are held with the patient on an ongoing basis about his/her needs and preferences and the outcomes of these discussions are documented in the Healthcare Record (Standard 1.4).
- The patient's capacity to participate in decisions and to make choices regarding end-of-life care is assessed, optimised and regularly reviewed.
- Consent by the patient is easily and clearly identifiable either on a consent form, which is retained as part of the Healthcare Record, or in the case of verbal consent, documented within the Healthcare Record.
- Where a patient has a written Advance Care Directive, this is recorded and forms part of the Healthcare Record (Standard 1.7).
- Where a patient does not have a written Advance Care Directive, s/he is made aware of the option to provide one in either a written form or verbally.
- Each patient's preferences are regularly reviewed in consultation with the patient.
- If a patient is unable or does not wish to participate in discussions and decision-making, this is documented in the Healthcare Record and reviewed regularly.
- The patient is facilitated to access an independent advocacy service when making decisions relating to treatment or care if s/he so wishes.
- If it is the patient's wish, and deemed to be in his/her best interest, family members are facilitated in assisting with the personal care of the patient.

# Standard 3 The Patient

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## 3.4 PAIN AND SYMPTOM MANAGEMENT

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Pain and symptom management for each individual patient takes full account of the multifaceted nature and individual experience of pain.

### How do we know that we are meeting this Standard?

- The patient's experience and description of pain and symptoms, including verbal, non-verbal and behavioral expressions of discomfort and pain, are identified, regularly assessed and responded to promptly.
- There is ongoing dialogue with the patient regarding his/her experience of pain, distress and other symptoms and the level of comfort obtained from different interventions.
- There is documentation within the Healthcare Record of regular monitoring of the patient's symptoms and the effectiveness of interventions.
- Specialist palliative care advice is sought as required and in accordance with the patient's wishes.

# Standard 3 The Patient

## 3.5 DISCHARGE HOME/OUT OF HOSPITAL

The patient is actively involved in discussions and decisions regarding admission, discharge home, or transfer to another setting for end-of-life care.

### How do we know that we are meeting this Standard?

- The hospital has a process of proactive admission and discharge planning that addresses the patient's individual needs.
- There is timely and clear communication with the General Practitioner and/or other service providers regarding the patient's admission and discharge.
- Written information provided to the General Practitioner/and or other service providers is formulated so that essential relevant information is easily identifiable and accessible.
- Information provided to the General Practitioner/and or other service providers includes:
  - Relevant clinical information
  - Patient /family awareness of prognosis
  - The patient's wishes regarding preferred place of death
  - Any other non-clinical information that is important
- The Community Pharmacist is notified of any unusual medication requirements.
- Prior to discharge from hospital, the patient, and family members where appropriate, is provided with information and advice both verbally and in writing on the various aspects of providing end-of-life care in the home.
- The core content of these discussions and communications is documented in the Healthcare Record.
- The GP and other service providers are notified of any patient decisions regarding preferred place of dying to minimise inappropriate return to hospital if the patient is seriously ill or unconscious.

# Standard 3 The Patient

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## 3.6 THE DYING PATIENT

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The particular needs of a patient whose death is imminent are assessed and provided for in a sensitive and culturally appropriate manner.

### How do we know that we are meeting this Standard?

- The needs of the dying patient are assessed and prioritised to ensure that as far as possible his/her wishes are respected and that the best possible level of comfort is provided.
- Particular attention is given to deploying staff to ensure that the patient is not left alone while dying, particularly if the patient's family are not present.
- The patient's family are advised as a matter of urgency when death may be imminent and are facilitated to be present with the patient, where this is not contrary to the patient's wish.
- The dying patient is cared for in a private and dignified space and as far as possible in a single room unless otherwise requested.
- Policies and guidelines for the care of the dying patient are adhered to by all staff. (Standard 1.2)

# Standard 4 The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during, and after the patient's death.



*“We would like to be involved, but our mother’s wishes are paramount.”*

# Standard 4 The Family

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## Standard 4 The Family

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Family members are provided with compassionate support and, subject to the patient's consent, given information, before, during, and after the patient's death.

- 4.1 COMMUNICATION WITH FAMILY MEMBERS – GENERAL
- 4.2 COMMUNICATION WITH FAMILY MEMBERS – WHERE DEATH MAY BE ANTICIPATED
- 4.3 COMMUNICATION WITH FAMILY MEMBERS – SUDDEN/UNEXPECTED DEATH  
OR SUDDEN IRREVERSIBLE DECLINE IN HEALTH LEADING TO DEATH
- 4.4 PATIENT DISCHARGE HOME
- 4.5 SUPPORTING FAMILY MEMBERS
- 4.6 RESPONDING TO THE NEEDS OF FAMILY MEMBERS AFTER A DEATH.

# Standard 4 The Family

## 4.1 COMMUNICATION WITH FAMILY MEMBERS<sup>41</sup>: GENERAL

All communication between hospital staff and family members is governed by the expressed wishes of the patient and, where these are unknown, by the best interests of the patient.

### How do we know that we are meeting this Standard?

- The hospital has a policy and related guidelines to assist in communicating with family members of patients who may be approaching end of life or dying. Staff use, and are trained in accordance with their roles, to use these Guidelines.
- Staff assist family members to come to terms as far as possible with the reality of what is happening and to support the patient during the period of his/her dying.
- Opportunities are provided by clinicians and nursing staff for family members to clarify issues and concerns about the patient's well-being, provided this is in keeping with the patient's wishes.
- Feedback from family members is acknowledged and noted in the Healthcare Record and complaints are dealt with promptly and sensitively.

<sup>41</sup> Family members may include the immediate biological family and/or other relatives, partners (including same sex and *de facto* partners) or friends. They may have a close, ongoing, personal relationship with the patient, be chosen by the patient to be involved in treatment decisions, and have themselves indicated that they are ready to be involved in such decisions.

# Standard 4 The Family

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## 4.2 COMMUNICATION WITH FAMILY MEMBERS: WHERE DEATH MAY BE ANTICIPATED

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Where death may be anticipated, as in the advanced stages of progressive life-limiting illness, family members (with the consent of the patient) are given factual information to enable them to plan ahead and to access the supports they may require.

### How do we know that we are meeting this Standard?

- There is timely information and communication with family members relating to the patient's condition throughout the advanced illness and dying period.
- There is ongoing consultation, with the patient's consent, with family members with regard to the patient's care plan.
- There are Guidelines for ascertaining and responding to the support needs of family members which are used by staff as relevant to their roles and in accordance with hospital communications policy (Standard 1.2).
- Relevant information is provided to family members (where the patient has consented to the sharing of information) both verbally and in written form as required.
- With the patient's consent, family members are advised of any Advance Care Directives made by the patient and of any specific patient wishes with regard to end-of-life ceremony or religious ritual.
- The core content of conversations between staff and patients/family members and the information provided is documented within the Healthcare Record.
- Relevant information leaflets/booklets are provided in accessible formats and language and their content is sensitively discussed with family members.

# Standard 4 The Family

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## 4.3 COMMUNICATION WITH FAMILY MEMBERS: SUDDEN/ UNEXPECTED DEATH OR SUDDEN IRREVERSIBLE DECLINE IN HEALTH LEADING TO DEATH

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In cases involving a sudden change in the patient's condition likely to lead to death and in cases of sudden/unexpected death, the patient's family is provided with prompt and clear information as appropriate.

### How do we know that we are meeting this Standard?

- The clinical decision that a patient may no longer be responding to treatment and may be dying is communicated clearly and sensitively to the patient's family as appropriate.
- The hospital has Guidelines on consulting families to ascertain the patient's known wishes in respect of resuscitation and organ donation (Standard 1.2). All relevant staff use, and are trained to use, these Guidelines.
- Family members are advised of any advance care directives by the patient that they may not be aware of.
- The core content of conversations between staff and patients/family members is documented within the Healthcare Record (Standard 1.4).
- Staff ensure that information regarding any changes in the patient's status is communicated clearly, sensitively and promptly to the family members as appropriate.
- Information provision to family members in the case of a sudden or unexpected death takes account of the person's capacity for understanding, any additional communication needs (Standard 1.3) and his/her religious, cultural and ethnic preferences.

# Standard 4 The Family

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## 4.4 PATIENT DISCHARGE HOME

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When a patient is to be discharged home, this is organized, with the patient's consent, in consultation with the patient's family, and occurs when the appropriate supports and services are in place.

### How do we know that we are meeting this Standard?

- Prior to the patient's discharge from hospital, family members are given opportunities to discuss the care plan with staff.
- Families are provided with advice on supporting the patient at home, e.g. assisting with personal care, medication, if the patient so wishes.
- Families are provided with detailed information concerning the level and source of ongoing supports and services following discharge.
- Families are provided with names and contact details of healthcare professionals to be involved in the ongoing care of the patient.
- As appropriate, families are provided with information and advice on the various aspects of providing end-of-life care at home (Standard 3.5).
- The views of the patient are fully taken into account in any discussions with family members about discharge home.

# Standard 4 The Family

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## 4.5 SUPPORTING FAMILY MEMBERS

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Family members are treated compassionately and are provided with practical assistance in dealing with the different aspects of the end of life of a loved one.

### How do we know that we are meeting this Standard?

- Guidelines are in place for identifying the needs of and supporting family members of a patient who may be approaching or at end of life. All relevant staff are aware of and use these Guidelines where appropriate.
- Families are offered timely bereavement supports before and after the death of a loved one which respond to their varied grief needs associated with their individual and cultural and spiritual experiences of dying and death (Standard 1.13).
- If the patient wishes, family members are offered the opportunity and practical guidance to assist in the personal care of the patient.
- If it is the patient's wish, family members are, as far as possible, facilitated to accompany the patient during treatments and/or procedures.
- When a death is believed to be imminent, the patient's family is informed and facilitated as far as possible and in accordance with the patient's wishes to spend as much time as they wish with the patient, including overnight stays if feasible.

# Standard 4 The Family

## 4.6 RESPONDING TO THE NEEDS OF FAMILY MEMBERS AFTER A DEATH

Family members are treated with compassion and in a caring manner following the death of a loved one.

### How do we know that we are meeting this Standard?

- Guidelines are in place for identifying the needs of and supporting family members after a person's death. All relevant staff are aware of and use these Guidelines where appropriate.
- Families are given time and space to mourn at the bedside; their needs are sensitively attended to.
- Families receive the deceased person's valuables and belongings in either his/her own bag/suitcase or in a designated relative's handover bag as appropriate.
- Where a Post-mortem is required (Coroner's Post-mortem) or requested (Hospital Post-mortem), family members are informed in a sensitive, timely and accurate manner (Standard 1.12).
- The Doctor completes the Death Notification Form within three working days of the patient's death (this will not apply where the Coroner is involved).
- A letter/sympathy card is sent to the patient's families within two weeks of the person's death.
- Any requests for payment of hospital bills are scheduled to ensure that they arrive after the sympathy letter/card. (Standard 1.13).
- All supports and services consider and respond to individual, cultural and spiritual requirements.
- Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. (Standard 1.13) This information may be offered on more than one occasion.
- Where a family member(s) may be vulnerable to risk factors, (e.g. personal attributes, the nature of the relationship with the deceased, the nature of the death) which may result in complicated bereavement, referral to relevant professional support is offered as appropriate. (Standard 1.13)

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**Advance Care Directives:** An “*advance care directive describes the advance expression of wishes by a person, at a time when they have capacity to express their wishes, about certain treatment that might arise at a future time when they no longer have capacity to express their wishes (because, for example, of the effects of Alzheimer’s disease, coma or stroke).*”<sup>1</sup>

**Advance Care Planning:** Refers to a process of discussion between an individual, his/her care providers, and often those close to them, about future care. Advanced care planning usually takes place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others. Issues which may be discussed are the individual’s concerns, his/her values or personal goals for care, his/her understanding of their illness or prognosis, in addition to particular preferences for types of care or treatment and preferred place of care in the future.<sup>2 3</sup>

**Advocacy:** A process of empowerment of the individual which takes many forms; includes taking action to help people say what they want, secure their rights, represent their interests or obtain the services they need; it can be undertaken by individuals themselves, by their friends and relations, by peers and those who have had similar experiences, and/or by trained volunteers and professionals.<sup>4</sup>

**Advocate:** A person independent of any aspect of the service or any of the statutory agencies involved in purchasing or providing the service, who acts on behalf of, and in the interests of, the person using the service. In the context of residential care settings for older people, an advocate facilitates a resident, in so far as possible, to make informed choices regarding healthcare, social care and quality of life.<sup>5</sup>

**Autonomy:** Is the capacity of self-determination; it is a person’s ability to make choices about their own life based on their own beliefs and values.<sup>6</sup>

**Best Interests:** Refers to both a duty of the professional not to act negligently and to have regard to emotional, psychological, spiritual and social benefit when considering best interests.<sup>7</sup>

1 Law Reform Commission, 2009. ‘Bioethics: Advance Care Directives’. Report, September, Dublin: Law Reform Commission

2 Royal College of Physicians, 2009. ‘Clinical Standards Department. Concise Guidance to Good Practice. A series of evidence based guidelines for clinical management’. Number 12. Advance Care Planning. London: Royal College of Physicians.

3 NHS. The University of Nottingham, 2008. ‘Advance Care Planning: A Guide for Health and Social Care Staff’. Available at <http://www.endoflifecare.nhs.uk/eolc/files>

4 Health Information and Quality Authority, (HIQA), 2008. ‘National Quality Standards for Residential Care Settings for Older People in Ireland’. Cork: Health Information and Quality Authority.

5 Health Information and Quality Authority, (HIQA), 2008. ‘National Quality Standards for Residential Care Settings for Older People in Ireland’. Cork: Health Information and Quality Authority.

6 Hospice friendly Hospitals Programme, 2010. ‘An Ethical Framework for End of Life Care’. Dublin: The Irish Hospice Foundation.

7 Adapted from O’Shea, E., Murphy K., Larkin P., Payne, S., Froggatt, K., Casey D., Ní Léime, A. & Keys, M., 2008. ‘End of Life Care for Older People in Acute and Long-Stay Settings in Ireland’. Dublin: Hospice Friendly Hospitals Programme.

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**Bereavement:** The entire experience of family members and friends in the anticipation of death, and subsequent adjustment to living following the death of a loved one.<sup>8</sup> Also refers to the objective situation of having lost someone significant through death.<sup>9</sup>

**Bereavement Support Services:** Contemporary research acknowledges and affirms bereavement and the pain of grief as a natural part of the human experience. It is generally accepted that most people will adjust over time without any professional interventions or with low-level interventions only. However, grieving is an individual process, and some deaths, such as sudden or unexpected death, or a death by violent means, may predispose individuals or families to an increased risk of developing complicated grief. The needs of children and adolescents, whose way of understanding, expressing and coping with grief can be quite different to that of adults may need particular support.<sup>10 11</sup>

The aim of bereavement support is firstly, to provide information on the grief process as a normal life experience for the majority of people. A second aim is to identify those at risk of developing a complicated bereavement. A third aim is to develop access to formal interventions and services to prevent complex bereavement problems and to treat those who already have complications.<sup>12 13</sup>

Bereavement support includes anticipating severe grief reactions, and preparing the family for the loss of their loved one, helping them face unresolved issues, and encouraging and assisting them to say goodbye. Other issues identified as being important in reducing the risk of complicated grief include the concept of a “good death” being realised, effective communication with those providing care and support to the patient, and effective symptom control for the patient. Privacy at the time of death is important in the grief process.<sup>14</sup>

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National Council on Ageing and Older People. Chapter 3. The Legal Framework.

8 Christ, G.H., Bonnanno, G., Malkinson, R. & Rubin, S., 2003. Bereavement Experiences after the death of a child. In IOM (Ed.) When children die: improving palliative and end of life care for children and their families. Washington DC, National Academy Press.

9 Stroebe M.S., Hansson R., Schut H., Stroebe W., 2008. 'Handbook of Bereavement Research and Practice'. Advances in Theory and Intervention. Washington DC: National Academy Press.

10 Department Of Health, England. 2008. End of Life Care Strategy: Promoting high quality care for all adults at the end of life'. London: Department Of Health.

11 National Institute for Clinical Excellence. (NICE), 2004. 'Guidance on Cancer Services. Improving Supportive and Palliative Care for adults with cancer. The Manual'. London. National Institute for Clinical Excellence.

12 National Institute for Clinical Excellence. (NICE), 2004. 'Guidance on Cancer Services. Improving Supportive and Palliative Care for adults with cancer. The Manual'. London. National Institute for Clinical Excellence.

13 Department of Health and Children, 2001. 'Report of the National Advisory Committee on Palliative Care'. Dublin: Stationary Office.

14 Department of Health and Children, 2001. 'Report of the National Advisory Committee on Palliative Care'.

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A tiered component model of bereavement support provides a targeted approach to provision of appropriate services and ensures that people's individual needs are addressed through a graded service provision.<sup>15</sup>

The first level of bereavement care seeks to facilitate awareness and understanding of loss and grief through provision of information about the experience of loss and bereavement, and how to access other forms of support. Health and social care professionals providing day-to-day care to families provide that information, and family and friends tend to provide much of the required support.

The second level offers a more formal opportunity to the bereaved relative to review and reflect. Along with bereavement support services provided by hospitals, voluntary bereavement support services, self-help groups, faith groups and community groups provide much of the support at this level.

The third level refers to the minority of people, including children and young people, who require specialist interventions such as mental health services, psychological support services, specialist counselling or psychotherapy services, specialist palliative care services and other services providing care for those bereaved by particular kinds of death.

**Burnout:** Burnout is a form of mental distress manifested in individuals who experience decreased work performance resulting from negative attitudes and behaviours.<sup>16</sup>

**Capacity:** *"The ability to understand the nature and consequences of a decision in the context of available choices at the time the decision has been made".* Capacity should be enabling rather than restrictive.<sup>17</sup> In the context of medical care, an adult is presumed to have capacity to give or withhold consent unless the contrary is established. An informed consent process represents a process of communication during which he/she has learned about his/her illness and treatment options and reached a decision from an informed perspective to proceed with, restrict, or decline the proposed intervention.<sup>18</sup>

**Cardiopulmonary Resuscitation (CPR):** Cardiopulmonary resuscitation measures include external/internal chest compression, artificial respiration and defibrillation. Cardiopulmonary resuscitation (CPR) is instituted immediately following an unexpected collapse and if initiated promptly

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Dublin: Stationary Office.

15 Walsh T., Foreman M., Curry P., O'Driscoll S., and McCormack, M., 2008. 'Bereavement Support in an Acute Hospital: An Irish Model', *Death Studies*, 32:8,768-786.

16 Kearney M.K., Weininger R.B., Vachon M.L.S., 2009. 'Self-care of Physicians Caring for Patients at the End of Life: Being Connected...A Key to My Survival' *Journal of the American Medical Association JAMA*; 301(11):1155-1164.

17 Adapted from O'Shea, E., Murphy K., Larkin P., Payne, S., Froggatt, K., Casey D., Ní Léime, A. & Keys, M., 2008. 'End of Life Care for Older People in Acute and Long-Stay Settings in Ireland'. Dublin: Hospice Friendly Hospitals Programme. National Council on Ageing and Older People. Chapter 3. The Legal Framework.

18 Law Reform Commission, 2009. 'Bioethics: Advance Care Directives'. Report, September, Dublin: Law Reform Commission.

can sometimes restart the heart and lungs of patients whose heart is stopped or/and who may have stopped breathing.<sup>19</sup>

**Care plan:** A care plan is based on information gathered during patient assessment that identifies the patient's care needs and lists the strategy to met those needs, documents treatment goals and objectives, outlines the criteria for ending interventions, and documents the individual's progress in meeting specified goals and objectives. Patient care processes are planned to achieve optimal outcomes for the patient. The care plan forms part of the Healthcare Record.

The care plan must be related to the patient's identified care needs. These needs may change as a result of clinical improvement, new information from a routine assessment (for example, abnormal due to laboratory or radiology results) or may be evident from a sudden change in the patient's condition (for example, loss of consciousness). As needs change, the plan for the patient's care also changes. Changes are written in the Healthcare Record as notes to the initial plan, as revised or new care goals, or may result in a new care plan.

The format of the plan in some organisations may be guided by specific policies and procedures, protocols, practice guidelines, clinical paths or a combination of these. The plan of care may also include prevention, care, treatment and rehabilitation.<sup>20</sup>

**Child:** Throughout this document, child refers to infant, child and adolescent.

**Chaplain:** A Chaplain is a person who is certified by the Healthcare Chaplaincy Board and/or has been nominated by their Ecclesiastical Authority. Chaplains belong to a particular faith group and are usually nominated to act on behalf of their church. In some Healthcare Facilities, as Pastoral Care Workers. Chaplaincy is understood as the Profession and Pastoral Care as the role.

The Chaplain engages in a relationship with people as they seek to understand and find meaning in their own experience. The Chaplain may experience at first hand the absence of meaning, created as a result of a sudden break with the normal network of relationships that support and connect us to our lives. The pastoral relationship can reveal great acceptance and grace and also very real soul pain.

#### *Pastoral Support for patients and relatives*

Chaplains respect the dignity, culture, beliefs, practices and spiritual needs of each person and the right of people to have access to a minister of their own religion and denomination. Where requested,

<sup>19</sup> Adapted from: The General Medical Council, 2009. 'End of Life Treatment and Care: Good Practice in Decision Making'. UK. Available at: [www.gmc-uk.org/end\\_of\\_life\\_care](http://www.gmc-uk.org/end_of_life_care).

<sup>20</sup> Joint Commission International, 2007. 'Joint Commission International Accreditation Standards for Hospitals'. 3rd Edition. Page 98. USA: Joint Commission International.

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Chaplains provide pastoral support to patients and relatives in their struggle with illness, pain and suffering through: accompaniment, bereavement support, liturgical celebrations and ritual expression. (For further information see Pastoral Care).

### *Pastoral Support for hospital staff*

All Chaplains are trained to:

- Provide a supportive presence to all staff
- Be involved in trauma and crisis intervention
- Be actively involved in the Health & Safety Procedures of their Healthcare facility and/or Major Disaster Plan.

Some Chaplains are qualified in Pastoral Counselling, Psychotherapy, Critical Incident Stress Management (CISM) and other related areas.<sup>21</sup>

**Compassion:** The virtue of compassion is a trait combining an attitude of active regard for another's welfare with an imaginative awareness and emotional response of deep understanding, tenderness and discomfort at the other person's misfortune or suffering. It is expressed in acts that attempt to prevent and alleviate the suffering of another person.<sup>22</sup>

**Compassion fatigue:** Compassion fatigue has been described as "the cost of caring" for others in emotional pain that has led helping professionals to abandon their work with traumatized persons. Symptoms of compassion fatigue include disturbed sleep, irritability or outbursts of anger, hypervigilance, not wanting to go there again, and the desire to avoid thoughts, feelings, and conversations associated with the patient's pain and suffering; and re-experiencing intrusive thoughts or dreams, and psychological or physiological distress in response to reminders of work with the dying.<sup>23</sup>

**Confidentiality:** Confidentiality refers to protection of the right to privacy. The right to privacy is not absolute and is balanced against other factors. The Data Protection (Amendment) Act and the Freedom of Information Act 1997 supplement the right to confidentiality by protecting personal information and protecting safeguards against disclosure.

There is a duty on medical staff to abide by the ethical guide which states "*confidentiality is a time honoured principle of medical ethics. It extends after death and is fundamental to the doctor patient relationship. While the concern of relatives is understandable, the doctor must not disclose information to anyone without the consent of the patient*".<sup>24</sup>

21 National Association of Healthcare Chaplains, (N.A. H.C), 2006. 'Guidelines For Best Practice In Healthcare Facilities'. Available at: [NAHC.ie/resources/guidelines for best practice](http://NAHC.ie/resources/guidelines%20for%20best%20practice).

22 Adapted from Firth-Cozens J., Cornwell J.; 2009. 'The point of Care. Enabling compassionate care in acute hospital settings'. London: The Kings Fund.

23 Kearney M.K., Weininger R.B., Vachon M.L.S., 2009. 'Self-care of Physicians Caring for Patients at the End of Life: Being Connected...A Key to My Survival' Journal of the American Medical Association JAMA ; 301(11):1155-1164.

24 Adapted from O'Shea, E., Murphy K., Larkin P., Payne, S., Froggatt, K., Casey D., Ní Léime, A. & Keys, M., 2008. 'End of Life Care for Older People in Acute and Long-Stay Settings in Ireland'. Dublin: Hospice Friendly Hospitals Programme. National Council on Ageing and Older People. Chapter 3. The Legal Framework.

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**Consent:** A valid consent is one that is made by a person (a) with capacity (b) is voluntarily given, without any element of duress and (c) with the requisite information, in a form and language they can understand, of why they need the treatment, the risks, side-effects and alternatives, so that the patient is in a position to make an informed decision as to whether or not to proceed with treatment.<sup>25</sup>

**Context of care:** The environment or setting in which people receive health care services.<sup>26</sup>

**Criteria:** Supporting statements that set out how a service may be judged to meet the standard.<sup>27</sup>

**Culture:** Refers in this context to the workplace encompassing individual and organizational values and beliefs and ultimately behavioural norms.<sup>28</sup> Cultural values and beliefs contribute to shared meaning, understandings and expectations and are understood and distinctive to a particular group and passed on to new members.<sup>29</sup> Values persist over time, are shared by people in a group and are at the deepest level of culture. Values are linked with what individuals believe ought to be done and are connected with moral and ethical codes. Beliefs are unconscious basic assumptions, accepted as true and accurate and often taken for granted.<sup>30</sup>

**Death:** the state or condition of being without life, animation or activity.<sup>31</sup> The Uniform Determination of Death Act, formulated by the National Conference of Commissioners on Uniform State Laws, states that: *“An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.”* This definition was approved by the American Medical Association in 1980 and by the American Bar Association in 1981.<sup>32</sup>

**Dignity:** Being worthy of self-esteem or respect, so there is a value accorded to the person.<sup>33</sup>

**Disability:** In relation to a person, (disability) means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural

25 Dublin Hospitals Group Risk Management Forum, 2006. ‘Guidelines in Relation to Obtaining Patient Consent’. Page 5. Dublin.

26 McCormack, B., Manley, K., Garbett, R., (Eds). 2004. ‘Practice Development in Nursing’. Oxford: Blackwell Publishing.

27 Health Information and Quality Authority, (HIQA), 2008. ‘National Quality Standards for Residential Care Settings for Older People in Ireland’. Cork: Health Information and Quality Authority.

29 Manley, K. 2004. ‘Transformational Culture: A Culture of Effectiveness’. In McCormack, B., Manley, K., Garbett, R. 2004. (Eds). Practice Development in Nursing Oxford: Blackwell Publishing.

29 Louis, M.R., 1980. ‘Organisations as culture-bearing milieux’. In McCormack, B., Manley, K., Garbett, R., (Eds), 2004. Practice Development in Nursing. Oxford: Blackwell Publishing.

30 Hofsteede, G., Nneuijen, B., Ohayv, D., Saunders, G., 1990. ‘Measuring Organisational Culture: a qualitative study across twenty cases’. Administrative Science Quarterly, 35:285-316

31 Shorter Oxford English Dictionary. Volume 1. 2002. 5th Edition. Oxford University Press

32 Medicine net. Available at: [www.medicinenet.com/medterms/dictionary/death\\_definition](http://www.medicinenet.com/medterms/dictionary/death_definition)

33 Adapted from O’Shea, E., Murphy K., Larkin P., Payne, S., Froggatt, K., Casey D., Ní Léime, A. & Keys, M., 2008. ‘End of Life Care for Older People in Acute and Long-Stay Settings in Ireland’. Dublin: Hospice Friendly Hospitals Programme. National Council on Ageing and Older People.

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life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.<sup>34</sup>

**Do not resuscitate order:** Do not resuscitate orders refer **only** to withholding Cardiopulmonary Resuscitation and do not imply that other forms of **active** treatment will be withheld or stopped.<sup>35</sup>

**Dying:** The term “dying” is usually used when a diagnosis of dying has been made using specific clinical criteria. The term dying is usually used to describe a time period when death is imminent, and life expectancy is limited to a short number of days, hours or less.

*A diagnosis of dying often follows:*

- A presentation with signs of dying and a recent history of active progression of a life-limiting illness.
- A clinical decision that recognises a patient is no longer responding to active treatment. In emergency situations and depending on the urgency of the situation, this decision may emerge in seconds/minutes, for example catastrophic internal bleeding following trauma or during a cardiopulmonary arrest.

It is important to note that a patient may be diagnosed as dying but may demonstrate significant improvement in accordance with clinical criteria to indicate that he/she is no longer considered to be dying.<sup>36</sup>

**Disability:** *“In relation to a person, (disability) means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.”<sup>37</sup>*

**End-of-Life Care:** The HFH Programme adopts a broad systems approach to improving the culture of care and organisation in and across hospitals and between hospitals and community care. It acknowledges the central role of those who provide clinical care and works to ensure that end-of-life care is central to the mission and everyday business of the hospital.

In the context of the HFH Programme end-of-life care relates to all care - clinical, administrative and support - provided by hospital staff in relation to all aspects of end of life, dying, death and bereavement regardless of age or diagnosis or whether death is anticipated or unexpected. It includes:

- death in the womb and in infancy
- death in accidents and traumatic events regardless of scale
- people living with advanced life-limiting conditions (for whom death within a period

<sup>34</sup>Hospice friendly Hospitals Programme, 2010. 'An Ethical Framework for End of Life Care'. Dublin: The Irish Hospice Foundation.

<sup>35</sup> Adapted from: The General Medical Council, 2009. 'End of Life Treatment and Care: Good Practice in Decision Making. UK'. Available at: [www.gmc-uk.org/end of life care](http://www.gmc-uk.org/end_of_life_care).

<sup>36</sup> Adapted from Department of Health and Children, 2001. 'Report of the National Advisory Committee on Palliative Care'. Dublin: The Stationary Office.

<sup>37</sup> National Disability Authority, 2006. 'Code of Practice on Accessibility of Public Services and Information provided by Public Bodies: Plain English Edition'. Dublin: National Disability Authority.

of 1-2 years is a distinct possibility)

- people in the terminal phase of illness
- the care and support required by families and friends and by the staff who care for them
- care for the body of the deceased and for the bereaved who live on.<sup>38</sup>

**Family:** May include the immediate biological family and/or other relatives, partners (including same sex and *de facto* partners) or friends. They may have a close, ongoing, personal relationship with the patient, be chosen by the patient to be involved in treatment decisions, and have themselves indicated that they are ready to be involved in such decisions.<sup>39</sup>

**Family-Centred Care (FCC):** 'Family-centred care' (FCC) has developed as one way of caring for children in hospital. FCC means that during a hospital admission, care is planned by the health staff around the whole family, not just the individual child. When a child comes into hospital, the whole family is affected. In giving care, nurses, doctors and those caring for the child must consider the impact of the child's admission on all the family members. However, with the way family structures are changing in society, questions are being asked about how care is best delivered. To make sure that children are cared for in ways that minimise emotional trauma and assist in recovery, it is important that such ways of delivering care are measured to see if they are effective<sup>40</sup>.

**Good Death:** Refers to a good death as referred to in hospice philosophy and practice only. The following 12 principles are commonly associated with a good death.

- To know when death is coming and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptoms
- To have choice and control over place of death (i.e. at home or elsewhere)
- To have access to timely and relevant information and expertise
- To have access to any spiritual and emotional support required
- To have access to hospice care in any location, not just in hospital
- To have control over who is present at time of death
- To be able to issue advance directives which ensure that wishes are respected
- To have time to say goodbye and control over other aspects of timing
- To be able to leave when it is time to go and not to have life prolonged pointlessly.<sup>41</sup>

38 Hospice Friendly Hospitals, 2009. 'Statement of context'. Dublin: The Irish Hospice Foundation.

39 Hospice friendly Hospitals Programme, 2010. 'An Ethical Framework for End of Life Care'. Dublin: The Irish Hospice Foundation.

40 Shields L, Pratt J, Davis L, Hunter J., 2007. 'Family-centred care for children in hospital'. Cochrane Database of Systematic Reviews, Issue 1. Art. No.: CD004811. DOI: 10.1002/14651858.CD004811.pub2

41 Al-Qurainy, R., Collis, E., Feuer, D., 2009. 'Review Article. Dying in an acute hospital setting: the challenges and solutions'. International Journal of Clinical Practice; 3:508-515.

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**Grief:** A primarily emotional reaction to the loss of a loved one through death.<sup>42</sup> Grief may be compounded by the manner in which death occurred or significant past experiences of loss and change in the lives of family members.<sup>43</sup> Therefore some relatives will suffer from “complicated grief”, a condition characterised by chronic grief symptoms such as intense separation distress, intrusive memories, a sense of meaninglessness, and difficulties moving on with life.<sup>44</sup>

**Guidelines:** A guideline is defined as a principle or criterion that guides or directs action.<sup>45</sup>

**Healthcare Record:** The healthcare record contains all records relating to the patient and facilitates documentation of the chronology of events and all significant consultations, assessments, observations, decisions, interventions and outcomes.<sup>46</sup>

**Hospice Philosophy/Principles:** Within this document hospice refers to a philosophy of care which includes but is not solely reflected in a medical speciality. The philosophy goes beyond palliation and is characterised by a holistic (physical, psychosocial and spiritual) attention to illness. The focus of a hospice philosophy should not be exclusively on dying and death but rather should be based on providing holistic care and symptom control as soon as possible in the disease trajectory.<sup>47</sup>

**Hospice Friendly Hospital:** represents the multidimensional characteristics of care appropriate for the widest constituency of people (patients and families) facing life threatening conditions.<sup>48</sup>

**Intra-uterine death:** An infant who dies in utero (in the womb) and is born showing no sign of life.<sup>49</sup>

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42 Stroebe, M.S., Hansson, R.O., Stroebe, W. & Schut, H., 2001c. 'Handbook of Bereavement Research: Consequences, Coping and Care'. Washington DC: American Psychological Association.

43 Bereavement Care Standards UK Project, 2001. 'Standards for Bereavement Care in the UK'. London. Available at: [http://www.crusebereavementcare.org.uk/PDFs/UK Standards Bereavement Care. PDF](http://www.crusebereavementcare.org.uk/PDFs/UK%20Standards%20Bereavement%20Care.pdf)

44 Currier J.M., Holland J. M., 2007. 'The Efficacy of Grief Therapy: Reviewing the Evidence and Looking Ahead'. Grief Matters: The Australian Journal of Grief and Bereavement; Volume 10. Issue 3.

45 Concise Oxford Dictionary.1995.Oxford University Press. Oxford.

46 Health Service Executive, 2007. 'National Hospitals Office Code of Practice for Healthcare Records Management'. Dublin: Health Service Executive.

47 O'Shea, D., Keegan, O. and McGee, H., 2002. 'End-of-life care in general hospitals. Developing a quality approach for the Irish setting'. A statement of The Irish Hospice Foundation. Dublin: The Irish Hospice Foundation. Page 11&12.

48 O'Shea, D., Keegan, O. and McGee, H., 2002. 'End-of-life care in general hospitals. Developing a quality approach for the Irish setting'. A statement of The Irish Hospice Foundation. Dublin: The Irish Hospice Foundation. Page 11&12.

49 The Stillbirths Registration Act, No.1/1994. Available at: [http://www.irishstatutebook.ie/1994/Act\\_1/1994\\_001.html](http://www.irishstatutebook.ie/1994/Act_1/1994_001.html); Office of the attorney general.ie/Irish statute book/ Statutory instruments

## Miscarriage

**Early miscarriage:** the loss of a baby up to 16 weeks gestation.<sup>50</sup>

**Late miscarriage:** the loss of a baby up to 23 weeks + 6 days.<sup>51</sup>

**Ectopic pregnancy:** a pregnancy that occurs outside the womb.<sup>52</sup>

**Recurrent miscarriage:** the loss of three or more babies during consecutive pregnancies.

**Mourning:** The social expression or acts expressive of grief that are shaped by the practices of a given society or cultural group.<sup>53</sup>

**Multidisciplinary Working:** A group of professionals from various disciplines who work as part of a team.<sup>54</sup>

The key principle of multidisciplinary working is that all patients approaching or at end-of-life have the opportunity for prospective treatment and care planning by a multidisciplinary team that reflects the stage of the patient's disease. The following principles may be considered in implementation of a multidisciplinary approach to end-of-life care:

- Multidisciplinary care is centered around the patient, (and in accordance with his/her wishes relatives), ensuring his/her input to the development of treatment plans that reflect the patient's end-of-life care needs.
- Multidisciplinary teams may comprise some or all of the following: Medical Staff, Nursing Staff, Healthcare Assistants, Physiotherapists, Occupational Therapists, Social Workers, Psychotherapists, Psychologists, Chaplaincy, Speech and Language Therapists, Dietician/Clinical Nutritionist, Pharmacist, Complementary Therapist, Volunteer Coordinator, Educational Personnel, Librarian, Administrative, Secretarial and General Support Staff, Professionals from Specialist Disability Organisations.
- Team membership is reflective of the individual needs of patient and the stage of the disease such as early, recurrent, advanced, palliative or any combination of these stages.
- Effective team communication depends on regular team member attendance at multidisciplinary meetings, communication skills, and policy, guidelines and processes that direct team conduct,

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<sup>50</sup> The Stillbirths Registration Act, No.1/1994.

Available at: <http://Office of the attorney general.ie/Irish statute book/Statutory instruments>

<sup>51</sup> The Stillbirths Registration Act, No.1/1994.

Available at: <http://Office of the attorney general.ie/Irish statute book/Statutory instruments>

<sup>52</sup> Blacks Medical Dictionary, 40th edition, 2002. Editors Gordon MacPherson, A&C Black, London.

<sup>53</sup> Stroebe, M.S., Hansson, R.O., Stroebe, W. & Schut, H., 2001c. 'Handbook of Bereavement Research: Consequences, Coping and Care'. Washington DC: American Psychological Association.

<sup>54</sup> Health Information and Quality Authority, (HIQA), 2008. 'National Quality Standards for Residential Care Settings for Older People in Ireland'. Cork: Health Information and Quality Authority.

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communication and referrals within and beyond the team

- The availability of full therapeutic range depends on the presence or linkage to all relevant disciplines
- The focus on quality of care is maintained through development of evidence-based policies, guidelines and processes with monitoring of activities through audit, clinical review and peer review.<sup>55</sup>

**Requirements for effective multidisciplinary working include:**

- Good leadership
- Positive team dynamics that include full participation of all team members. Individual roles are meaningful and rewarding, contributions are identifiable, shared objectives are clearly identifiable, mutual respect is encouraged and feedback on achievements and failures are available.
- Administrative support
- Staff time
- Funding<sup>56</sup>

**Mourning:** The social expression or acts expressive of grief that are shaped by the practices of a given society or cultural group.<sup>57</sup>

**Neonatal death:** A death among live births during the first 28 completed days of life. Neonatal deaths may be subdivided into early neonatal deaths, occurring before the first seven days of life, and late neonatal deaths, occurring after the seventh day but before 28 completed days of life.<sup>58</sup>

**Pain:** Pain is described as an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. Pain can be described as acute, chronic and /or recurrent. Acute pain is associated with acute injury or disease. Chronic pain is defined as pain that has persisted longer than three months or past the expected time of healing following injury or disease. Pain that comes and goes is called recurrent pain. Depending on his/her underlying illness, a patient may be affected by one or a combination of two or three different types of pain.<sup>59</sup>

55 Metropolitan Health and Aged services Division, Victorian Government Department of Human Services, 2007. 'Achieving best practice cancer care. A guide for implementing multidisciplinary care'. Australia. Department of Health, State Government of Victoria. Accessed at:[www.health.vic.gov.au/cancer/Victorian\\_governmentcancer\\_initiatives/cancer\\_service\\_improvement\\_policies\\_and\\_frameworks/multidisciplinary\\_care](http://www.health.vic.gov.au/cancer/Victorian_governmentcancer_initiatives/cancer_service_improvement_policies_and_frameworks/multidisciplinary_care)

56 Flessig A., Jenkins V. Catt S., Fallowfield L., 2006. 'Multidisciplinary teams in cancer care: are they effective in the UK?' The Lancet; Volume 7:935-943.

57 Stroebe, M.S., Hansson, R.O., Stroebe, W. & Schut, H., 2001c. 'Handbook of Bereavement Research: Consequences, Coping and Care'. Washington DC: American Psychological Association.

58 World Health Organisation, 2004. 'International Statistical Classification of Diseases and Related Health Problems'. Tenth Revision, Volume 2. Second Edition. Available at:[http://www.who.int/classifications/icd/ICD-10\\_2nd\\_ed\\_volume2.pdf](http://www.who.int/classifications/icd/ICD-10_2nd_ed_volume2.pdf)

59 The Royal College of Anaesthetists. The Pain Society, 2003. 'Pain Management Services. Good Practice'. London: The Royal College of Anaesthetists. The Pain Society.

Pain is a subjective experience and is influenced by circumstances, only the person in pain can really say how painful something is, therefore pain is what the person feeling it says it is.<sup>60</sup> Patients at end of life may also experience other symptoms related to the disease process or treatments or may require support to address the psychosocial, spiritual, and cultural issues associated with end of life and dying.<sup>61</sup>

Pain and its relief must be assessed and documented regularly. Pain intensity should be regarded as a vital sign and along with the response to treatment and side effects should be recorded as regularly as other vital signs such as pulse or blood pressure. The prescription of analgesic (pain relieving medication), should be reviewed regularly to ensure that the pain medication is effective and appropriate to the level of pain experienced by the patient.<sup>62</sup>

**Palliative Care Approach:** A palliative care approach aims to promote both physical and psychosocial wellbeing and is informed by a knowledge and practice of palliative care principles by all health professionals. This approach is a vital and integral part of all clinical practice relating to end of life care, whatever the illness or its stage. It takes into account the fact that many patients with progressive and advanced disease can have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.<sup>63</sup> (For further information, see Palliative Care for Adults and Palliative Care for Children).

**Palliative Care for Adults:** World Health Organisation definition (WHO)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death

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60 The British Pain Society, 2004. Understanding and Managing Pain: Information for Patients. London: The British Pain Society.

61 Joint Commission International, 2007. 'Joint Commission International Accreditation Standards for Hospitals'. 3rd Edition. Page 104. USA: Joint Commission International.

62 The Royal College of Anaesthetists. The Pain Society, 2003. 'Pain Management Services. Good Practice'. London: The Royal College of Anaesthetists. The Pain Society.

63 Department of Health and Children, 2001. 'Report of the National Advisory Committee on Palliative Care'. Dublin. The Stationary Office

# Glossary

- Offers a support system to help the family cope during the patients illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

**Palliative Care for Children:** World Health Organisation definition (WHO)

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.<sup>64</sup>

**Pastoral Care:** Pastoral Care deals explicitly though not exclusively with spiritual aspects of reality. It is the spiritual and emotional support of people in their search for meaning through willingness to listen, hear and value what people have to say through. Pastoral Care:

- Facilitates people to articulate and claim their own story
- Allows them to explore the meaning of their lives and their sense of belonging
- Creates a safe, trusting space where each person's story can be heard and honoured
- Empowers a person on their journey
- Respects each person's individuality

Pastoral Care recognises that religious freedom is a fundamental human right and they respect a person's right to choose whether or not they wish to participate in religious activities. Pastoral Care respects the right of people to have access to a minister of their own religion and denomination.

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<sup>64</sup> World Health Organisation, 2010. <http://www.who.int/cancer/palliative/definition/en/>

**Person Centered Care:** Person-centeredness is an approach to practice established through the fostering of therapeutic relationships between all care providers, patients and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self determination, mutual respect and understanding.<sup>65</sup>

**Policy:** A policy is a written statement of organisational intent for a given issue and clearly indicates the position and values of an organisation on a given subject.<sup>66</sup>

**Principles of Palliative Care:** The principles of palliative care are:

- Communication which is open and sensitive
- A whole person approach which takes into consideration a person's circumstances, spirituality and sexuality;
- Quality of life including the best possible symptom control
- Care for all concerned (family and those important to the patient)
- Respect for patient autonomy and choice<sup>67</sup>

**Patterns/Trajectories at End of Life:** When stages or indicators along the end of life continuum can be identified and death reasonably well predicted, there is usually an associated underlying disease process that has become actively progressive that will often follow well documented stages in the disease process. This does not relate to sudden or unpredicted deaths.<sup>68</sup>

**Practice Development:** In the context of the standards practice development is the continuous process of developing effective workplace cultures that have embedded within them person-centered processes, systems and ways of working to achieve the ultimate purpose of evidence-based person-centered care.<sup>69 70</sup>

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65 McCormack, B., Dewing, J., Buckley, M., J., Breslin, L., Coyne-Nevin, A., Kennedy, K., Manning, M., Peelo-Kilroe, L., McCall, S., Tobin, C., 2010. 'National Practice Development Programme to introduce a Person-centered Framework'. (in press).

66 Adapted from Parsley K., Corrigan P., 1999. 'Quality Improvement in Healthcare'. Second Edition. UK: Stanley Thornes Ltd.

67 O'Shea, D., Keegan, O. and McGee, H., 2002. 'End-of-life care in general hospitals. Developing a quality approach for the Irish setting'. A statement of The Irish Hospice Foundation. Page 10. Dublin: The Irish Hospice Foundation.

68 Adapted from: Dy S., Lynn J., 2007. 'Getting services right for those sick enough to die'. British Medical Journal BMJ ; 334: 511-513

69 Manley, K., McCormack, B., Wilson, V., (Eds), 2008. 'International Practice Development in Nursing and Healthcare'. Oxford: Blackwell Publishing.

70 Garbett, R., McCormack, B. In McCormack, B., Manley, K., Garbett, R., 2004. (Eds). 'Practice Development in Nursing'. Oxford: Blackwell Publishing.

# Glossary

**Quality of Caring:** Quality of caring as distinct from quality of care emphasises the relationship between the carer and the care recipient.<sup>71</sup>

**Quality of Care:** Refers to the standard international definition of the US Institute of Medicine, which has six criteria: patient-centred, safe, effective, timely, efficient and equitable.<sup>72</sup>

**Religious Care:** Refers to supporting patients and families in their struggle with illness, pain and suffering through Liturgical Celebrations and Ritual Expression. See Pastoral Care.

**Resuscitation:** Resuscitation is a term used to identify a wide variety of events in the acute care setting. Clinically it refers to a sequence of events, including invasive procedures, which are initiated to sustain life and or prevent further deterioration of the patient's condition.<sup>73</sup>

**Specialist Palliative Care Services:** Services with palliative care as their core specialty and which are provided by an inter disciplinary team, under the direction of a consultant physician in palliative medicine.<sup>74</sup>

**Spiritual Care:** See Pastoral Care

**Stillbirth:** A child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life.<sup>75</sup>

**Standard:** A measure by which quality is judged. It sets out an expected or desired level of performance.<sup>76</sup>

**Standing Committee on Dying, Death and Bereavement:** The Standing Committee operates under the authority of the senior management team and is representative of all key hospital disciplines, perspectives and stakeholder interests, including independent representatives of the public

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71 The Irish Hospice Foundation & NCAOP, 2008. 'End-of-Life Care for Older People in Acute and Long-Stay Care settings in Ireland'. A joint statement by The Irish Hospice Foundation and the National Council on Ageing & Older People (NCAOP). Dublin: Hospice Friendly Hospitals. National Council on Ageing and older People.

72 Institute of Medicine. Crossing the Quality Chasm: A New Health System For The 21st Century. March 2001. Available at: <http://www.iom.edu/~media/Files/ReportFiles/2001/Crossing-the-Quality-Chasm/QualityChasm2001>

73 Adapted from: The General Medical Council, 2009. End of Life Treatment and Care: Good Practice in Decision-Making. UK. Available at: [www.gmc-uk.org/end\\_of\\_life\\_care](http://www.gmc-uk.org/end_of_life_care)

74 Department of Health and Children. 2001. Report of the National Advisory Committee on Palliative Care. Page 32. Dublin: The Stationary Office.

75 The Stillbirths Registration Act, No. 1/ 1994. Available at: <http://officeoftheattorneygeneral.ie/Irishstatutebook/Statutoryinstruments>

76 Health Information and Quality Authority, (HIQA), 2008. 'National Quality Standards for Residential Care Settings for Older People in Ireland'. Cork: Health Information and Quality Authority.

interest. The designated member of the senior management team responsible for provision of End-of-Life Care in the hospital plays a leading role in the functioning of the Standing Committee and provides a two-way link with the senior management team. This person may, or may not, be the chairperson of the committee.

### **Indicative membership of the Standing Committee:**

Hospital Manager or Deputy-Manager (or member of senior management team with designated responsibility for End-of-Life - in the context of the service plan)

Director of Nursing / Asst Director of Nursing

Representative of the Public Interest

Nurse Practice Development

Operational Services Manager

Human Resources Manager

Representative of the Medical Board

Representative of Specialist Palliative Care Services

Quality & Audit Manager

Representative of Pastoral Care Services

Representative of Allied Health Professionals

Representative of Administrative and Support staff

Representative of Nursing homes in the catchment areas

General Practitioner from the catchment area

Public Health Nurse / member of primary care team(s) in catchment area

Representative of Community Hospitals within the catchment area

Representative of local hospice organisations

Staff & Trade Union Organisations

University Departments

Centre for Nurse & Midwifery Education.<sup>77</sup>

**Supportive Care:** Supportive care helps the patient and his/her relatives to cope with his/her condition and treatment-from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.<sup>78</sup>

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<sup>77</sup> Hospice Friendly Hospitals Programme, 2010. 'Terms of Reference for Standing Committees on Dying, Death & Bereavement'. Dublin: The Irish Hospice Foundation.

<sup>78</sup> UK National Council for Palliative Care, <http://www.npc.org.uk/palliativecare.html>

# Glossary

**Supervision:** Supervision is a process by which one worker is given responsibility by the organisation to work with another worker(s) in order to meet certain organisational, professional and personal objectives which together promote the best outcomes for service users. These objectives are: competent, accountable practice, continuing professional development, personal support and engaging the individual with the organisation.<sup>79</sup>

**Symptom management:** Symptom management includes pain and non- pain symptoms(including but not limited to shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion, and constipation).<sup>80</sup>

**Values:** things that matter to us; that we care about; goals or ideals we aspire to, e.g., health and happiness. Ethical or moral values express ideals of conduct and character that we expect of ourselves and each other, e.g., honesty, loyalty and justice.<sup>81</sup>

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79 Morrison T. Staff Supervision in Social Care, 2005. 'Making a real difference for staff and service users'. Third Edition. Brighton: Pavilion Publishing.

80 National Consensus Project for Quality Palliative Care. 2009. 'Clinical Practice. Guidelines for Quality Palliative Care'. Second Edition. Page 28. USA: National Consensus Project for Quality Palliative Care.

81 Hospice friendly Hospitals Programme, 2010. 'An Ethical Framework for End of Life Care'. Dublin: The Irish Hospice Foundation.

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# Appendices



# Appendix 1

## Quality Standards for Babies and Children at End of Life

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# Appendix 1

## Quality Standards for Babies and Children at End of Life

### About the Quality Standards for Babies and Children at End of Life

The *Quality Standards for End-of-Life Care in Hospitals* focus on adult patients in acute hospitals. In **Appendix 1** these Standards have been adapted to provide *Quality Standards for Babies and Children at End of Life*. This section also includes miscarriage, intra-uterine death, still birth and neonatal death.

For the purposes of this document, a **child** refers to **infant, child and adolescent**.

**'Family-Centred Care'** (FCC) has developed as one way of caring for children in hospital. FCC means that during a hospital admission, care is planned by the health staff around the whole family, not just the individual child. When a child comes into hospital, the whole family is affected. In giving care, nurses, doctors and those caring for the child must consider the impact of the child's admission on all the family members. However, with the way family structures are changing in society, questions are being asked about how care is best delivered. To make sure that children are cared for in ways that minimise emotional trauma and assist in recovery, it is important that such ways of delivering care are measured to see if they are effective.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of children and their families.

---

#### 1.1 A CULTURE OF COMPASSIONATE END-OF-LIFE CARE

---

*The Hospital Service Plan includes end-of-life care as a core component.*

##### How do we know that we are meeting this Standard?

- There is a clear and transparent hospital/departmental ethos of end-of-life care in place.
- The Hospital Service Plan includes provision for implementing the Quality Standards for End-of-Life Care in Hospitals
- A named senior member of the management team is allocated responsibility for developing the structures and processes necessary to implement the end-of-life care components of the Service Plan.
- The hospital operates a philosophy of family centred care
- The hospital has a Standing Committee on Dying, Death and Bereavement.

---

#### 1.2 GENERAL GOVERNANCE POLICIES AND GUIDELINES

---

*Governance policies and guidelines are in place in the hospital to ensure best practice in the implementation of the Quality Standards.*

##### How do we know that we are meeting this Standard?

- Hospital policies and guidelines for end-of-life care are set within the currently prevailing legal and ethical framework and are based on best national and international practice.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

- Policy and Guidelines on end-of-life care in the hospital are available and are easily accessible in all clinical areas. All staff use and are trained to use these Guidelines in accordance with their roles.
- All staff use and are trained to use these Guidelines in accordance with their roles.
- There is a system in place for reviewing all Policies and Guidelines relating to end-of-life care.

---

### 1.3 COMMUNICATION - EFFECTIVE COMMUNICATION WITH CHILDREN AND THEIR FAMILIES

---

**There is timely, clear and sensitive communication with each child and his/her family on all matters relating to end-of-life care.**

#### How do we know that we are meeting this Standard?

- All communication between hospital staff and patients or family members is governed by the expressed wishes of the child/family.
- Policy and Guidelines are available for communicating with patients diagnosed as requiring end-of-life care.
- The hospital communications policy includes evidence-based protocols for communicating prognostic information to patients.
- Advance care directives and patient preferences are clearly recorded in the Healthcare Record (see Adult Standard 1.4) and communicated to relevant staff.
- There is an acknowledgement on the part of all hospital staff that staff other than clinicians and nurses may have an important role to play in ensuring good ongoing communication with patients and families in respect of end-of-life care.

Reference should also be made to the following Standards and criteria:

[Adult Standard 1, Criterion 1.8](#)

[Adult Standard 3, Criteria 3.1, 3.2](#)

[Adult Standard 4, Criteria 4.1, 4.2 and 4.3.](#)

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

---

#### 1.4 THE HOSPITAL ENVIRONMENT

---

The physical environment where end-of-life care is provided supports high quality care and facilitates dignity and privacy.

##### How do we know that we are meeting this Standard?

- Key areas of the hospital environment related to end-of-life care are assessed against the Hospice Friendly Hospitals Programme '*Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*' and the annual service plan identifies and prioritises funding to refurbish these key hospital areas as required.
- The '*Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*' are promoted throughout all relevant hospital departments and copies are widely available throughout the hospital and are easily accessible to all staff.
- All refurbishments and new hospital buildings take into account the '*Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*'.
- Families approaching the end of life of a child are offered the choice of being accommodated in a single room.
- The hospital facilitates access to rooms and spaces where discussions between children, staff and family members (if appropriate) can take place in a quiet, comfortable environment where privacy is ensured.
- The hospital facilitates family members with overnight rest and refreshment facilities.

---

#### 1.5 MONITORING AND EVALUATING END-OF-LIFE CARE

---

End-of-life care in the hospital is continuously evaluated.

##### How do we know that we are meeting this Standard?

- Formal systems are in place for reviewing the implementation of the *Quality Standards for End-of-Life care in Hospitals*.
- Complaints about end-of-life care are recorded under a specific category for end-of-life care and are dealt with fully in a timely manner.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

- The hospital collects data on an ongoing basis that reflects the quality of provision of end-of-life care, this information is recorded and reported electronically and published annually.
- The quality of communication with patients and family members is monitored on an ongoing basis and the Communication Policy and Communication Guidelines (see Adult Standard 1.3) are revised accordingly.
- A system for review of deaths is in place for all wards, units and departments which entails regular meetings and inviting inputs from bereaved families

---

#### 1.6 ASSESSING AND RESPONDING TO THE END-OF-LIFE CARE NEEDS OF CHILDREN

---

All children who are at a stage where they may possibly need end-of-life care are identified and provision for their individual care is made accordingly.

#### How do we know we are meeting this standard?

##### Advance Care Planning

- End-of-life care for each child and family is guided by the lead clinician and multidisciplinary team, and the principle of advance care planning and Advance Care Directives are included as part of an individual care plan.

##### Assessment

- There are effective mechanisms in place to identify children who may be approaching or at the end of life.
- The needs of the child and family identified as approaching or having reached end of life are assessed in a physical, psychological and spiritual manner, with particular emphasis on pain and symptom assessment, and documented in the care plan within the Healthcare Record.
- There is ongoing consultation with the family and the child in an age appropriate manner with regard to outcomes of treatment and progress.
- Policy and guidelines identify and address any additional or special needs a child may have.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

#### The Care Plan

- The child's care plan, including pain and symptom management, is reviewed and updated regularly in accordance with his/her clinical condition, needs and preferences (See: Adult Standard 1, Criterion 1.3).
- The care plan is accessible to the family and all relevant healthcare staff and implemented by each person/team in carrying out their respective roles.
- Guidelines for 'Diagnosing Dying' are available to assist staff to identify when a patient may be dying and are referred to as part of care planning.

---

#### 1.7 CLINICAL RESPONSIBILITY AND MULTIDISCIPLINARY WORKING

---

**All children who are approaching or at end of life are supported by a named lead clinician(s) working in consultation/partnership with the multidisciplinary care team.**

- The Lead Clinician and/or the clinician responsible for the child's care is identified and documented in the Healthcare Record.
- The clinical diagnosis that a child may be approaching or has reached end of life is communicated to the family.
- The child/family are facilitated to discuss his/her care with the Lead Clinician.
- Policy and guidelines are in place for communication between disciplines, teams and service providers (both hospital-based and community-based).
- There is clear allocation and documentation of responsibility within and between clinical teams involved in the care of the child and family, particularly regarding discharge/transfer out of the hospital.
- When a child moves to a different clinical environment within the hospital and the responsible lead clinician changes for a period of the child's care, there is formal handover of information and accountability for the overall care of the child.
- Policy and guidelines are in place for communication between disciplines, teams and service providers whether hospital based or community-based in order to facilitate a planned approach to the patient's admission, care, and discharge/transfer out of the hospital.(See Adult Standard 1, Criterion 1.2)

# Appendix 1

## Quality Standards for Babies and Children at End of Life

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### Standard 1: The Hospital

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#### 1.8 PAIN AND SYMPTOM MANAGEMENT

---

**Effective pain and symptom management is provided as a key component of end-of-life care and education in the hospital.**

**(See: Adult Standard 3, Criterion 3.4)**

- A child is referred to Specialist Palliative Care Services as soon as their needs and symptoms and other care factors indicate a need for such expertise.
- There is a written hospital/department ethos regarding pain and symptom management that is evident through attitude, action and documentation. (See: Adult Standard 3, Criterion 3.4)
- The hospital/department has Guidelines for use during initial assessments and reassessments that assist staff in identifying a child who is experiencing pain.
- Evidence-based guidelines for pain and symptom management at end-of-life are easily accessible and adhered to at all times.
- There is documentation within the Healthcare Record of regular assessment, timely response, monitoring and review of symptoms according to need and the child's expressed experience of the symptom and intervention measures.

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#### 1.9 CLINICAL ETHICS SUPPORT

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**Hospital management ensures that each staff member has access to Clinical Ethics Support as appropriate to his/her role.**

- All staff provide care to children who may be approaching or at end of life in accordance with the mission, vision and values of the hospital.
- Each staff member ensures that s/he is familiar with and guided by the Professional Ethical Code of Conduct appropriate to his/her role.
- Hospital management promotes a positive ethical climate within the organisation in which all employees feel comfortable raising and discussing ethical concerns.
- Transparent and equitable processes and mechanisms for ethical decision-making are in place and may be used to resolve disagreements about the interpretation of policies or to address potentially difficult or contentious ethical issues that may arise in relation to end of life.
- Mistakes are acknowledged and there is ongoing evaluation and review to ensure that ethical challenges are accurately identified and constructively resolved.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

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#### 1.10 CARE AFTER DEATH

---

**Policies and Guidelines for care after death are respectful of the child and familie’s wishes and beliefs.**

- Policy and Guidelines are in place for “Care of the child after death”. All relevant staff use and are trained to use these.
- Hospital staff consult with the family members to ensure that the wishes of the deceased child and family are respected.
- Information is provided to family members on matters associated with post-mortems where relevant.
- The hospital has a clear procedure for formal notification of death to the authorities within 3 working days of the death occurring.
- The hospital notifies the child’s GP and other relevant primary and secondary care services on the first working day following the patient’s death.
- The hospital has a Policy and Guidelines to support staff members in acknowledging a child’s loss with the family.
- The hospital accounts department show appropriate consideration in the scheduling of bills.

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#### 1.11 POST-MORTEMES

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**The hospital manages all aspects of post-mortems in a transparent, timely and sensitive manner.**

- The loss being experienced by the family is recognised and acknowledged and staff are sensitive to avoiding the potential for further distress when communicating information about the post-mortem.
- Families are provided with verbal and written information regarding Hospital Post Mortems and Coroners Post Mortems.
- The hospital has policies and guidelines for post mortem examinations which address:
  - Requesting informed consent for House or Non Coroner’s Post Mortem.
  - The Role of the Coroner

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

- Hospital Post Mortem
- Coroner's Post Mortem
- A member of staff is available to talk with bereaved families where a coroner's post-mortem is to be carried out.
- Records are kept of all contact with the family regarding Coroner's Post-mortem.

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#### 1.12 BEREAVEMENT CARE

---

**The hospital provides assistance and supports to families in dealing with the loss of their child during the period approaching and following a death.**

#### How do we know that we are meeting this Standard?

- End-of-life care is managed in a multidisciplinary manner to ensure that all needs can be responded to effectively.
- Family member's questions about the child's condition are answered fully, promptly and in accordance with the child and family's wishes.
- Where there is clear indication that death may be imminent, family members are alerted, as appropriate.
- Where families have differences of opinion these are acknowledged and addressed sensitively.
- Families who are experiencing a high level of distress are referred to the appropriate member of the multidisciplinary team.
- If requested, the child's family can obtain further information or discuss concerns about the care and treatment of the child with a member of the multidisciplinary team.
- Families are offered timely bereavement supports- information, identification of risk factors and referral is made to local community supports services if appropriate.
- All supports and services consider and respond to individual, cultural and spiritual requirements. (See: Adult Standard 4, Criterion 4.6).

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 1: The Hospital

#### Identifying and responding to bereavement support needs

- Staff have an understanding of the range of responses to bereavement.
- Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. This information may be offered on more than one occasion. (See: Adult Standard 4, Criterion 4.6).
- Staff have an understanding of the types of factors which together may result in complicated bereavement (e.g. personal attributes, the nature of the relationship with the deceased child, whether death was perceived as sudden or expected, traumatic or peaceful).
- Staff have information on and access to appropriate professional support to address different types of risk factors and possible grief reactions.
- The bereavement support needs of children and teenagers are assessed and responded to appropriately.

#### Bereavement Services

- Formal bereavement support is offered by the hospital and with reference to other community and professional providers in the community.
- Bereavement services are guided by a standardised assessment process and families' bereavement needs are kept under review.
- Families are assured of confidentiality and privacy when using bereavement services, in accordance with current legal and ethical legislation.
- The bereavement service organises events that facilitate the grieving process such as remembrance services and public talks.
- Families are offered the opportunity to provide feedback to the service – this feedback informs service development and provision.

## Appendix 1

# Quality Standards for Babies and Children at End of Life

## Standard 2: The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

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### **2.1 SUPPORTING A CULTURE OF COMPASSIONATE END-OF-LIFE CARE AMONG STAFF**

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*All hospital staff have access to education and training opportunities in the delivery of compassionate end-of-life care in accordance with their roles and responsibilities.*

#### **How do we know that we are meeting this Standard?**

- The Hospital Manager ensures that there are education, training and staff mentorship programmes in end-of-life care for hospital staff in accordance with the size, complexity and specialties of the hospital.
- The design of staff education and training programmes involves key stakeholders with relevant experience and knowledge.
- A core group of hospital staff with the required expertise in end-of-life care (clinical and non-clinical) are facilitated and supported to deliver end-of-life care education and training to hospital staff.
- The hospital facilitates staff, as appropriate, to undertake additional formal education and training in end-of-life care.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

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### Standard 2: The Staff

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#### 2.2 STAFF INDUCTION

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All newly recruited staff are inducted on the general principles and components of end-of-life care in the hospital.

##### How do we know that we are meeting this Standard?

- The hospital's general induction programme includes a component on end-of-life care.
- The *Quality Standards for End-of-Life Care in Hospitals* are introduced and explained.

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#### 2.3 STAFF EDUCATION AND DEVELOPMENT NEEDS

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The education and development needs of staff are assessed relative to their roles in end-of-life care and according to emerging national consensus on competencies and standards.

##### How do we know that we are meeting this Standard?

- Hospital staff are competent to deliver high quality end-of-life care in accordance with best practice.
- Competency statements are developed for different categories of staff in accordance with their individual roles, and performance management systems used measure this aspect of care.
- An audit of education and training needs in end-of-life care is conducted every two years.

## Appendix 1

# Quality Standards for Babies and Children at End of Life

## Standard 2: The Staff

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### 2.4 STAFF EDUCATION AND TRAINING PROGRAMMES

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Staff education and training programmes have defined objectives that reflect evidence-based best practice and legislation.

#### How do we know that we are meeting this Standard?

- Staff education and training programmes cover the key elements of the *Quality Standards for End-of-Life Care in Hospitals*, and specifically address pain and symptom management and how to support patient preferences and values.
- The hospital provides and maintains resources and facilities for education, training and continuous professional development in co-ordination with the regional education and training services of the HSE.
- Education and development programmes relating to end-of-life care are revised annually by a team that includes the hospital manager and other disciplines directly involved in end-of-life care.
- Priority groups of staff members who would benefit from specialised education in end-of-life care are identified every two years and their participation in standard and accredited education programmes on an ongoing basis is facilitated by the hospital.
- If the hospital implements an *Integrated Care Pathway for End-of-Life Care*, appropriate support and training is provided in accordance with specific guidance from the relevant experts.

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### 2.5 STAFF SUPPORT

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Staff support services relating to end-of-life care reflect the need for peer support and professional support systems.

#### How do we know that we are meeting this Standard?

- The Hospital Management Team facilitates the provision of formal and informal structures and support systems for practical and emotional support to each staff

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 2: The Staff

member. These supports address both the professional and personal needs of the individual involved in the provision of end-of-life care.

- Written information is provided to each staff member on:
  - Skills and techniques for effective self care
  - Opportunities for reflective practice
  - Supervision
  - Recognition of burnout and compassion fatigue
  - Support services available and how to access these support services
- Each staff member takes personal responsibility for his/her self-care.
- Each staff member has access to Clinical Ethics Support as appropriate to his/her role (See: Adult Standard 1, Criterion 1.10).
- Policy and Guidelines are in place to support staff involved in dealing with trauma or sudden deaths.
- Issues and challenges arising from the delivery of end-of-life care, care of the dying patient and care of the deceased child, form part of team discussions and are addressed in reviews of end-of-life care.
- Private space is available to enable staff to discuss and address issues that may arise when providing end-of-life care and dealing with death.
- Staff who use support services to address issues that may arise during provision of end-of-life care are facilitated to provide feedback on their appropriateness and value.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

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### Standard 3: The Child & Family

Each child receives high quality end-of-life care that is appropriate to his/her needs and wishes.

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#### **3.1 COMMUNICATING A DIAGNOSIS OF A NEED FOR END-OF-LIFE CARE**

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**There is timely, clear and sensitive age appropriate communication with each child and family in respect of a diagnosis that the child may be approaching or at end of life.**

##### **How do we know that we are meeting this Standard?**

- Communication with the child and his/her family is undertaken within the existing legal framework that relative to the child's age, protects the rights of the child and ensures his/her best interests are represented.
- Direct communication with the child gives due consideration to the child's age, experience and understanding of his/her illness.
- The legal and ethical framework governing informed consent recognises that in the majority of cases parents are responsible for giving consent on behalf of their child. Consideration should be given to a child's age, experience and understanding of his/her illness.
- Specific consideration is given to children within the legal guardian ship of the HSE, for example where a child is currently in foster care.
- The hospital has a policy and related guidelines to assist in communicating with the family of a child who may be approaching or at end of life. Staff use, and are trained in accordance with their roles, to use these Guidelines
- Communication is always addressed towards the family and the child is involved in discussions that are conducted in an age appropriate manner and directed by the family.
- Confidentiality is always maintained in respect of any matters relating to diagnosis of a possible need for end-of-life care.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 3: The Child & Family

- The manner and style of communication takes account of the family, the child's age, and both parties capacity for understanding religious, cultural and ethnic preferences.
- If a child and family have additional communication needs arising from a disability or from language or literacy difficulties, these needs are identified, documented and responded to individually.
- All communications with the family of clinical decisions that their child may be approaching or at the end of life is recorded in the Healthcare Record.
- Staff assist family members to come to terms as far as possible with the reality of what is happening and to the experience of their child.
- Opportunities are provided by clinicians and nursing staff for family members to clarify issues and concerns about their child's well-being.

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### 3.2 CLEAR AND ACCURATE INFORMATION

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**Clear and accurate information is provided as appropriate to the child and family about their condition, treatment options, prognosis and care plan in a timely and culturally appropriate manner and in accordance with the family and child's preferences (age appropriate).**

#### How do we know that we are meeting this Standard?

- Information is shared sensitively with the family and child, but according to the families' wishes.
- As part of family centred care unexpected changes to the child's condition or care plan are communicated to the family in a timely manner.
- Details of the information provided to the family and child are documented in the Healthcare Record.
- General information on end-of-life care and support services is provided both verbally and in written form and in a format which is age appropriate for the child.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 3: The Child & Family

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#### 3.3 CHILD AND FAMILY PREFERENCES

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The family are consulted to ensure the child receives care in a manner that is most appropriate for the child and the family.

##### How do we know that we are meeting this Standard?

- Family centred care facilitates the child being placed at the centre of care by supporting the family as the primary representatives of the child's best interest.
- The child is cared for in a manner that protects his/her rights and best interests.
- The core content of ongoing discussions with the family, and as appropriate the child, regarding the child's needs and preferences are documented in the Healthcare Record. (See: Adult Standard 1, Criterion 1.4).
- The child's capacity to participate in decisions respects the age of the child and his/her experience of treatment.
- Decisions and choices regarding that are important to the child and his/her family are regularly assessed, optimised and reviewed by the multidisciplinary team in consultation with the family.
- Consent by the family (parents/guardians) of the child is easily and clearly identifiable either on a consent form, which is retained as part of the Healthcare Record.
- Where a family have written an Advance Care Directive for their child, this is recorded and forms part of the Healthcare Record (See: Adult Standard 1, Criterion 1.7).
- Each child's condition is regularly reviewed in consultation with the family.
- The child and/or his/her family is facilitated to access an independent advocacy service when making decisions relating to treatment or care if s/he so wishes.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 3: The Child & Family

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#### 3.4 PAIN AND SYMPTOM MANAGEMENT

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**Pain and symptom management for each individual child takes full account of the multifaceted nature and individual experience of pain.**

##### How do we know that we are meeting this Standard?

- Specialist palliative care advice is sought as required for symptom control by the multidisciplinary team as part of a care plan.
- The child's experience and description of pain and symptoms, including verbal, non-verbal and behavioral expressions of discomfort and pain, are identified, regularly assessed and responded to promptly.
- There is ongoing dialogue with the patient regarding his/her experience of pain, distress and other symptoms and the level of comfort obtained from different interventions.
- There is documentation within the Healthcare Record of regular monitoring of the child's symptoms and the effectiveness of interventions.

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#### 3.5 THE DYING CHILD

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**The particular needs of a child whose death is imminent are assessed and provided for in a sensitive and culturally appropriate manner.**

##### How do we know that we are meeting this Standard?

- Where the family wishes their child to die at home or in another community setting, this is facilitated as far as possible.
- The needs of the dying child are assessed and prioritised to ensure that as far as possible his/her wishes are respected and that the best possible level of comfort is provided.
- Particular attention is given to deploying staff to ensure that the child is not left alone while dying, particularly if the child's family are not present.
- The child's family are advised as a matter of urgency when death may be imminent and are facilitated to be present with their child.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 3: The Child & Family

- The dying child is cared for in a private and dignified space and as far as possible in a single room unless otherwise requested.
- Policies and guidelines for the care of the dying child are adhered to by all staff. (See: Adult Standard 1, Criterion 1.2)

#### 3.6 DISCHARGE HOME/OUT OF HOSPITAL

**The family is actively involved in discussions and decisions regarding admission, discharge home or transfer to another setting for end-of-life care for their child.**

#### How do we know that we are meeting this Standard?

- The hospital has a process of proactive admission and discharge planning that addresses the child and family's individual needs.
- There is timely and clear communication with the General Practitioner and/or other service providers regarding the child's admission and discharge.
- Written information provided to the General Practitioner/and or other service providers is formulated so that essential relevant information is easily identifiable and accessible.
  - Information provided to the General Practitioner includes:
    - Relevant clinical information
    - Family/child awareness of prognosis
    - The family/child's wishes regarding preferred place of death
    - Any other non-clinical information that is important
- The Community Pharmacist is notified of any unusual medication requirements.
- Prior to discharge from hospital, the family are given opportunities to discuss the care plan with staff.
- Families are provided with detailed information concerning the level and source of ongoing supports and services following discharge
- Families are provided with advice on supporting their child at home, e.g., assisting with personal care, medication.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 3: The Child & Family

- Families are provided with names and contact details of members of the healthcare professionals to be involved in the ongoing care of their child.
- Prior to discharge from hospital, the family, and the child where appropriate, is provided with information and advice both verbally and in writing on the various aspects of providing end-of-life care in the home (See: Adult Standard 4, Criterion 4.4).
- The content of conversations between staff and family members is documented within the Healthcare Record (See: Adult Standard 1, Criterion 1.4).
- The GP and other service providers are notified of any patient decisions regarding preferred place of dying. This is to minimise inappropriate return to hospital if the child is seriously ill or unconscious.

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### **3.7 COMMUNICATION WITH THE FAMILY IN THE EVENT OF A CHILD'S SUDDEN/UNEXPECTED DEATH OR SUDDEN IRREVERSIBLE DECLINE IN HEALTH LEADING TO DEATH**

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**In cases involving a sudden change in the child's condition likely to lead to death and or in cases of sudden/unexpected death of a child, the child's family is provided with prompt and clear information as appropriate.**

#### **How do we know that we are meeting this Standard?**

- The clinical decision that a child may no longer be responding to treatment and may be dying is communicated clearly and sensitively to the family.
- The hospital has Guidelines on consulting families to ascertain their child's known wishes in respect of resuscitation and organ donation where age appropriate (See: Adult Standard 1, Criterion 1.2). All relevant staff use, and are trained to use, these Guidelines.
- Information provision to the family in the case of a sudden or unexpected death takes account of understanding, any additional communication needs (See: Adult Standard 1, Criterion 1.3) and religious, cultural and ethnic preferences.
- Information regarding any changes in the child's status is communicated clearly and sensitively to the family as appropriate.

## Appendix 1

# Quality Standards for Babies and Children at End of Life

## Standard 4: Bereavement Care

### Bereavement Care before and after a Child's death

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#### 4.1 SUPPORTING THE CHILD'S FAMILY BEFORE DEATH

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The Family are treated compassionately and are provided with practical assistance in dealing with the different aspects of the end of life of their child.

#### How do we know that we are meeting this Standard?

- Guidelines are in place for identifying the needs of and supporting family members of a child who may be approaching or at end of life. All relevant staff are aware of and use these Guidelines where appropriate.
- Families are offered timely bereavement supports before and after the death of their child which respond to their varied grief needs associated with their individual and cultural and spiritual experiences of dying and death. (See: Adult Standard 1, Criterion 1.3)
- Family members are offered the opportunity and practical guidance to assist in the care of their child.
- Families are, as far as possible, facilitated to accompany the child during treatments and/or procedures and are allowed to stay with their child throughout their time in hospital.

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 4: Bereavement Care

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#### 4.2 RESPONDING TO THE NEEDS OF THE FAMILY AFTER A CHILD'S DEATH

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The Family are supported in a compassionate and caring manner following the death of their child.

##### How do we know that we are meeting this Standard?

- Guidelines are in place for identifying the needs of and supporting family members after the death of their child. All relevant staff are aware of and use these Guidelines where appropriate.
- Family needs are sensitively attended to and the family are given the time, space and opportunity to remain with their child, for example at their child's bedside or in the mortuary.
- The family receives the deceased child's belongings in either a family handover bag or a memory box as appropriate.
- Where a Post Mortem is required (Coroner's Post Mortem) or requested (Hospital Post Mortem), family members are informed in a sensitive, timely and accurate manner (See: Adult Standard 1, Criterion 1.12).
- The Doctor completes the Death Notification Form within three working days of the child's death (this will not apply where the Coroner is involved).
- Families are advised to register their child's death within a week of issue of the Death Notification.
- Families are offered timely bereavement supports before and after the death of their child which respond to their varied grief needs associated with their individual and cultural and spiritual experiences of dying and death (See: Adult Standard 1, Criterion 1.3).
- Hospital Policy and Guidelines ensure that the loss of the child to his/her family is acknowledged.
- The Hospital Accounts Department show appropriate consideration in the scheduling of bills.
- All families are offered a follow-up appointment with their child's consultant after a child's death. This appointment responds to the needs of the family, including

# Appendix 1

## Quality Standards for Babies and Children at End of Life

### Standard 4: Bereavement Care

assessing the required level of bereavement support and information required and is scheduled at an agreed mutually convenient time for the family and the consultant.

- The family are invited to have the deceased child included in the Book of Remembrance, if that is their wish.
- The family are invited to participate in the hospital remembrance service if they so wish.

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#### 4.3 MISCARRIAGE: SUPPORTING PARENTS FOLLOWING EARLY<sup>1</sup> OR LATE MISCARRIAGE<sup>2</sup>

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Parents of a deceased baby are facilitated and supported in the aftermath of the baby's death.

##### How do we know that we are meeting this Standard

- In all miscarriages, both early and late, staff acknowledge the loss of the baby to the mother/parents and that miscarriage encompasses both the beginning and end of life for the baby.
- Presentation of the deceased baby to the parents is undertaken in a sensitive manner.<sup>3</sup>
- Depending on the faith/beliefs and wishes of the mother/parents, a service is organised for the deceased baby in the hospital chapel.
- The mother/parents are offered choices regarding burial or cremation of the deceased baby.
- **Post-mortem:** Discussion is undertaken in a sensitive manner regarding Hospital Post-mortem (see Adult Standards Criterion 1.12)

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<sup>1</sup> Up to 16 weeks gestation.

<sup>2</sup> Post 16 weeks and up to 23 weeks and 6 days gestation.

<sup>3</sup> This refers to presenting the baby to the mother/parents in "Wrapped in love" clothes and blankets. These are available in a variety of different sizes suitable for all babies. Available from ISANDS.2009.

## Appendix 1

# Quality Standards for Babies and Children at End of Life

## Standard 4: Bereavement Care

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### 4.4 INTRA-UTERINE DEATH OF A BABY, STILLBIRTH AND NEONATAL DEATH: SUPPORTING FAMILIES FOLLOWING THE INTRA-UTERINE DEATH OF A BABY<sup>4</sup>, STILLBIRTH<sup>5</sup>, AND NEONATAL DEATH<sup>6</sup>.

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The mother/parents of a baby who dies intra-utero, is stillborn or dies soon after birth (within 28 days) are facilitated and supported in the aftermath of the baby's death.

#### How do we know that we are meeting this Standard?

- Mother/Parents: Staff members acknowledge the loss of the baby to the mother/parents and recognise that intra-uterine death, stillbirth and neonatal death encompass both the beginning and end of life for the baby.
- Hospital policy and guidelines ensures care and support for the mother/parents.

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<sup>4</sup> Intrauterine death: An infant who dies in utero and is born showing no sign of life.

<sup>5</sup> Still Birth A child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life.

<sup>6</sup> **Neonatal death:** The death among live births during the first 28 completed days of life. Neonatal deaths may be subdivided into early neonatal deaths, occurring before the first seven days of life, and late neonatal deaths, occurring after the seventh day but before 28 completed days of life.

## Appendix 2

# Supporting parents/families following the death of a child

### Supporting parents/families following the death of a child:

#### Facilitating parents as follows:

- It is very important to consult with parents regarding what their preferences are and to request permission to undertake any sensitive tasks such as cutting a lock of the deceased child's hair.
- Hospital policy and guidelines ensures care and support for the mother/parents regarding the following:
  - Spending time with the deceased child
  - Holding, touching, sitting or lying beside the deceased child
  - Creating memories of the child if they so wish by, for example:
    - Taking a photograph
    - Taking a print of the child's hand or foot
    - Cutting a lock of the child's hair
    - Keeping the ID bracelet
  - Washing and dressing the deceased child if they wish
  - Lifting the deceased child into the coffin
  - Taking the deceased child's body home
  - Accompany the deceased child to the mortuary
  - Staying with the deceased child in the mortuary
  - Writing a goodbye note or placing a toy, keepsake or drawing in the coffin if they so wish.
  - Planning the child's funeral
- Accommodation of the mother/parents in a private room
- Sensitive communication;
- Breaking bad news of an intrauterine death/still birth
- If parents have chosen a name, the baby is referred to by name at all times.
- Provision of information: Booklet: "A little lifetime"<sup>1</sup> "Memories of a little lifetime booklet"
- Management of labour and the birth of the baby including addressing possible fears the mother may experience-what to expect if this is a woman's first pregnancy and, how long labour may take.
- What the baby may look like if s/he has been dead for a while
- Post-mortem examination
- Funeral and Burial Arrangements
- Registration of the birth and death of the baby.<sup>2</sup>
- Follow-up: Ensuring the mother is reviewed separately to mothers of normal babies

<sup>1</sup> ISANDS, 2007. 'A Little Lifetime'-publication to support the mother/parents in making choices and outlining some emotions she/they may be experiencing.

<sup>2</sup> ISANDS, 2007. A Little Lifetime. Stillbirth registration. Birth and Death Certificates. Page 26, 27.

## Appendix 3

# Development Process for Standards

**These Standards define the elements of high quality end-of-life care and set out a desired level of performance to be achieved. They have been informed by:**

- Hospice (palliative care) principles and philosophy
- The experience of the Hospice Friendly Hospitals Programme
- Extensive reviews of the literature
- Consultation with national and international experts in the fields of palliative care, end-of-life care and related specialties
- The following consultative groups:
  - The HFH Programme Standards Development Hospitals:
    - Mater Misericordiae University Hospital
    - Connolly Hospital
    - Royal Hospital, Donnybrook
    - Our Lady's Children's Hospital, Crumlin
  - Patient representative groups
  - Carer representative groups
  - Lay representation
  - Voluntary groups
  - Health Services National Partnership Forum
  - The Irish Hospice Foundation

**The following were the main stages in the development process:**

### 1. Evidence Base Review

The Standards Development Team reviewed the international evidence regarding current best practice. This included:

- Key documents including commissioned literature reviews by the Irish Hospice Foundation and the Hospice Friendly Hospitals Programme.
- Best national and international practice regarding end-of-life care.

## 2. Draft standards were prepared for Workgroups

Two sets of Workgroups were convened.

- **What matters most to patients and families:** This workgroup consisted of representation from various Voluntary Groups, participating Standards Development Hospitals and Lay representation.
- **What matters most to staff:** This workgroup consisted of representation of staff interests from participating Standards Development Hospitals and various other sectors of The Health Services.

Through a series of meetings both Workgroups engaged in a process of developing and refining these standards.

- **What matters most to patients and families:** ten meetings.
- **What matters most to staff:** five meetings.

3. Comments from the work groups, representing a wide range of opinions, perspectives and inputs were integrated into the draft Standards document.

4. Draft Standards were produced and reviewed by The Hospice Friendly Hospitals Programme National Steering Committee.

5. Draft Standards were reviewed by a Standards Reference Group.

6. Draft Standards were revised in light of comments by the Hospice Friendly Hospitals National Steering Committee and the Standards Reference Group.

7. Draft Standards were submitted to broad public consultation in June 2009; 152 submissions were received to this public consultation.

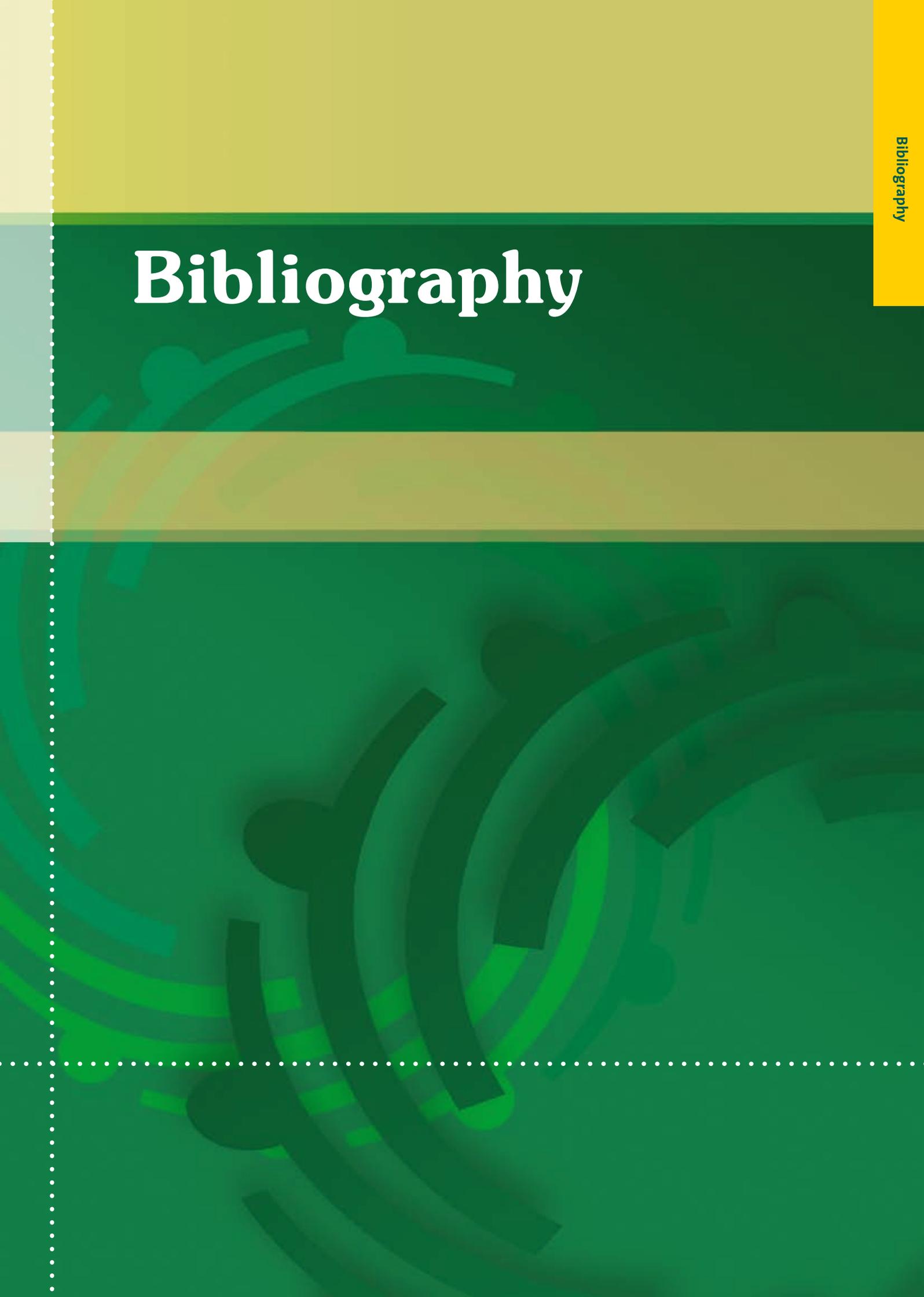
8. Draft Standards were revised following public consultation process.

9. The revised *Quality Standards for End-of-Life Care in Hospitals* was handed over to The Hospice Friendly Hospitals Programme National Steering Committee for final review.

10. Any amendments sought by The Hospice Friendly Hospitals Programme National Steering Committee were incorporated into the final revised *Quality Standards for End-of-Life Care in Hospitals*.



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