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

Hospice *friendly* Hospitals
PROGRAMME

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Ageing and Older People
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Aosú agus Daoine Aosta

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

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Foreword

The National Council on Ageing and Older People (NCAOP) and the Irish Hospice Foundation (IHF) are pleased to present this report, *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland*. The report details the results of research that focuses, for the first time in Ireland, on the quality of life and quality of care at the end-of-life for older people in various care settings including acute hospitals, public extended care units, private nursing homes, voluntary nursing homes and welfare homes.

The report provides a new model for care at the end-of-life which goes beyond specialist palliative care provision to embrace a compassionate approach that supports older people who are living with, or dying from, progressive, chronic and life-threatening conditions, and attends to all their needs: physical, psychological, social and spiritual.

Every person's end-of-life trajectory is different and needs differ in intensity and quality over time. The NCAOP and the IHF believe, therefore, that end-of-life care must adapt to the varying and changing needs of the individual over time and that it cannot be limited to certain settings or services. The provision of good end-of-life care should be driven primarily by the concern to enhance quality of life at end-of-life, and should encompass all of its determinants and components.

The report also provides a comprehensive account of current legal issues surrnounding end-of-life decision-making in Ireland. In this regard, the NCAOP and the IHF agree that a robust legal framework is required to guarantee autonomy in decision-making, which is important for quality of life at end-of-life.

The study raises many important issues for policy-makers and for service planners and providers. Most fundamentally, however, it raises the question of the value placed by our society on how its members are supported and cared for at the end of their lives. The process of dying is reflective of broader social values and the study findings suggest that neglect of end-of-life care for older people may reflect ageist attitudes in our society. Clearly, the eradication of ageism in all its manifestations must be a primary concern for leaders in society and all those charged with promoting equality of treatment for all.

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Executive Summary

Executive Summary

End-of-Life Care

This report is an exploration of end-of-life care for older people in acute and long-stay settings in Ireland. The focus is on end-of-life care for all types of illnesses and conditions in acute and residential care settings because this is where the majority of older people die in Ireland. End-of-life care is broader in scope than palliative care and allows a longer lead time to death. It takes into account the potential uncertainty surrounding dying and death, including the possibility that some people follow complex and non-linear pathways to death. End-of-life care is, therefore, intimately bound-up with quality of life issues for older people living in acute and long-stay care settings. Loss and decline are common and recurring features of life in long-stay care settings, from admission, through on-going care, to death. The challenge for the future will be to find an equilibrium between the care of the living and dying in acute and long-stay care settings. This report provides a potential framework for the development of an integrated care structure for end-of-life care that embraces living and dying as part of the normal care structures and processes in all care settings.

Methodology

The purpose of the study is to provide a contemporaneous account of service provision and care for older people dying in acute hospitals and long-stay settings in Ireland. The study aims are as follows:

- To undertake a survey of Irish acute hospitals and long-stay institutions in relation to contextual epidemiology of death and dying, facilities, staffing levels, access and liaison with services, and training and education needs of staff
- To explore key stakeholder and direct care managers' perspectives on the current provision of end-of-life care for older people
- To explore the experience of the older person in receipt of end-of-life care.

A mixed methods approach was adopted for the study based on the application of quantitative and qualitative methodologies. A total of 592 care facilities were surveyed as part of the quantitative analysis. The overall response rate to the survey was 55 per cent. Qualitative interviews were carried out in six randomly selected sites, chosen to reflect the range of care facilities where older people die. 35 interviews were conducted with direct care staff and 30 interviews were conducted with patients identified by staff as being on a pathway to death, even if death was not imminent. The mixed methods approach offers the potential of collecting rich and deep contemporaneous data on older people currently in receipt of end-of-life care in Ireland.

Legal and Ethical Issues

The key challenge in enhancing quality of life for older people at end-of-life is the preservation of the person's surviving autonomy and dignity balanced against inevitable paternalism. Respect for the person's dignity and autonomy are at the core of their human rights and the law on consent upholds these rights. The current law on decision-making at the end-of-life is based on the principles of autonomy and self-determination. However, if these principles do not hold during all of their time in care, beginning at admission, it is difficult to give them meaning at the end stage of dying and death. The first challenge therefore is to involve older people directly in all matters related to their care. This means more information and enhanced communication between providers of care, families and patients.

In Ireland, there is also a need for legislative reform in relation to vulnerable older people and the key issue of capacity. In the meantime, it should be possible to have guidance in the form of codes of practice that would incorporate these issues until legislation is enacted. Beginning with the transition from home, and having regard to the least restrictive alternative, the person's wishes should be considered at all stages of the care process. There is a role for an independent advocate in assisting the person to make a decision about their care and treatment, if and when required. In this regard, knowledge of the patient's wishes or any advance directive made prior to the onset of incapacity should be central to decision-making. While there is no legislation at present to underpin advance directives, either formal and informal, they are a means of ensuring wishes are respected following the onset of incapacity and not just at the end-of-life.

Facilities, Services and Procedures

The majority of older people in Ireland die in acute and long-stay settings. However, the number of designated palliative care beds in the system is extremely low. While all settings provide end-of-life care, with some patients transferred specifically for that purpose, there are very few designated palliative care beds available for patients who need such care. The availability of single rooms at time of death is highest, as one might expect, in private nursing homes and lowest in acute and psychiatric hospitals. The majority of care staff across all facilities have not received any formal qualifications in palliative care, with less than one third of all facilities reporting that their qualified nurses hold a post-registration qualification in palliative care. In relation to other staff, only one third of all facilities responded that their care/support staff had attended short courses in end-of-life care and only 12 per cent replied that doctors/consultants in their facility had received any form of specialised training in palliative care/medicine. These figures suggest a significant education and training gap in relation to palliative care provision.

There are generally low levels of access to consultant-led palliative care teams, especially within long-stay facilities, where only two fifths of respondents indicated that they are connected to the service. Access to 24-hour advice on resident/patient care from specialist palliative care services is higher, as might be expected. Routine visiting/service provision within long-stay settings from geriatricians, public health nurses (PHNs), social workers, psycho-geriatricians, phlebotomists and counselor/psychologist/CPNs is very low. These providers are likely to visit only when asked or not at all. Such low levels of provision reflect existing resource constraints, but may also reflect the sequestration of dying people from living people by healthcare professionals. Older dependent people receiving end-of-life care may not only be physically separated from the rest of society through their admission to long-stay care facilities, but they may be further isolated through the work practices and work patterns of healthcare providers.

Overall, there is a low provision of formal bereavement support structures available before and after death within acute and long-stay settings in Ireland. Similarly, the availability of private space for engaging in confidential consultations with relatives and friends is scarce in all settings. There is very little internal accommodation available for family and friends wishing to stay overnight with their loved-ones when death is imminent.

Written guidelines for end-of-life care are generally more available in the private long-stay sector than in the public or voluntary long-stay sector. Care in the last hours of life, last offices and contacting a patient’s priest/minister/spiritual advisor are well covered in written guidelines, achieving 80 per cent coverage or above in public, private and voluntary facilities. Symptom control and informing other patients of the deaths of relatives are less well covered. The existence of written policies on advance directives is low overall, particularly in public long-stay facilities. Similarly, coverage in relation to written policies/guidelines on the needs of residents from ethnic minority groups is low across all sectors.

Living and Dying Experiences

The qualitative interviews showed that older people were capable of conceptualising dying and death, but were less willing to talk about their own position on the end-of-life continuum. There was recognition of loss and transition upon admission to long-stay care, but no overt willingness to engage in discussion about dying and death. Some participants appeared unaware that they were close to death. It is impossible to know if this kind of response was self-deception or self-protection, or some combination, on the part of patients, or whether they were genuinely unaware of their own impending death.

Information and openness around dying and death were contentious issues in all of the sites visited. Only a small number of staff regarded it as part of the patient's rights to be informed of their prognosis, in keeping with the general belief that discussion of death was unsettling for residents and therefore not to be encouraged. The majority of staff only discussed death and dying if the resident brought up the topic first and acknowledged that they were dying. Inhibitory factors against open communication included a perceived lack of knowledge and skills among staff and finding the right time to raise the subject with them. Strategies such as keeping cheerful, reassuring the resident that they would be fine and distraction were used to steer staff-patient discussions away from death.

When death was explicitly acknowledged by patients, being able to achieve a sense of closure over their life was important. Patients often rationalised their deaths either through a belief in God as an external influence on the time and manner of death or as a normal and inevitable pattern of the life-cycle. Some patients reported that they not only accepted but actually looked forward to death as a way of meeting again with family members who had pre-deceased them. A 'good' death, when articulated, was described generally as one which was neither protracted nor painful, but allowed for reconciliation with family and friends. Most participants were aware of the need to balance physical care with the spiritual dimension of life closure.

The vast majority of staff described care within their facility as person-centred, individualised and based on resident choice. However, staffing shortages sometimes prevented the realisation of this model of care. Staff simply did not always have the time to give dedicated personal care to patients who were dying. Staff in all sites referred to low staffing levels as a barrier to spending time with patients, though there were significant differences in staffing ratios across the sites. There was some recognition of the emotional labour involved in caring for those at end-of-life, making it difficult for staff to move seamlessly between care of the dying and care of the living. The value of education and training in end-of-life care was a constant refrain in discussions with staff during the site visits as a counterbalance to the physical and emotional needs of the job.

The physical environment was highlighted by staff participants as a real issue in end-of-life care. Sometimes the lack of physical space meant that patients and their families could not always have privacy at the time of death. Few of the facilities that we visited had a single room that could be used when a resident was at the final stage of their life. Where single rooms were available, they were prioritised in relation to clinical need (e.g. MRSA infection). Most staff valued the single room as a resource that created privacy for the patient and enabled relatives and friends to stay with the person in their final days and hours.

Conceptualising New Approaches to Care

The data identified many barriers to the development of new conceptual approaches that seek holistic, person-centred solutions over a longer time horizon than the *ad hoc* approach allows. There are resource constraints, capacity problems, infrastructural weaknesses, education deficiencies, and poor attitudes and expectations in relation to quality of life for older people at end-of-life. Ageism within society generally and within the health and social care system in particular makes it difficult to sanction investment in end-of-life care for older people. Moreover, until recently, there has been little engagement with quality of life issues for older people in long-stay settings.

The frameworks outlined in this report are based on the view that while older people should be at the heart of decision-making with respect to end-of-life care, institutional structures and processes, and social relationships also matter. Thus, while autonomy and independence for older people are important, so too are issues of understanding, empathy, information and communication. An understanding of the human condition is central to good quality care for older people at end-of-life. Four key dimensions are identified as critical for good end-of-life care: knowing and revealing needs; expressing values and preferences; interacting with others; and developing knowledge. These dimensions are important whether the care provided is fundamental, enhanced, advanced or complex.

End-of-life care must be flexible, contemplative and responsive to need in order to capture the uncertainty associated with dying and death. Trajectories of dying are not always linear, as older people move in and out of the zone of 'living and dying'.

Neither are losses within long-stay facilities confined to individual dying and death; older people have to come to terms with many ‘absences’ within long-stay care and bereavement is a constant feature of life in such settings. Therefore, the neat separation of end-of-life into a defined period when palliative care services can be mobilised and administered is not possible. The need for end-of-life care can arise far away from actual death, depending on the physical, mental and emotional state of patients and their families.

Recommendations

Six key recommendations arise from this report. The first is for greater consultation with older people in order to establish needs and preferences with respect to end-of-life care. The second argues for an improvement in the physical environment where people die, particularly with respect to the availability of single rooms and facilities for families and friends. The third seeks greater cultural awareness and understanding of dying and death, including consideration of the current disparity of esteem between younger and older deaths within the health and social care system. The fourth calls for policy reform to ensure that end-of-life care is recognised as an important public health issue, separate to palliative care but inclusive of many of its key elements. The fifth is concerned with measures to develop practice to ensure that end-of-life care for older people is integrated into the everyday life and work of acute hospitals and long-stay facilities. The sixth and final recommendation argues for the testing of new models and approaches that bring about a greater fusion between end-of-life care and gerontological care within all long-stay settings in Ireland.

Chapter One

Introduction

Chapter One

Introduction

1.1 Opening Remarks

This research project focuses on the quality of life and the provision of care at the end-of-life for older Irish people in various care settings. These settings include acute hospitals, public extended care units, private nursing homes, voluntary nursing homes and welfare homes. 'Quality of life' is a complex issue which includes, but is not reducible, to 'quality of care', and needs to be assessed through person-centred subjective and objective methods. In compiling this report, quantitative information on the physical environment, facilities, services, staffing and support mechanisms of acute hospitals and long-stay settings was gathered. In addition, qualitative investigations were conducted to elicit the views and experiences of people receiving end-of-life care, as well as exploring the perspectives of management and staff within care settings to end-of-life care.

Defining the term 'end-of-life' care for people in acute hospitals and long-stay settings is problematic. When does care become end-of-life care? Who decides this? Does the person who is in the terminal stage of an illness realise or accept that this is the case? The answers to these questions can vary depending on the type of illness trajectory the person has, where they are being cared for and who is providing the care. For many people in late old age, dying may be a protracted process with a slow decline, making it difficult to delineate patterns or degrees of care. For example, when does end-of-life care begin for people with dementia who may survive up to ten years following diagnosis or first signs of symptoms? And even when agreement is reached on the definition of end-of-life care, patients, families and care staff may all have different perspectives on what constitutes quality of care and quality of life in later life.

In this report, the term end-of-life care is used in relation to death and dying, since the focus of the research is on all conditions leading to death in a wide variety of care settings, as distinct from palliative care which has come to be associated with care for people with the particular diseases of cancer and AIDS, and with the provision of care in a particular setting. The main policy developments regarding care of people who are dying in Ireland in recent years have, however, been closely associated with the concept of palliative care rather than end-of-life care. The challenge for the future is to transfer best practice from hospice settings to long-stay care settings and to older non-cancer patients.

1.2 Purpose of the Project

The aim of the research report is to map the current status of end-of-life care for older people in acute hospitals and long-stay care settings in Ireland. Specific objectives are as follows:

- To identify levels of palliative care provision in different care settings
- To map different physical, environmental and social contexts
- To describe patient experiences of end-of-life care
- To describe typical 'patient journeys'
- To outline legal and ethical frameworks
- To make best practice and policy recommendations.

1.3 Defining End-of-Life Care

Terminology in respect of the care of people who are dying and close to death is potentially confusing and has shown transitions over time from terminal care to palliative care to end-of-life care (Praill, 2000). End-of-life care is being increasingly used as a generic term in preference to palliative care when considering the needs of people with conditions other than cancer, particularly in community settings and long-stay care settings. The term originates from North America and encompasses more than the phase immediately before death. However, the meaning of the term is not always clear and many studies have noted the lack of a coherent broadly accepted definition of end-of-life (Seymour *et al.*, 2005). This is probably because end-of-life care is best described as a continuum, rather than a point in time. For example, Lorenz *et al.* (2005) define end-of-life as 'a chronologically indefinite part of life when patients and their caregivers are struggling with the implications of an advanced chronic illness'. This definition emphasises the uncertain trajectory associated with death, even when expected, and includes a range of different conditions such as heart disease, cancer, strokes, chronic conditions and multiple co-existing conditions. Similarly Ross *et al.* (2000) provide an elongated definition for end-of-life care that allows for care for older people who are 'living with, or dying from, progressive or chronic life-threatening conditions'. The latter go further, however, suggesting that such care must be 'sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement'.

It is clear, therefore, that end-of-life care applies to people with a variety of conditions and involves a longer time-period than the days or weeks immediately before death. It is also clear that end-of-life care is not synonymous with palliative care, which is much narrower in focus, given its original emphasis at any rate on cancer patients, hospital settings and pain relief.

The distinction between end-of-life care and palliative care is becoming increasingly blurred, however, through the diversification and expansion of palliative care within all facets of medicine, not just oncology, and its expansion into different care settings (Clark and Seymour, 1999). The World Health Organisation (WHO) also now promotes an explicitly public health orientation to the promotion of holistic palliative care that is relevant to all those with chronic illness and their families in different care settings from the early stages of an illness. Specifically, WHO (2002) define palliative care as:

> The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychosocial, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and families. Many aspects of palliative care are applicable earlier in the course of the illness in conjunction with other treatments.

It should come as no surprise to find ambiguity at official level about optimal care at end-of-life and divisions about when end-of-life care begins (Seymour *et al.*, 2005). In the UK, the term end-of-life care has been used rather loosely by policy-makers, without a clear definition being given, although it is generally accepted that end-of-life care begins when it is possible to know someone is actually dying (National Institute for Clinical Excellence, 2004). Similarly, the time frame for end-of-life care in Australia is short and is currently equated with the last few days of life (Commonwealth of Australia, 2004). This is in contrast to Canada where a much longer view is taken.

In Ireland, the extension of palliative care services to meet the needs and preferences of those with cancer or other long-term conditions has been adopted as an aim of Government policy, without reference to timescale or definitions. This is reflected in the adoption of an end-of-life care standard in the *National Quality Standards for Residential Care Settings for Older People in Ireland* that links end-of-life care to palliative care services, but without reference to time-scale (Health Information and Quality Authority, 2008). Of course, all definitions and policy guidelines come up against the problem that assigning a time limit to 'end-of-life' is always going to be somewhat arbitrary. The process of dying is often long-term, complex and uncertain (Seymour *et al.*, 2005). It may only be possible to define end-of-life retrospectively as medical staff are frequently unable to say with certainty when death will occur.

1.4 Older People and End-of-Life Care

As this study specifically considers end-of-life care issues for older people, we need to consider the relationship between gerontological and palliative care within acute hospitals and long-stay settings. Both types of care have common concerns and aim in terms of 'promoting quality of life, dignity and autonomy … controlling symptoms and seeking to avoid overuse of medical investigations and aggressive treatments', as well as focusing on the family and the person, and establishing multidisciplinary and community-based models of care (Seymour *et al.*, 2005). However, there has been little integration between the two specialties, perhaps because of the tendency of healthcare systems to focus narrowly on cure, to the detriment of the care provided for older people who are dying (Lloyd, 2000; Klinkenberg *et al.*, 2005).

In addition, the tendency in recent years within policy circles and care structures is to think about ageing mainly in positive terms, which leaves little room for much deliberation on end-of-life issues. It can also lead to fatalism, especially for highly dependent older people, whereby death is seen as a relief, rather than an aspect of the human condition which must be addressed in a holistic and dignified manner. Too often nowadays, the deaths of the old are undervalued; increasingly seen as 'natural', relatively straightforward and 'on schedule' (Howarth, 1998).

The way that older people are supported and cared for through the process of dying is reflective of broader social values (Lloyd, 2000). There is evidence, for instance, that doctors are less likely to treat pain in older people, particularly in relation to non-malignant diseases (Lynn *et al.*, 1997; Davies and Higginson, 2004). Symptom control may not always be a priority for care staff, sometimes for practical reasons such as lack of time, more likely because of problems with continuity of care. The neglect of end-of-life care for older people may reflect ageist attitudes that older people are somehow more prepared for death, or that their deaths are somehow less important than those of younger people. Such ageist thinking may also influence the allocation of scarce resources both to the care of older people and to the care of those who are dying. It may also lead to a weak emphasis on quality of life for people at end-of-life and a consequent failure to personalise care up to, and including, death.

Attitudes to death and dying may also influence end-of-life care. Some people may want to talk about death while others may not. Certainly, there is no evidence that being older makes it easier to express a preference or take part in a general discussion of death. Some people may deliberately avoid any discussion of death as a way of coping, particularly if their illness is long-term. Similarly, families and care staff may not always be equipped to engage with the issues that dying and death brings for them as carers. They may not have experienced death before, or, if they have, may not have dealt with the issues that may have affected them as a result of the death of family members, friends or even other patients. It is difficult in such circumstances to imagine much openness in discussions about end-of-life concerns between carers and older people.

There may also be differences in cultural attitudes to dying and death between care staff and patients which impact on quality of care and quality of life in all settings. The increasing number of foreign staff in long-stay settings in Ireland may result in a different approach to end-of-life care, which may be at variance with the wishes of patients and their families.

Similarly, indigenous care staff may have different values with respect to end-of-life care for older people than their increasingly ethnically diverse patients and residents. These various differences should be easily reconciled, but require awareness that they exist in the first place and then resolve that something can and should be done about them, as part of a person-centred approach to care.

An integration of palliative care and gerontological care is necessary to create a new model of end-of-life care for older people – one that values the medical, health and psychosocial dimensions of caring in the care plans and provision for older people at end-of-life. This is particularly important for older people living in long-stay care settings. Entry to a long-stay setting represents a major transition in a person's life (Reed *et al.*, 2002). The majority of people admitted to long-stay care facilities will most likely die there, or be transferred somewhere else to die. That process may be short or long, depending upon the diagnosis and trajectory of the illness. Froggatt (2004) identifies three stages associated with end-of-life care in long-stay settings: the living and losses experienced in the care home; the actual dying and death; and the bereavement that follows a person's death. If that is the case then neither palliative care nor gerontological care is enough on their own. Instead, end-of-life care has to be integrated as a key element of all care provided, from the time of admission to bereavement. This requires a longer-term perspective than just the death of an individual and the time period immediately preceding this (Froggatt and Payne, 2006). It also requires a generic focus on quality of life that mixes concern for the needs of the living with those of the needs of the dying.

1.5 Dying and Death in Ireland

Almost 30,000 people die each year in Ireland, of whom just over three quarters are aged 65 years and over (CSO, 2006). Two fifths of these older deaths occur in acute hospital settings (Table 1.1). Data from the CSO suggests that a further 20 per cent of older people die at home, while 15 per cent die in private nursing homes, leaving the remaining 25 per cent to die in other settings, mainly public long-stay care facilities. As people age they are less likely to die at home and more likely to die in private nursing homes and public HSE residential care. Unfortunately, we cannot be much more precise on deaths in public long-stay facilities since the classification system used by the CSO to record place of death does not allow comparison with the Department of Health and Children's (DoHC) categorisation of long-stay care settings. We do know that broadly similar patterns are reported in the UK, where deaths data for all ages showed that 56 per cent of deaths occur in hospital settings, 19 per cent at home, 18 per cent in a care home and 4 per cent in a hospice (Seymour *et al.*, 2005). While the Irish categories do not correspond directly with the UK classification system, the proportion of those dying at home is similar in both countries.

Table 1.1: Total Number of Deaths and Deaths in Acute Hospitals for People Aged 65 Years and Over

Age Group	Total Deaths	Deaths in Acute Hospitals
65-74 years	5,280	2,453
75-84 years	9,412	4,079
85+ years	7,382	2,286
Total	22,074	8,818

Source: Vital Statistics, 2004; HIPE, 2004

Where people die is not always where they would like to die (Levine and Zuckerman, 2000). Recent Irish research suggests that almost two thirds of older people would prefer to be cared for at home if they were dying (Weafer *et al.*, 2004). In fact, as we saw earlier, only 20 per cent of older Irish people die at home, while most die in acute hospitals and long-stay care settings. A study by Tiernan *et al.* (2002) of patients referred to a Palliative Home-Care service found that four fifths of referrals expressed a preference to die at home, while only half of these people actually died at home. A similar situation obtains in the UK where most older people would prefer to remain at home to die, but most actually die in hospitals or care homes (Seale and Cartwright, 1994; Addington-Hall and McCarthy, 1995).

Some of the features of dying at home that are seen as desirable from the point of view of the person are as follows: being in familiar surroundings; being able to see family, friends and neighbours freely; having continuity of care by the local GP and PHN and possibly by family members and/or local paid carers. However, for some people, dying at home may not always be ideal, even if this is where they would like to die. Some people may not have an appropriate caregiver, others may not want to place a 'burden' on family, have their children provide intimate care, or have their children witness their suffering, while specialist equipment may not always be available in home settings (Gott *et al.*, 2004). In such circumstances, rather than dismissing in-patient care as inappropriate for end-of-life care, practices and facilities in institutions may need to be developed so that people can die in a way that incorporates some of the good qualities that are typically associated with death at home.

To fully assess the needs of older people at the end-of-life it is important to understand the principal causes of death among older people. As people are living longer, they are suffering from diseases that have a longer and less predictable care trajectory. Death no longer comes 'abruptly' as it tended to do previously with the onset of acute diseases such as pneumonia. Advances in medical care and technology have helped people to live longer. However, older people now often suffer severe chronic illness and disability in the last phase of their life (Lynn and Adamson, 2003). That said, older people tend to die from the same diseases as younger people (Table 1.2). People may also die from multiple causes, making it difficult to ascertain which of these led most directly to death. Similarly, dementia is also an important and increasing cause of death among older people, but is not generally recorded as the primary cause of death. The result is a lack of awareness of the terminal nature of the condition in its advanced stages and a failure to integrate end-of-life care and gerontological care.

Table 1.2: Cause of Death by Age Group

Cause of Death	65-74 years	75-84 years	85+ years	%
Diseases of circulatory system	34	40	45	41
Neoplasms (cancer)	39	26	14	25
Diseases of respiratory system	10	16	21	16
Diseases of digestive system	3	3	3	3
Injury and poisoning	2	2	2	3
Diseases of the nervous system and sense organs	2	2	3	2
Mental and behavioural disorders	1	1	2	2
Other	8	9	10	8
Total	100	100	100	100

Source: *Vital Statistics*, 2004

1.6 Policy Developments

The Irish experience of palliative care extends back to the nineteenth century when the Irish Sisters of Charity established Our Lady's Hospice in 1879. They were influenced by their experience of visiting people who were dying in their own homes; many of these people were dying from tuberculosis and did not have care available to them due to fears of infection within hospitals. This hospice was considered to be the first institutional provision of its kind beyond the mainland of Europe. Other early initiatives included 'The Rest for the Dying', which was founded in 1904 for Protestants suffering from incurable diseases, and Milford House, which was founded in Limerick in 1928 by the Little Company of Mary.

Over the following decades as the pattern of disease changed from acute to chronic and cancerous diseases, there was a growing concern about care for the elderly and the dying, but little or no further developments. Community-based hospice care or home care only developed in the mid-1980s as local health professionals began to take a greater interest in the palliative care needs of their patients.

It was not until after 1995, when palliative medicine was approved for inclusion in the list of medical specialties, that there was a recognised urgent need to develop policy that would support and foster the development of services in this area. The Irish Government's commitment to developing palliative care services was first reflected in the national health strategy entitled *Shaping a Healthier*

Future – A Strategy for Effective Healthcare in 1994. This document endorsed the aspiration to develop services in a structured manner in order to achieve the best quality of life for both patients and families. The role of palliative care for cancer patients was specifically referred to by setting out a number of targets in this area. This commitment resulted in the publication of the *National Strategy for Cancer Services in Ireland* in 1996 encompassing the following principles:

- Patients should be enabled and encouraged to express their preference about where they wish to be cared for and where they wish to spend the last period of their life.
- Services should be sufficiently flexible and integrated as to allow movement of patients from one care setting to another depending on their clinical situation and personal preferences.
- The ultimate aim should be for all patients to have access to specialist palliative care services where these are required.

The 2001 health strategy, *Quality and Fairness – A Health System for You,* reaffirmed the Government's commitment to the development of a national palliative care service. Its main focus was on reducing health inequalities by focusing on equity of access to services. It committed each health board area to complete a needs assessment study for specialist palliative care services and it also commissioned research on the specialist palliative care service requirements of non-cancer patients. Published in the same year, *Primary Care – A New Direction* recognised the potential for primary care providers to deliver much of the care currently being provided by specialist services such as palliative care. It proposed an interdisciplinary approach to care which was predicated on greater integration between primary and specialist care providers.

The most fundamental policy commitment to palliative care was the establishment of the National Advisory Committee on Palliative Care (NACPC) in 1999. This resulted in the publication of the *NACPC Report* in 2001 which highlighted deficiencies in palliative care provision and made recommendations based on quality research evidence for the future of palliative care services in Ireland. The following were the key elements of this report.

Structured planning and delivery of services

The Committee recommended that palliative care should be structured in three levels of specialisation, each referring to the degree of training and expertise of the staff providing the service:

- Level 1 – Palliative Care approach: All healthcare professionals should appropriately apply palliative care principles
- Level 2 – General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of healthcare professionals who, although not engaged in full-time palliative care have some additional training and expertise
- Level 3 – Specialist Palliative Care: These services provided by people whose core activity is limited to the provision of palliative care.

All three levels should be available to all palliative care patients in all care settings – at home, in a nursing home or in a community hospital.

Specialist palliative care services to be provided in each health board area

A key recommendation was that each area should have its own in-patient unit for hospice palliative care and there should be a minimum of eight to ten specialist palliative care beds per 100,000 population. All specialist palliative care services should have a minimum core of professionally trained staff with recognised post-registration qualifications in palliative care. Palliative care services should be consultant-led instead of nurse-only teams.

Education, training and research

It was recommended that medical schools should develop an academic Department for Palliative Care with a core curriculum for undergraduate courses. Each specialist palliative care unit should set up a nursing practice development unit to develop, implement and monitor nursing practice in the unit. All health professionals working within palliative care should be given the opportunity to engage in research which requires specific training in research methodology and interpretation of research data.

Funding and accountability

The future of palliative care services relies on the ongoing provision of an adequate level of public funding. Since there was found to be wide regional variation in funding, it was recommended that statutory funding should be made available to meet the core running costs of all specialist palliative care services. It was also recommended that there should be a separate protected budget for specialist palliative care services and funding priorities should be determined at the health board level. Also, all day-to-day palliative care expenditure should be met by the health board palliative care budget.

Bereavement support

> Bereavement support is an essential component of palliative care services. It was recommended in the report that bereavement support should be available in all care settings and be incorporated into all specialist palliative care programmes. It should also begin early on in the disease process, long before the death of a patient and be provided by appropriately trained personnel.

The Government responded positively to the publication of this report and committed itself to the staffing recommendations over a five to seven-year period at an estimated cost of €56m. However, many of the recommendations made in the report have not been implemented. Despite the Government's stated intention of committing more resources to palliative care, a recent report by the Irish Hospice Foundation (2006) indicates that there are many gaps in the provision of palliative care services. There are regional imbalances in the provision of consultant-led specialist care teams, inadequate training, inadequate funding in many areas and lack of integration of care between different care settings. In addition, the focus remains on palliative care for cancer patients only and there have been few initiatives with respect to end-of-life care for older people in long-stay settings in particular. Much of the current impetus to widen and deepen policy on end-of-life care has arisen from those involved with the provision of palliative care who believe that this type of care should be available to all Irish people at the end-of-life. What is not clear is the extent to which palliative care and end-of-life care are seen as being one and the same.

The most recent reference to end-of-life care in official policy documents is its inclusion as an explicit standard in the *National Quality Standards for Residential Care Settings for Older People in Ireland* (HIQA, 2008). The standard on end-of-life care states that each resident should 'continue to receive care at the end of his/her life which meets his/her physical, emotional, social and spiritual needs and respects his/her dignity and autonomy'. There are 13 criteria listed as necessary to achieve this goal incorporating: assessment of palliative care needs; respect for individual choices and preferences with respect to care and place of death; referral to specialist palliative care services; staff training and guidance in end-of-life care; services and facilities for families; and bereavement support.

While standards of care are necessary conditions for the provision of good quality care they are not sufficient. Moving from the adoption of standards to practical developments which impact on patients' quality of life will require a major transformation of the culture of care within acute hospitals and long-stay settings. This report is concerned with how this cultural change can be brought about in Ireland.

1.7 Structure of this Report

Following this chapter, the report begins in **Chapter 2** with an examination of quality of care and quality of life issues for people receiving end-of-life care in Ireland. The literature on quality of life at the end-of-life will be reviewed and key domains identified. There will be an attempt to define what constitutes a 'good death' for older people in Ireland. International research suggests that older people have identified pain and symptom management, patient consultation and control, relieving caregiver burden, continuing relationships with loved ones, and spiritual and/or psychological well-being as the important features in contributing to a 'good death'. Many of these issues will be considered in the context of end-of-life care in Ireland.

Chapter 3 is concerned with the contribution that the law can make to enhancing the quality of life of people receiving end-of-life care in acute hospitals and long-stay settings. One of the important ethical challenges faced by families and society is the situation where an older person needs a higher level of care but does not want to move to a residential centre. The forced removal of that person for care raises many legal and ethical issues for society, and raises the inevitable conflict between personal freedom and welfare. This chapter also outlines the legal framework that applies to older people in the context of decision-making in long-stay care and at the end-of-life. The right of autonomy and self-determination are central to such decisions and when the capacity to assert these core human rights is reduced it is necessary to have a robust system in place to safeguard people. The law on consent, incorporating the fundamental issue of capacity is outlined, as well as related issues including, advance directives, DNR orders, enduring powers of attorney, and rights to privacy and confidentiality.

The methodology used in the study is outlined in **Chapter 4**. This chapter provides justification for both the quantitative and qualitative approaches used in the study. Attention is focused on the survey methodology and on the interview schedules used to elicit responses from care staff and patients. The findings from the postal survey questionnaire of acute hospitals and long-stay facilities are presented in **Chapter 5**. A number of different dimensions are covered including: beds, residents, staff, services and facilities, communication and liaison, bereavement support, and policies and guidelines. The perception of nurse manager respondents in each facility with respect to the meaning of end-of-life care, optimal quality care for people at end-of-life and barriers to the implementation of good practice is also explored.

Chapters 6, 7 and **8** record the views of care staff and patients with respect to end-of-life care in selected care sites in Ireland. Although written as discrete chapters, they provide an integrated and evolutionary description of the patient experience from first realisations of deteriorating health to personal expectations of a good death, through the reality of the dying experience. They describe an oscillatory path of deteriorations and improvements over time, eventually resulting in a terminal, yet unpredictable, state of decline. For this reason, many of the patients interviewed were aware of their poor health but not that it necessarily indicated their dying, since some of them had 'bounced-back' on previous occasions. **Chapter 6** deals with living and dying, **Chapter 7** covers transitions into dying, while **Chapter 8** reports on the organisation and ethos of care within acute hospitals and long-stay settings.

Chapter 9 proposes models for the interpretation of end-of-life care for older people living and dying in acute hospitals and long-stay institutions in Ireland. Account is taken of the individual older person's experiences at end-of-life, as they move from life to death, their location in a wider family, organisational and societal context, and the identification of service workforce configurations that can flexibly respond to these often fluctuating, unpredictable needs. The approach is illustrated using two models, which are operationalised as a series of frameworks for good practice and care. The policy implications of the research and its conclusions are presented in **Chapter 10** and key recommendations are made to guide policy-making in the future.

Chapter Two

Quality of Life and Quality of Care at the End-of-Life for Older People

Chapter Two

Quality of Life and Quality of Care at the End-of-Life for Older People

2.1 Introduction

Quality of life is a domain commonly proposed as an end-of-life outcome. However, the association between quality of life and end-of-life care could be strengthened by clear definitions and consistent measurements of quality of life. This chapter provides an overview of how quality of life of older people at the end-of-life has been conceptualised and measured. The separate but related issue of quality of care for older people at the end-of-life is also discussed. The concept of a good death is explored for its meaning and relevance in acute hospitals and long-stay care settings. The main structural and process barriers that exist to providing good care at the end-of-life are documented. Finally, some international models of best practice in end-of-life care provision are examined to see if anything might be learned from an Irish perspective. The chapter begins, however, with a brief overview of quality of life issues for older people generally.

2.2 Quality of Life for Older People

Quality of life is a complex, multi-dimensional concept that is difficult to define and measure. Its meaning changes over time and is perceived differently in different cultural contexts. Definitions of quality of life often depend on the objectives and perspectives of those engaged in research. For example, researchers in the disciplines of medicine, nursing, economics, psychology, sociology and philosophy emphasise different aspects of quality of life. There is, however, general agreement that any measure of quality of life should encompass both subjective and objective components (see Stewart *et al.*, 1999; Ventegodt *et al.*, 2003; Davies and Higginson, 2004; Bond and Corner, 2004; Lorenz *et al.*, 2005).

For many years, researchers have developed scales to measure quality of life for the general population. Recently, there have been attempts to develop scales for specific groups in the population such as older people. The research on quality of life for older people is vast and is impossible to cover in a few brief paragraphs (for readers interested in this literature see Murphy *et al.* (2006) for a useful summary).

Bowling *et al*. (2002) found that community-dwelling older people identified the following domains as important to their quality of life:

- Social comparisons and expectations
- Personality and psychological characteristics – self-efficacy and optimism
- Health and functional status – physical functioning, health status, longstanding illness
- Social capital (personal and external), social activities, social contacts, social support, pets, frequency of loneliness, increase in loneliness, quality and safety.

This highlights the importance of social and psychological factors in determining quality of life. In other words, health and physical function form only a part of the factors that influence older people's quality of life.

Research into the quality of life of residents in long-stay care in the USA identified the following domains as important (Kane *et al*., 2003): autonomy, individuality, dignity, privacy, enjoyment, meaningful activity, relationships, security, comfort, spiritual well-being and functional competence. For this group, social comparisons are less important than for the community-dwelling group while issues such as privacy, individuality, autonomy and spiritual well-being arguably become more significant as people strive to retain or recreate their sense of self and identity after they move into residential care (Reed *et al*., 2002).

Since many older people at the end-of-life may have a variety of severe physical and mental conditions, it is important to establish what domains have been identified as important to them. Tester *et al*. (2004) looked at how people suffering from severe physical and/or mental disabilities perceived the quality of their lives in institutional care. The researchers used a combination of interviews with older people and carers together with observational methods and identified the following four domains as important:

- Sense of self – perceptions of own and others' frailties and strengths, appearance, personal possessions and privacy
- Care environment – autonomy, control, choice, independence and staff/resident relationships
- Relationships – social interaction, relationships with other residents and relationships with family
- Activities – meaningful activities, organised activities and religious activity.

For this group, a key domain is again concerned with maintaining a sense of self, which is likely challenged by their disability. The care environment including the degree of autonomy, control, choice and independence they have can affect their quality of life. This includes control over choice of food, clothing, personal possessions, getting up in the morning, going to bed at night and whether they have to fit in to a routine generally. Their relationship with staff (and family and friends) is crucial, reflecting the fact that they are often reliant on care staff to complete the activities of daily living. Finally, having access to meaningful activities is important for the quality of life of this group.

2.3 Quality of Life of Older People at End-of-Life

There are a number of issues that arise in relation to conceptualising and measuring quality of life at the particular period known as the end-of-life. First, there are many different illness trajectories for older people; prognosis is often difficult and patients have different levels of functioning and needs depending on their condition.

Many older people tend to have a number of chronic conditions such as diabetes, heart disease and arthritis. In such cases, it is often difficult to identify whether they are in fact approaching death or when death may take place (Lynn and Adamson, 2003; Murray *et al.*, 2005). Many older people may live for years with multiple conditions (Higginson, 2005). People's quality of life is also likely to be affected by age, gender, socio-economic group, culture and religion among other factors. Other issues arise when healthcare staff and/or older people themselves are reluctant to discuss death openly and the older person may not actually be aware that s/he is dying (Kendall *et al.*, 2007). The setting in which care is provided is also likely to impact on the quality of life. The significance of all of these factors has come to be recognised and researchers have developed assessment instruments appropriate to different conditions and settings.

Most researchers agree that quality of life at end-of-life shares some of the features of quality of life in old age but also needs to incorporate aspects that are specific to the dying process and its immediate aftermath (Stewart *et al.*, 1999; Chappell *et al.*, 2003). A recent review of the literature found that there is relatively little research that draws on carer and patient perspectives in seeking to establish what constitutes a 'good death' (Kendall *et al.*, 2007). They attribute the lack of this type of evidence-based research to practical, ethical, methodological and emotional difficulties associated with interviewing people who are dying (Stewart *et al.*, 1999; Waldron and O'Boyle, 1999). However, a recent study has found that in fact many people who are dying are willing to participate in research and even that such participation can be a very positive event for the person (Kendall *et al*., 2007; Lo *et al*., 2002). It is also being increasingly recognised that the way that the family perceive the patient being treated at and just after death forms a significant part of quality of life at end-of-life (Hanson *et al*., 1997). Moreover, dying is a social process as well as a biological event, so a wide range of domains (apart from health and functional status) are relevant for assessing quality of life. Patients may have poor health and yet, if they feel spiritually fulfilled, for example, may have a good overall quality of life at the end-of-life.

Despite the relative lack of research, certain dimensions or domains of quality of life at end-of-life have been identified as important in the literature (Stewart *et al*., 1999). As already noted, when measuring quality of life, it is important to develop ways of measuring outcomes that are appropriate to the group who are of interest. Several measurement scales have been developed in the last ten years or so that attempt to measure quality of life at the end-of-life. However, many of these scales have been designed to look at quality of life for people with specific conditions such as cancer or heart disease or who are in a particular care setting such as a hospice. However, a scale that was developed in 2002 (the QUAL-E) is particularly appropriate in terms of the current study (Steinhauser *et al*., 2002). It is designed to identify the important end-of-life domains for people suffering from a range of conditions who may not be aware that they are dying.

A recent systematic review of the end-of life care literature (Mularski *et al*., 2007) identified the following domains as important in assessing quality of life.

- Life completion: This is concerned with the person's sense that they have achieved what they want to achieve. It includes being able to help others, saying important things to loved ones, having a sense of meaning, being at peace and having time with family.

- Relationships with the healthcare system: This emphasises the person's relationship with the healthcare system and includes a sense of control about treatment decisions, knowing where to get information, participating in care decisions, knowing what to expect about the illness and being treated as a person.

- Preparation/anticipatory concerns: This includes worry about being a burden, about whether their family is prepared for the future, fear of dying, financial strain and regrets about life.

- Symptom impact: This domain has been identified as central in most studies of end-of-life care. Control of symptoms is crucial in promoting the comfort of the patient and ensuring that their quality of life is as good as possible approaching death. Typical symptoms include pain, fatigue and nausea, and patients report on the frequency and severity of symptoms, how much it interfered with enjoyment of life and concerns about the future.
- Connectedness and affective social support: This assesses whether the person has a confidant to share their deepest thoughts, and how much and how frequently they spend time with family/friends.

These domains are relevant for the present study given that people with a range of conditions are included in a variety of care settings.

Elements of these key domains are evident in other studies that have concentrated on specific aspects of quality of life as elicited from patients (Singer, Martin and Kelner, 1999; Stewart *et al*., 1999; Tilden *et al*., 2002; Berglund and Ericsson, 2003; Chappell *et al*., 2003; Vig and Pearlman, 2003). The following factors were identified as being important for quality of life:

- Receiving adequate pain and symptom management
- Good management of psychological symptoms
- Timely, negotiated decision-making
- Dying a natural death (neither prolonging nor shortening life)
- Having culturally appropriate spiritual support available
- Achieving a sense of control (for example, over where to die, who is present)
- Not being a burden and strengthening relationships with loved ones
- Finding acceptance of one’s own life
- Being mentally aware
- Being treated as a ‘whole person’.

2.4 Quality of Care for Older People at End-of-Life

In recent years, national and international policy agencies have become concerned with defining and measuring quality of care at end-of-life. This includes the quality of care of the dying person, but also, importantly, includes the way in which family and friends of the dying person are treated.

Donabedian's work has been influential in providing a conceptual framework for measuring the quality of care (Donabedian, 1980; Donabedian, 2005). The framework emphasises structure, process and outcomes that can be applied to end-of-life in the following terms:

- The structure of care is concerned with the physical environment and staffing.
- The process of care relates to what is done, when it is done and how well it is done – that is, how appropriate is the care, how timely it is and how technically efficient it is. Other issues covered here are transitions to care, advance care planning, availability of services and the ratio of suitably qualified staff to residents.
- Care outcomes would necessarily include an emphasis on health and functional status, as well as on pain relief and other areas of symptom control. But it would also have to include the promotion of continued relationship with family and friends, control over decision-making and spiritual well-being.

The problem is how to measure care outcomes in such a sensitive area. The US Institute of Medicine has identified six elements, some of which overlap, that can be used to assess the quality of care provided to people at end-of-life as follows (Field and Cassel, 1997).

Quality of life

Many instruments have been developed to measure the overall quality of life of people at the time of death. As well as the scales developed and administered to patients themselves, measures have been developed to assess the quality of life prior to death in cases when the patient is unable to participate in research themselves. These may be administered to family members or medical staff. One such measure is the Quality of Dying and Death (QODD) instrument, which tries to capture the experience of patients at the time of death (Mularski *et al.*, 2004).

Physical well-being and functioning

Measures to assess outcomes in this domain are well-developed and it is relatively easy to measure the individual's physical well-being and function.

Psychosocial well-being and functioning

Similarly, a variety of scales have been developed to measure psychological well-being, emotional and cognitive symptoms, grief and bereavement, satisfaction and quality of care, and caregiver well-being. However, a recent study identified that there are significant gaps in the literature in terms of measures to assess continuity of care, advance care planning, spirituality and caregiver well-being (Mularski *et al*., 2007).

Spiritual well-being

The issue of spirituality has been identified as an important domain in assessing outcomes at end-of-life. As we have seen, being at peace spiritually can profoundly affect quality of life at the end-of-life and in qualitative research with older people, attaining spiritual well-being at the end-of-life has been identified as an issue of concern to many of them (Vig and Pearlman, 2003). Two recent reviews of the literature found that the area of assessing spiritual well-being is relatively under-developed (Teno, 2005; Mularski *et al*., 2007).

Patient perception of care

The following domains have been identified as important in studies that have elicited patient perspectives: receiving adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving a sense of control; relieving burden and strengthening relationships (Singer *et al*., 1999). However, it is generally agreed that more research is required to assess patients' perspectives of quality of care in different care settings and cultural contexts (Singer and Bowman, 2002).

Family well-being and perceptions

This includes assessing how families are themselves treated by staff in the period before death: whether they are facilitated to visit and care for their relative, thus strengthening their relationship; how they perceive their relative to be treated in the time leading up to death; whether a patient's prognosis and treatment are discussed with them; and how the death itself and its aftermath are dealt with by staff and management. This may include observance of religious rituals where appropriate, and care of the body and the environment around the body after death. Finally, it may also include access to bereavement care for family and friends.

Generating taxonomies of quality end-of-life care from patients tends to generate similar, if simpler and more straightforward models. Singer *et al*. (1999) identified five domains from the patient's perspective as follows:

- Receiving adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control

- Relieving burden
- Strengthening relationships with loved ones.

The similarities between the two models, one derived from experts, the other from patients, support the general validity of the conceptual domains, even if slight differences are evident. More recent evidence on the relationship between care provision and outcomes at end-of-life are broadly in accord with both of the above (Cassarett *et al.*, 2006; Mularski *et al.*, 2007). The latter suggest that while the experience of dying is individual-specific and hence variable, certain types of outcomes can be used to define and measure the quality of end-of-life care. These are:

- Patient physical comfort
- Patient spiritual and psychological well-being
- Family psychological, spiritual and social well-being
- Patient and family access to information and control over treatment
- Continuity of care across providers and care settings
- Family adjustment after death.

While there is considerable agreement in the literature on optimal care-giving at end-of-life, it would be wrong to assume that our knowledge is complete, or that healthcare systems have managed to translate existing information into effective person-centred action. Circumstances surrounding end-of-life remain poorly understood and end-of-life care is often fragmented among providers and care settings, leading to a lack of continuity of care and impeding the ability to provide interdisciplinary care. The absence of knowledge and information with respect to dying and death in Ireland is particularly acute.

2.5 What is a Good Death?

Before going on to explore the barriers that exist to providing good quality care, this section discusses some of the conceptualisations of a good death that have been articulated in national and international policy documents and elsewhere. As governments and the WHO have become more concerned in recent years with end-of-life care, the issue of what constitutes a good death has been debated by national policy groups and others (Age Concern, 1999; Smith, 2000; DoHC, 2001). In many countries, including the UK and Ireland, the idea of what constitutes a good death has been articulated primarily by the Palliative Care or Hospice movement. This is not surprising, given that these organisations have been to the fore in pushing for and providing high standards of care for those who are dying.

A UK policy organisation, Age Concern, produced a framework of the good death in 1999, which was heavily influenced by the perspective of the palliative care movement (Seymour *et al.*, 2005). They identified the following principles:

- 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 symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have control over who else is present and shares the end
- 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.

One of the main criticisms of these principles is that there is an over-emphasis on choice and control, which may not be available to many older people at the end-of-life. Further, there is an assumption that people who are dying want a high degree of control over their death; for some older people, this may not be the case. For example, while some people may wish to plan their funerals, they may not feel that they have much control over the timing of their death or their treatment options (Chappell *et al.*, 2003). It has also been suggested that while a palliative care approach may be appropriate for people with particular diseases, it may need to be adapted to meet the needs of older people dying from different conditions.

Within the palliative care movement a good death is defined as dying in a way that is consistent with how the person has lived, that is meaningful and dignified, pain-free and peaceful. This model of death implies that the person should ideally face their death in a particular way – that is they should be openly aware of their own impending death and accept it. However, Sandman (2005) interrogates many of these features of a good death from a philosophical perspective. He uses a value framework that evaluates features of the palliative care model of a good death against a range of factors that the person may value such as achievements, intimate personal relationships, reality contact, being a certain kind of person, self-determination and freedom. He argues that there is at least as good a case for denial as for awareness of death and, consequently, the latter should not be assumed to be the ideal by carers or medical staff. Some people may not see any meaning in their death and may instead wish to try to find comfort in what remains of life.

There are cases when awareness of death is not crucially important to the individual. Some people may not have a strong need for control – for example, they may be religious and content to leave their death in the hands of God or to 'let nature take its course' as a recent Chinese end-of-life study found (Lo *et al.*, 2002). It is probable that at least some older Irish Catholic people may have a similar way of accepting and assigning meaning to their death (Donnelly, 2005). The desire for control and consultation may be a particularly secular, western, rational concept and should not be assumed to apply universally. Therefore, some features of a good death endorsed by advocates of palliative care should not be accepted uncritically as universal principles. They are useful as a basis for discussion, but patients should be facilitated to decide what is a good death for them, given their own values and circumstances (Sandman, 2005).

Arguably, a more fluid definition of a good death is that provided by the US Institute of Medicine Committee on End-of-Life Care. They define a 'good death' as:

> one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical cultural and ethical standards.
> (Field and Cassel, 1997)

This definition is more capable of accommodating the diversity of perceptions of what is a good death according to cultural, socio-economic and/or religious background. There is such a variety of world-views in post-industrial society, from secularist to a wide variety of diverse religious/ spiritualist approaches, that the concept of a 'good enough death', where people are helped, insofar as possible, to be symptom-free and enabled to have control over how they die, is perhaps the most that can be achieved (McNamara, 2004). In other words, there is no ideal death, only death. Dying may occur in a crowded noisy environment or in a private room; death may involve rituals or it may not. In general, in an increasingly secular and ethnically diverse society, there is less certainty over what constitutes a good death.

Not surprisingly, therefore, the palliative care model of a good death has been found to be alienating to particular groups. For example, Travellers in Ireland rarely avail of palliative care in hospices. One reason for this may be that when a Traveller is dying it is traditional to have most of the family nearby. Often hospices and hospitals do not have space for large family groups or staff may consider it disruptive to other patients. For this and other reasons, such as Travellers feeling socially isolated in hospitals and subject to prejudice in institutions, this ethnic group may avoid palliative care and not benefit from the pain and symptom relief it could afford them (Van Doorslaer and McQuillan, 2005). In general, many groups experience end-of-life care differently, and these differences remain too poorly understood to allow for easy agreement to be reached on what constitutes a good death.

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

A good death, therefore, is always a bounded concept, influenced by time, space and resource constraints. But it can be person-centred even within the most trying of personal circumstances and physical conditions.

2.6 Barriers to End-of-Life Care

There are many barriers that can affect the delivery of good quality care at the end-of-life. It is useful, therefore, to briefly reference some of the main issues that can undermine the delivery of effective care for people at end-of-life.

2.6.1 Continuity of Care

At the healthcare system level, one of the biggest problems is that care is fragmented, consisting of multiple providers, and requires patients to make many transitions in their care. There is sometimes a lack of continuity among caregivers and an associated lack of communication between staff in primary care settings, long-stay care settings and acute hospitals. This can result in a less than smooth transition for the patient from one setting to another. Patients may also be abruptly transferred from home to hospital at the end-of-life or from nursing home to hospital, leading to discontinuities in care provision (Mezey *et al.*, 2002; Brazil *et* *al*., 2004). Research has shown that a change in setting can in itself be disruptive to older patients and can lead to confusion and deterioration in their condition (Buchanan *et al*., 2006).

2.6.2 Organisation of Care

The organisation of care within a care setting can also interfere with optimal end-of-life care. For example, if the organisation is primarily oriented towards cure (as is the case in many acute hospitals) rather than alleviation of symptoms, this may result in a tendency towards over-intervention with inappropriately aggressive treatments towards the end-of-life (Keegan *et al*., 1999; Mezey *et al*., 2002). Research also suggests that there is a difficulty for staff in trying to provide a home-like atmosphere for those residents who are relatively well and simultaneously dealing with the needs of those residents who are dying (Froggatt, 2001). In a recent Irish study of long-stay care settings, it emerged that staff are often too immersed in routine to be able to facilitate patient choice to any great degree, including choice with respect to end-of-life care (Murphy *et al*., 2006).

2.6.3 Education and Training

Lack of appropriate education and training in gerontological care and end-of-life care among care staff and medical staff in all care settings can impede good quality care. This may affect physical care such as pain and symptom management. Although considerable research is available on the use of medications in the management of pain, these protocols have not been widely incorporated into practice.

If staff in long-stay settings are not trained in the use of specialist equipment, this may result in patients being needlessly transferred to hospital. Without effective training, doctors may not communicate clearly with patients regarding their prognosis and care. High staff turnover can, in turn, affect the delivery of such training.

Similarly, training of managers is also important as they can have a significant impact on the ethos of care in an organisation. Training may also be needed to encourage managers to value 'emotional labour' inputs that provide psychological support to the dying person (Field, 1989).

The need for specialist education and training of palliative care specialists (for example, clinical nurse specialists) has long been recognised (Froggatt, 2002; Higginson, 2005; Larkin, 2005; Ling, 2005). Short training courses in palliative care are also becoming increasingly available for GPs, nurses and care assistants. Palliative care is also now being included as part of university training in nursing and medical faculties. However, education and training for all staff dealing with patients at the end-of-life is desirable, given the range of staff and potential interactions within acute hospitals and long-stay settings. Care assistants are likely to particularly benefit from training given that they have most day-to-day contact with people who are dying and may develop particularly close relationships with patients and residents.

Providing training and education in palliative care to members of staff is necessary but not sufficient to provide good quality end-of-life care. Management also need to be supportive of change in care practices and organisational structure, or the result may be that staff gain a knowledge of what end-of-life care should be, but may not be in a position to provide it (Froggatt, 2002).

2.6.4 Cultural Awareness

Another possible impediment to good quality care at the end-of-life is a lack of awareness among staff of the cultural diversity of those who are dying. Lack of accommodation of people's cultural beliefs and traditions around death and dying may profoundly affect the experience of the patient and their families (Lothian and Philp, 2001).

Given that Ireland is rapidly becoming a multi-cultural society, there is a need for training of staff and management in cultural awareness of diverse traditions and beliefs around death and dying, including awareness of religious practices other than the previously dominant Catholic tradition (Tracey and Ling, 2005). Conversely, increasing numbers of the workforce in care homes and hospitals are from cultural backgrounds other than Irish Catholic so they too may benefit from gaining familiarity with Irish traditions around death and dying (Tracey and Ling, 2005). In 2004, nurses from 76 different countries were working in Ireland – over 2,000 nurses were from other EU countries, while over 5,000 were from countries outside the EU. Without some understanding of end-of-life care and shared respect for cultural traditions in respect of dying and death, there are limitless opportunities for confusion and disparities in access to and provision of optimal care.

2.6.5 Staffing

Poor staffing levels in many long-stay care facilities may prevent the type of responsive, person-centred care that is regarded as a desirable component of good palliative and gerontological care. Time is an essential component in the provision of good quality care. Communication, counselling, teamwork and integrated provision of care require significant time inputs from staff, something which is difficult to achieve if staffing levels are low. Indeed, having time to sit with a person who is dying is regarded as desirable by care staff themselves, both for patient and provider (Hopkinson *et al.*, 2003; Brazil *et al.*, 2004). However, poor staffing levels in some settings means that some patients, particularly those without family and friends, may not be receiving adequate social and emotional support from busy staff. It has also been found that low nurse staffing levels and high staff turnover in nursing homes tend to increase hospitalisation at end-of-life.

2.6.6 Physical Resources

The physical environment sometimes does not lend itself to the provision of the ideal setting for people who are dying. For example, the physical limitations in many acute hospitals and some public long-stay facilities mean that some people die on wards with up to six beds. This means that the ideal of a peaceful, dignified death for the patient and family cannot be realised in some cases. Sometimes, for example, death takes place against a background of noise from other patients, televisions and so on (Keegan *et al.*, 1999). The physical environment in hospitals and many long-stay care settings cannot accommodate the visiting needs of family and friends. Often, there are very few private spaces in which medical staff can communicate with families regarding the patient's prognosis and treatment (Keegan *et al.*, 1999). Some nursing homes do not have family rooms where families can rest or facilities where they can have refreshment. Time constraints and lack of training also affect the ability of staff to attend adequately to the emotional needs of families (Parker and McLeod, 2002).

There may also be a lack of equipment needed to deal with pain and symptom management at the end-of-life. Research in the UK has found that in many care homes, there may be a lack of specialist equipment such as syringe drivers and TENS machines, which would help in this regard (Froggatt and Payne, 2006).

Another issue that affects the quality of care is access to specialist palliative care support for nursing homes and community hospitals – research in the UK indicates that the level of access is variable and that consistent well-developed links with these services are not always present (Froggatt and Payne, 2006). The situation is similar in Ireland. Resource constraints in all care settings may also affect the availability of activities such as physiotherapy, occupational therapy and creative activities, which have been found to promote the continued autonomy and/or well-being of the person at the end-of-life. A recent Irish study suggests that there are varying levels of provision of these services in the different settings with higher levels generally available in public facilities (Murphy *et al.*, 2006).

2.6.7 Spiritual and Psychological Support

Spiritual care is an important contributor to quality of life at the end-of-life for many patients. A study on spiritual care in care homes in the UK found that there are many barriers to the provision of appropriate spiritual care (Orchard, 2002). A shortage of staff, a primary emphasis on physical care, lack of clarity over who should provide spiritual care, embarrassment and lack of awareness and training with regard to the spiritual needs of patients, particularly those belonging to an ethnic or religious minority, were all found to act as limitations to the provision of good quality spiritual care.

Lack of psychological support for patients may constitute a barrier to good quality end-of-life care. There has, however, been little research into the psychosocial needs of older patients at the end-of-life (Parker and McLeod, 2002). Many older people enter long-stay care having experienced losses of various kinds – including perhaps bereavement, loss of home and loss of physical function (Reed *et al.*, 2002).

Similarly, older people in care homes can become very attached to other patients and experience bereavement when they die (Reed *et al.*, 2002). A recent survey showed that the availability of formal psychological services in the UK and Ireland is quite limited, even in hospice settings (Price *et al.*, 2006). Social work provision and psychological support was found to be low in all long-stay care settings for older people in Ireland (Murphy *et al.*, 2006). There is no current information on whether bereavement or other counselling is available in settings other than hospices in Ireland.

2.6.8 Communication

One of the criteria acknowledged as necessary for good quality of care is that of helping patients to understand the process of dying and enabling them to feel some sense of control over it (Singer *et al.*, 1999; Reed *et al.*, 2002). One way in which people may be given a sense of control over their dying is by having an 'open awareness' of death in a given care facility. 'Open awareness' exists where it is explicitly acknowledged by staff that the patient is likely to die and the patient is given the opportunity to discuss their concerns and make plans. It has been found in some studies in the UK that there is in fact an ethos of 'closed awareness' in many care facilities (Reed *et al.*, 2002; Hopkinson *et al.*, 2003). Where there is 'closed awareness', staff and families may be aware that the person is nearing death, but may collude in reassuring the patient that he/she will recover. In such circumstances, the outward signs of death are often hidden from public/patients' view. This ethos may act as a barrier to achieving a high standard of care. It should be noted, however, as discussed earlier, that 'open awareness' may not be appropriate or indeed desired by all older people at the end-of-life.

The lack of clear communication from medical staff to patients means that the patient is not enabled to plan for the kind of care they would prefer (Keegan *et al.*, 1999). Similarly, bereaved families are not always clearly told their relatives are dying and thus are not able to make plans or say good-bye to their loved ones (Keegan *et al.*, 1999; Ellershaw and Ward, 2003). There are many possible reasons for this lack of communication. It has been found that for older patients (particularly those in nursing homes) with diseases that do not have a predictable trajectory, medical staff often do not identify that the person is dying until it is too late to discuss their wishes with them (Addington-Hall and McCarthy, 1995; Ellershaw and Ward, 2003). Even where staff do accurately assess that people are dying, they may not communicate this to them in an attempt to shield them from the impact of the news, or because they find the subject difficult to broach themselves (Vallis and Boyd, 2002).

Even where there are communication procedures in place, it is not always easy to decide when is the best time to explore with patients issues about dying, death and preferred care options. The time of admission to residential care may not be the best time to initiate dialogue on dying and death, as the older person is already typically dealing with loss of home and independence and possibly illness at this time (Vallis and Boyd, 2002). Advance care planning with the person's GP at an earlier stage is one possible way of ensuring that patients' wishes regarding their care are followed on admission to long-stay care. However, while mechanisms for advance care planning have been developed in several countries, relatively few patients actually make advance care plans and even when they do, these plans are not always followed by doctors (Bradley *et al.*, 1998).

2.7 Initiatives to Improve End-of Life Care in all Settings

The hospice movement has been very successful in promoting specialist palliative and end-of-life care for cancer patients. However, it is only in recent years that there has been an emphasis on applying this knowledge to care for people with other diseases in other care settings. In the UK and Australia, funding has been devoted to develop models of best practice for end-of-life care in long-stay settings. Various interventions have been introduced such as educational programmes and the introduction of specialist palliative care nurses to link palliative care to long-stay care settings. In the UK, a three-year end-of-life government-funded programme to meet the needs of people dying in long-stay care is using a number of tools to effect improvement for people in a variety of care settings.

This final section describes a small number of international and national initiatives in the field as a means of identifying elements of good practice that might be relevant for Ireland. Most of the initiatives identified below aim to improve provision of general palliative care for all and to prompt referral to specialist palliative care services as necessary. Facilitating practice development using evidence-based guidelines from innovative and experimental programmes in other countries may be one way to develop quality end-of-life care in acute hospitals and long-stay settings in this country, although what follows should not be taken as an endorsement of particular approaches, given the absence of formal evaluation or detailed analysis. Indeed, most of the current initiatives in end-of-life care are based on existing specialist palliative care expertise for cancer patients. New knowledge and models are likely to be required, therefore, to shape services to meet the needs of older people with complex co-morbidity needs and illness trajectories at the end of their lives.

2.7.1 Liverpool Care Pathway

The Liverpool Care Pathway (LCP) has been developed in the UK to transfer the hospice model of care into other care settings and has become recognised as a comprehensive model of good care (Ellershaw and Ward, 2003). It provides an evidence-based framework for end-of-life care at the very last stages of a person's life. It gives guidance on different aspects of care, including medications and discontinuation of inappropriate interventions, psychological and spiritual care, and family support. It comes into use when multi-professional team members agree that a patient is dying and provides a template outlining 'good practice' for the care of dying patients. It categorises care into three phases: initial assessment and care; ongoing care; and care after death. It also covers issues such as the need for medical staff to ensure that there is clear communication with patients and their relatives or carers regarding diagnosis and recognition of dying.

Current medication and treatment options are assessed partly to avoid invasive, futile, painful procedures being carried out. Religious and spiritual needs are assessed and documented, and families are given information regarding facilities available to them at the hospital/care home. The GP is informed of the patient's condition and a plan of care is to be drawn up with the patient and/or family. The LCP also covers post-death issues such as contacting the GP, laying out the body (considering religious needs), care of valuables, information regarding legal requirements, post-mortems and written information regarding bereavement care.

Although the LCP was originally designed with cancer patients in mind, some studies suggest that it may be suitable for people dying from other conditions and across care settings, including hospitals and care homes (Ellershaw and Ward, 2003). However, the introduction of this approach within long-stay care facilities would have to be carried out in a sensitive manner, to take account of established practices in long-term care settings (Froggatt, 2002; Watson *et al.*, 2006). In addition, getting individuals to change their behaviour and approach to care may not be enough; the overall culture of care must also change, necessitating the need for widespread institutional reform.

2.7.2 Gold Standards Framework

The Gold Standards Framework (GSF) is another programme developed in the UK to improve the delivery of palliative care in general practice. The emphasis is on continuity, communication and co-ordination of care. The main aims of the GSF are to identify patients in need of supportive palliative care, assess their needs and preferences, plan their care and communicate across all relevant agencies throughout the care process. GSF was originally developed for community and hospital use, but is now being adapted for use in long-stay care and for people with conditions other than cancer. A pilot project is currently under way that will adapt the GSF for use in care homes. Since the application of this framework is at an early stage, it is unclear as yet what impact it will have on end-of-life care (Amass, 2006). An evaluation of uptake and further research into clinical outcomes is required (Thomas and Noble, 2007).

2.7.3 Preferred Place of Care

Another initiative in the UK is the Preferred Place of Care (PPC) programme. This is designed to facilitate patient choice in relation to care. The aim is to initiate and develop a sensitive conversation around preferred place of care and death among patients, carers and healthcare professionals to achieve a greater likelihood of fulfilling the patients' wishes. The latter are documented and the PPC is given to all professionals who are involved in patient care. This enables discussion of end-of-life issues and helps minimise inappropriate interventions. The PPC is currently being piloted in the care home sector in the UK; early descriptive evaluations suggest that the PPC is having a significant impact on patients being cared for in a place of their choice (Storey, 2003). However, rigorous evaluation of this initiative has yet to be carried out so it is not yet possible to be definitive about the effect of the programme.

2.7.4 Respecting Patient Choices Program – Advance Care Planning

In Australia, an initiative called 'Respecting Patient Choices Program' has been piloted (www.health.gov.au/palliativecare) and is now being rolled out around the country. It is a comprehensive advance care planning programme for health professionals which aims to ensure patients' choices about their end-of-life care are respected. It provides patients with a mechanism for discussing and recording their choices about healthcare in an advance care plan. It encourages people to appoint a guardian/enduring power of attorney and to record an advance directive in the form of an oral or written instruction about their future medical care in the event that they become unable to communicate.

2.7.5 Hospice to Hospital Programme

A recent initiative by the Irish Hospice Foundation (IHF) is the 'Hospice to Hospital' programme campaign (IHF, 2002). This initiative emerged partly from a recognition that many people die in hospitals and that it is not possible (or even appropriate) for everyone to be cared for in a hospice at the end-of-life. This programme introduces the principles of palliative care to staff in the acute hospital sector. It was piloted in an acute hospital and is now being implemented in other hospitals around Ireland. While this programme is likely to improve care for people at the end-of-life, evidence from UK research suggests that care should be taken to ensure that a palliative care approach is not simply imposed 'from without' but is integrated with existing structures and processes within hospitals and other care settings and that it works in tandem with existing expertise (Froggatt, 2002).

2.7.6 Guidelines for a Palliative Approach in Residential Aged Care

The Australian government has funded a comparatively well-developed research and policy programme on palliative care. They have recently produced a comprehensive set of guidelines on introducing a palliative approach in residential aged care (Australian Government National Health and Medical Research Council, 2005). The programme presents the typical characteristics of older people dying in care homes and offers suggestions to staff on how best to deal with them. These guidelines are evidence-based and cover all facets of a palliative approach, including early identification and treatment of physical, cultural, psychological, social and spiritual needs. They were developed to provide guidance for the delivery of a palliative care approach within all types of aged-care facilities across Australia. The guidelines were introduced through workshops and funding was given to support staff to implement the guidelines for a further two years. The purpose of this funding is to help foster a change of culture in organisations.

2.7.7 My Home Life

The My Home Life (MHL) programme is a UK-wide initiative aimed at promoting quality of life for those who are living and dying in care homes for older people. MHL provides a vision for improving the quality of life for those living, dying, visiting and working in care homes for older people and is based on the findings generated from a literature review on good end-of-life care in care homes (NCHR&Forum, 2007). As well as identifying challenges to the provision of good quality care, it provides some examples of good practice in addressing these challenges. It is interesting because it adopts a systemic approach to the issue of promoting good end-of-life care in care homes. The challenges identified are the need to develop a culture of care that values both living and dying – the emphasis is on normalising dying while maximising life. The programme encourages an open approach to end-of-life care, supported by relationship-centred care. The programme also emphasises resident choice and control, and encourages the use of existing standards, frameworks and tools to support good palliative care. A recent review highlights the need for various supports for care staff to enable them to blend palliative care with everyday work in care homes (Nicholson, 2007).

2.8 Conclusion

Quality of life is a complex issue, difficult to conceptualise and measure, particularly for people at end-of-life. There is a growing body of research related to specific care interventions designed to improve outcomes, including quality of life, for people at end-of-life. These include intervention in symptom management, improvements in services and facilities, education and training, increased communication, spiritual awareness and bereavement support.

Currently there are many barriers to the provision of good end-of-life care, including organisational, institutional and resource barriers, lack of information and poor understanding of end-of-life care. A selected number of initiatives have been described in this chapter, some of which have the potential to overcome existing barriers. However, new programmes are not enough on their own, particularly if they are not comprehensive enough or adaptable to respond to the needs of older people at the end of their lives.

If the culture of care at end-of-life is to be transformed, then public attitudes and expectations must also change about dying and death. Simultaneously, end-of-life care must become part of mainstream care within acute hospitals and long-stay settings.

Older people have a right to a good quality of life up to and including death. That right needs to be recognised and valued by patients themselves and by management and staff in the various settings where people die.

Chapter Three

The Legal Framework

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The Legal Framework[1]

3.1 Introduction

Admission to long-stay care signals the beginning of end-of-life care for many older people. For some of them, that subsequent period of end-of-life care is short; for others it is long. It is not always possible to tell beforehand the various trajectories that may be involved in respect of dying and death. For all patients, the transition to long-stay care and to end-of-life care is a period of great uncertainty. Information on what is to be expected in long-stay care, or at the end-of-life, can often be inaccessible or unavailable, so people may be disempowered in their decision-making. The pre-admission assessment to a long-stay care facility is critical, therefore, in order to establish the person's views and wishes, and to ascertain their level of decision-making capacity. So too is the legal context for decision-making at end-of-life. Without a legal framework, it may be difficult to protect the rights of older people and guarantee the autonomy in decision-making that is increasingly seen as important for quality of life at end-of-life.

This chapter outlines the legal framework that applies to older people in the context of decision-making in long-stay care and at the end-of-life. The rights of autonomy and self-determination are central to such decisions and, when the capacity to assert these core human rights is diminished, it is necessary to have a robust system in place to safeguard these vulnerable people.

Autonomy is not a stand-alone concept that exists in a vacuum but rather is 'developed, enunciated and ultimately exercised in the embrace of others' (O'Neill, 2001). The contribution that the law can make to enhancing the quality of life of people who are in the long-stay care of others is considered in the context of issues such as human rights and the capacity to make decisions. The law on consent, incorporating the fundamental issue of capacity, is also explored, as well as related issues including advance directives, DNR orders, enduring powers of attorney, and rights to privacy and confidentiality. Finally, the proposed reforms that have led to the Draft Scheme of a Mental Capacity and Guardianship Bill 2007 are considered.

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[1] This chapter was written by Mary Keys.

3.2 Human Rights

Ireland is a signatory to a number of human rights conventions, including the UN Convention on Human Rights, that recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The right to dignity is the 'anchor norm' of human rights and focuses on the individual. Dignity means being worthy of esteem or respect, so that where dignity is lacking there is a problem with the value placed on that person. The principles at the core of these human rights commitments underpin the fulfilment of all civil and political, social and economic rights of persons. These are core quality of life issues that include autonomy and self-determination and equality affirmed by the European Court of Human Rights (Pretty, 2002). The EU Charter of Fundamental Rights specifically includes the equality rights of the older person in the dignity principle and proclaims the right of the older person 'to lead a life of dignity and independence'.

The right to respect for private life in the European Convention on Human Rights, now part of Irish law, includes a person's physical and psychological integrity and requires that any interference with such integrity must be justifiable as necessary for the protection of health. The interference must be proportionate to the aim to be achieved. An example might be where an older person does not want to live in residential care but is being forced to do so despite the availability of adequate supports in the community:

> …the personal autonomy protected by Article 8 means that in principle it is for the competent patient, and not his doctor, to decide what treatment should or should not be given in order to achieve what the patient believes conduces to his dignity and in order to avoid what the patient would find distressing.
> (Pretty, 2002)

The presumption of capacity and the right to independent living are included in the most recent human rights convention, the UN Convention on the Rights of Persons with Disabilities. Both these rights are important in light of the worldwide move toward community living and the creation of appropriate accommodation for adults with varying levels of ability. The Convention emphasises the recognition of the person in law and this contrasts with the Irish wardship law which effectively negates legal personhood. There is a worldwide trend away from this Victorian view of the human person (Quinn, 2007). This is reflected in this new Convention, especially the notion that persons should be supported in their decisions and in their decision-making capacity if needed. It reflects the principle of proportionality requiring that any interventions in a person's life must be in proportion to the aim to be achieved, also known as the least restrictive alternative.

The recognition of the fundamental connection between ageing and disability is increasingly regarded as a priority as our population increases and people live longer. Arising from this issue is the need for policies linking both issues and identifying best practices worldwide.

3.3 Equality and Non-Discrimination

The aim of equality is to give all people, regardless of age, gender or disability, an equal choice of alternatives to pursue their own version of the good life (Fredman and Spencer, 2003). The issue of ageism arises where allocation of resources and decision-making based solely on age result in older people being treated less well.

The Equality Authority stated in a report on older people and equality that 'negative and ill-informed assumptions as to the relationship between a person's age and capacity all too often shape decision-making' (Equality Authority, 2001). A body of opinion indicates that there is a need to highlight the difference in treatment for older people, particularly those who lack capacity. One study found that older people were more likely than other patients to suffer from over-prescription, being prescribed incorrect medication, and poor monitoring of side-effects and adverse reactions (Royal College of Physicians, 1997). The impact of inappropriate drug therapy can be severe and result in hospital admission. Greater safeguards are needed to ensure parity of esteem in monitoring and treatment. Medical treatment which results in sufficiently severe side-effects could involve a breach of human rights law. This law provides that treatment which is particularly intrusive should be used only where no less intrusive means of providing appropriate care is available (Council of Europe, 2004).

There is evidence of ageism in the provision of services to older people (NCAOP, 2005). This includes age limitations on the provision of preventive services, despite evidence of good outcomes, and lack of supports for independent living thereby leaving no other choice but residential care. The tendency towards use of multiple medications, with little information offered as to why particular drugs were used, or the possibility of adverse reactions, is also recognised. There is a concern that the failure to inform the older person, along with the evidence of over-prescribing, is ageist (NCAOP, 2005). Currently, there are no formal robust means for dealing with these issues.

The Equal Status Act 2000 prohibits discrimination on nine grounds, including age and disability, in the provision of goods and services. While this legislation is extremely valuable following complaints on an individual level, it fails to embrace broader issues such as the ingrained societal attitude towards older people. This issue requires a more holistic approach to promote the value and status of older people. Human rights standards to which Ireland is committed should be followed in all actions concerning older people.

3.4 The Right to Decide and Consent to Treatment

Self-rule is the core ethical principle of the right of autonomy. Decisions are within the person's control. The tension between paternalism, the perceived need to protect those regarded as in need of protection, and autonomy, ensuring that the person's own choices are respected, lies at the heart of this issue. Very often efforts at protection will come from the person's family and may range from minor intrusions on the person's autonomy to actions which have a more severe and damaging impact. The capacity of the person to exercise their right of autonomy and self-determination through giving or withholding consent to treatment and care is fundamental.

The right to refuse medical treatment incorporates three elements: capacity, information and voluntariness. It is recognised as part of the right to dignity, privacy and bodily integrity, and is contained in Article 40.3.1 of the Constitution. The right of autonomy in the context of medical treatment, as a related right of privacy, was affirmed by the courts (*In Re A Ward*, 1995; Hogan and Whyte, 2003). The Irish courts have said that the constitutional rights of every person, include the right to privacy, autonomy and self-determination (*In Re A Ward*, 1995). These rights apply to people without capacity to consent equally with those who could consent. The position regarding the right to consent to treatment was clearly outlined by the Supreme Court:

> Medical treatment may not be given to an adult person of full capacity without his or her consent. There are a few rare exceptions … This right arises out of civil, criminal and constitutional law. If medical treatment is given without consent it may be a trespass against the person in civil law, a battery in criminal law, and a breach of the individual's constitutional rights.
> (*In Re A Ward*, 1995)

There is, therefore, no doubt about the right of adults with capacity to make decisions about their own treatment. Arising from principles of autonomy and self-determination, and in compliance with the European Convention on Human Rights, consent, given by an adult of full capacity, is a matter of that person's choice. This is supported in Regulations and in the Residential Care Standards (*Nursing Homes Regulations*, 1993 and *National Quality Standards for Residential Care Settings for Older People in Ireland*, 2008).

Clearly, a fundamental element in such decision-making is having the necessary capacity to choose. There is little or no guidance from the courts or legislature to date on this issue and how capacity is to be assessed. The Law Reform Commission (LRC), however, has published a Draft Scheme of a Mental Capacity and Guardianship Bill setting out proposals for vulnerable adults and decision-making (LRC, 2006; Seanad Debates, 2007).

There is no statutory definition of general consent in Irish law. The Mental Health Act 2001 provides a definition of consent that applies to people detained under the Act and states that consent in relation to such a patient means 'consent obtained without threats or inducements', where both:

- The patient is capable of understanding the nature, purpose and likely effects of the proposed treatment
- The patient has been given adequate information, in a form and language that the patient can understand, on the nature, purpose and likely effects of the proposed treatment.

This means that the person must have capacity to understand, when given adequate information in an understandable form on the type of treatment, what it is intended for and possible side-effects. The following paragraphs describe legal capacity in Irish law and how it is assessed followed by a discussion of the best interests approach.

3.4.1 Legal Capacity in Irish Law

Mental capacity is one element of consent to treatment. It is central to participation in society and key to what immunises a person from most uninvited interferences with their choices in life. The presumption of capacity attaches to adults in relation to decision-making unless this presumption is proved otherwise. The definition of capacity as 'the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made' has been proposed by the LRC (LRC, 2006). Irish law provides that mental incapacity does not result in the reduction of personal rights under the Constitution, including the right to life, to bodily integrity, to privacy and the right to refuse medical care or treatment (*In Re A Ward*, 1995). The law provides that these rights are administered in a different way by, for example, the Court acting as a proxy decision-maker. This proxy decision-making is crucial to supporting the wishes of the person with reduced or fluctuating capacity.

The Medical Council states, in relation to a seriously ill patient who is unable to communicate or understand, that 'it is desirable that the doctor discusses management with the next of kin … prior to the doctor reaching a decision particularly about the use or non-use of treatments which will not contribute to recovery from the primary illness' (Medical Council, 2004). The Guide states that a second opinion should be sought from a suitably qualified and independent medical practitioner if a dispute arises.

When a person lacks capacity to take decisions about medical treatment, it is necessary for other persons with appropriate qualifications to take that decision for him or her (*Re F*, 1990). Normal hospital practice involves medical staff taking decisions on behalf of incapacitated older people in conjunction with others such as family and carers. Hospital staff will usually consult the family of the person. There is no legal basis for this informal system of obtaining substitute consent from the next of kin. This is made more difficult when next of kin are not available. A further aspect is that non-relatives, with greater interest and contact with the person, should be consulted, but frequently are not.

Where the various parties disagree, doctors are in a difficult position. The issue for the hospital staff is whether there is an emergency or immediate necessity for the treatment. In that instance, the doctor will act on the basis of the common law doctrine of necessity and in the best interests of the person having regard to the urgency of the situation. The doctrine of necessity provides the legal basis for the treatment and care of patients who are not capable of making a decision. The principle of necessity applies and the requirements of the principle are that:

- There must be a necessity to act when it is not possible to communicate with the individual.
- The action taken must be what a reasonable person would in all circumstances take, acting in the best interests of the person.

The High Court set out principles in relation to the medical treatment of a seriously ill patient as follows:

- A competent terminally ill adult is entitled to require that life support systems be either withdrawn or not provided as appropriate. In other words, the person has the right to refuse treatment.
- Where a person does not have capacity and is terminally ill, the medical staff, in agreement with the appropriate surrogates (family and friends), acting in the best interests of the patient, may lawfully withdraw or refrain from providing life-support systems.

- Where the person is without capacity and terminally ill, and when medical staff support withdrawal of treatment but the family disagrees, a second opinion should be obtained from a suitably qualified independent medical practitioner. If that opinion affirms the hospital stance, the hospital can lawfully act accordingly, preferably having the agreement of the family with the aid of the second opinion. If the second opinion affirms the family view, the appropriate life support systems should be maintained or provided as the case may be.

- Where the person lacks capacity, whether terminally ill or not, and the family supports the withdrawal of treatment or non-provision of treatment and the medical staff disagree, such systems should be maintained or provided unless an order of the High Court to the contrary is obtained by the family (*In Re A Ward*, 1995).

These principles are applicable to all patients and are supported by the medical profession in their guide to ethical conduct:

> Patients are entitled to a second or further medical opinion about their illness. Doctors must either initiate or facilitate a request for this and provide the information necessary for an appropriate referral.
> (Medical Council, 2004)

The Medical Council refers to patients with disabilities as being entitled to the same treatment options and respect for autonomy as any other patient. In the case of an older person, who may have a disability, this has direct relevance. The Guide states that disability does not necessarily mean a lack of capacity and any decision on intervention in the case of a person with a disability requires his or her consent. Where capacity is lacking, the Guide proposes that 'a wide-ranging consultation involving … appropriate carers should occur' including a second opinion to assist in complex decisions (Medical Council, 2004).

There are a number of different approaches to the assessment of capacity:

- The *status approach* defines people as being incapable of decision-making by virtue of a particular status – for example, having a diagnosis of dementia or being a Ward of Court. It is a blanket or general approach to a person's decision-making ability without addressing specific decisions at particular times.

- The *outcome approach* focuses on the result of the decision so, if an older person rejects the doctor's suggestion in relation to treatment or care in favour of what is perceived to be a less suitable course of action, there is a temptation to link such a decision with a lack of capacity. Both these approaches have been rejected by the LRC as not supporting or enabling the maximum possible autonomy in relation to decision-making, in favour of the functional approach.

- The *functional approach* requires that capacity is assessed on an *issue-specific* and *time-specific* basis so that having capacity for one decision does not necessarily imply the requisite capacity for another decision which might have different requirements. A person may understand that they need to be in hospital and be able to consent to such action, but may not understand the nature of the proposed treatment in order to make a decision about it. Using the functional approach, the capacity of the individual is assessed in relation to a particular decision at a particular time and has the important benefit that it ensures the least invasion of a person's decision-making autonomy. The functional approach takes account of fluctuating capacity also and this element is important where a person has an acute confused state or has fluctuating memory loss. The LRC acknowledges that where 'the lack of capacity is profound and enduring', a new functional assessment of capacity may not be necessary in every situation in which a decision has to be made (LRC CP 83-2006).

The right to self-determination and the support for the wishes of the person have been affirmed by the English courts prior to the introduction of mental capacity legislation. An individual with a serious mental illness was deemed to have capacity to refuse treatment for a life-threatening condition using the functional approach. This person was a long-term resident of a high security psychiatric hospital in which the Court held he had the requisite capacity to refuse a lower leg amputation due to gangrene (*In Re C*, 1994). The man stated that he would rather die with two legs than live with one leg. The Court applied a threefold test and held he had capacity on the grounds that:

- He understood and retained the relevant information
- He believed the information regarding the seriousness of the illness
- He arrived at a decision understanding the consequences that if he did not consent he might become seriously ill and die.

The Court held that the relevant question in such cases was whether it is established that the patient's capacity is so reduced by his mental illness that he does not fully understand the nature, purpose and effects of the treatment. While this case concerned a person with a mental illness, the test could be applied to other forms of mental disability where there may be reduced decision-making capacity. It is also supportive of the subjective experience of the particular person making the decision.

The LRC stressed that the law on capacity should reflect capacity, rather than lack of capacity, ensuring that it would be enabling rather than restrictive. In assessing capacity the requirements proposed are:

- The decision must be worded in such a way as to make it as comprehensible as possible to the level of cognition present.
- Assess if the person understands in broad terms the reasons for and the nature of the healthcare decision to be made.
- Establish if the person has sufficient understanding of the principal benefits and risks in the treatment option being presented and relevant alternative options.
- Options should be explained to the person in a manner and language appropriate to the individual level of cognitive functioning.

The functional approach is gaining support. The Health (Repayment Scheme) Act 2006 was introduced to repay people who had been wrongly charged for care, some of whom have reduced decision-making capacity. In order to deal with this situation the HSE has published the guidelines regarding patients' property which state that mental capacity should be assessed primarily using the functional approach.

The impact of reduced capacity to make one's own decisions is significant as it may mean that personal wishes are frustrated. The question then arises as to who will make the decision on behalf of another person and the basis on which these decisions are made.

The test of 'best interests' is used widely in decision-making on behalf of adults with reduced capacity. Its boundaries are unclear, however, as it is based primarily on paternalism rather than the wishes of the individual. The requirement to act in the best interests of an incapacitated adult is well established at common law. This includes all kinds of decision-making, not solely in relation to medical treatment. The best interests test was the basis of the decision in *In Re A Ward*, where the Court acted in the *parens patriae* role of the prudent, good and loving parent. The High Court decision combined evidence of what the Ward's wishes might have been if she could have anticipated such circumstances and said:

> Whilst the best interests of the Ward is the acid test, I think that I can take into account what would be her own wishes if she could be granted a momentary lucid and articulate period in which to express them …
> (*In Re A Ward*, 1995)

In applying such a test it is arguable that the judge was accepting both fluctuating capacity as a basis for the decision, as well as a notion of an advance directive, though not expressed in those terms. The Court weighed a number of factors in the balance in arriving at a decision on best interests. The Court took account not only of medical best interests but of a very broad range of factors, including the Ward's life history, the views of family, carers and spiritual aspects of her life. From the point of view of an older person with limited capacity these broader elements of the decision are important and indicate strong support for the importance of autonomy balanced alongside the best interests test.

The LRC comment that the best interests notion is taken from child law and as such is 'imbued with undertones of paternalism' (LRC, 2006). The LRC is of the view that:

> the major objection to a best interests test for intervention in the life of an adult who has been found to lack capacity is that its application may simply equate to what the decision-maker subjectively thinks is best for the person. (LRC, 2006)

Where best interest is the yardstick, then it is the 'inner world' of the older person which 'must be assessed subjectively and not related to the observer's own youthful or middle-aged experience' (Mason, 2006).

The test of best interests is referred to in the Mental Health Act 2001 as the principal consideration in any decision regarding care and treatment. There is no further guidance on what this means. The test of best interests in Irish law has not been subjected to the same judicial scrutiny as in English law where a balance sheet approach is applied, weighing advantages and disadvantages against each other. These would be presented as options to the judge who would make the final decision. The best interests test has been subjected to a double test: the duty not to act negligently, in other words to act in accordance with the standard of one's profession, together with a separate duty to act in an incapacitated person's best interests.

The best interests test encompasses 'medical, emotional and all other welfare issues', not solely medical interests (*In Re A*, 2000). The advice to legal practitioners in the English system refers to the need to have regard to the emotional, psychological and social benefit when considering the best interests of the adult (Official Solicitor, 2001). While the decision in *In Re A Ward* acknowledged a broader approach than medical best interests, this could be expanded and would be very useful for the interpretation of the test of best interests and would lead to consideration of the individual circumstances.

An alternative approach is the *substituted judgement* test and in the United States when a decision is to be made on behalf of a person without capacity, the courts have asked what the person would have wished in the circumstances. This is known as substituted judgement. It is an attempt to protect the person's autonomy as far as possible and is person-focused. A surrogate or proxy can make the decision based on the knowledge of the person's wishes as to what they would have done if they had capacity to make the decision.

The informally expressed wishes of the person is a major issue, particularly for older people who may not want to be involved in formal systems of future decision-making, such as a statutory advance directive, and who may have fluctuating capacity. They may express their preferences to someone involved in their care as to what their wishes are, particularly in a long-stay care situation, during a period of temporary lucidity. Where the person, while competent, has given sufficiently clear and unequivocal information on the treatment and care he or she would want if particular circumstances arise, then the situation is clearer for the carers. Where this has not happened and the person is incapable of expressing their wishes or making the decision, the only option is to act on the basis of their best interests.

There are two obvious situations where the substituted judgement will not be feasible – where the individual never had either the capacity or the opportunity to address such a decision. This would include a person with a profound intellectual disability who has communication difficulties. However, those working closely with this person will frequently understand non-verbal reactions to various forms of care and treatment and could formulate a view of what preferences the person may have. Many people do not anticipate the circumstances that might befall them in the future. Neither do they want to contemplate such circumstances and so do not imagine that decisions will have to be made on their behalf. In these circumstances the best interests test will be used along with any information as to what the person would have liked to happen to them based on the clearest information available.

3.4.2 Disclosure of Information and Consent to Treatment

The disclosure of information is the second requirement for consent. Information regarding the risks or side-effects of treatment is an essential component of decision-making. Donnelly refers to 'facilitating' the person in reaching an understanding rather than simply disclosing the information (Donnelly, 2002). While disclosure relates to information regarding the nature, purpose and likely effects of a proposed treatment, the manner of disclosure is also very important, particularly with older persons with reduced decision-making capacity. Information disclosure should be patient-centred and not simply a one-size-fits-all approach. Information is usually disclosed verbally but written and visual information could increase the level of communication and understanding involved. There is evidence that not enough time is taken to explain aspects of treatment to enable capacity to decide (NCAOP, 2005).

Capacity to consent can be enhanced and improved by appropriate methods of communication aimed at the particular person and acknowledging their level of cognitive functioning (Gunn *et al.*, 1999). Studies show that when greater efforts are made using a variety of methods, including, for example, pictures and diagrams, patients who had previously been found incapable were able to make the decision in question.

The Medical Council's ethical guide refers to access to information generally and also in relation to informed consent to treatment. The Guide states that a request for information from a patient always requires a positive response. Doctors, in general, should ensure that a patient, and with patient's consent, the family, are as fully informed as possible about matters relating to an illness. It also states that when patients do not fully understand the information and advice from the doctor that they should be encouraged to ask questions. Non-technical information should be used in order to promote understanding and cooperation. The Guide also states that the doctor 'should keep a note of such explanation and if it is felt that the patient still does not understand, it may be advisable to ask the patient's permission to speak to a relative'. Greater awareness of the contents of the Guide should assist in understanding what is intended in practice. Based on this very clear guidance on the doctor's responsibility regarding the clarity of information and the flexible approach to the patient's needs there should not be a problem if the guidelines are embedded in practice.

More specifically in relation to informed consent, the Guide refers to both verbal and written consent in certain circumstances and states, 'informed consent can only be obtained by a doctor who has sufficient training and experience to be able to explain the intervention, the risks and benefits, and the alternatives'. There is a requirement that the doctor is satisfied that the patient understands what is involved by explaining in appropriate terminology along with a record in the patient's notes (Medical Council, 2004). There is, therefore, very clear recognition of the doctor's role in giving information and ensuring that the patient understands what is involved, using appropriate language and recording this fact. The Guide is person-focused and supportive of autonomy, and these elements could be included in a code of practice related to this specific aspect of long-stay or end-of-life care. This right to information is not an absolute right and allows for therapeutic privilege where the medical staff believes disclosure poses a risk of detriment or damage to a patient. Withholding of information from a patient where there is a duty to disclose must be justified as necessary.

The role of a personal representative or advocate (not a legal representative), should not be overlooked as playing a part in assisting a person with reduced decision-making capacity who does not have the support of family or friends and is facing an important medical decision. The Citizen's Information Service provides a range of advocacy services but only to those under 65 years of age. The English Mental Capacity Act 2005 underpins the provision of advocates to assist people making some healthcare decisions.

3.4.3 Voluntary Consent

The third element for consent is the requirement that it must also be voluntary and free from coercion. The voluntary refusal of medical treatment by an adult of full capacity who has been informed of all the issues is conclusive. This element of consent to treatment is particularly relevant where an older person is unwell and being overly influenced by others. Even where the person is capable of understanding and making the decision, their vulnerability may lead them to doubt themselves and feel coerced into doing so. The key question on this issues is whether the patient,

> really means what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself?
> (*In Re T*, 1992)

The impact of fatigue, depression and pain on the will of the person, as well as the influence of close family members, are also considerations. It is essential, therefore, to take into consideration the vulnerability and the inability, in some cases, to complain coherently or at all about how the person is being affected by any particular form of treatment or care. These factors are particularly pertinent to an older person who is not in their own home and may be under the influence of other adults, family and carers, and who may not feel free to make the decision they would like. Where someone has had a stroke that person may feel completely disempowered unless there is a very sensitive care system around them. There is a role here for the independent advocate who is a neutral party and whose role is to support the individual in reaching a solution that suits them in the circumstances.

3.5 Confidentiality of Medical Information

The Irish Constitution provides for the protection of the right to privacy as an aspect of personal rights under Article 40.3.1, though there is no specific reference to medical confidentiality. The right to privacy is not absolute and is balanced against other factors. The Data Protection (Amendment) Act 2003 and the Freedom of Information Act 1997 supplement the right to confidentiality by protecting personal information and providing safeguards for disclosure. There is an ethical 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' (Medical Council, 2004).

The Guide also provides that it may be necessary to obtain information about a patient from a third party such as a relative but this information is also governed by the same rules of confidentiality (Medical Council, 2004). Any information disclosed without the person's consent will have to withstand the necessity test, have a legitimate aim and be proportionate to the achievement of that aim in order to comply with both national and human rights law and ethical standards.

3.6 Advance Healthcare Directives

Major problems arise for family members in relation to decision-making for family, carers and medical staff where a person is unable to consent. Advance directives began as a method of dealing with the gap in the legal system when a decision was required concerning the treatment of an individual who was unable to communicate. Many people believe that they need such assurance to offset any doubts about their future management and they see an advance directive as a means of securing that future. The advance directive, like DNR orders (Section 3.7.4), have a role in promoting communication and discussion with the patient and family rather than something which might appear to trump the real benefits of the ongoing positive relationship with the doctor. The challenge lies in creating a climate of confidence in the way in which older people are perceived and managed in the care system in order to act as a bulwark against the perception that the law is the only way to ensure respect for one's wishes, or that it can do so with certainty at all.

The Irish Council for Bioethics (ICB) defines an advance healthcare directive as:

> a statement made by a competent adult relating to the type and extent of medical treatments she or he would or would not want to undergo in the future should he/she be unable to express consent or dissent at that time. (ICB, 2007)

The advance directive was intended to have a number of purposes such as relieving the family of the burden of the decision, enabling participation of the person in decision-making and moving away from medical paternalism towards autonomy and self-determination (Madden, 2002). Support for advance directives is found in human rights law, and the European Convention on Human Rights and Biomedicine (1997) refers to advance directives and states that the 'previously expressed wishes relating to medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account'.

An advance directive or 'living will' is the content of an oral or written statement made by an individual to become effective under stated conditions anticipated in the future. It can include the patient expressing to their doctor what they would like to happen to them if they are not able to decide themselves. Where specific legislation exists, these wishes are often written into a particular format such as a living will, an enduring power of attorney or a directive to doctors regarding a natural death.

The directive involves a person making a decision or series of decisions on what they would like to happen to them in future medical treatment. This would then take effect should the person lack the requisite capacity to make the relevant decision at a future date (LRC, 2006). Donnelly states that 'this method of making decisions works best where a person while competent has given clear and unequivocal indications of what kind of treatment he would have wanted' (Donnelly, 2002).

There is no legislation on advance healthcare directives in Ireland. They have been promoted for decades elsewhere. Legislation is developing in many European countries since the mid-1990s providing, in a variety of ways, for advance directives. The LRC commented that, since it was possible to nominate another person to make personal and property decisions under an enduring power of attorney, it ought to be possible to make medical treatment decisions oneself and have them carried out by others following the onset of incapacity (LRC, 2003). Despite the common perception of advance directives, they are not confined to end-of-life issues and can also refer to day-to-day care, particularly when the person already has an illness requiring care into the future, for example, a neuro-degenerative disease. This element is of great importance for people in long-stay care where their wishes are reviewed regularly in conjunction with their medical and nursing staff.

There is no case law in Ireland on the legal status of clearly expressed wishes made in anticipation of future healthcare. In England, prior to the introduction of the

Mental Capacity Act 2005, which provides a statutory basis for advance directives, the courts stated that advance refusals of treatment, in other words the expressed wishes of the person, were legally binding as long as there was unequivocal evidence that the patient had capacity at the time it was made, that the decision was voluntary and it related directly to the actual circumstances in question. This is the key aspect that must be satisfied in order to ensure the wishes are carried out. Where there is doubt about the expressed wishes, then the courts will make the decision based on the best interests of the person.

One such decision concerned a young person in the late stages of a neurological disease (*Re AK*, 2001). He had earlier made it known that he wished treatment to be withdrawn and that he be allowed to die when his last means of communication failed. The hospital asked the court for clarification on the lawfulness of such action and the court supported his instructions and outlined the requirements for a valid advance directive at common law:

- The doctors must be satisfied that the patient has full capacity at the time it is made
- The refusal of treatment must be voluntary
- It must relate to the circumstances anticipated
- Care must be taken to ensure it still represents the patient's view
- It must have specifically anticipated the particular situation that has arisen.

Where these conditions are satisfied, English law recognises the advance directive as binding. A number of difficulties will arise in ensuring that the wishes have not changed, particularly if there is a disagreement from others involved. Another difficulty relates to the known progression of a disease that will make anticipation easier, but this will not apply in all situations.

The court accepted that where the individual had capacity to make an advance directive at the time it was made, that directive remains binding and effective even where there is subsequent loss of capacity (*Re C*, 1994). There is no Irish decision on the issue, but the courts have indicated that the wishes of a person were relevant to a court decision permitting withdrawal of treatment (*In Re A Ward*, 1995).

Not all directives will be acceptable and advance requests may not be legally binding. The directive must concern legally permitted treatments. In one English case, the court said 'a patient cannot demand that a doctor administer a treatment which the doctor considers adverse to his clinical needs' (Re Burke, 2005). Aside from clinical factors, resource issues can also impact on the wishes of a patient for a particular form of treatment.

In a case involving an advance directive from a mentally competent adult who refused life supporting treatments, the English courts found that the Hospital Trust was guilty of trespass in treating the patient following confirmation of her competence to make the decision to discontinue her treatment (*In Re B*, 2002).

The court set down clear guidelines for the conduct of similar cases in the future:

- Where there is no disagreement about capacity but doctors are unable, for any reason, to carry out the patient's wishes, they have a duty to find doctors who will.
- Where the patient has different values this is not an indication of absence of capacity.
- The doctors must not allow their emotional reaction or strong disagreement with the decision of the patient to cloud their judgement in answering the primary question – whether the patient has the mental capacity to make the decision.
- The patient should be kept as involved in the decision-making process as possible, resolving any dispute as promptly as possible.

This decision highlighted what the court referred to as 'the serious danger exemplified in this case, of a benevolent paternalism which does not embrace recognition of the personal autonomy of the severely disabled patient'. The case highlights the vulnerability of a person who had capacity to refuse treatment but had difficulty in asserting her own view. It also raises the need for awareness training in the context of older people where they are not in a system that is careful about establishing and respecting what their views might have been before the onset of reduced decision-making capacity.

The English Mental Capacity Act 2005 provides that persons over 18 years with capacity can make an advance decision to refuse treatment. They must meet stringent conditions in the context of refusing life-sustaining treatment. The decision will not have effect if the treatment in question is not what is specified in the directive or the circumstances are not what the patient anticipated.

Alternative solutions should be considered, such as a consensual approach with the family, using both substituted judgement and best interests, and offering a second medical opinion if agreement cannot be found. According to Madden, elements of this solution are already in place in Ireland (Madden, 2002). She refers to the practice of the medical team, 'to consult fully with the family and with nursing staff to ensure that such a decision is unanimous and to avoid any possibility that the decision would later be challenged'.

O'Neill suggests that the future resolution of these care issues 'may be better handled in a relationship of trust and beneficence' and puts forward the notion of a 'present' directive rather than an advance directive; what he refers to as a 'real time adaptive mode of relating with a physician that recognises the complexities, change and growth that occurs during the course of a severe illness' (O'Neill, 2001). This would recognise that communication with the patient and carers evolves and changes over time alongside illness progression and changes in circumstances. This is undoubtedly the ideal solution but, in the absence of any certainty that this practice will be anything but arbitrary, the demand for something visible and reassuring will continue.

There is considerable difference of opinion on the usefulness of advance directives. There is some concern that the courts will have to be used more frequently to confirm the validity of advance directives. Establishing the individual's understanding at the time of the decision and the level of information then available will prove difficult. Arguments in favour of legislation for advance directives refer to the need for adequate protections to be built in. One commentator stated that he had many clients 'who are terrified of receiving unnecessary medical treatment where they are surviving from an incurable or irreversible condition which would result in their death within a relatively short time' (Costello, 2005).

Clearly, there are a variety of arguments for and against the introduction of statutory advance healthcare directives. Some commentators argue that it is too onerous for medical staff to search for one when faced with a patient in a coma (Mason, 2006). Others believe reliance should be placed on the trust in the relationship between doctor and patient to have one's wishes honoured. The ICB commented on the limited uptake of advance directives in the US, where the figures are between 20-25 per cent. In Germany between 15-18 per cent make an advance directive. A survey by the IHF suggested that the uptake in Ireland might be around 14 per cent. During the ICB consultation process, 11 per cent of respondents said they had made advance directives. Some of the reasons posited by the ICB are the reluctance to face death, lack of public awareness and complexity of the documentation. Even if people are fully informed about the medical issues that are being addressed in the advance directive, the complexities of planning for the future cannot be simple and easily expressed in one document.

The English common law decisions on advance directives are useful and are relevant to the Irish context where it is anticipated that the introduction of a statutory basis for such decision-making will take time. In the interim, the common law and Constitution will continue to apply, and to support the right to self-determination and respect for the wishes of the person, provided the key evidence test is satisfied. It seems, therefore, and based on the right to consent recognised in Irish medical ethics and law, that (a) where the evidence is unequivocal that capacity was present at the time the decision was made, (b) it was voluntary and (c) was made in anticipation of the circumstances in question, then our legal system would be supportive of such action. However, there is as yet no clear legal decision on the matter and no statutory basis for advance directives.

3.7 Proxy Decision-Making in Irish Law

3.7.1 Ward of Court System

The Ward of Court system is the only formal proxy decision-making mechanism for adults in Irish law. The majority of people in wardship are older people with dementia. The capacity test used for wardship is that the person is of unsound mind and incapable of managing himself or his affairs. It is therefore a general capacity test which results in the person being deemed incapable for all other legal decisions. This is known as the status approach to capacity. Current best practice is now supportive of the functional approach. This means that the person is assessed in relation to a particular decision at the time the decision needs to be taken.

Current procedures leading to wardship are unfair and are very likely in breach of human rights law. The consequences of being made a Ward of Court are profound and are disproportionate, resulting in invisibility in the legal system. The 'Committee of the Person', the person to whom the Ward's affairs are committed, will take minor decisions, including minor medical decisions of an everyday nature on behalf of the Ward (*Re D*, 1987). Any decision to transfer the person from one care centre to another, or from home to a care centre, must be notified to the Ward of Court office. The President of the High Court will make all serious medical treatment decisions for the individual whose welfare is the paramount consideration, subject to the principle that, in an emergency, a doctor is entitled to take urgent action to preserve life and health (*JM*, 2003; Lunacy Regulation (Ireland) Act 1871).

The blanket approach to assessing the capacity of Wards is now recognised as a disproportionate interference with decision-making autonomy. The same system applies to all individuals, regardless of circumstances and with no regard for individual abilities. It could not be regarded as supportive of the principle of the least restrictive intervention. In addition, there is no review system built in to continuing wardship. Wards of Court who are receiving inpatient mental healthcare do not benefit from the safeguards of the Mental Health Act 2001 with regard to review of continuing detention. Nor do they have any safeguards for consent to treatment, such as second opinions. Even though they may have voluntary status while inpatients, they are not truly voluntary. Nor are they in a position to leave or refuse treatment. They are effectively detained without the protections that should apply. This is a breach of the requirements under the European Convention on Human Rights.

3.7.2 Enduring Power of Attorney

An alternative legal mechanism for ensuring one's wishes are honoured, following the onset of incapacity is an enduring power of attorney (EPA) and is in effect an advance directive. It is the only legal mechanism, apart from wardship, that provides for the proxy management of an incapacitated person's affairs. An EPA is a legal instrument signed by the donor giving the donee, the attorney, the power to act on behalf of the donor should the donor become incapacitated. It endures after the onset of incapacity. This is a power which comes into effect if the donor of the power becomes mentally incapable of managing his/her affairs. Mental incapacity is defined as 'incapacity by reason of a mental condition' to manage and administer his property and affairs (Powers of Attorney Act 1996). Like wardship, a general assessment of capacity is made rather than using a functional approach. However, the right to self-determination is upheld in this process to the extent that people can choose who they wish to act for them in the event of incapacity and the range of decisions they would like made for them within the confines of the Act.

Some jurisdictions permit a wide range of decisions to be made using this mechanism. The enduring power covers property, finance and limited personal care decisions. The definition of personal care includes: where the donor should live and with whom, whom the donor should see and not see, the training and rehabilitation the donor should get, the donor's diet and dress, the right to inspect the donor's papers as well as housing, social welfare and other benefits for donor. Personal care does not include the authority to make medical or surgical decisions for the donor, though in reality if a person is living, for example, in a hospital or nursing home, it is very likely that there will be some day-to-day healthcare decisions made on their behalf. In the context then of needing a major healthcare decision by a proxy decision-maker, the Irish EPA is limited in its current form and will not assist an incapacitated person needing a third party to act formally on their behalf. Even if such powers were extended to cover healthcare decisions, this would not provide a solution for adults who never had capacity to execute such a power or did not execute a power when they had the capacity to do so.

The EPA intends power to be effective during any subsequent mental incapacity of the donor. An assessment by a doctor is required at the time of creating the power and the individual's capacity to do so must be affirmed by a solicitor. The power is only activated if and when the person becomes incapacitated. The figures for registering of EPAs in Ireland are low. It is likely there are a number of reasons: the population at large is unaware of the existence of such a procedure, or that they do not understand that they maintain full control over their lives unless, and until, they become mentally incapacitated. There has never been a public awareness promotion of the EPA. The English Mental Capacity Act 2005 provides for an EPA that recognises advance decisions to refuse treatment to the extent stated within the donor's wishes and can include end-of-life decisions (Mental Capacity Act 2005). Costello advises all people over 65 to make an EPA in order to avoid wardship where possible (Costello, 2005).

Concerns about the lack of supervision of attorneys call into question the rights of vulnerable adults and the need for a higher standard of protection. In order to eliminate the possibility for exploitation, improved supervision of attorneys is a priority. This includes the lack of independent monitoring of the acts of the attorney, along with the lack of an independent medical assessor and legal adviser. Although some safeguards exist, these are not adequate to ensure that those appointed always act in the best interests of the incapacitated person. The LRC recognised these issues in their consultation papers and have made proposals for reform that are included in their report *Vulnerable Adults and the Law* with a focus on assisted and substitute decision–making regimes (LRC, 2006).

3.7.3 Individual Care Plan

The Mental Health Act 2001 requires that a treatment plan is in place for all residents in mental health centres. This plan helps to identify progress and define responsibilities for care. When the treatment is not adequate the plan acts as a reference point. It had long been recognised that there were inadequate care plans for people living in mental health centres and a statutory basis for the plan was introduced. Similar statutory safeguards may be useful for older people in long-stay care.

3.7.4 Do Not Resuscitate Orders

End-of-life decisions may include consideration of what is known as a Do Not Resuscitate (DNR) order. This is a written order, normally a note written by the doctor in a patient's file, not to attempt cardiopulmonary resuscitation (CPR) on that patient, should the patient have a cardiac arrest. Some jurisdictions have comprehensive guidelines on the use of such orders. There are no specific guidelines for DNR orders in Ireland, but the common law duty of care requires that medical staff act according to the standard of the profession when carrying out such a decision. One of the concerns about DNR orders is that they are more often made in relation to older patients, which is not surprising, but this highlights the need to have knowledge and understanding on all sides about their use. Research also notes the relevance of the age of the physician in making the decision (Mason, 2006).

The capacity of the patient to participate as far as possible, and make a decision, is central to the discussion on whether a DNR will be used and accords with international standards in ethics and human rights. If the patient does not have capacity to make the decision at the time, then an advance directive refusing such treatment may apply where the evidence of the patient's capacity is clear and unequivocal and relates to the circumstances that have arisen. Where the patient has diminished decision-making capacity, the medical team, in consultation with the family, make the decision based on the best interests of the patient.

The legal basis for making a DNR order for a patient who is incapable of consenting is the common law doctrine of necessity, with the medical staff acting in the best interests of the patient. The law in Ireland accepts that prolonging life in all circumstances is not necessarily in the patient's best interests and, 'a view that life must be preserved at all costs does not sanctify life' (*In Re A Ward of Court*, 1995). The belief that all patients would want to have CPR is not necessarily the case. Routine use of CPR will not always be in the patient's best interests (Madden, 2002). A decision to make a DNR order follows consultation with the patient who makes the decision, if they have capacity.

The Medical Council states in relation to treatment at the end-of-life:

> Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible. In these circumstances a doctor is not obliged to initiate or maintain a treatment which is futile or disproportionately burdensome. Deliberately causing the death of a patient is misconduct.
> (Medical Council, 2004)

The Medical Council guidelines are general in nature rather than having specific application to DNR orders but require that there is respect for the dignity of the person. The right to dignity presupposes a right to respect for privacy and the right to consent to treatment. The ethical requirements in other sections of this chapter regarding consent and respect for the patient's wishes are relevant to this matter. The DNR order can be used to stimulate discussion and to clarify the appropriateness of such actions in an individual case. It can have an important role in ensuring, what is intended for dying patients by the Medical Council – the dignity, comfort and limitation of suffering for the person as far as possible. The patient cannot insist on having CPR carried out in all circumstances where the medical opinion is that treatment is futile.

The British Medical Association (BMA) and the Royal College of Nursing (RCN) state that:

> Each case involves an individual patient with his or her own particular circumstances and it is important to ensure that these circumstances are central to each decision rather than applying the same decision to whole categories of patients. (RCN/BMA, 2001)

This idea of an individual assessment of each patient is supported also by other commentators. These commentators disagree with a bias against treating people on the grounds of 'quality of cognitive life' and say that a decision must be based on the individual patient's circumstances (Mason, 2006). Guidelines developed jointly by the BMA and the RCN indicate that DNR orders should be considered if the following conditions are met:

- The patient has refused CPR
- The patient's condition is such that effective CPR will not be successful
- Where there is no benefit in restarting the patient's heart – if for example, imminent death cannot be avoided
- Where the expected benefit is outweighed by the burdens such as a high risk of brain damage.

The guidelines also provide that treatment is decided by the clinician in charge of a patient's care in light of the best available clinical evidence, possible outcome, quality of life outcome and the view of the rest of the healthcare team. Withholding or withdrawal of CPR should include the opinion of a senior clinician outside the team. The guidelines recognise the importance of consultation with nursing staff. It should not be necessary to go to court unless there is serious disagreement with no possible resolution. There are very few court decisions on DNR orders. One such English decision concerned a young man with multiple and severe disabilities. Clinical staff and his mother supported a DNR order but the care centre he attended opposed it (*Re R*, 1996). The court reviewed his circumstances and looked at the quality of life the patient would have to endure if CPR were carried out in the event of a further arrest. Upholding the decision not to resuscitate, the court decided treatment could be withheld from a patient at the point where life became 'so afflicted as to be intolerable' and interventions would have to be considered in light of the benefits conferred on the patient. Where a DNR order has not been made and the patient's wishes are unknown, then it is appropriate to attempt CPR if there is an arrest.

Further guidance provides:

- Patients who have decision-making capacity should be involved unless they do not wish to be
- Effective and sensitive communication is essential and advance discussion with the patient or family should be encouraged but not forced (RCN/BMA, 2001)
- Information given to the patient and family should be realistic and include limits and potential benefits of treatment
- The discussion should focus on the particular patient and be reviewed regularly. Where the patient has reduced decision-making capacity people close to them may help to reflect their views
- The aim of the decision-making should be general agreement and where no advance decision can be reached a note should be made of the reasons
- Where there is a serious challenge to the clinical decision it may be necessary to seek a legal review.

The introduction of urgently-needed guidelines setting out a proper framework, embracing ethical and legal issues, will help to clarify the issues and stimulate discussion for patients and families as well as medical staff (Sheikh, 2005). Policies should outline when a legal review should be sought and how it can be obtained speedily. Ideally, written information on such policies should be available for the patient and family.

3.8 Law Reform Commission Proposals

The LRC broadly addressed two issues: how the law should approach the concept of capacity to make decisions and what structures are needed to support vulnerable adults when making decisions. The reforms proposed provide for informal decision-making on behalf of adults who lack capacity in certain circumstances. It proposes the establishment of a guardianship board which will appoint personal guardians to deal with property, financial matters and welfare of adults who lack capacity. The proposal is to replace the Ward of Court system and increase the type of decisions under an EPA to include some health decisions. The principles outlined in the Draft Scheme of the Mental Capacity and Guardianship Bill 2007 include the following:

- Any intervention must be the means of achieving the purpose of the intervention which is least restrictive of the person's freedom
- Account must be taken of the person's past and present wishes where they are ascertainable
- Account must be taken of the views of the person's relatives, primary carer, the person with whom he or she resides, any person named as someone who should be consulted and any other person with an interest in the welfare of the person or the proposed decision where these views have been made known to the person responsible
- Due regard shall be given to the need to respect the right of the person to dignity, bodily integrity, privacy and autonomy.

A presumption of capacity will apply to all adults unless the contrary is established. This presumption is important for older people where age and incapacity are often incorrectly linked. The Bill proposes a predominantly functional approach to the assessment of legal capacity while recognising that where an adult's lack of capacity is profound and enduring, a new functional determination may be unnecessary in every situation. Personal guardians can be appointed to make a wide range of substitute decisions, where the person lacks capacity in relation to that decision, including minor healthcare decisions on behalf of the protected adult, but not major decisions. The LRC considers that attorneys under the EPA system should also be entitled to make these decisions if the specific authority is contained in the EPA. The LRC recommends that certain major healthcare decisions, such as the removal of life support or organ donation, would only be made by the President of the High Court.

One of the proposals that will have an impact on people working in long-stay centres is in relation to informal decision-making. The proposal is that such decision-makers will be excused from any liability in relation to the informal or assisted decision-making in connection with personal care or treatment of another person provided certain conditions are met. The obligation arising is that the assistant must take on board the principles in the Bill and take reasonable steps to establish whether the other person lacks capacity in relation to the matter and is unable to consent. The act must not be done negligently or in a criminal manner. The LRC recommends that intervention orders could be made by the Guardianship Board in relation to once-off decisions such as the sale of property or consent to medical treatment or change of residence. It is foreseeable that such orders would be useful in relation to older people in long-stay care.

The LRC has proposed that a Working Group on Capacity to Make Healthcare Decisions would be set up under the proposed capacity legislation and this group would formulate a code of practice in this area that would provide guidance on the assessment of capacity (LRC, 2006). It is also proposed to provide guidelines on the approach to be taken to a variety of decisions, including urgent medical treatment without consent, the type of treatment permitted where capacity will return quickly, and the kinds of decisions that would require court involvement. This would enable best practice to be widely applied and eliminate the arbitrary approach to capacity that currently applies.

It will take some time before these recommendations are in place. In the meantime, elements of best practice should be adopted in order to maximise capacity through consultation with the person involved and the provision of appropriate information, thereby respecting their dignity and autonomy. Best practice supports the functional approach to the assessment of capacity which takes account of fluctuating capacity.

3.9 Conclusion

This chapter outlined the framework for personal care decisions and the impact diminished capacity has on these decisions. The key challenge in enhancing quality of life is the preservation of the person’s surviving autonomy and dignity balanced against inevitable paternalism. In this regard knowledge of the patient’s wishes or any advance directive made prior to the onset of incapacity should be considered. Respect for the person’s dignity and autonomy are at the core of their human rights and the law on consent upholds these rights. Where there is diminished capacity, it is important to have a robust system in place to provide alternative decision-making and safeguards.

There are significant gaps in the law. The LRC proposals need to be introduced as a matter of urgency as they contain some of the most important proposals for legislative reform in relation to vulnerable older people and the key issue of capacity. In the meantime, it is possible to have guidance in the form of codes of practice that would incorporate these issues until legislation is enacted. Beginning with the transition from home, and having regard to the least restrictive alternative, the person's wishes should be considered, including whether residential or hospital care is unavoidable. The assessment prior to admission must address the broader needs of the person along with their view of their care. This information is relevant to forming a substitute judgement in future decision-making based on the best interests of the person. An expansion of the best interests test to include the broader aspects, as in other jurisdictions, would result in a more individualised approach.

Disclosure of information for consent must be individualised in order to enhance decision-making capacity. There is a role for an independent advocate in assisting the person to make a decision about their care and treatment. While there is no legislation at present to underpin advance directives, both formal and informal, they are perceived as a means of ensuring wishes are respected following the onset of incapacity and not just at the end-of-life. It would seem that there is legal support for the common law advance directive based on the right to consent to treatment and respect for the person's wishes. While there is no decision to date on this matter, decisions in the English courts would have some influence. The difficulty in asserting views while in long-stay care should not be underestimated but can be supported by positive relationships with the medical and nursing staff.

The proposal to repeal the wardship legislation and replace it with a comprehensive system based on best practice is welcome. In addition the proposal to add minor medical decisions to the enduring powers of attorney and provide additional safeguards is also welcome. The introduction of an individual care plan should be considered and included in a code of practice to offset the arbitrary approach throughout the country. Such plans are individualised and could be subject to regular review. Individual care plans would also ensure that the issue of DNR orders would be addressed in a more proactive way. Clearly there is an urgent need to have a code of practice or guidelines on the use of DNR orders for all concerned in order to fill the information deficit.

The human rights principle of age-indifference in policies and practices requires that each person is entitled to the same respect and regard as any other person. There is evidence of ageism in the Irish health and social care system. This results in negative attitudes and behaviours towards older people; attitudes and behaviour that can have a profound impact on their quality of life.

Chapter Four

Methodology

Chapter Four

Methodology

4.1 Introduction

This chapter describes the study methodology, sampling methods and strategies used to collect and analyse the data. The purpose of this study was to provide a contemporaneous description of service provision and care for older people[2] dying in acute and community hospitals and nursing homes in Ireland. The study aims were as follows:

- To undertake a survey of all known Irish acute hospitals and long-stay institutions in relation to contextual epidemiology of death and dying, facilities, staffing levels, access and liaison with services and training and education needs of staff
- To explore key stakeholder and direct care managers' perspectives on the current provision of end-of-life care for older people
- To explore the experience of the older person in receipt of end-of-life care.

In addition, the research team were commissioned to provide a critical review of the policy context in which older people experience end-of-life[3] care, define the legal and ethical frameworks that influence end-of-life care for older people, including issues of equity and discrimination, and make recommendations for best practice approaches to end-of-life care for the older person.

Given the lack of agreement on both definition and components of end-of-life care, the approach taken in this study is a mixed methods design incorporating mutually supporting quantitative and qualitative elements. The quantitative approach involved a survey of all known acute and long-stay settings in Ireland using an adapted postal questionnaire that had previously been administered to a similar population in the UK. The qualitative element of the study was informed by a phenomenological approach which allowed older people and staff to talk about their experience and interpretation of quality of care and quality of life at end-of-life.

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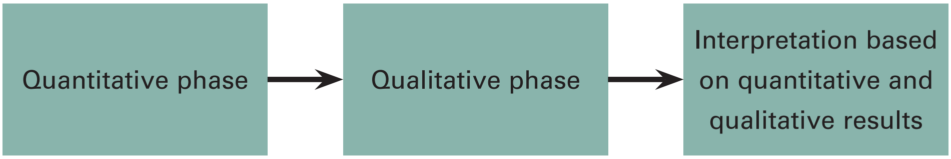
[2] For the purposes of this document, older people are defined as people aged 65 years and over, unless otherwise stated.

[3] The term end-of-life care cited here is based on the definition proposed by Ross *et al.* (2000), which encompasses a sensitive, individually-focused, compassionate and supportive approach to living with or dying from progressive or chronic life-threatening conditions for older people.

4.2 Research Design

This study employed a mixed method research design. Mixed method research is defined as the use of two or more research methods within a single study, of which four major mixed method study designs have been identified: triangulation design, embedded design, exploratory design and explanatory design (Denzin 1989; Boyd 2001; Tashakkori and Teddlie, 2003; Creswell and Clark, 2007). Within this study an explanatory sequential mixed method design is utilised (Figure 4.1). This approach uses qualitative data to explain and interpret the findings of a predominantly quantitative study (Creswell *et al.*, 2003). The quantitative work is followed by a qualitative study involving a smaller sample, where the aim is to explore the results generated from the quantitative study in greater depth (Creswell and Clark, 2007). This mixed method design was in keeping with the aims of this study.

Figure 4.1: Explanatory Sequential Design (Creswell and Clark, 2007)


Quantitative phase
Qualitative phase
Interpretation based on quantitative and qualitative results

4.3 Ethical Approval

Ethical approval was sought from the National University of Ireland (NUI) Galway Research Ethics Committee. Informed consent was obtained from both patients and direct care staff. Given the vulnerable nature of the patient group (Polit and Beck, 2004), the Research Assistant ensured that a minimum of 24 hours elapsed between explanation of the study and obtaining their agreement to participate. All participants were assured of their right to withdraw from the study at any time and that their anonymity would be preserved. Once consent was obtained, participants were only identified by their allocated code number relating to their status (patient/staff) and place of residence/work. A similar system was used for the coding of questionnaires, and codes and numbers were only made available to the research team members responsible for data processing and analysis. In this way, confidentiality was maintained at all times.

4.4 Survey of Acute and Long-Stay Facilities

The quantitative survey of acute and long-stay facilities provided an insight into the likely impact of physical, environmental and staffing issues on end-of-life care for older people in these settings. It extends and develops previous work done by the NCAOP on quality of life in residential care settings in Ireland (Murphy *et al.*, 2006). All known acute hospitals, psychiatric hospitals and long-stay facilities were included in the study. In total, we succeeded in identifying 635 potential long-stay facilities in public, private and voluntary settings. We identified 49 acute hospitals suitable for the study and 21 psychiatric hospitals. This gave us an initial total of 705 facilities for inclusion in the study. After final cleaning to account for some closures and some double-counting we were left with a sample population of 675 facilities.

The DoHC currently divides long-stay facilities into the following five categories:

- Health board extended care units
- Health board welfare home
- Voluntary home/hospital for older people
- Voluntary welfare home
- Private nursing home.

However, not all long-stay facilities are included on the DoHC's database, particularly those in the private sector. We found an additional 150 nursing homes that were not listed within the DoHC Long-Stay Statistics databases (2004). We located these facilities through a search of various online databases including the HSE, the Irish Nursing Homes Organisation and Retirement Services for Older People. There were also difficulties in the voluntary sector, where facilities were sometimes included in both public and private databases.

These discrepancies had to be checked before a final list could be developed. On checking, we found differences between how facilities were categorised on the lists received from various official sources and how they categorised themselves. Most confusion centred on private/voluntary classification and extended care unit/welfare home classification. A small number of private nursing homes listed in official sources had closed and were not included in the study. Overall, there were considerable difficulties in categorising long-stay facilities, similar to our previous work in this area (Murphy *et al.*, 2006).

4.4.1 Questionnaire Design

The questionnaire used in the survey was developed from a previous study into end-of-life care in nursing homes in the United Kingdom (Froggatt and Payne, 2006). The questionnaire was modified to accommodate the broader nature of the Irish study population, particularly the inclusion of acute and psychiatric hospitals. Some of the questions were also adjusted to ensure cultural sensitivity to the Irish context. The following thematic areas were included in the questionnaire: beds and patients/residents; dependency; deaths; services and facilities; staffing, education and training; communication and liaison with other services; bereavement support; and policy and guidelines. The quantitative survey also included three open-ended questions covering: understanding of end-of-life care; elements of good quality end-of-life care; and barriers to care. Questionnaires were coded according to type of facility, region and number of facilities in the region. Following the results of the pilot survey and team consultation, a small number of changes were made to reflect the needs of this study.

4.4.2 Pilot Survey

Prior to the main survey, a pilot questionnaire was sent to 30 randomly selected acute, psychiatric and long-stay facilities across the country. All of the categories of acute, nursing home and long-stay facility listed above were represented in the stratified sample selection. Facilities were included from all regions and every effort was made to ensure an appropriate urban/rural mix. The number of facilities used as pilot sites in each long-stay category reflected the percentage of total beds accounted for by each, given that greater bed numbers were more likely to be indicative of greater numbers of deaths. For example, as private nursing homes accounted for 30 per cent of all beds in the study, nine facilities from that setting were included in the pilot study.

Each pilot site was allocated a code and data entered into SPSS using this code. In addition, feedback was gathered from respondents by telephone in relation to content, structure and layout of the questionnaire. Non-responders were contacted by telephone to encourage them to complete the questionnaire. The final pilot response rate was 70 per cent (21 questionnaires).

A number of important issues were identified at the pilot phase, particularly in relation to content and length of questionnaire. Respondents felt the questionnaire was too long, which meant that some questions had to be omitted or shortened for the final version. Respondents did not have easy access to data on deaths within their facility, particularly in the acute hospitals. For that reason, questions relating to the last death within the facility had to be dropped because they proved too difficult to answer without nurse managers engaging in significant research, something they were not prepared to do. Similarly, the questions on services and facilities, and policies and procedures had to be adjusted to make them easier for respondents to answer. In general, we encountered significant survey fatigue among respondents, leading to resistance to completing our survey. To counteract this, we devoted additional resources at project management level to ensure a satisfactory response rate in the final survey.

4.4.3 Main Survey

The questionnaire was coded as previously described. 675 questionnaires were posted with a covering letter addressed to the Director of Nursing/Person in Charge stating the purpose of the study and the completion date. Respondents were tracked and those who had not returned the survey by the completion date were followed-up with a reminder letter and telephoned individually. Where it was established that the questionnaire had not been received by the appropriate person in charge, a second questionnaire was posted or e-mailed to the designated person in charge.

Follow-up phone calls revealed that some of the facilities targeted were not valid for the survey, either because they were no longer in operation or did not have long-stay beds. These were removed from the initial census count, leaving a final valid count of 592. A final response rate of 55 per cent was achieved, which is excellent for a postal questionnaire of this type, but which would not have been achieved without intensive project management (Table 4.1). Voluntary welfare homes had the highest response rate at 85 per cent, while psychiatric hospitals and HSE welfare homes both had the lowest response rate at 38 per cent. More than half of all private nursing homes responded to our survey. It should be noted that some facilities categorised themselves differently than our original classification, most notably HSE welfare homes.

Two factors led to a lower response rate in the final survey than in the pilot survey. First, the data collection took place during a period of national industrial action by nurses, which limited their involvement in administrative duties, such as the completion of forms and questionnaires. Second, the private nursing home sector reported a high volume of other surveys at that time from official sources (DoHC) and some were only willing to complete those considered to be ‘compulsory’.

Table 4.1: Questionnaires Administered and Returned by Type of Facility

	HSE Extended Care Units	HSE Welfare Homes	Vol. Homes/ Hospital	Vol. Welfare Homes	Private Nursing Homes	Acute Hospitals	Psych. Hospitals	Total
Number of Questionnaires Administered	84	32	47	13	361	34	21	592
Number of Questionnaires Returned	61	12	24	11	195	16	8	327
Response Rate	73%	38%	51%	85%	54%	47%	38%	55%

The data from the questionnaires was entered into SPSS V14 using double data entry, which was then validated. A comparison of datasets was made using EpiInfo to verify that data entry was correct. Descriptive statistics were used to determine means and create the various tables shown in the Chapter 5. The Pearson chi-squared test and the Mann-Whitney test were used to establish if there were significant differences across facility types on important variables.

4.5 Resident, Patient and Staff Interviews

In keeping with the mixed method design, the qualitative interview data provided information on the experiences of patients and staff. The terms of reference for this study required the research team to undertake in-depth interviews with direct care staff involved in the delivery of end-of-life care to older people and interviews with recipients of that care. Interviews were undertaken in six sites representing the distribution of places of care in which older people die. The study sites enabled contextual data to be obtained which illuminated the 'holistic and meaningful characteristics of real life events' (Yin, 2003). A total of 65 interviews were undertaken; 35 with direct care staff and 30 with patients in receipt of end-of-life care.

The focus on location of care provides an understanding of the structures and processes involved in end-of-life care, and allows staff and patients to narrate their own personal journeys around and towards death in a way that makes sense to them. Sometimes this does not involve any direct reference to death and dying at all; other times it does. The methodology is not one of case study; we do not provide detailed comparative accounts of these places of care. Instead we focus on the direct experiences of the providers and recipients of care across the various settings. This allows maximum information to be provided, although not necessarily always comprehensive information, while at the same time respecting and protecting the anonymity of all of the respondents.

4.5.1 Selection of Study Sites

A stratified random sampling strategy was utilised in the selection of sites, based on the need to provide contemporaneous data reflective of the various types of care facility where older people may die in both urban and rural settings (Table 4.2). The scale of the facilities had to be reasonably large to ensure a high probability of finding people in receipt of end-of-life care when the research team visited. In the selection process, the following criteria for selection of a nationally distributed reflective sample were agreed with the Consultative Committee overseeing the project:

- One acute hospital typical of the range of healthcare facilities across Ireland, which should be >500 beds and <1,000 beds to ensure an equal chance of selection beyond large Dublin teaching hospitals (usually >1,000 beds)
- Two HSE extended care units with not less than 100 beds (one urban, one rural), representing the typicality of a large long-stay institution available in the country
- A private nursing home (one urban, one rural), typical of the 'for-profit' sector, either purpose-built or converted. One had to have between 50-75 beds; the other over 100 beds
- A long-stay unit attached to a palliative care centre to allow for the potential of cross-fertilisation and learning between the two settings.

Table 4.2: Study Sites

Setting	Urban	Rural
Acute Hospital	1	
Extended Care Unit	1	1
Private Nursing Home	1	1
Long-Stay Unit Attached to Palliative Care Centre/Hospice	1	

4.5.2 Gaining Access

Each randomly chosen site was initially contacted by telephone and invited to take part in the study. An overview of the research study was given, as were assurances that their facility would remain anonymous. All but one facility from the first wave of selection agreed to participate following discussion with the Project Manager. Where permission was refused, the next randomly selected facility in that category was approached. Gaining access to the two private nursing homes was more timeconsuming because of the need to gain the consent of the owner, as well as the direct care staff. Once consent was given, an information pack was sent to the six sites, consisting of:

- A copy of the letter from NUI Galway Research Ethics Committee, confirming that the study had received ethical approval
- An Agent Nomination form (in accordance with Data Protection Acts 1998 and 2003)
- A detailed information briefing sheet, which clarified the role of the Research Assistant, the type of questions to be asked and materials to be obtained, including access to medical files. Contact numbers of the research team were then provided to allow people raise any concerns or issues, if appropriate.

A further phone call was made to each facility to confirm that the facility would act as a research site and the consent form was signed and returned.

4.5.3 Visits to the Study Sites

A research assistant was assigned to each study site to prepare a comprehensive profile of the facility, and to identify and obtain verbal and written consent from both direct care staff and patients to take part in an interview. Training was organised for the research assistants and the interviewers, introducing them to the study, the tools that would be used during the site visit and the nature of the interviews. Two interviewers visited each study site. The interviewers were experienced qualitative researchers with competence of interviewing frail, older people and/or vulnerable people in receipt of end-of-life care. The research assistant typically visited the site two days prior to the interviewers' visit to prepare the site.

At each research site, the research assistant obtained photocopies of documentation, policies and guidelines relative to end-of-life care for older people, including:

- Dependency levels of people in the unit
- Nursing assessment records, including any tools used for such assessments
- Off-duty rota for the assessment of staffing levels across a 24-hour period
- Medication charts of those patients to be interviewed
- Clinical records, both medical and nursing, of those patients to be interviewed.

Patient data was limited to 30 days prior to entering the study site. Dependency levels of patients participating in the study were determined by the use of the KATZ scale and the Karnofsky Performance Status (KPS) scale. The KATZ scale is used to measure the function of older people, both as an assessment tool and a self-report measure (Reijneveld *et al.*, 2007). The KPS scale is commonly regarded as a gold standard measurement of performance in debilitating illness and offers a three-dimensional assessment of health status (activity, work and self-care), which can be administered by any healthcare professional and has been adapted for use in palliative care (Abernethy *et al.*, 2005).

The research assistant also obtained a description of the care environment, including a sketch map of the care setting, indicating the layout of rooms, proximity to nursing office, etc.

4.5.4 Sampling Strategy

Purposive sampling is typical of sampling strategies used in qualitative research. It offers the possibility to 'sample a specific locale according to a preconceived but reasonable initial set of dimensions' (Cutcliffe, 2000). There are no specific rules regarding the size of sample, since it is depth and quality rather than a generalisable representation that is sought. Generally, therefore, samples are usually small (Tuckett, 2004) and given the goal of the study to obtain a rich and deep expression of the experience from both patients and direct care staff, as many available interviewees as possible were sought in each centre using criteria outlined below.

4.5.5 Patient Interviews

A list of up to 10 patients considered suitable for interview was supplied by the senior nurse in each facility. The criteria for selection were agreed by the research team prior to entering the study site, based upon reported literature regarding sampling and interviewing of patients in end-of-life studies (Payne *et al.*, 2007; Seymour *et al.*, 2005). Criteria included:

- Patients over 65 years of age, orientated and able to discuss their experiences
- A diagnosis suggestive of chronic life-limiting illness (e.g. cancer, chronic obstructive airways disease etc.)
- Patients with complex health issues requiring regular medical attention
- Patients whom the senior nurse would not be surprised if they died within 6-9 months of the interview, given their overall state of health
- A gender balance reflective of older person demographics (60 per cent female, 40 per cent male).

The initial list of patients for potential interview was agreed by the research assistant and senior nurse. Patients who could not participate for physical or mental health reasons were subsequently excluded. Where a patient declined to participate, another was selected from the agreed list. The goal of the study was to include the perspective of as many patients as possible. A pragmatic decision was taken, therefore, to interview as many patients as possible within the time available to the interviewers visiting the site. The final interview figure was 30, six higher than originally expected.

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

4.5.6 Direct Care Staff Interviews

Senior nurses were invited to suggest direct care staff who could be interviewed as part of the study. A range of experienced professional and non-professional personnel involved in the delivery of end-of-life care to older people were sought across the six sites, reflecting the need to represent the views of all those involved in the direct care of patients at end-of-life. These included GPs, registered nurses, care assistants and allied health professionals (physiotherapist, occupational therapist). Criteria for selection included a gender and age mix (where possible) to reflect the different exposure to training and education. Interviewees also had to have worked consecutively for at least three months in the unit to ensure they had both knowledge and experience of care services therein. Table 4.3 shows the range of staff interviewed for the study.

A total of 35 direct care staff were interviewed. Most interviews of staff took place during their rostered shift. The three GPs were interviewed by telephone in their own surgeries because the time of interviewing did not coincide with their routine visit to the care facility.

Table 4.3: Staff Interviewed for the Study

Staff	Total Number Interviewed	Care Setting
Registered Nurse (RGN)	16	All Settings
Registered Nurse (Managerial or Specialist Grade)	4	All Settings
Healthcare Assistant (including 1 Occupational Therapist Assistant)	10	All Settings
General Practitioner	3	1 Extended Care Unit Attached to Hospice 1 Private Nursing Home
Physiotherapist	1	Extended Care Unit
Occupational Therapist	1	Extended Care Unit

4.5.7 Interview Schedules

Two interview schedules were developed based on previous work as reported in the literature and in consultation with co-partners in the research team (Payne *et al.*, 2007; Hawker *et al.*, 2006). The interview schedule was modified to be culturally sensitive to the Irish context. The schedules were piloted before the main data collection and minor modifications made to both. For patients, topics included their understanding of the reasons for admission, experience of care received and their physical environment. Issues around death and dying were introduced indirectly in terms of their concerns and/or worries over their future. For staff, interviews covered their understanding of end-of-life care, attitudes to care, interface with specialist services, descriptions of care, education and training, and personal support mechanisms. The complementary data obtained from staff and patients provided a rich context for interpreting the experiences of caring and being cared for at end-of-life.

4.5.8 Qualitative Data Analysis

Data from all interviews was recorded and transcribed verbatim. A computerised qualitative data analysis package (Atlas Ti) was used to manage the data and a grounded theory approach to data analysis was employed. This involved the use of the constant comparative technique, which means that data collection and analysis occurred simultaneously (Glaser and Strauss, 1967). In this way continuous comparisons were made between '…words, sentences, paragraphs, codes and categories', the purpose of which was to identify similarities and differences in the data (Bluff, 2005). First level or open coding (Strauss and Corbin, 1998) was then undertaken allowing similar areas to be grouped together into categories. After the principal categories were established, axial or second level coding was undertaken. This process established connections between categories and subcategories and a conceptual framework began to emerge. In this process, the data was dissected and put back together in a different way (McCann and Clark, 2003). Finally selective or level three coding was completed, where all the categories and subcategories were united to form a core or over-arching category (Charmaz, 1990; Bluff, 2005).

The data is presented thematically from across the six sites. This approach protects the anonymity of participants as they might be easily recognised within each study site if the data was presented on a case-by-case basis (Large *et al.*, 2005). In addition, as the aim of the qualitative phase is global in nature, that is, to explore direct care managers' perspectives on the current provision of end-of-life care for older people, the findings from all direct care managers are presented in totality rather than dividing them up into their respective care-giving roles.

4.6 Conclusion

This chapter provides an overview of the research methodology utilised in this study. A mixed method approach was adopted. In all, 592 care facilities were surveyed, with an overall response rate of 55 per cent. Qualitative interviews were carried out across six sites reflecting the range of care facilities where older people die, 35 with direct care staff and 30 with patients. The mixed methods approach offers rich and deep contemporaneous data. It should be noted that it is beyond the scope of this report to analyse and present all of the data gathered and further output can be expected.

Chapter Five

Services and Facilities for End-of-Life Care for Older People in Ireland

Chapter Five

Services and Facilities for End-of-Life Care for Older People in Ireland

5.1 Introduction

This chapter examines services and facilities for end-of-life care for older people across acute hospitals, public long-stay facilities, and private and voluntary nursing homes in Ireland. Currently, we know very little about the services and facilities that are available across various settings for end-of-life care. The aim of this chapter is to describe the services and facilities available for the provision of end-of-life care for older people residing in hospitals and long-stay care settings in Ireland, based on responses to our postal questionnaire. The questionnaire was completed by the nurse manager or their proxy within the various care settings, so it is their perspective that underpins the data collection process.

The chapter begins with a discussion of the care settings included in the survey, including details on regional distribution and number of long-stay beds. This is followed by a discussion of long-stay residents and their characteristics, with particular reference to overall dependency levels. The number of deaths in facilities responding to the survey is recorded, as is the usual location at time of death. Details of end-of-life care are then presented, incorporating data on the number of palliative care beds, staffing levels and services, and facilities specific to death and dying. Information is also provided on communication and liaison with specialist and other services inside and outside the care setting. Bereavement support data is also reported. So too are the various policies and guidelines for end-of-life care in the various settings, including reference to quality initiatives across the sector. The chapter concludes with an extended discussion of quality of care and quality of life issues for end-of-life care based on the reported experiences of the nurse managers who completed the questionnaires.

5.2 Care Settings

The overall response rate to the postal survey was 55 per cent. Long-stay facilities make up 93 per cent of all responses with the remainder comprising acute hospitals and psychiatric hospitals (Table 5.1). Private nursing homes accounted for the majority of facilities in the study, at just under 60 per cent.

Table 5.1: Distribution of Respondents by Facility Type

Facility Type	Number of Facilities	% of All Facilities
Private Nursing Home	195	59.6%
HSE Extended Care Unit	61	18.7%
HSE Welfare Home	12	3.7%
Voluntary Home/Hospital	24	7.3%
Voluntary Welfare Home	11	3.4%
All Long-Stay Facilities	**303**	**92.7%**
Psychiatric Hospital	8	2.4%
Acute Hospital	16	4.9%
All Facilities	**327**	**100%**

Table 5.2 shows the number of long-stay beds in each setting, excluding acute hospitals and psychiatric hospitals[4]. More than half of all long-stay beds (55 per cent) in the survey are in private nursing homes. One third of the long-stay beds are in HSE long-stay care settings, while just over one tenth of the long-stay beds are in the voluntary sector. The coverage of our study can be compared to the official Long-Stay Activity Statistics generated by the DoHC. Our study accounts for 72 per cent of all long-stay beds in Ireland. We account for 82 per cent of private beds and 71 per cent of HSE extended care beds. The degree of coverage achieved in the study is impressive for a postal questionnaire and enhances the validity of the inferences drawn from the data later on in the report.

Table 5.2: Long-Stay Beds by Facility Type

	Survey		Actual DOHC Beds	Survey/ DOHC %
Facility Type	N	Number of Beds (%)		
Private Nursing Home	194	8,506 (55%)	10,350	82%
HSE Extended Care Unit	61	4,408 (29%)	6,199	71%
HSE Welfare Home	12	516 (3%)	1,500	34%
Voluntary Home/Hospital	24	1,567 (10%)	2,875	55%
Voluntary Welfare Home	10	442 (3%)	554	80%
All Long-Stay Facilities	**301**	**15,439 (100%)**	**21,478**	**72%**

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[4] Patients in long-stay beds in acute hospitals have been included in the HSE Extended Care Unit category.

5.3 Long-Stay Patients/Residents

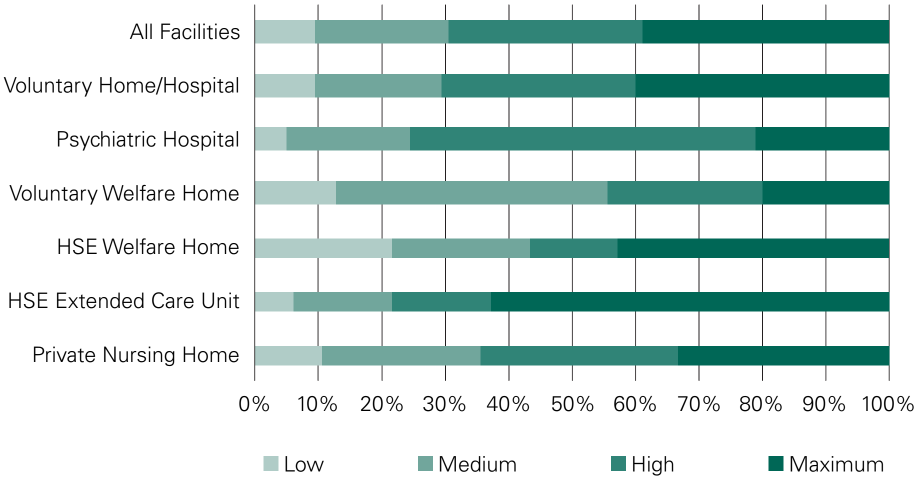
The survey covers 14,104 patients/residents in long-stay care settings, excluding psychiatric hospitals (Table 5.3). This is equivalent to 73 per cent of all long-stay residents in the country. The survey covers 83 per cent of private nursing home residents and three quarters of all HSE extended care residents. More than 90 per cent of all long-stay residents in the survey are aged 65 years and over. In all facilities, women are the dominant gender, representing 66 per cent of all patients/residents aged 65 years and over. This gender dominance is greatest in private nursing homes, where females represent 72 per cent of all patients/residents.

Table 5.3: Long-Stay Residents by Facility Type

Facility Type	Adult Patients/ Residents		Latest DOHC Long-stay Residents	Survey/ DOHC %
	N	Number of Long-stay Residents (%)		
Private Nursing Home	193	7,627 (54%)	9,166	83%
HSE Extended Care Unit	61	4,227 (30%)	5,665	75%
HSE Welfare Home	12	458 (3%)	1,333	34%
Voluntary Home/Hospital	24	1,381 (10%)	2,664	52%
Voluntary Welfare Home	10	411 (3%)	512	80%
All Long-Stay Facilities	**300**	**14,104 (100%)**	**19,320**	**73%**

Figure 5.1 shows the percentage of patients/residents within each long-stay facility distributed by dependency category. Almost two fifths of all patients/residents are maximum dependency, while one third are in the high dependency category. The distribution of dependency matches data from DoHC Long-Stay Activity Statistics where, for all long-stay facilities, 43 per cent of residents are maximum dependency, while 31 per cent are classified as high dependency. There are significant differences across long-stay care settings in relation to dependency. HSE extended care units have the highest proportion of maximum dependent older people at just over 60 per cent; while voluntary welfare homes have the lowest at just under 20 per cent.

Figure 5.1: Percentages of Residents by Dependency Category by Facility



HSE welfare homes have the highest proportion of patients/residents in the low dependency category, clearly catering for a higher proportion of so-called ‘social cases’. These are people who are not physically dependent but, for a variety of reasons, are not able to live at home or with family and friends. Similarly, voluntary welfare homes have the highest proportion of patients/residents in the combined low and medium dependency categories, which together account for 55 per cent of all classified patients/residents in that setting.

Respondents were also asked to give details on the numbers of patients/residents with dementia. Table 5.4 shows that approximately one third of all patients in all long-stay facilities are classified as having dementia. This is slightly higher than the official data from the DoHC, where 28 per cent of all patients are classified as having dementia. Prevalence is highest in private nursing homes where just over two fifths of patients are classified as having dementia. This suggests that the prediction made in Abbey *et al.* (2006) that long-stay care facilities will become the ‘hospices of the future’ caring for people with a long trajectory to death, especially patients with dementia, is relevant in an Irish context. Almost 60 per cent of residents with dementia are classified as having advanced dementia. That proportion rises to almost 80 per cent for people with dementia in voluntary welfare homes. We do not have information on the scale or intensity of dementia in acute hospitals since data on dependency was only collected from facilities with long-stay beds, which excluded all but one acute respondent; the latter was grouped with HSE extended care facilities for the purposes of analysis.

Table 5.4: Patients/Residents with Dementia by Facility Type

Facility Type	% of Patients with Dementia
Private Nursing Home	41.2%
HSE Extended Care Unit	36.4%
HSE Welfare Home	34.7%
Voluntary Home/Hospital	32.5%
Voluntary Welfare Home	16.5%
All Long-Stay Facilities	**32.3%**

5.4 Deaths

Table 5.5 shows that the total number of deaths of people aged 65 years and over in the facilities that responded to the survey was 5,479 in 2006, accounting for 90 per cent of all deaths in these settings during that period. Three fifths of all recorded deaths of older people in the respondent population occurred in long-stay care settings; half of these occurred in private nursing homes. Acute hospitals account for 40 per cent of recorded deaths in the survey. Respondents were also asked if patients/residents are sometimes transferred to their facility to specifically receive end-of-life care. Almost three quarters of HSE extended care units responded positively to this question. Psychiatric hospitals had the least positive response to this question with only 13 per cent of facilities responding that patients/residents are sometimes transferred there to specifically receive end-of-life care.

Table 5.5: Number of Deaths by Facility Type

Facility Type	N	Number of Deaths of People Aged 65+ Years	% Distribution of Deaths	% Transfer for End-of-Life Care
Private Nursing Home	178	1,647	30%	59%
HSE Extended Care Unit	55	1,216	22%	73%
HSE Welfare Home	12	89	2%	42%
Voluntary Home/Hospital	22	248	5%	70%
Voluntary Welfare Home	9	77	1%	44%
All Long-Stay Facilities	**276**	**3,277**	**60%**	**58%**
Psychiatric Hospital	6	26	0%	13%
Acute Hospital	10	2,176	40%	63%
All Facilities	**292**	**5,479**	**100%**	**60%**

Respondents were asked about usual location at time of death in their facility (Table 5.6). The purpose of this question was to investigate whether people usually died in single rooms or in multi-bedded wards. Nearly all residents who die in private nursing homes do so in single rooms. In contrast, multi-bedded ward location at time of death was more prevalent in acute hospitals and psychiatric hospitals at 56 per cent and 57 per cent respectively. Somewhat surprisingly, almost three quarters of HSE extended care units responded that their patients are usually cared for in a single room at the time of death. This contradicts recent evidence on the lack of single rooms for people dying in hospitals in Ireland (Tribal Consulting, 2007). The difficulty may be that the survey instrument seeks information on generic usual location at time of death rather than actual location for named patients/residents, which may have resulted in some overestimation by nurse managers of single room placement. This is supported later in this report by the qualitative analysis of practice and process in six selected sites which suggests that single room placement may be less prevalent than is suggested by the quantitative analysis. The results may reflect the aspirations of nurse managers in terms of their preferred location for their patients rather than the multi-bedded ward reality for patients, particularly within public long-stay facilities and acute hospitals.

Table 5.6: Location at Time of Death by Facility Type

Facility Type	Single Room	Multi-Bedded Ward
Private Nursing Home	97%	3%
HSE Extended Care Unit	74%	26%
HSE Welfare Home	67%	33%
Voluntary Welfare Home	80%	20%
Voluntary Home/Hospital	67%	33%
Total Long-Stay Facilities	**77%**	**23%**
Psychiatric Hospital	43%	57%
Acute Hospital	44%	56%
All Facilities	**87%**	**13%**

5.5 Services and Facilities for End-of-Life Care

5.5.1 Palliative Care Beds

A key element of end-of-life care is the availability of designated palliative care beds. For the purposes of the study, designated palliative care beds are defined as beds that are only used for palliative care. HSE extended care units have the highest number of designated palliative care beds at 49, followed by the private nursing home sector at 41 (Table 5.7). There are no designated palliative care beds in the acute hospitals that responded to the survey. In general, the number of designated palliative care beds in the system is extremely low at 0.5% of all beds. With the exception of the voluntary home/hospital sector, almost all reported designated palliative care beds are in single rooms. It is clear that while all settings provide end-of-life care, with some patients transferred specifically for that purpose, there are very few designated palliative care beds available for patients who need such care.

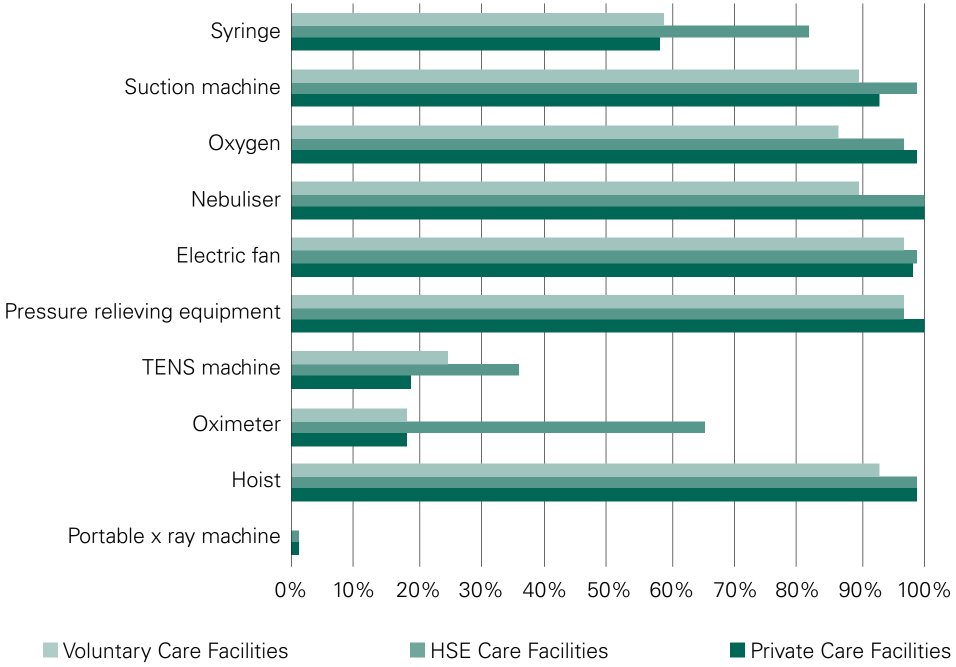
Table 5.7: Palliative Care Beds by Facility Type

Facility Type	Total Beds	Designated Palliative Beds	Designated Palliative Beds as % of Total Beds	Palliative Care Beds in Single Rooms as % of Total Palliative Beds
Private Nursing Home	8,506	41	0.5%	100%
HSE Extended Care Unit	4,408	49	1.1%	96%
HSE Welfare Home	516	2	0.4%	100%
Voluntary Home/Hospital	1,567	15	1.0%	13%
Voluntary Welfare Home	442	0	0.0%	0.0%
Total Long-Stay Facilities	**15,439**	**107**	**0.7%**	**86%**
Psychiatric Hospital	495	1	0.2%	100%
Acute Hospital	4,146	0	0.0%	0.0%
All Facilities	**20,080**	**108**	**0.5%**	**86%**

5.5.2 End-of-Life Equipment

The range and type of equipment that is available in facilities for use in end-of-life care in long-stay facilities is illustrated in Figure 5.2. Because of the range of equipment under consideration, we have aggregated long-stay facility types into three broad categories: public (HSE), private and voluntary settings. The majority of long-stay facilities have the following equipment available: suction machine, oxygen, nebuliser, pressure-relieving equipment and hoists. Syringe drivers, TENS machines and oximeters are less available, particularly within the private and voluntary sectors. Acute hospitals have high levels of access to end-of-life care equipment, with all respondents in this category reporting availability of all types of equipment, with the exception of TENS machines, for which only 73 per cent of hospitals reported availability.

Figure 5.2: Type of Equipment Available by Long-Stay Facility Type



5.6 Staffing Issues

Nurse staffing levels in all sectors were recorded in this survey. The results mirror data collected by Murphy *et al.* (2006) in their study on quality of life in long-stay care settings. Table 5.8 shows that acute hospitals have a qualified nurse to patient/resident ratio of 1:0.6 compared to a similar ratio for private nursing homes of 1:5.3. The ratio for HSE extended care units is 1:2.1. Overall, acute hospitals have, as expected, the best ratios, while public long-stay facilities have better ratios than private nursing homes. Differences in registered nurse staffing levels across facilities may have implications for the quality of care provided to patients/residents at end-of-life.

Table 5.8: Number of Full Time Equivalent (FTE) Nursing Staff by Facility Type

Facility Type	N	Mean FTE Qualified Nurses	Staff: Patient/ Resident Ratio
Private Nursing Home	183	7.5	1:5.3
HSE Extended Care Unit	57	33.4	1:2.1
HSE Welfare Home	12	10.9	1:3.5
Voluntary Home/Hospital	20	19.5	1:3.0
Voluntary Welfare Home	10	7.3	1:5.3
Total Long-Stay Facilities	**282**	**15.7**	**1:3.4**
Psychiatric Hospital	8	85.2	1:1.1
Acute Hospital	12	286.8	1:0.6
All Facilities	**302**	**26.43**	**1:2.0**

This study is particularly interested in the level of experience and education of staff in relation to palliative care and end-of-life care, given that education is the means by which a palliative care approach can be facilitated in all care settings (Froggatt, 2001). Less than one third of all facilities and only a quarter of long-stay facilities reported that their qualified nurses hold a post-registration qualification in palliative care (Table 5.9). This proportion ranges from only 9 per cent of voluntary welfare homes to 42 per cent of voluntary homes/hospitals. In contrast, three quarters of respondents from the acute sector report that some of their nurses have post-registration qualification in palliative care. A higher proportion of all facilities contain qualified nurses with significant experience working in a palliative care setting or have nurses who have attended short courses/training in end-of-life care. Most learning is facilitated through attending short courses/training in end-of-life care rather than through attaining formal credentials.

In relation to other staff, only one third of all respondents responded that their care/support staff had attended short courses in end-of-life care and only 12 per cent replied that doctors/consultants in their facility had received any form of specialised training in palliative care/medicine. Despite performing well in relation to nurse awareness of palliative care, only one third of acute hospital respondents reported that their care/support staff had attended training in end-of-life care. Moreover, only 43 per cent of acute hospitals reported that their doctors/consultants had received specialised training in end-of-life care. Clearly much remains to be done across all facilities to improve education and training among staff in relation to end-of-life care.

Table 5.9: Education and Training in Palliative and End-of-Life Care by Facility Type

Facility Type	Qualified Nurses: Relevant Post-Registration Qualification	Qualified Nurses: Significant Relevant Work Experience	Qualified Nurses: Relevant Training	Care/ Support Staff: Relevant Training	Doctors/ Consultants: Relevant Specialised Training
Private Nursing Home	26%	43%	55%	31%	12%
HSE Extended Care Unit	35%	52%	77%	43%	9%
HSE Welfare Home	18%	46%	73%	42%	0%
Voluntary Home/ Hospital	42%	32%	52%	38%	9%
Voluntary Welfare Home	9%	36%	46%	18%	0%
Total Long-Stay Facilities	**26%**	**42%**	**60%**	**34%**	**6%**
Psychiatric Hospital	13%	13%	38%	13%	13%
Acute Hospital	75%	75%	81%	31%	43%
All Facilities	**30%**	**45%**	**60%**	**33%**	**12%**

5.7 Communication and Liaison with Other Services

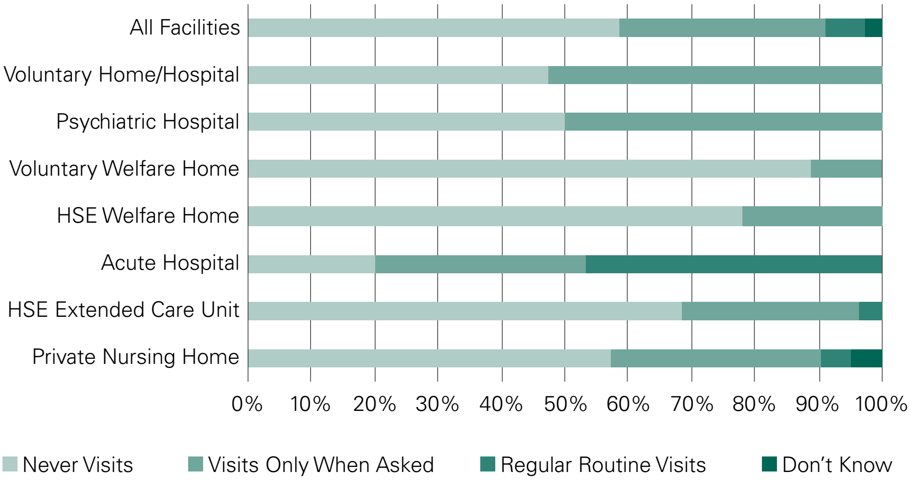
Table 5.10 shows the level of access across facilities to different types of palliative care support. There are generally low levels of access to consultant-led palliative care teams, especially within long-stay facilities, where only two fifths of respondents indicated that they are connected to the service. Access is especially low among HSE extended care units, which is surprising given the public nature of these facilities. Access is also low for voluntary welfare homes where only 20 per cent of facilities indicated that they have direct access to consultant-led palliative care teams. There are generally higher levels of access across all facilities to 24-hour advice on resident/patient care from specialist palliative care services, as might be expected. Approximately two thirds of all long-stay facilities report access to advice, ranging from 27 per cent in voluntary welfare homes to 74 per cent in HSE extended care units. These results correspond to similar evidence from the UK, which found that 65 per cent of care homes there had access to 24-hour palliative care support (Froggatt and Payne, 2006).

Table 5.10: Access to Palliative Care Support by Facility Type

Facility Type	Direct Access to Consultant-Led Palliative Care Team	Access to Advice from Specialist Palliative Care Services
Private Nursing Home	44%	73%
HSE Extended Care Unit	33%	74%
HSE Welfare Home	55%	70%
Voluntary Home/Hospital	46%	73%
Voluntary Welfare Home	20%	27%
Total Long-Stay Facilities	**39%**	**63%**
Psychiatric Hospital	57%	86%
Acute Hospital	63%	56%
All Facilities	**43%**	**71%**

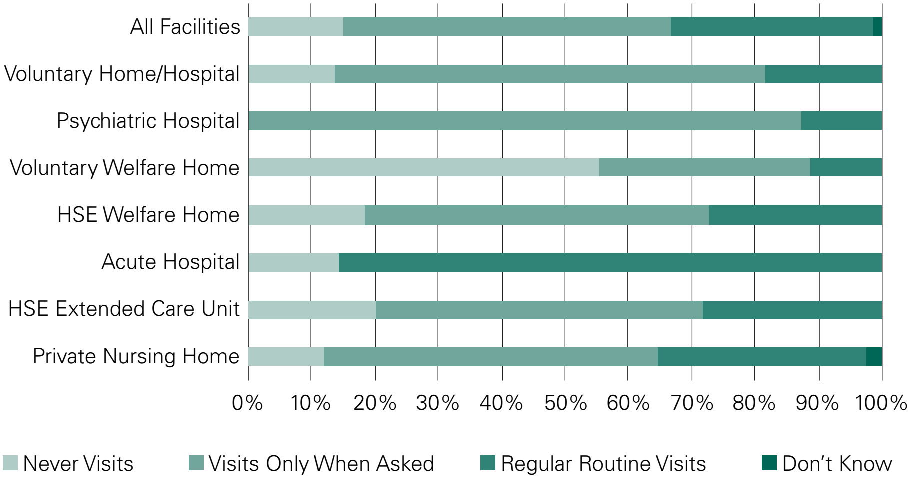
Respondents were also asked about the extent to which a range of external service providers, including consultants in palliative care, clinical nurse specialists in palliative care and other health professionals, visit older people receiving end-of-life care in their facility. More than half of all facilities (57 per cent) never receive any visits from consultants in palliative care (Figure 5.3). The proportion of respondents reporting no visits is lowest for acute hospitals and highest for voluntary welfare homes.

Figure 5.3: Visits by Consultant in Palliative Care



There is a greater level of visiting/provision by clinical nurse specialists in palliative care across all facilities (Figure 5.4), suggesting that they may play a more significant role than consultants in the provision of palliative care services in Ireland. One third of private nursing homes report that the clinical nurse specialist makes regular visits and/or provides services – slightly higher than the corresponding figure for HSE extended care units at just under 30 per cent. However, most of the involvement of the clinical nurse specialist occurs by request; for example, 53 per cent of private nursing homes, 68 per cent of voluntary homes/hospitals and 55 per cent of HSE welfare homes report visits only when asked. These results are similar to the findings of Froggatt *et al.* (2002) who found that much of the specialist work undertaken in nursing and residential homes in the UK was reactive, with the majority of visits instigated by other health professionals, home staff, patients or relatives. This also seems to be the general pattern experienced in Ireland. This may be an efficient use of available resources, but it does little to promote the culture of end-of-life care within the various settings.

Figure 5.4: Visits by Clinical Nurse Specialist in Palliative Care



Visits by health and social care providers to older people in receipt of end-of-life care in private, public and voluntary long-stay facilities are reported in Tables 5.11, 5.12 and 5.13. There is generally low level of routine visiting/service provision from geriatricians, PHNs, social workers, psycho-geriatricians, phlebotomists and counsellor/psychologist/CPNs. These providers are likely to visit only when asked or, in some cases, not visit at all. Such low levels of provision are likely to reflect acknowledged resource constraints, but may also reflect the sequestration of dying people from living people among healthcare professionals. Older dependent people receiving end-of-life care may not only be physically separated from the rest of society through their admission to long-stay care facilities, but they may also be further isolated through the work practices and work patterns of healthcare providers. The priest/clergy/minister of the faith is the most regular visitor to people receiving end-of-life care across all long-stay sectors, reflecting the enduring importance of spirituality for older people. There is also significant visiting by volunteers across the three sectors.

Table 5.11: Visits by Health and Social Care Providers in Private Long-Stay Facilities

Service Provider	Never Visits	Visits Only When Asked	Regular Routine Visits	Don't Know
GP	0.5%	23.1%	76.4%	0.0%
PHN/Community RGN	55.0%	34.5%	10.5%	0.0%
Social Worker	62.2%	30.6%	3.9%	3.3%
Geriatrician	61.0%	33.7%	2.9%	2.3%
Psycho-Geriatrician	39.8%	47.7%	9.7%	2.8%
Medical Officer	57.9%	18.2%	15.1%	8.8%
Phlebotomist	81.9%	8.4%	6.5%	3.2%
Counsellor/Psychologist/CPN	49.1%	36.7%	12.4%	1.8%
Volunteers Visiting	33.0%	15.3%	47.2%	4.5%
Priest/Clergy/Minister of the Faith	0.5%	3.8%	95.6%	0.0%

Table 5.12: Visits by Health and Social Care Providers in Public Long-Stay Facilities

Service Provider	Never Visits	Visits Only When Asked	Regular Routine Visits	Don't Know
GP	22.2%	23.6%	54.2%	0.0%
PHN/Community RGN	56.1%	36.4%	7.6%	0.0%
Social Worker	59.2%	28.2%	12.7%	0.0%
Geriatrician	59.4%	30.4%	10.1%	0.0%
Psycho-Geriatrician	43.5%	46.4%	10.1%	0.0%
Medical Officer	20.0%	16.9%	61.5%	1.5%
Phlebotomist	84.5%	6.9%	8.6%	0.0%
Counsellor/Psychologist/CPN	64.6%	29.2%	6.2%	0.0%
Volunteers Visiting	32.9%	15.7%	51.4%	0.0%
Priest/Clergy/Minister of the Faith	0.0%	15.7%	84.3%	0.0%

Table 5.13: Visits by Health and Social Care Providers in Voluntary Long-Stay Facilities

Service Provider	Never Visits	Visits Only When Asked	Regular Routine Visits	Don't Know
GP	8.8%	32.4%	58.8%	0.0%
PHN/Community RGN	40.7%	51.9%	7.4%	0.0%
Social Worker	67.7%	19.4%	6.5%	6.5%
Geriatrician	51.6%	29.05	16.1%	3.2%
Psycho-Geriatrician	40.0%	50.0%	6.7%	3.3%
Medical Officer	35.5%	22.6%	38.7%	3.2%
Phlebotomist	62.1%	17.2%	13.8%	6.9%
Counsellor/Psychologist/CPN	53.3%	40.0%	3.3%	3.3%
Volunteers Visiting	9.4%	25.0%	59.4%	6.3%
Priest/Clergy/Minister of the Faith	0.0%	12.1%	87.9%	0.0%

5.8 Bereavement Support

End-of-life care encompasses bereavement support facilities that are available to friends/families and carers of patients/residents before and after death. The *NACPC Report* (2001) recommended that bereavement support 'should be an essential part of all specialist palliative care programmes and should be offered in all palliative care settings' (Irish Hospice Foundation, 2006). Overall, there is a low provision of formal bereavement support structures available before and after death within the acute and psychiatric sector in Ireland (Table 5.14). Two fifths of acute hospitals do not have a private space for engaging in confidential consultations with relatives and friends.

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

Table 5.14: Bereavement Support Structures (Before and After Death) in Acute and Psychiatric Hospitals

Bereavement Support Structures	Acute Hospitals	Psychiatric Hospitals
Private room for confidential consultations with relatives/friends	60%	100%
Sleeping facilities for relatives/carers in separate overnight room	7%	0%
Sleeping facilities for relatives/carers in patient's room (e.g. fold-up bed)	25%	0%
Tea/coffee/snack-making facilities for relatives/carers	31%	50%
Quiet room for relatives/carers and/or residents	56%	88%
Mortuary attached to facility/hospital	94%	88%
Regular memorial service for all deceased patients/residents	44%	63%
Specific memorial service for each person who dies	0%	25%
Inform other residents/patients when someone dies	47%	88%
Meet and greet system	63%	88%
Bereavement officer/family liaison nurse	31%	29%
Formal support structures	33%	71%

Figure 5.5 shows the facilities available for family and friends around the time of death in public, private and voluntary facilities. Private facilities generally perform better in respect of the availability of facilities for families and friends visiting residents/patients who are dying. In contrast to the acute hospital sector, the majority of long-stay facilities across the three sectors have private rooms available for confidential consultations with family and friends of the person dying. Quiet rooms are also generally available, although more so in the private sector than in the public sector. In contrast, sleeping facilities for relatives, both in private rooms and on the wards, are in short supply. Public facilities outperform private facilities in the provision of mortuary services, which might be expected given relative size differences.

Figure 5.5: Facilities Available for Family/Friends/Carers in Long-Stay Facilities

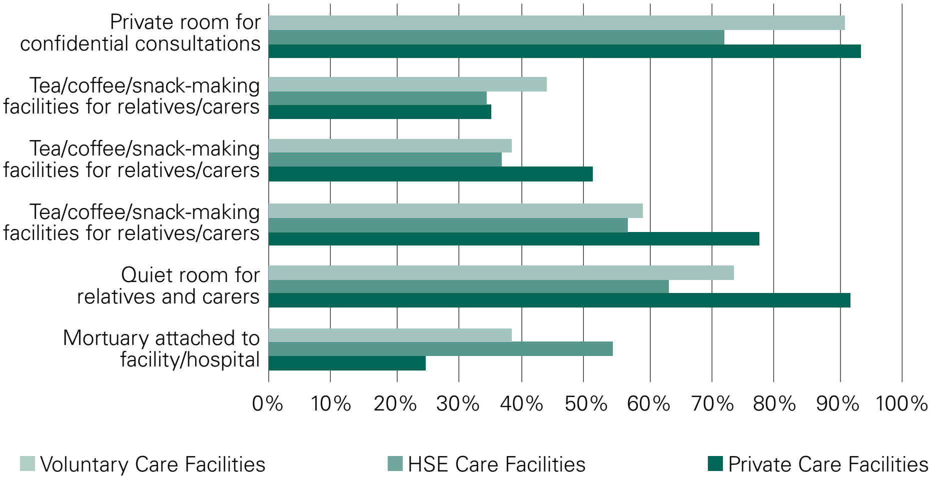
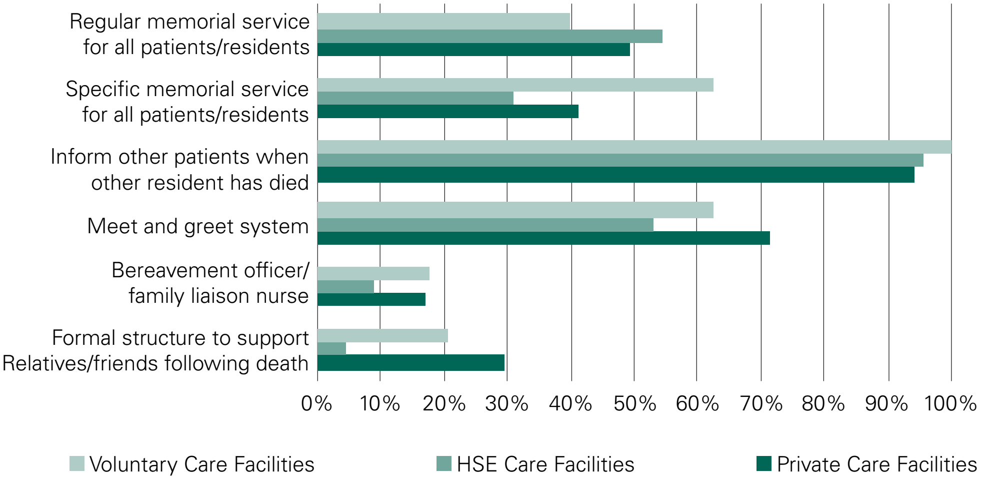


Figure 5.6 shows the availability of bereavement support structures following death across public, private and voluntary long-stay facilities. In general, bereavement support structures for families following death are weak in the long-stay sector and, in some areas, such as the availability of formal support services, weaker than the acute hospital sector. In particular, very few public HSE care facilities report having formal bereavement support structures in place to support the family and friends of the deceased. Similarly, the data shows a general absence of bereavement officers/family liaison nurses within the long-stay sector. The absence of specific or even general memorial services for deceased patients in many facilities across the public, private and voluntary sectors is also noteworthy.

Figure 5.6: After-Death Bereavement Support in Long-Stay Facilities



5.9 Policies and Guidelines

The existence of written policies and guidelines is a key indicator of the level of awareness of issues in relation to palliative care and end-of-life care within hospitals and long-stay facilities. Table 5.15 shows that while written policies on end-of-life care are available in the majority of facilities (80 per cent), they are not uniformly available within the long-stay care sector. In addition, we have no information on procedures and practices within the facilities (20 per cent) without written guidelines. Availability of guidelines ranges from 85 per cent in acute hospitals to 40 per cent in voluntary welfare homes. Written guidelines are more available in the private long-stay sector than in the public or voluntary long-stay sector.

Table 5.15: Written Guidelines/Policies on End-of-Life Care by Facility Type

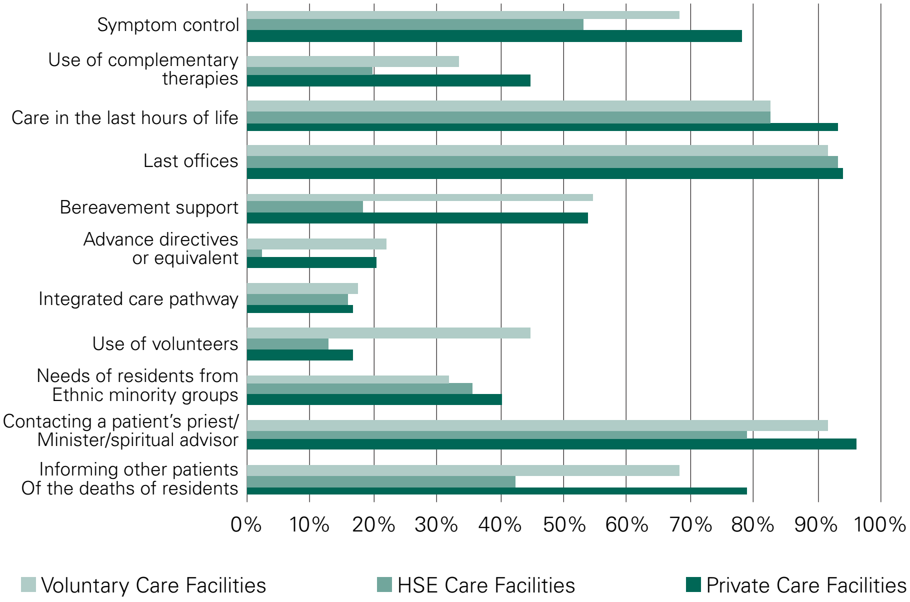
Facility Type	N	Written Guidelines
Private Nursing Home	185	85%
HSE Extended Care Unit	55	76%
HSE Welfare Home	11	55%
Voluntary Home/Hospital	24	75%
Voluntary Welfare Home	10	40%
Total Long-Stay Facilities	**285**	**66%**
Psychiatric Hospital	8	75%
Acute Hospital	13	85%
All Facilities	**306**	**80%**

Figure 5.7 provides more information on the topics covered under written guidelines/protocols/policies within public, private and voluntary long-stay facilities. Care in the last hours of life, last offices and contacting a patient's priest/minister/spiritual adviser are generally well catered for within written guidelines, achieving 80 per cent coverage or above in public, private and voluntary facilities. Symptom control and informing other patients of the deaths of residents achieve or exceed 60 per cent coverage, although there is scope for improvement in relation to each of these policies.

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

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

Figure 5.7: Topics Covered by Written Policies/Guidelines by Facility Type



Respondents were also asked about the participation of their organisations in different quality initiatives designed to improve the quality of care and quality of life of people in long-stay care and at end-of-life. The Hospice Friendly Hospitals Initiative, a new development introduced just prior to the survey, is an important programme in respect of palliative care. Therefore, it is heartening to see that 50 per cent of acute hospitals in the survey had already adopted the programme (Table 5.16). The absence of long-stay participation in this programme is explained by the fact that this initiative is focused mainly on hospitals, rather than evidence of any resistance on the part of the long-stay sector. More than half of all HSE extended care units participate in the Healthy Ageing Initiative in Residential Care (HAIRC), which is also popular in HSE welfare homes. Private sector participation in this programme is, however, only 14 per cent. The Essence of Care Programme has been incorporated into half of all long-stay facilities and just under one third of acute hospitals. Once again, private sector take-up is low, with only 14 per cent coverage reported.

Table 5.16: Participation in Quality Initiatives by Facility Type

Facility Type	Hospice Friendly Hospitals	HAIRC	Essence of Care
Private Nursing Home	9%	14%	27%
HSE Extended Care Unit	5%	51%	88%
HSE Welfare Home	0%	36%	67%
Voluntary Home/Hospital	11%	11%	44%
Voluntary Welfare Home	0%	22%	30%
Total Long-Stay Facilities	**5%**	**27%**	**51%**
Psychiatric Hospital	14%	17%	43%
Acute Hospital	50%	9%	31%
All Facilities	**10%**	**22%**	**42%**

5.10 Meaning and Understanding of End-of-Life Care

The term 'end-of-life care' is a relatively new term in the Irish healthcare setting, therefore opinions on what constitutes its meaning are quite broad and cover a wide range of factors. Recent literature has shown that there is a lack of a coherent broadly-accepted definition of this term (Lorenz *et al.*, 2005; Seymour *et al.*, 2005). As part of the quantitative survey, respondents were asked an open-ended question on their understanding of end-of-life care for older people in their facility. The results are shown in Table 5.17. In defining end-of-life care as opposed to other types of care, there were some differences across facilities. These ranged from 'the quality of care given in the last six months of life' to 'care that is provided when death is expected' to 'not terminal care'. End-of-life care is generally seen as different to other types of care such as terminal care or palliative care. Given the limited profile of end-of-life care in Ireland, this is an encouraging revelation. Maintaining and improving quality of life for patients and their families was also a key factor referenced by respondents in relation to end-of-life care.

In terms of the components used to define end-of-life care, common keywords that emerged from the analysis across all facilities were 'holistic care', 'maintaining dignity', 'pain relief', 'symptom control' and 'open communication'. Allowing patients to 'live until they die' by providing a peaceful, comfortable environment with suitably trained staff appears to be paramount in the provision of this type of care. In addition to caring for patients, catering for the needs of families and friends is also perceived to be important. Meeting both their and the patients' 'physical, spiritual and psychological needs' was one of the most common phrases referred to when defining end-of-life care.

Attending to patients' physical needs requires the use of pain control and symptom relief to ensure the patient is in no discomfort. It is recognised that symptom control should not necessarily include the use of intensive treatment to prolong life; rather it should ensure that the patient is comfortable and can experience a pain-free death – 'cure is no longer or always the goal of treatment'. It was also stressed by some respondents that this type of care should be patient-led and that families should be involved in decisions regarding the type of care that is provided.

In relation to psychological and spiritual care, respondents emphasised the need for appropriate emotional support to allow patients to die in peace and comfort. There is a strong ethos that the provision of this type of care is also available for families and friends so that they, as well as the dying patient, are provided with the necessary emotional support that they require at this difficult time. Within private long-stay facilities especially, there is a strong emphasis on open communication and talking with patients and their families regarding any concerns or anxieties that they might have. 'Forward planning' is also a term that emerged from the responses; ensuring that structures and processes are in place to allow health professionals to anticipate the needs of the patient and their family when death is imminent. This is more apparent in long-stay facilities where staff, patients and families may have developed strong relationships over a longer period.

Respondents also spoke of the need for cultural awareness of end-of-life care in recognition of the growing numbers of multinational patients and residents now occupying long-stay facilities. Staff may also have different interpretations of end-of-life care; migrant care workers may, for example, be influenced by different cultural traditions when it comes to death and dying. Reaching a common understanding of end-of-life care can be difficult, therefore, in an increasingly complex multi-cultural care environment. Providers' own direct experience and understanding of death, irrespective of cultural tradition, may also influence the meaning and understanding of end-of-life care. If staff have unresolved issues themselves with respect to loss and bereavement in their own life, this can affect attitudes to care and the approach to care of the dying.

Table 5.17: Meaning and Understanding of End-of-Life Care for Older People

Facility Type	Key Issues Identified
Voluntary Home/ Hospital	■ Provide holistic care for patients who are dying ■ Respect and dignity during death; provide comfortable, pain-free, peaceful environment ■ Provide for all needs (physical, spiritual, psychological) of the patient ■ Involve the family ■ Emphasise good pain management
Voluntary Welfare Homes	■ Care around time of death for a client and their family ■ Provide a supportive and comfortable environment ■ Respect for desires and wishes of the patient while providing for their holistic needs (physical, social, psychological and spiritual)
Psychiatric Hospital	■ Care for the terminally ill/those nearing the end of their life; death is expected ■ Caring for the dying with dignity and respect ■ Symptom/pain management
HSE Welfare Homes	■ Care for the dying ■ Providing a comfortable, peaceful environment ■ Allow people to live until they die, die with dignity ■ Support the needs of the patient (physical, emotional, spiritual, psychological)
HSE Extended Care Units	■ Providing a peaceful, relaxing, comfortable, dignified, home-like environment during death; when end-of-life is imminent (i.e. terminal illness) ■ Attend to physical, psychological, social and spiritual needs of patient; provide pain relief as they approach death ■ Involving/informing relatives and friends; advising them and listening to their concerns ■ Respecting the rights and wishes of the patient; communicate with patient and family ■ Kind, compassionate and supportive staff ■ Care that ensures the quality of life until death, patients live until they die

Facility Type	Key Issues Identified
Private Nursing Homes	■ Holistic, person-centred, patient-led care ■ Treated with dignity and care ■ Providing for a pain-free and peaceful death ■ Providing physical, psychological and spiritual care ■ Maintaining/helping to improve quality of life ■ Care for people no longer receiving intensive treatment ■ Relieving anxiety about death by talking to patients ■ Supporting relatives and caring for the resident ■ Forward planning/anticipation of needs ■ Quality of care given in last six months ■ Care delivered through evidence-based dignified manner ■ Not just terminal care
Acute Hospitals	■ Holistic individually planned care ■ Die with dignity ■ Good symptom control ■ Spiritual/religious/psychological support ■ Pain-free and comfortable death ■ Good communication ■ Involves cancer and non-cancer patients ■ Provide best quality of life for patients and their families ■ Cure is no longer the goal of treatment

5.11 Perceptions of Good End-of-Life Care

Respondents were also asked to identify the principal/key factors that contribute to the provision of good end-of-life care for older people (Table 5.18). Given some of the differences that were outlined above, it would be expected that there would also be some differences in facilities' perceptions of what constituted good end-of-life care. Many of the components of end-of-life care that were referred to in relation to 'meaning and understanding' were reiterated such as 'pain control', 'physical comfort', attending to 'physical, psychological and spiritual needs' and 'open communication'. This again accords well with the documented literature (Singer *et al.*, 1999).

Across all facilities it is clear that providing for a pain-free, comfortable death, where the patients' needs, both physical and emotional, are satisfied is high on the agenda of what constitutes 'good end-of-life care'. To achieve this, it is necessary to nurture and support a person-centred approach to care involving well-trained, educated and supportive staff who are aware of end-of-life needs of patients from an early stage of the process. Making the patient aware of their prognosis and encouraging them to make decisions regarding the type of care that they would like is an important aspect of care. Involving family in the care of the patient is also a priority; this can be done by keeping relatives informed of the condition of the patient, allowing frequent and flexible visiting, and having appropriate facilities for relatives to use while visiting.

Differences do, however, emerge with regard to the level of engagement that facilities have with both patients/residents and their families. Private nursing homes particularly refer to the need for staff to be comfortable with death so that they can discuss openly with patients and families any concerns that they might have. Taking the time to listen to patients and comfort them on their 'final journey' is clearly a central component of the type of care provided in the smaller long-stay facilities, both private and public. Respondents from smaller facilities spoke of the importance of 'continuity of care' in respect of the provision of end-of-life care. Staff in smaller facilities may have more opportunities to build relationships with patients and their families over a longer period of time and, therefore, may be better able to anticipate patients' needs as they advance through the final phase of their lives.

Differences exist with regard to the range of staff who are involved in patients' care. Acute hospitals have a greater level of specialised care available in their facilities and this is apparent in their responses to this question. They particularly refer to the availability of specialist services such as CNS in Palliative Care, counsellors, Pastoral Care Teams and social workers. Good links with homecare services are also referred to through the availability of Community Liaison Nurses. Availability of these specialist services is not apparent in other facilities wherein the only external service providers referred to are Specialist Homecare Teams, Pastoral Care Teams and GPs. Given the lower level of specialist services available, these facilities are limited in the type of therapies they can provide to patients. Respondents were adamant that access to specialist palliative services was important for good quality care. Some spoke of the need to bring these services to patients rather than having to move patients to avail of services. Integrated provision of care was seen as critical to good quality care. People wanted a palliative influence within long-stay settings, but it had to be integrated with existing care structures and processes and reflect the lived experience of all of the patients/residents in the setting from time of admission.

Education and training are identified as key components of good quality care. Respondents from all facilities highlight having suitably trained staff as critical to the caring process. That awareness translates into action in many cases through the attendance of staff at short training courses and bereavement support training. The importance of education and training seems to be particularly strong in smaller facilities where people are conscious of their separation from specialist services. Overall, the majority of facilities do realise the importance of knowledge in the provision of good end-of-life care for older people. Unfortunately, the level of formal education and training programmes available may not be able to meet current needs in this regard. This is an area that requires further investigation.

The availability of single rooms is one of the most common key factors referred to in the provision of good end-of-life care across all facilities. This provision appears to be available in private nursing homes but is less available elsewhere. Respondents spoke about the unsatisfactory nature of people dying in multi-bedded wards and its impact on the dignity of patients and their families. The importance of having a family room available to provide family and friends with a greater level of privacy was also mentioned as important. The availability of privacy for patients and their families is not as apparent in acute hospitals as it is in long-stay care settings, with only some facilities referring to the availability of private rooms for patients, and none referring to the provision of family rooms. Overall the message is one of the importance of holistic, person-centred end-of-life care that goes beyond pain relief or symptom management and involves the dying and their families.

Table 5.18: Perceptions of Key Factors Contributing to Good End-of-Life Care

Facility Type	Key Factors
Voluntary Home/ Hospital	■ Relaxed, friendly, comfortable, peaceful, supportive environment ■ Meet all the needs of the patient: physical, psychological, spiritual, social, emotional ■ Provide privacy, single rooms ■ Involve family, keep relatives informed, allow visiting freely, have facilities for relatives ■ Symptom management, pain-free ■ Good communication, discuss anxieties surrounding death ■ Well-trained, caring staff
Voluntary Welfare Homes	■ Provide comfort, pain relief and privacy (single rooms) ■ Opportunity to spend time with and talk to friends/family; have facilities for relatives ■ Caring, sensitive staff who form trusting relationship with patient, providing personal care ■ Spiritual support/ pastoral care ■ Warm, safe, friendly environment

Facility Type	Key Factors
Psychiatric Hospital	■ Staff that are committed, well-trained and have a positive attitude ■ Facilities that provide privacy and enable family and friends to visit ■ Treat patient with respect and dignity ■ Spiritual support/dignity
HSE Welfare Homes	■ Support from family and staff at a physical, social, psychological and spiritual level ■ Pain/symptom control ■ Privacy, single rooms, comfortable environment ■ Staff insight, knowledge, experience and dedication
HSE Extended Care Units	■ Patient-centred care: dignity, respect and privacy for patient ■ Staff who are caring, sensitive, motivated, well-trained and educated; good staffing numbers ■ Pain relief, symptom management ■ Meet all the needs of the patient: spiritual, physical, psychological, social, emotional ■ Create comfortable, peaceful environment ■ Good communication and active listening ■ Involve family and friends: flexible visiting, facilities for relatives, keep them informed ■ Palliative care team, pastoral care team ■ Quality time spent with patient, family and staff
Private Nursing Homes	■ Staff comfortable with death ■ Individual care plans in place ■ Patient aware of prognosis and encouraged to make decisions about care ■ Good staff/family/resident relationships with good communication; allowing for continuity of care ■ Providing physical comfort and pain control ■ Family room to allow for privacy for families/friends ■ Attending to spiritual and psychological needs ■ Comfortable environment with single rooms ■ Support from Specialist Homecare Team ■ Education and staff training in bereavement support ■ Time to listen, comfort patient on their final journey
Acute Hospitals	■ Provision of palliative care services ■ Homecare support ■ Single room for patients who are dying ■ Availability of counsellor/spiritual support ■ Use of complementary therapies ■ Refreshment facilities ■ Open communication between all involved in patient care ■ Interdisciplinary team ■ Meeting needs of families ■ Educated staff

5.12 Barriers to Delivering Good Quality Care

Respondents were also asked to identify the key barriers/constraints that currently prevent their facility from delivering the best possible care to older people who are nearing the end of their life (Table 5.19). This question has been reviewed in the literature (Brazil *et al.*, 2006) in which potential barriers were clustered into three main groups: a facility's capacity to provide palliative care; education and support; and the need for external resources. These issues are well aligned with the responses received in this survey, although divergent views across facilities emerged as to the key barriers. For everyone, however, lack of funding is a major issue as without the appropriate financial resources no improvements can be made. All sectors indicate a lack of funding as an impediment to the provision of optimal care in their facilities.

Lack of trained staff was a key issue for all facilities. For example, respondents from the private nursing homes sector expressed concern that some of their staff had no previous experience with death. Without common training it was difficult to establish an ethos of care that put the patient first. Increases in staff from other countries are also leading to communication problems, according to respondents. The provision of personal care at the time of death requires a high level of communication and if staff cannot communicate because of language problems then care is likely to suffer. This is also true on the other side, with concerns expressed that patients of other nationalities are not receiving optimal care as Irish staff have little knowledge of their spiritual and cultural beliefs. Therefore, even if staff are doing their utmost to provide the best possible care, gaps may still exist if the patients' spiritual and emotional needs are not being attended to because of lack of knowledge. Increased training is seen as necessary to address all of these issues.

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

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

The presence of family and friends at the time of death may also create problems. Some respondents referred to the lack of respect shown to health professionals by family members visiting the patient. Others highlight the problem of overcrowding when there are too many friends and relatives visiting a patient, particularly in smaller facilities where there is a lack of space. Uninformed relatives, family disharmony and lack of respect for patients' wishes also appear to be problems that can interfere negatively with the caring process at end-of-life.

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

Table 5.19: Barriers to the Provision of Good End-of-Life Care

Facility Type	Key Barriers
Voluntary Home/ Hospital	■ Lack of space, not enough single rooms ■ Limited staff knowledge/expertise; need more training ■ Lack of funding/financial resources ■ Limited community involvement ■ Not as much time for relatives as hoped
Voluntary Welfare Homes	■ Not enough quality staff; hard to meet needs of patients ■ Limited financial resources ■ Interference in care plan (i.e. patient gets relocated) ■ Not enough privacy (i.e. single rooms, palliative care beds)
Psychiatric Hospital	■ Lack of educated staff; poor training and attitude ■ Poor facilities, not enough space for single rooms or for relatives
HSE Welfare Homes	■ Unsuitable facility/environment; lack of designated palliative care beds, no family room, no private room ■ Staffing constraints: lack of available staff, lack of training, low staffing levels ■ Funding constraints/ financial issues
HSE Extended Care Units	■ Lack of space, no single rooms ■ Inadequate staffing levels (leads to difficulty meeting needs of patients) ■ Budget constraints, lack of resources ■ Lack of facilities for relatives ■ Poor communication ■ Time constraint ■ Different views on 'end-of-life' care; cultural differences ■ Bereavement counselling not always available ■ Lack of palliative care specialists
Private Nursing Homes	■ Lack of space – no provision for relatives' room or snack-making facilities ■ Cultural differences – knowledge of all religious needs ■ Lack of trained staff – staff have no previous experience with death ■ Inability to provide pain control in nursing homes where staff cannot prescribe drugs ■ Attitudes of visitors – lack of respect for health professionals ■ Lack of cooperation between hospitals/HSE and nursing homes ■ Lack of external support from health professionals e.g. GPs & specialist palliative care services ■ Offering support to staff who may know patient for a long time ■ Insufficient staff numbers and multicultural staff who do not understand issues involved ■ Lack of bereavement support services for family members

Facility Type	Key Barriers
Acute Hospitals	■ Not enough single rooms/lack of privacy ■ Lack of palliative care consultants ■ Lack of training and education for medical and nursing staff ■ Having to continuously move patients who are dying ■ Lack of hospice beds or community services to enable transfer of patients ■ Busy hospital environment/patient mix/noise levels ■ Lack of dedicated space for older people who are dying ■ Access for palliative care only for cancer patients ■ Limited facilities for relatives ■ Lack of communication

5.13 Conclusion

This chapter has identified services and facilities within acute hospitals and long-stay settings with respect to end-of-life care in Ireland. These settings contain many older people who are already on the journey to death, even if death for some is not imminent. There is an awareness of the importance of end-of-life care among staff in the various settings but also a recognition that much work needs to be done to develop a shared understanding and ethos of care that is person-centred and allows people to die with dignity. Education and training of staff are essential to this process.

The physical infrastructure is poor in many facilities. Care at end-of-life is provided in multi-bedded wards, especially in public facilities, making it difficult to guarantee privacy and dignity. Investment in physical infrastructure is needed urgently, in public facilities in particular, for optimal provision of care.

The absence of specialist provision and support is also an issue, particularly in long-stay care settings. This can lead to inferior quality care, poor pain management and unnecessary transferring of patients. Bereavement support also needs to be enhanced at all levels, including the provision of facilities for families around the time of death and the provision of formal emotional support services following death. Policies and guidelines in respect of end-of-life care also need to be formalised, particularly in respect of advance directives, bereavement support and the needs of people from minority groups.

While all issues to do with end-of-life care cannot be captured in a survey such as this, we now, at least, have a benchmark against which future progress can be measured. There are significant gaps in provision, and services and facilities are poorly provided in some settings. While much work remains to be done to enhance services and facilities, there is a willingness among respondents to engage with best practice in end-of-life care. This makes it more likely that we will see improvements over time in quality of care, provided that new initiatives and resources can be agreed.

Chapter Six

Living, Dying and Relationships within Acute and Long-Stay Settings

Chapter Six

Living, Dying and Relationships within Acute and Long-Stay Settings

6.1 Introduction

In the following three chapters, the findings from the staff and patient interviews are reported. Although written as discrete chapters, they represent an evolving description of the patient experience of dying and death in acute and long-stay care settings. They describe an oscillatory path of deteriorations and improvements over time, eventually resulting in a terminal, yet unpredictable, state of decline. For this reason, many of the patients interviewed were aware of their poor health, but not that it necessarily indicated their dying, since they had 'bounced-back' on previous occasions.

Views are documented from across the continuum; from first realisations of deteriorating health through the reality of the dying experience to personal expectations of a good death. Information is provided on the way that end-of-life care is managed and organised. Additionally, the perspectives of the direct caregivers and managers of that care are also reported. This is necessary to provide a contextual framework in which to consider the totality of the end-of-life experience. The findings are described under three distinct yet interrelated themes: living, dying and relationships within acute and long-stay settings; transitions into dying; and organisation and ethos of care. This chapter considers issues of living, dying and relationships, beginning with the experience of increasing frailty.

6.2 The Experience of Increasing Frailty

Frailty was described by most patients as a decline or recognition that improvement in response to treatment and care was slower or less than expected. The degree of frailty experienced by patients was variable, with some patients able to retain greater independence than others. Patients who had experienced urgent and unplanned deterioration in their health (such as a fall, stroke or unresolved infection) were very conscious of a major change in their health status. Some patients likened frailty and decline to the dependency of childhood:

Of course, I mean I'd love to be able to walk around the room and to the loo on my own, but I need help everywhere you see. But I can't dress myself now and I can't undress so there are a lot of restrictions, but I can do nothing about it. (GRT5, Patient 03, Voluntary Home)

Yes, I got a stroke there in October, I was in bed one night, I went up to bed as a 77 year old man, got up the following morning a two year old. Only had one leg, one hand. (BLT6, Patient 01, Extended Care Unit)

I was like a baby, I had to go around and learn how to walk. (BLW4, Patient 01, Extended Care Unit)

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

Well I'd be in bed and out of bed, I feel weak, I have been so long in bed that I feel fairly weak, it's a similar, since I came here, well I have improved a bit but not as much as I thought I would have, you know. (BLW4, Patient 02, Extended Care Unit)

I am, I feel, a little bit better now but, I'll go home but I don't think I'd be really able to manage on my own. (SAZ12, Patient 03, Acute Hospital)

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

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

Patients were not always resigned to frailty as an inevitable consequence of ageing. One lady with a dense hemiplegia to her left side remarked how the staff would enlarge a copy of the crossword so that she could see it sufficiently to complete as part of her cognitive and motor skills maintenance programme.

6.3 Activity and Occupation

Both staff and patients from all care settings considered activity and occupation an important enhancement to patients' quality of life. However, the range of activities varied between different care settings and overall, there was concern expressed by staff regarding a lack of opportunities for patients. It was particularly noted that those without families or those who were immobile were particularly disadvantaged:

> If they don't have an awful lot of family you know they are left sitting in the chair all day – the only interaction they get is with us when we come in to assist them with some part of their daily lifestyle. So they need … it is horrible to see that you know. And then they get depressed and everyone is wondering why they are depressed. (SA12, Staff 01, Acute Hospital)

> It's nothing, they're got up in the morning now and, like, they're sat into chairs and they're left there all day long looking out the window and then go back in to bed. I think it's terrible. (BL6, Staff 02, Extended Care Unit)

Clinical support services that had the possibility of improving quality of life were also lacking. Staff expressed regret that there were not more therapeutic interventions such as physiotherapy, occupational therapy and alternative therapies including massage. They suggested that the latter would enable older patients to relax, unwind and communicate more freely:

> We had far more services for elderly care going back a number of years ago here, like the input of physio and OT into wards. Now is very, very minimum really. (BLW6, Staff 03, Extended Care Unit)

> I think they need more occupational therapy, more physiotherapy but these services are not provided for them. (BLT6, Staff 04, Extended Care Unit)

There were some examples of excellence in therapeutic services with patients and families, particularly in relation to the use of aromatherapy massage. Staff regarded these services as having a very good effect on well-being, particularly for those unable to communicate verbally. However, a range of supportive therapies was only available in one of the six sites investigated and, overall, there was insufficient attention given to the wide range of activities deemed both possible and necessary to promote good life quality for older people:

> Mary [name changed] is the aromatherapist and they love her. Even people that are ill … she'd go up and give them a massage and play lovely music and you know those scented oils, you know. And they love it and she even does it for the families as well if the families want to. So that's great. (GR5, Staff 08, Voluntary Hospital)

6.4 Personal and Professional Relationships

The value of creating and sustaining relationships was important to understanding the end-of-life experience from both professional caregiver and patient perspectives. In the following sections, three sub-categories of the 'Personal and Professional Relationships' theme are described: knowing the person, a sense of belonging and the meaning of loss.

6.4.1 Knowing the Person

The description of relationships encompassed the importance for staff of 'knowing' the patient and family in order to ensure that the best possible quality of care could be given. For the patients, they particularly appreciated the common courtesies, such as being greeted by name:

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

Knowing the patient was an important component of providing both day-to-day care and care in the period immediately preceding, during and after death. This was particularly noted in long-stay institutions where patients may be resident for a number of years. Patients did not specifically identify staff members as being particularly close to them, but described their relationships with staff in warm, if somewhat general, terms:

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

Conversely, staff also felt that creating a close relationship with the patient at an individual level was an important determinant of quality care in order to interpret treatment and care wishes when communication was no longer possible:

> Well, I call it chain-linking, you know. You find something that someone is interested in and … you get to know the person's likes, dislikes, qualities. That's why when somebody first comes into the home, because some people are here for just a respite purpose, some people are here long-term, and then when it comes to the end-of-life, you have a good picture of what that person likes or the person doesn't like. (PIX48, Staff 04, Private Nursing Home)

Staff also described how getting to know the person enabled them to distinguish between normal behaviour patterns and episodes of distress that warranted referral and intervention by another member of the team. A number of staff indicated that they did indeed form close attachments to their patients during their lifetime, their dying and in memory after their death:

> I mean you do get to know, you know maybe when they were upset or they're worried or, you know, if anything is bothering them or would they like to maybe have a chat with you or the pastoral care sister. (BL6, Staff 03, Extended Care Unit)
>
> How do we know? Well they're, I suppose when you're nursing the elderly for such a long time you know exactly. You know about their general condition and they're like a second family. (BLW6, Staff 01, Extended Care Unit)
>
> I have seen nurses come in here in their own time and hold a man's hand when there be no one else to hold his hand, or attendance or care assistance was there long beyond their time to be with him a man that's dying who has no one to hold his hand you know. It makes me cry to think it. (BLT5, Staff 05, Extended Care Unit)
>
> You get attached to them and then all of a sudden they're not there any more and you still, we still, mention (name), she's dead about two or three years, something would come up: 'Oh do you remember (name) doing this?' (BLT6, Staff 02, Extended Care Unit)

Some staff, particularly care assistants, revealed that they had been advised not to form any close attachment to the patients, based on an ethos of keeping a professional distance from them. However, these were the views of a minority of direct care staff and a strong sense of the caring ethos was evident, both in the descriptions of staff-patient relationships and from the patients' appreciation of that caring:

> You know they're elderly, they are going to pass on … and they say don't get attached because it'll upset you and it'll interfere with your work. Now I haven't been told that here, but in other nursing homes that I've worked in and I thought it wasn't very nice. (PIX33, Staff 01, Private Nursing Home)
>
> We would do anything we can to make that patient as comfortable and that's it, there's no ifs or anything, there is not such thing as 'it's not my job' or 'it's not my duty. I'm not getting paid.' You just do it and it's not even questioned you know. (BL4, Staff 05, Extended Care Unit)
>
> Kindness yeah, exactly the kindness yeah. They're so obliging you know. (GRT5, Patient 01, Voluntary Hospital)

6.4.2 A Sense of Belonging

Specifically where patients were in long-term care, many staff saw the care setting as the home of the patients. They tried to accommodate the individual wishes of the patients and make their visitors welcome. In some care settings, there was a sense among the patients that the facility was a 'home away from home', particularly if they lived there for many years:

> We can get very attached to the patients – it's really their home. (GRT5, Staff 02, Voluntary Hospital)

However, not everyone shared this view and some patients just longed to be at home. These patients did not feel that their current accommodation was 'home-like' and suggested that their care was focused on the routine of the staff rather than their personal wishes. For example, it was perceived by one patient that if staff wanted to leave early, she would have to go to bed early.

Other patients just wanted to be in their own home and it was this desire to be at home rather than anything particularly lacking in the care setting that prevented them from feeling at home. For example, one patient said he just wanted to be at home sitting in his own chair. One of the staff members suggested that some people never settle in residential care – their sense of loss of freedom prevented them from entering fully into life in the care facility. It is notable that this specific problem was only described by patients resident in private nursing homes and not in the other care settings of the study:

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

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

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

Staff also noted that patients developed close friendships with other patients, particularly when sharing a room. This was a significant source of support and social interaction for them and included an extended relationship between patients and their friends' family. Overall, it seemed that staff in the sites visited generally created an environment which fostered sustained connections:

> When they're in a double room they actually become close, you know. They become friends, they look after each other and things like that, and we've had one recently you know and they were the best of friends, used to constantly be looking after each other and things, you know, because she was in bed and like the two of them used to be up every morning and helping each other get each other dressed and things, but we just explained to her friend that you know she was really, really ill and it was her time to go and she just understood that like you know, and the resident that was actually dying. (PIX33, Staff 01, Private Nursing Home)

6.4.3 The Meaning of Loss

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

> I had a kind of a tentative booking here then, so the day he [husband] died I came in here. I was caring for him for about seven years at home … Well there was because there was a room booked and I mean I might have lost it if I didn't come here. We all have to make hard decisions in our lives and I couldn't ever live at home again anyway because I had to sell my home and my car and I have, my peripheral vision is non-existent and my other eye isn't too great either, but I would never be able to drive a car again, and I couldn't live on my own. I had a lot of control over it insofar as my family just, we are a very close family so there was no, there was no concern about it overall. It was just that I went to my husband's funeral from here. (GRT5, Patient 03, Voluntary Hospital)

Some had lived alone for many years or had lived with other family members prior to the transition to the care setting. This sometimes translated into a desire to be reunited after death with partners and/or relatives who had already died. There was also evidence that staff took trouble to sustain those links during the final days of a person's life and into their death:

> A great comfort altogether. You learn things from that. So I'm going to meet them all above. So there'll be the two of us and she saying 'why did you do this and that?' (laughing). I always quote the words of St Paul. He was a great

> man. And he would say, 'no eye has seen, nor ear heard, nor mind conceived the things God has prepared for those who love me.' It's grand to know and believe it with your heart and soul there's something wonderful waiting for you. It makes the whole process easier. (GRT5, Patient 05, Voluntary Hospital)

> This particular lady had a knitted doll that she told me her grand-daughter had knitted. Nine years old and the doll meant a lot to this woman. So every day when we wash her and freshen her up and all that we talk about the doll and when she did die the last thing I did was put the doll in beside her you know … to me it was a connection you know. It meant a lot to me to be able to do it. (SAZ12, Staff 01, Acute Hospital)

Conscious of losses in patients' lives, staff emphasised continued family involvement with the patients. Continuing interaction with family and friends was seen as contributing to patients' psychological well-being: one of the patients interviewed was surprised and pleased that the staff made an effort to get to know her family and made them welcome, greeting her sister by name when she visited. Staff clearly indicated that a strong relationship with the family was valued and encouraged:

> You get to know them and you get to know their bad ways and good ways and what way to take them and the family as well … You get very attached to them like. And the families as well. (GRT5, Staff 08, Voluntary Hospital)

> If a new patient is coming in now we just tell the family we know they can come at whatever time … We're happy to see them coming in and all that. (BLW6, Staff 01, Extended Care Unit)

The importance of a strong relationship with families became more apparent as the patient's death approached. Examples of trying to accommodate families at this traumatic time were given by staff, although the facilities to meet this need were variable and a source of concern to staff:

> The last few people that died we had mattresses that you could just throw on the floor and sleep in the room with the people themselves. (GRT5, Staff 07, Voluntary Hospital)

> Well, we actually have a room on the third floor and it's for family, for the families of people who are passing away if they want to. Like if someone is dying but it's taking a little longer there's a room on the third floor for the families to go to if they need a rest. (PIX33, Staff 01, Private Nursing Home)

6.5 Conclusion

The findings suggest that patients retain a strong capacity for living even in the face of physical frailty. They are, for the most part, fully engaged individuals for whom both internal (within the care setting) and external (family and community) relationships remained important. Experiences of care provision are largely positive from the patient perspective, although there are noted weaknesses in the provision of activities and services to support the social and rehabilitative needs of patients. There are acknowledged dangers into reading too much into positive patient satisfaction data given unequal power relationships within existing service paradigms. However, staff showed an awareness of patient needs, particularly in relation to their desire for greater connectedness with their inner selves and with other people. There is also evidence that the nature and intensity of relationships are mutually sustaining for both patients and direct care staff.

Chapter Seven

Transitions into Dying

Chapter Seven

Transitions into Dying

7.1 Introduction

In this chapter, the findings in relation to patterns of life closure are described. The analysis defined four sub-categories which demonstrate the experience, impact and care context of death and dying for the patients interviewed. As one purpose of the qualitative findings is to focus on the patient experience, the chapter begins with a description of patients' accounts of death, followed by their perceptions of a 'good' death. Issues relating to the management of symptoms at end-of-life are also discussed. To conclude the chapter, staff perspectives are addressed, including professionals' recognition of, and the rituals and practices associated with, dying and death.

7.2 Older People's Accounts of Death

One of the challenges of this report was to find ways to sensitively elicit the views of older people on death and dying. Ethical constraints meant that the subject had to be approached indirectly. Maybe that is why dying, when raised by the patient, is frequently described in terms of the death of others; either members of their own family or of other patients. Patients usually recognised certain signals that somebody else was about to die although only a very small number discussed their own impending death. Where this was explicitly acknowledged, being able to achieve a sense of closure over their life was important for respondents. Patients often rationalised their deaths through a belief in God who would decide on the time and manner of death. They spoke about death as a normal and inevitable part of the life-cycle, over which they had little influence. Some patients reported that they not only accepted death but actually looked forward to it as a way of meeting again with family members who had pre-deceased them. This belief appeared to sustain them in the face of death. In most cases, death was perceived to be beyond their control:

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

> No, no, God no. I'm looking forward to it. Because I know I'm going to meet (those who died) before me. You know the Catholics and priest and all my reading of the Bible. (GR5, Patient 05, Voluntary Hospital)

Patients' first exposure to the dying process was signalled by someone being moved when close to death. Some staff interpreted this as a positive thing, reducing the anxiety and burden to the other patients, particularly if they were sharing a room:

> I seen them go upstairs. And he went upstairs and I was told he died … If you go upstairs, anyone that went upstairs they died … that's the way, you get sick and you go. A lot of them went upstairs and died up there. They went away, that's the way to look at it you know. A lot of men went upstairs in a wheelchair and you are gone the next morning. (BLT6, Patient 03, Extended Care Unit)

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

Patients also shared their feelings about the impact of the death of other patients to whom they had become close. Staff generally handled this area with sensitivity and kindness:

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

Although patients adopted a somewhat fatalistic attitude towards their future and the likelihood of death, a 'good' death was described as one which was neither protracted nor painful. Additionally, death did not always imbue fear, often related to the belief that they would be reunited with someone already dead:

> Well I can only hope that my future goes alright … I didn't bother about it when I was 30 so there's no use worrying my life away, whatever is left. (SAZ12, Patient 01, Acute Hospital)

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

7.3 Experiences of Symptom Management

This section examines the resident/patient and staff experiences of the management of complex symptoms at end-of-life. The data represents patient experiences of living with complex symptoms, their perception of their clinical management and, secondly, clinical assessment and management, including the referral to and use of specialist palliative care services.

The description of knowledge, skills and attitudes required to provide optimal end-of-life care mirrored the physical, psychosocial and spiritual triad which underpins good palliative care practice. Most staff had some knowledge of the principles associated with pain management, such as anticipation of need and regular evaluation of outcome. Furthermore, it was apparent that many services were supported by at least a specialist palliative care nurse in conjunction with a local physician or GP and that there had been significant changes in understanding of the palliative care role. Patients generally found a responsive approach to their symptoms. Sometimes, however, patients' descriptions of their pain management were suggestive of gaps in knowledge regarding principles of pain management, such as explanation about medication and the avoidance of sub-therapeutic doses:

> No I haven't been in pain at all. They're very good for giving you tablets, painkillers. They'd get a doctor if you were in pain. The first night I came in I was in very severe pain with the breathing and they got a doctor immediately for me and he diagnosed what he thought might help and I found them very helpful. (SAZ12, Patient 01, Acute Hospital)
>
> I'm getting some what a tablet or, I'm getting something. I don't know what it is, it's not doing no harm anyway. (PIX48, Patient10, Private Nursing Home)
>
> Sometimes I get loaded in the water, you see, and I get Panadol sometimes and that's as near as they can go. (PIX48, Patient 04, Private Nursing Home)

Most staff did recognise that the practice of good pain management was a key feature of optimal end-of-life care. The need for rapid response to patient need was emphasised and staff were keen to indicate that systems and trained personnel were available to address symptom needs quickly:

> If a doctor prescribed a different pain medication we wouldn't wait hours to get it from pharmacy, we would get it immediately. Oh yeah the patients would take priority. (GRT6, Staff 03, Voluntary Hospital)

Staff described the types of analgesia commonly used in the treatment of chronic intractable pain often associated with end-stage cancer pain, such as the use of oral morphine tablets (MST) and transmucosal analgesia. They also described clinical cases where oral medication was not seen as sufficient and a subcutaneous syringe driver was introduced to provide continual delivery of analgesia over a prescribed period:

> If they are very bad, they do the morphine patches, you have on them and then if they need we'll say more pain relief than that, then the hospice nurses usually tell them what to give them out, I think they do. I'm not too sure. (BLW6, Staff 02, Extended Care Unit)

> If a person was in a lot of pain they probably increase the patch – like Durogesic: we use a lot of that here. We usually start with a low dose of maybe 25 then we go up to 75 and at that stage if a person still has pain we do call the hospice team in you know. (BLT6, Staff 01, Extended Care Unit)

> You know at that stage, you know, the patient would be on the morphine pump, you know the day before that they possibly would have been having some sort of cyclomorph [combined morphine and anti-emetic injection], things like that, regularly for pain relief, and then if things deteriorated we would have some, would have got the pump prescribed by the doctor and then to start the pump ourselves. (SAZ12, Staff 03, Acute Hospital)

The descriptions given regarding pain management showed a marked variability in practices between the centres, particularly dictated by the access to specialist support services. The acute hospital setting, for example, would have been able to access the hospital-based palliative care team for clinical advice and guidance. In the voluntary hospital and private nursing home, much palliative care was provided by local GPs, some with extensive experience in the field, largely on a visiting or consultation basis. In some centres, palliative care advice was provided by a nurse specialist visiting the centre. Again, this was on a consultation basis and dependent on the referral system. Overall, support from the specialist services was welcomed by staff:

> Oh we'd only see a palliative care nurse. There would be a team of those nurses, so they wouldn't necessarily be the same nurse that you would see all the time, but they would be quite familiar with the patient you know. (BLW4, Staff 04, Extended Care Unit)

An issue raised across the care settings was the perceived continuation of treatment 'to the end'. On the one hand, many direct care staff regarded it as important that patients be offered treatments that relieve pain and other distressing symptoms until the end-of-life, as well as treatment that enhances their lives such as physiotherapy and alternative therapies. On the other hand, many staff expressed the view that patients should not be subjected to invasive or aggressive treatment at the end of their lives. This includes treatment such as chemotherapy or operations. Continuing treatment was usually interpreted as offering a clear message to relatives that the team were caring for the dying person well. One care assistant described how a bowel resection had been particularly distressing for a patient in his last weeks of life:

> He went into hospital to query bowel cancer and he was in there for ages. He came out with a colostomy bag and he was a different man when he came out. Always anxious, even if the bag was a small bit full he would be ringing the bell and he stopped going to Mass. He wouldn't go to Mass any more because he was afraid it was going to burst in the church … I think they should have just left him. (GRT5, Staff 08, Voluntary Hospital)

More common interventions described included the use of intravenous or subcutaneous fluids with an implicit suggestion that to withdraw such treatments would be interpreted as 'giving up' and therefore unacceptable:

> We would still treat them up till the very last but if we felt they weren't able to take their medication, we would we give it to them IM up to the very last. We never say 'that's it like we're stopping'. We would continue with everything even if they were on a subcutaneous or IV up to the very last … It mightn't be doing them any good but to those [family] they think it is a big thing and he is, we're still carrying out treatment like and all that. (BLT6, Staff 01, Extended Care Unit)

There were also some positive examples of intervention at end-of-life given in relation to the work of physiotherapists in providing comfort measures to relieve distress in terminally ill patients, although it was noted that this was largely focused on the acute hospital setting where physiotherapists were readily available to the team:

> But like even like if somebody needs their chest cleared or anything like that … the physios will come and help them right up till the last minute. Right till the last minute … It's never not important, you know. (SAZ12, Staff 02, Acute Hospital)

A further observation was the dichotomy of views between specialist palliative care practitioners and care staff regarding intervention to increase or sustain life, which often involved transfer to a hospital or other centre:

> And you know just because somebody is elderly doesn't mean that it shouldn't be investigated. They're actively, if they're well and active … (BLW5, Staff 06, Extended Care Unit)

> If you are going to give them a lot of aggressive interventions that is not going to change the outcome, then would you be just kinder to leave them there in the room that they are used to in their old familiar surroundings and we can do as much for them as possible then? (PIX33, Staff 04, Private Nursing Home)

Overall, there were both positive and negative aspects to best practice in symptom management. What appeared to be good palliative care practice included rigorous assessment and attention to detail, listening carefully to how a symptom was described and experienced, and re-evaluating an intervention or change to treatment systematically. Poor practice included limited information gained from a patient on which to base a clinical decision, failure to evaluate progress so that people became fatalistic about the nature of their pain, limited openings for two-way communication and missed opportunities in terms of understanding the interrelationship between psychological and physical pain. There were evident gaps in knowledge around pain management but it was also clear that where palliative care services were involved, staff were well supported to give good end-of-life care. However, the generalised descriptions of care given by patients were indicative of limited involvement and understanding regarding clinical aspects of their care.

7.4 Staff Perspectives on Recognising Dying in Older Adults

Although it was often difficult to predict when somebody was going to die (people may appear extremely frail and subsequently recover), staff were able to intuitively identify and act upon signs of approaching death. Beyond the management of physical symptoms, there was a strong emphasis on supporting patients at a psychological and spiritual level, and some staff gave clear evidence of having specific skills in addressing the reality of life closure with patients:

> It was so gradual. You could see the difference. I had been on night duty for a week and I could see the difference coming in for the week. I just said to the girls I think you know that (name) won't be with us for much longer. You could see there was just a difference coming on her. (GRT5, Staff 04, Voluntary Hospital)

> [I said] you are actually very ill these days and maybe the time has come that you will have to leave this world that you have been living in but we all hope we will go to a brighter place. Would you like to go to that brighter place? I remember she said: 'Nurse I wouldn't mind; I've lived a very good life.' (BLT6, Staff 03, Extended Care Unit)

However, for many of those patients interviewed, it appeared that they were unaware that they were close to death and simply did not discuss their own dying at all as a matter for concern. Instead they focused on how they would manage following discharge and expressed concern for how their family would manage to care for them and the financial burden of care:

> I have concerns that when I go home eventually that they have organised my home, changed it, switched it around, put in a ground floor loo and things like that for me … My wife is living alone … hopefully, she'll be able to look after me. (SAZ12, Patient 02, Acute Hospital)

Information and openness around dying and death were certainly contentious issues in all of the sites visited. A small number of staff regarded it as part of the patient's rights to be informed of their prognosis:

> I think if the person asks you, you have to be honest. They have a human right to know, you know: it's their body, it's their fears, their anxieties that they're actually having to deal with. (PI48, Staff 01, Private Nursing Home)

However, there was a general belief that discussion of death was unsettling for residents and therefore was not encouraged. The ethos of end-of-life care was to make people as happy and comfortable as possible, which generally was understood to mean not telling people they were dying. Strategies such as keeping cheerful, reassurance that the resident would be fine and distraction were used to steer staff-patient exchanges and communications away from dying and death:

> You're not going to be drawing attention, you're going to maybe focus on living rather than dying. That would be my way of doing it anyway and making their life comfortable while they are here with us rather than focusing on death. (BTO6, Staff 03, Extended Care Unit)
>
> Actually, we don't discuss dying with them at all to be honest. (BLT6, Staff 04, Extended Care Unit)
>
> Oh I am just try to reassure not its nothing, no don't think like that. That is bad for you to think like that and you will be fine. And even if I know they have an hour left or whatever left, I keep on reassuring them like, 'you will be fine, you will see, you will be fine, yeah', so try to reassure them. (PIQ48, Staff 04, Private Nursing Home)

In a number of cases, a system of 'closed awareness' existed, where dying was not discussed, even though both parties knew that death was imminent. Staff also reported using blocking techniques such as telling patients they would soon improve, closing the potential for any open discussion:

> I say 'oh sure you'll be okay', but I know and he knows he is on his last legs … You don't want to just brush him off. (BLW4, Staff 01, Extended Care Unit)

> No, you might say 'You're not so well today, Mary, but you'll be feeling better tomorrow' even though you'd know the person might not last very long. You just try to make them feel better. (GRT5, Staff 02, Voluntary Hospital)

On balance, only a small number of staff described instances where they recognised the residents' need to talk about death and had open discussions with them. Many staff only discussed death and dying if the resident brought up the topic first and acknowledged that they were dying. Inhibitory factors included perceived lack of knowledge and skills and finding the right time to raise the subject with them.

However, staff regarded it as important that family should be kept informed and facilitated to be present as much as possible in the last few days or weeks of the patients' lives. Contacting families as death approached was a priority of care. This role was undertaken mainly by nurses, but occasionally by care assistants. Although most staff managed to find some private space to speak with families about their relatives' failing health, this was often very difficult, particularly in an acute hospital setting. Notwithstanding the problem of finding suitable places to talk with relatives, it is clear that staff found it easier to talk to families about dying and death than to patients themselves.

7.5 Sensitivity to the Rituals and Practices Surrounding Death

It was evident from the data that staff were sensitive to the needs of the dying and their families. The first comfort measure mentioned by all staff was the need to provide food and drinks to relatives of the dying patient, both during the dying process and after death:

> Well we'd always provide tea and things. We have a canteen that they can go and get a meal if they want it but we'd provide tea and sandwiches and things here for them if they're going to be here during the night, we'd try and make up, give them a cup of tea and sandwiches or something just to keep them going. (SAZ 12, Staff 02, Acute Hospital)

Detailed aspects of the patient's care when they were dying included holding hands, talking to the person or simply being present to ensure they did not die alone, a role that in some cases would be undertaken by a member of the pastoral care team:

> It's the simple things … a sip here, a word of encouragement even though you think he can't hear you he doesn't understand, still the words of encouragement … hold his hand for a few minutes you know if you get a chance … (BLW4, Staff 05, Extended Care Unit)
>
> There is always somebody with a resident when they are passing away. (PIX033, Staff 01, Private Nursing Home)
>
> She [pastoral care] sits there for an hour holding her hand and, like we be really busy now, busy times, she'd come and sit with her which is great I think … (BLT6, Staff 02, Extended Care Unit)

A related issue was the transfer of patients from nursing homes or long-stay units to more acute hospitals when they are nearing death. In half of the care sites visited, staff reported that they usually tried not to transfer patients from the place with which they were familiar, often in support of families' and patients' wishes:

> Unless there's a need for them to go to hospital, the family don't want them to really. They'd prefer them to stay here even in the end they might be able to relieve symptoms for just a short time in hospital, in an acute hospital you know it's often decided that no, they don't want them to go down that road. Or the people themselves that can say I'm not going, I don't want to go. (GRT5, Staff 07, Voluntary Hospital)

The respect and sensitivity exhibited toward the dying and their families continued when the resident was dead. The importance of allowing the family time after death to remain in the resident's space or room was described:

> We leave the room preserved as it is, until the family comes in and obviously until the body has gone, even after the body is gone, we leave the room intact. Until after the funeral and then the family come in to clear the room. We never rush them … it's their room and it's their domain and they want to see the things. (PIX33, Staff 04, Private Nursing Home)

Ensuring that the resident was well groomed in death was equally important for both the staff and the family:

> She used to like her hair done and her make-up done, and she never received guests without her earrings on, her face powder and her lipstick, and just before the family come up … I said, 'hang on a second, I had to do the face powder, the earrings and the lipstick'. And the daughter said 'What I remember seeing is the face powder, the lipstick and the earrings', she said, 'and that will be such a memory for me, for the rest of my life, rather than looking at my Mum looking washed out.' (PIQ48, Staff 01, Private Nursing Home)

The switching off of televisions and radios was routinely undertaken as a mark of respect for the dying and their relatives. When a resident died on a shared ward the curtains were pulled around the other residents' beds just prior to dying and left in place until the body was removed from the ward. In other instances, the curtains on the sitting room were closed when the body was being removed from the facility. These customs and rituals were undertaken in an effort to protect residents and to reduce their anxiety, even though it was clear that patients understood the meaning of such rituals:

> When removing the remains, we pull all the curtains around the other beds and then remove the curtains that's around the remains so that they don't actually see. (BLW4, Staff 05, Extended Care Unit)

> We have to be very sensitive when the curtains are being pulled around. They know why … They know exactly why but it's just not to be pushed into their face you know. (BLT6, Staff 02, Extended Care Unit)

> Yes, well we don't have to do it so much any more because a lot of that is done in the undertaker … that has changed a lot. They would go to the undertakers and be embalmed or whatever. And the undertakers are more involved in all that side of things now. There was a time you know when you did all this washing, we don't do that any more. It's not done any more. (GRT5, Staff 04, Voluntary Hospital)

Death rituals and customs relating to Catholic religious beliefs were reported. In such instances, reciting prayers at the bedside, putting a crucifix in the room and lighting candles were important considerations when the patient was dying. Many participants described the ritual of leaving the body untouched for one hour after death and opening the window. However, although participants adhered to these latter rituals, it was evident that the rationale for their implementation was now often unknown. Further, although negotiation of last offices and accompanying the remains to the mortuary were traditional nursing practices, there was increasing evidence of the funeral director taking on many of these roles:

> I think that one of the most important things, of the dying patient, is to pray with him or her before they leave this world … You're there and you light the candles and you say all the prayers and that … (BLT6, Staff 04, Extended Care Unit)

> After death then that's their body will be totally respected and minded as well you know and that usually people got an hour for the body to be, they leave the body for an hour after they have died. It's a custom to open the windows. (BLW4, Staff 05, Extended Care Unit)

7.6 Conclusion

It is evident that most patients accept death as an inevitable consequence of old age and that a belief in reunion with significant others after death was a sustaining factor for them in coming to terms with this realisation. The sensitive care of patients and their families at end-of-life was encompassed by detailed attention to ritual and practices which balanced physical care with the spiritual dimension of life closure. This was often framed by discourse surrounding faith (predominantly the Catholic faith) as providing hope and meaning in the dying experience for patients, supported by sensitive end-of-life care ritual and practice. Staff felt that older people at the end-of-life should be treated with respect, that their dignity be maintained, that they have choices about their treatment, that they be pain-free, that they be facilitated to live as fully as possible until they die, maintaining relationships with staff, family, friends and other patients.

Patient interviews confirmed that by and large they were treated with respect. This was particularly so where the institution responded to what the patients themselves wanted in terms of treatment and of opportunities to talk about dying. There was also evidence that access to specialist palliative care support services impacted on symptom management and, where limited support was available, gaps in knowledge regarding pain and symptom management were apparent.

Chapter Eight

Organisation and Ethos of Care

Chapter Eight

Organisation and Ethos of Care

8.1 Introduction

The focus of this chapter is on the organisation and underlying ethos of care within facilities providing end-of-life care for patients. We explore staff perceptions of end-of-life care and the key factors influencing the organisation of care within the various settings. It is clear from Chapter 6 that it is not always possible to separate gerontological care from end-of-life care. Patients are people, with human needs that must be satisfied, whether they are in the early stages of transition to long-stay care or in the later stages of end-of-life care. People value good quality care at all stages of the continuum from admission to the facility to final exit through death. The way care is organised matters for patients and its organisation depends upon the physical infrastructure available to staff and patients within the facility. Another key factor is the ethos of care among managers and staff in the facility. A positive person-centred philosophy is more likely to lead to enlightened care and higher quality of life for patients and staff.

8.2 Defining End-of-Life Care

The majority of staff see end-of-life care as palliative care, while recognising that the latter is mainly directed towards people who are dying from cancer, even if this is a changing phenomenon. They do not immediately see themselves as having a key role to play in end-of-life care and would not be confident in carrying out such a role even if opportunities arose. Most staff believe that palliative care should be provided by the hospice and palliative care teams and not by themselves:

> Well palliative care to me always … I associate it more with hospice and cancer, I think that's where I could have, respite care is. We've palliative care here, I suppose, to a certain extent, I think I would have associated it more with hospice. (PIX48, Staff 03, Private Nursing Home)

> I think most of the staff have a very good understanding of palliative care but you are trying to change the way of thinking … there's a lot of people with other diseases that are maybe at the end stages, like heart disease and neurological disorders. To recognise that as palliative care as well. I think some people still associate it very much with cancer. (GRT5, Staff 05, Voluntary Hospital)

One GP specifically remarked on confusion over boundaries and role delineation in contemporary palliative care:

> I think that the role of the palliative teams have, they've gone beyond their boundaries. I think they're getting more and more wrapped up in treatments, that may or may not be appropriate. You know I think in the past they had a clear, clear defining line. Whereas I feel you know that they're providing kind of an additional service which may confuse what the role is. (GRT5, Staff 01, Voluntary Hospital)

Generally, most staff had some sense of the core principles of palliative care. Of interest is that some care attendants were very knowledgeable about palliative care, whereas some of the registered nurses had limited understanding, both in terms of definition and what might be considered best practice:

> To me, palliative care is almost end-of-life, and that is an end-of-life sort of package – to make sure that that person's whole being is attended to. Most people think of sort of pain, you know, and the Palliative Care Team come but it's the spiritual needs, their mental needs, they have to be attended to. It's no good coming in and just doping somebody with drugs, you know, you have to look at the whole person's needs. (GRT5, Staff 09, Voluntary Hospital [care attendant])

> Palliative care – is that something to do with their palate mouth you mean? (PIQ48, Staff 04, Private Nursing Home [registered nurse])

8.3 Care as a Philosophy and Practice

Staff participants were asked to describe the philosophical focus of end-of-life care within their facility. Many staff participants described care within their facility as person-centred, individualised and based on resident choice. Two broad descriptions were offered. The first emphasised comfort and dignity in physical care terms. The second offered a more eclectic view, emphasising both space and easy access to staff:

> Well, if you define it as being the last few months … I suppose it's attending to hygiene needs and the physical – anything that they can't do we would do for them. So I suppose it's hygiene needs and offering comfort and care, making the life more comfortable but sometimes it's entertainment as well. (BLW4, Staff 05, Extended Care Unit)

> I think that the patients are made as comfortable as possible, that their medicine is to the right level … they have all the dignity as regards having their own privacy, having their own space that, you know, that there's place for the family to be there with them, on their own … the nursing staff is available to talk to at any time and that the doctor is, you know, easily reached. (BLW4, Staff 02, Extended Care Unit)

In these facilities care was structured around residents' needs and there was recognition of the importance of respect for resident choice. While staffing constraints were an issue for many of these facilities, care was organised to try and give residents maximum flexibility and there was an ethos of spending time with those who were dying. In some facilities resident and staff participants commented on the caring ethos and how this shaped care within the facility.

> We are dealing with patients who are dying you know, and we are giving the best possible care that we could … especially for the older person some things could be very private and of course we have to respect that and, we usually use the patient-centeredness … helping them, you know, to live as much as possible as they could, you know, happily and with respect and dignity. (BLW4, Staff 03, Extended Care Unit)

> I suppose our mission statement would be to create a home where our clients and staff can work in partnership to promote individualised quality care in a safe and happy environment and like that to incorporate respect, dignity, choices, independence, education, well-being in a friendly atmosphere and making the patient as comfortable as possible in every way. (BLT6, Staff 03, Extended Care Unit)

There was some recognition of the emotional labour involved in caring for those at end-of-life, based on supporting staff to care for residents who were dying as well as prioritising the needs of these residents within the daily workload. The role of management in shaping this ethos was globally recognised across the facilities:

> I think it always comes from, you know, from the top down really and I think certainly the interest shown here by the nurse managers over the years who have built up this centre has been truly fantastic actually. And it was actually thanks to the Director of Nursing here who actually was involved in the whole setting up of palliative care in the community, who saw it as a need. (BLW4, Staff 06, Extended Care Unit)

> Here, like … there is nothing that wouldn't be (supported), there is nothing I could not get, if I decided that the patient would benefit from, anything at all … I went to say that to the manager, that's no problem, if you feel that would help go ahead and do it. (SAZ12, Staff 02, Acute Hospital)

However, although this was evident in some facilities, for others, the ethos was to 'carry on' and contain emotions with little support or understanding given to staff who were emotionally distressed:

> I just carry on, you just have to carry on. (BLW4, Staff 05, Extended Care Unit)

The findings also suggested deficits in communication between staff and with patients in relation to their understanding of their diagnosis and prognosis. Although most managers stressed the importance of multidisciplinary teamwork, there was evidence that care attendants were given 'filtered' information about their patients that affected their perception of being part of the team:

> One of us would go in and give their attendants a report like really, now it wouldn't be as detailed as a nursing report but we would because, after all, it's all multidisciplinary team … we will inform the attendants like and all that but it's only x amount we would say like, really – you know. (BLT6, Staff 01, Extended Care Unit)
>
> When I started here three years ago and whenever you asked a question about a patient they'd say, 'sorry it's none of your business, you just look after the patient but it's none of your business what's wrong with him'. I think they were probably protecting confidentially, but you always felt you were sort of locked out. (BLT4, Staff 01, Extended Care Unit)

A significant number of the staff described communication methods which did not impart the seriousness of their condition to the patient, despite the patient's desire to be informed:

> I said: 'You're not dying. What's making you think that like? Don't be silly. You're not going to die. What makes you say that now?' 'Oh no I'm not feeling great. I think I'm dying', but often, more often then that they do die a couple of weeks later. I often wonder do they know or something, you know. (BLT6, Staff 02, Extended Care Unit)
>
> I'm not too behind the door when I want to know anything, you know. I'd ask them out straight: 'Am I going to die or am I going to live or am I going to get back?' (SAZ12, Patient 01, Acute Hospital)

Examples were also given where staff believed that patients had a right to know if they were dying. However, in general terms it appeared that the acknowledgement of death was largely reserved for the time shortly before death and exhibited through the caring response of direct care staff rather than a discussion of any kind prior to the terminal phase of life:

> If the patient wants to know and they have the cognitive capacity to know then they have a right to know and if the patient would like to know then they will be told in a very, you know, in a very reassuring way and sort of outlined the strategies. (SAZ12, Staff 03, Acute Hospital)
>
> I remember one night there was a man dying and the last few minutes of his life the nurse said to him 'no John don't be afraid'. I don't actually know what the man's experience was as he was dying but it was lovely for someone to say 'there no need, don't be afraid' I thought it was beautiful. (BLW5, Staff 05, Extended Care Unit)

A further issue in relation to communication was the degree of exposure to the palliative care service and understanding of the advisory and supportive role of the Specialist Palliative Care Team. Palliative Care Teams were usually contactable if a patient had complex symptoms, particularly pain. However, this tended to be through advice rather than a clinical visit, leading to a belief that their role was primarily consultancy:

> Well, I mean they, the main thing they do is consult. They are available to help out, you know, if there is something that we're querying or whatever, yeah. (BLW 4, Staff 04, Extended Care Unit)
>
> Yeah we have a palliative care service actually on site here. If you were to phone them about anything they would give you advice but they wouldn't be able to see the person. (BLW4, Staff 08, Extended Care Unit)

It was also noted that there was no evidence of formal end-of-life care planning which reflected any engagement with patients. Most staff members said they had not encountered people who had made plans for their end-of life care, such as advance directives, although some patients had told their families of their wishes in relation to their funeral or the disposal of their property in the event of their death. One manager had actually drawn up a care plan with a patient and had ensured, in so far as she could, that it was carried out, despite difficulties in providing the necessary support to the patient so that she could die at home:

> So we put the care plan in place and I actually wrote it with the woman herself, who had been a schoolteacher and had an MA and, although she might have been 97, she was still capable of being extremely articulate about her wishes. The woman herself actually signed it as, too, did her daughter. My next problem was out in the community. I mean, they knew this woman from when she had been admitted here four years previously and didn't want that sort of problem out in the community. (BLW04, Staff 08, Extended Care Unit)

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

8.4 Physical Environment and Resources

The physical environment was highlighted by staff participants as a real issue in end-of-life care. Few facilities had a single room that could be used when a resident was at the final stages of their life. Where single rooms were available, they were prioritised in relation to clinical need (e.g. MRSA infection). Most staff valued the single room as a resource that created privacy and enabled relatives and friends to stay with the person who was dying:

> You see we haven't got any sort of dying room … What we try to do is sort of put them into a corner … if a person is dying we usually put them into a corner, the other patients that would be around them. (BLT6, Staff 01, Extended Care Unit)

> If we have a spare single room we will offer it to them and say, like that's available do they want to take that. Just to give them the privacy and you know they can obviously stay with their relative as long as they want. (GRT5, Staff 05, Voluntary Hospital).

People spoke of the importance of dignity for patients who were dying. The view was strongly expressed that death should be private rather than public, in single rooms rather than multi-bedded units:

> Sometimes situations occur where a patient has to remain in a six-bedded unit because there might be infectious patients who need to be inside in single rooms … for infectious control like MRSA or CDIF or things like that … but I find it awful to be honest … because there is no privacy … so many people flying in and out that the curtain ends up just at one end and the patient is just exposed. (BLW04, Staff 06, Extended Care Unit)

Some staff felt that it was upsetting for other patients if someone dies in a multi-bedded setting:

> And the only thing that I'd find about that is that if someone dies in a four-bedded room and there are three other ladies or three other patients in the room you still have to lay out the body and the family come in, so it's tough on them as well, you know, because they are seeing this. And especially if there are long-term patients and they could be, if three people die in that room in the one year you know what I mean, I think it affects them. So I think if there was someone dying there should be a room put aside for the patient that is dying that they could go in there along with the family. (GRT5, Staff 05, Voluntary Hospital)

An alternative viewpoint suggested that a single room may be inappropriate where patients had formed a friendship with fellow patients, or where the move to a single room might be frightening if they were used to living in shared accommodation:

> I think in older-run hospitals where they are used to being in big environments and everything else, where to be put into a single room, it could become more scary, and these people have shared rooms for years and years and years. (PIQ48, Staff01, Private Nursing Home)

Staff in almost all facilities also referred to low staffing levels as a barrier to spending time with patients. They indicate that pressure in terms of limited time was largely due to trying to balance the needs of dependent older people with multiple nursing needs, the totality of end-of-life care and administration, which required scrupulous attention to detail, not only of the patient but the family as well:

> I've been nursing 24 years. This is the only place I've had to say in my working life that I don't have time, but it's because of the staffing levels. (BLW4, Staff 08, Extended Care Unit)

> You haven't time to sit down and talk to them because you're running, running, running here the whole time. (BLT6, Staff 02, Extended Care Unit)

> But I felt that, while we were with her during the night, it was the minute she died that we should have been able to spend more time with her then. I just felt we were very rushed. (BLT6, Staff 03, Extended Care Unit)

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

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

There was also a tension between what staff participants believed best practice to be and the reality of end-of-life care delivery – a particular dichotomy where there were links to a hospice with higher staffing ratios than long-stay facilities. This resulted in stress and anxiety for staff participants:

> I was on night duty and we were so busy I felt I didn't have enough time to give to this dying patient. I suppose if I went back previous to that I could honestly say within my conscience that I gave that dying man or woman much more of my time because I had that bit of extra time. But on this particular occasion I just didn't have the time to give her what she deserved and what I should expect of myself to give also. (BLT6, Staff 02, Extended Care Unit)

> Somebody dying needs more, like, one-to-one care, like they have upstairs (in the specialist unit) and here they have what – something like 10 nurses for 70 beds. That means at night you might have only one nurse to 24 beds. With that kind of staffing, you just can't have the kind of care you need when somebody is dying. (GRT5, Staff 03, Voluntary Hospital)

Although it was also suggested that there was a need to examine the way in which nurses work in order to provide optimal care, the problem for staff in these units was that they often felt pressured, unsupported and therefore less able to give support to others.

8.5 A Learning Culture

Two areas were discussed here by direct care staff: the importance of learning about cultural diversity and the need for formal education and training in palliative care. Staff were clearly aware that increasing ethnic diversity in Ireland raised particular challenges for end-of-life care and the need for further education in multicultural caring. There was a need to understand different cultural practices at end-of-life and to ensure that overseas staff appreciated end-of-life practices within Ireland. Irish staff were perceived by non-national colleagues as helpful in supporting them to understand Irish death practices. Many non-national nurses were themselves exposed to new learning about multicultural rituals around death and dying through in-house or external education programmes:

> When I first came into this country, I didn't know what the rules were. I am Orthodox myself so I am everything. But I find out what needs to be done so I know if they are Catholics I would put the beads in their hand, and I wouldn't know to say rosary or anything but if I know someone who knows, I would tell that person. I wouldn't know their prayers so I would send someone that knows their prayers. (PIQ48, Staff 04, Private Nursing Home)

Some Irish staff participants had undertaken further education around multicultural care but, in general, there was a perceived need for more education in this area. This applied not only to Irish nurses learning about other cultures but as a support to non-national nurses who were seen as often less skilled in end-of-life care management:

> We need cultural education around cultural issues for both working with other staff and their sort of understanding of, you know, end-of-life issues for maybe traditionally Irish people and, similarly, ours around, we're a totally multicultural community here in our town right now and so the issues are beginning to come up. And we're just gradually becoming more aware of the need for multicultural education around. (BLW004, Staff 6, Extended Care Unit)
>
> It (end-of-life care) would be (difficult) for some of the foreign nurses … I don't think they have actually had a lot of experience in end-of-life … Initially when we had foreign nurses here in the hospital they would actually run a mile rather than deal with it. They were afraid. (SAZ012, Staff 5, Acute Hospital)

Palliative care education was seen as central to providing best care. However, access to education opportunities were variable. Both positive and negative examples of this were given:

> The Director of Nursing was able to send a lot of people for different training courses including some of the care attendants who went for a care attendants' day to a hospice. So they really thoroughly enjoyed it and really felt the benefit of going off site to see other facilities as well. (BLW4, Staff 06, Extended Care Unit)
>
> I was never asked to go (on a course) or given the opportunity to go. I think that's where in care of the elderly, as opposed to giving palliative care in the hospice, I think we need it here in the care of the elderly as much as anywhere else. (BLT6, Staff 04, Extended Care Unit)

Staff also identified their specific educational needs and suggested training was important in order to give good end-of-life care. A range of particular needs were identified, including symptom management, pain management, use of syringe drivers, counselling and psychosocial care. Staff participants were also anxious that educational opportunities should be available to registered nurses and care assistants:

> And when you actually ask them what skills they need, it is coming down to functional things like usage: syringe drivers, obviously, providing adequate nutrition … if you're talking then about the attendants it's about the psychosocial care … the counselling end of things and trying to support families … just being able to communicate adequately and being able to kind of address issues. (BLW4, Staff 07, Extended Care Unit)

Notably, although many staff felt they lacked knowledge of palliative care and therefore could not give as good care as someone with this particular expertise, one participant suggested that staff sometimes did not recognise or value fully the skills that they had. She believed that many nurses already had the fundamental skills that were key to good end-of-life care but focused on their lack of specific skills. Overall, however, there was a global sense that education and training were a priority to develop good end-of-life care:

> I think staff feel at times that end-of-life care and palliative care … there's some specific special skill that they need … a lot of it is about the skills and knowledge that they already have. (BLW4, Staff 07, Extended Care Unit)

> Training, training, training is really where we need to be putting in our time now and developing policies and procedures and guidelines. (BLW5, Staff 06, Extended Care Unit)

8.6 Conclusion

There is diversity across facilities in the way end-of-life care is organised. Physical facilities are not always optimal and the lack of single room accommodation is a problem in some settings, particularly in acute hospitals and public long-stay settings. The majority of staff believe that a single room is the best place for a patient to die, providing privacy and dignity for patients and families, while not disturbing other patients. There is little evidence on this, however, from the patient interviews since most of them do not explicitly discuss the merits of a single room at the time of death, except for those who say they would like to die at home rather than in acute or residential care settings.

It is evident that a good learning culture exists in some facilities, although it is also true that this is not a universal finding. The basic palliative care premise of being a caring presence alongside the dying person was emphasised by a number of respondents, described as:

> Just being there for people, what more can you do? (BLT6, Staff 01, Extended Care Unit)

There is clear evidence of good practice in the care of older people at end-of-life, with a visible caring and considerate attitude on the part of staff who work in this area of practice. Cultural competency presents challenges in terms of understanding how best to care for patients at end-of-life. However, while cultural diversity amongst direct care staff evokes different responses to end-of-life care, the approach to care is generally competent and sensitive. Overall, the findings suggest that staff are trying to a good job, sometimes in difficult circumstances. That said, there is still scope for staff to more effectively recognise end-of-life turning points, including the need for palliative care services, so that the principles of holistic care can be applied to dying and death in all settings.

Chapter Nine

Conceptualising New Frameworks for Understanding End-of-Life Care

Chapter Nine

Conceptualising New Frameworks for Understanding End-of-Life Care

9.1 Introduction

This section proposes an approach to develop ‘good practice’ in end-of-life care for older people living and dying in various care settings in Ireland. The approach has been influenced by the findings from both the quantitative and qualitative work undertaken for this report. It is based on the following premises:

- Older people in acute and community hospitals and nursing homes have needs for care and support
- There is often great uncertainty about the passage from life to death for individual older people
- Many domains are encompassed in ensuring a good quality of life and death towards the end-of-life including physical, psychological, cognitive, spiritual, social and economic dimensions
- Older people and their families live in complex social networks of mutual interdependency
- Communication underpins the process through which older people and their families are helped to explore issues and arrive at decisions in discussions with health and social care professionals. It is most effective where there is mutual understanding, respect and awareness of individuals’ roles and functions. Communication involves verbal and non-verbal behaviours that convey meaning.

We outline a number of elements to this approach that take account of the individual older person’s experiences towards the end-of-life, as they move from life to death: their location in a wider family, organisational and societal context; and the identification of service workforce configurations that can flexibly respond to these often fluctuating, unpredictable needs. We illustrate this approach using a model which is operationalised as a series of frameworks for good practice and care.

9.2 Conceptual Model for Understanding Older People's Experiences

We propose the following conceptual model to understand older people's experiences at the end-of-life. We identify four zones that are encountered by older people and their families in the context of hospitals and long-stay care settings (see Figure 9.1).

Living with Losses

There must be an enduring emphasis on living and life if the quality of life of long-stay residents is to be preserved. However, there must also be an awareness that the older person is living with many changes, including losses of function (physical, psychological, cognitive), status and identity, which may foretell their end-of-life. Some residents/patients may be more aware of the various transitions taking place in their life than others, but the majority of older people recognise admission to care as a major life-event.

Living and Dying

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

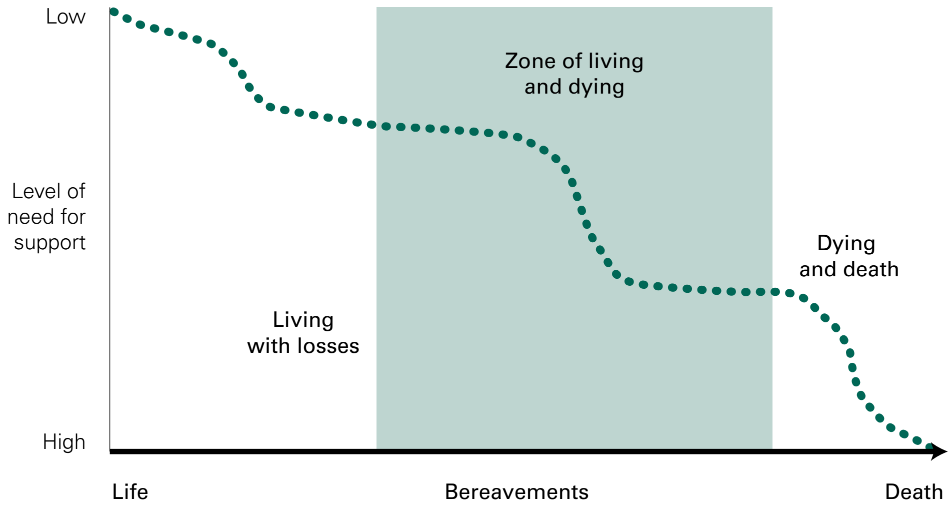
Dying and Death

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

Bereavements

Anticipatory and actual losses may be experienced concurrently within the *Living with Losses* zone for older people, their families and staff. These will become more prominent during the *Living and Dying* and *Dying and Death* zones. Following the death of the older person, bereavement may be experienced by families, friends, co-residents, co-patients and staff.

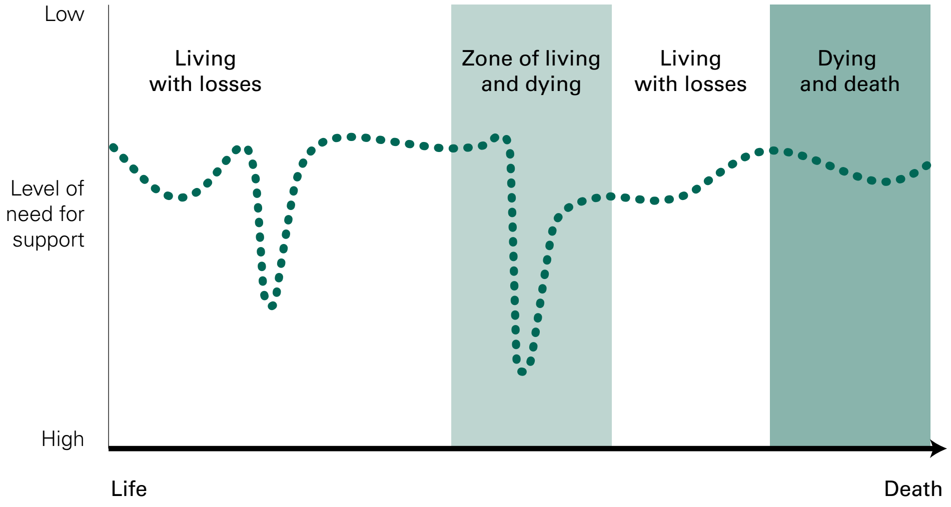
Figure 9.1: An Individual's Life–Death Trajectory



While we see these zones as predominantly sequential, the uncertainty of dying trajectories in late old age and in particular the phenomenon of 'bounce back' which was evident in this study and elsewhere (Froggatt, 2001), means that individuals may experience a number of episodes where they may be perceived to be in the *Living and Dying* zone (Figure 9.2). In the context of the model, there may well be 'fuzzy boundaries' between *Living with Losses, Living and Dying* and *Dying and Death* zones. For example, acute life-threatening events like a stroke or an acute respiratory infection in a person with heart failure may well mean that the person moves into the *Living and Dying* zone as there is considerable uncertainty about outcomes. Likewise, the 'bounce back' phenomenon, sometimes seen in late old age, represents another example where there is uncertainty that may be resolved with the patient's death or with a return to health and the *Living with Losses* zone will be reinstated. There are also situations where older people require increased support and care for reasons that are not life-threatening, for example as changes in cognitive function lead to behavioural disturbances and a need for specialist input from mental health specialists.

The presence of 'bereavement' recognises that anticipatory losses and feeling of bereavement may be experienced by older people, families and staff during the lifetime of the older person and especially as the reality of their future mortality becomes more apparent in the *Dying and Death* zone. It also acknowledges that staff as well as families and peers will be bereaved. Care for older people's families needs to continue after the death, as they face the future without the deceased, a time typically acknowledged as bereavement.

Figure 9.2: Living and Dying Trajectory



9.3 Framework for Good End-of-Life Care

In our conceptualisation of the complexity of older people's experiences, we have already begun to allude to the service responses required to meet the various needs that may arise. In order to develop the model further, we have identified the following premises about end-of-life care for older people living and dying in acute and community hospitals and nursing homes. End-of-life care provision will be:

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

More specifically, we identify that although this model is focused on the care of older people in particular health and social care settings, the wider social and cultural context is recognised to shape the values and practices in such organisations. We therefore present a framework to ensure the development of good end-of-life care for older people that meets their needs and aspirations (Table 9.1). The focus of good end-of-life care for older people incorporates both individual level and social level responses and illustrates the rights and responsibilities of all parties.

Table 9.1: Framework Required to Ensure Good End-of-Life Care for Older People

	Dimensions	Dimensions	Dimensions	Dimensions
Focus	Knowing and Revealing Needs	Expressing Values and Preferences	Interacting with Others	Developing Knowledge
Older person	Recognition of bodily, emotional, social, spiritual changes for self. Willingness to reveal these changes to others.	Expressing important values and decisions to others.	Helping others to understand what is needed for them to feel safe, comfortable, supported in distress. Respect for staff providing support and care.	Confidence and 'language' to express these things.
Family	Recognition of bodily, emotional, social, spiritual changes for self and older family members. Willingness to reveal these changes to others.	Ability to understand and express their own values and decisions. Recognise values of older person and other family members even if they differ.	Assisting older people in eliciting competent care/support compatible with their wishes. Helping others to understand what is needed to feel safe and comfortable and supported in their own distress.	Confidence and knowledge and ability to engage with the health and social care system on behalf of themselves and in partnership with the older person.
Staff	Recognition of changes and losses for older person and family. Recognition of own needs in context of dying and bereavement work.	Seeking to understand the values and preferences of older person and family members. Need awareness of their own (differing) values and beliefs.	Facilitating and eliciting experiences and views of older person and family members. Expectation of respect from older person and family.	Listening skills. Confidence to engage with difficult conversations. Models of loss and change. Ageing and dying.
Organisation	Recognition that older people and their families are facing losses and life changes. Recognition that staff are impacted by the loss and deaths of older people, and the distress of family members.	Agreed mission statement expressing the organisational values and culture. Written protocols for end-of-life care, including support systems for staff.	Facilitating communication and information provision which is respectful of patient and family styles and preferences. Acknowledging support needs of staff at all levels.	Supportive organisational culture. Leadership and knowledge in seeking to improve end-of-life care. Facilitating change, innovation and excellence.

	Dimensions	Dimensions	Dimensions	Dimensions
Focus	Knowing and Revealing Needs	Expressing Values and Preferences	Interacting with Others	Developing Knowledge
Society	Recognition of the value of societal death talk. Valuing and listening to older people and their advocates.	Articulating differing cultural values re end-of-life issues and care.	Identification of places where these interactions can occur e.g. schools, libraries, lifelong learning. Prevention of ageism and other forms of discrimination.	Dying, death and society. Place of dying in ageing. Loss and change.

While it may be obvious that the central player should be the older person who is facing the end-of-life, these people have largely been absent from the literature and too often are silenced; their views and presence are passively acknowledged rather than actively sought. Here we identify ways in which their voice can be heard at all stages of the process. Families have two roles within our model; firstly they are present as participants within their own right, having needs, views and preferences; secondly as the older person becomes less able to articulate their own views, they may have a role as proxies. Staff at all levels in organisations need to be able to recognise end-of-life and seek to improve the quality of care; and they have the right to expect respect and freedom in relation to the care that they provide. Organisations need to take responsibility for providing high quality end-of-life care and to facilitate their staff to do this.

Finally, individuals and organisations are embedded within and shaped by their wider societies. At this level, there is a need to engage with broader issues of how social groups regard death and dying, what are the available discourses, cultural practices and values that define and shape attitudes to ageing, death and dying, and bereavement. Only at this macro-level will it be possible to understand and deal with ageism, discrimination, resource allocation and priority-setting.

At each level of focus we have discussed four cross-cutting requirements, which are fundamental to good care towards the end-of-life, namely:

- Knowing and revealing needs
- Expressing values and preferences
- Interacting with others
- Developing knowledge.

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

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

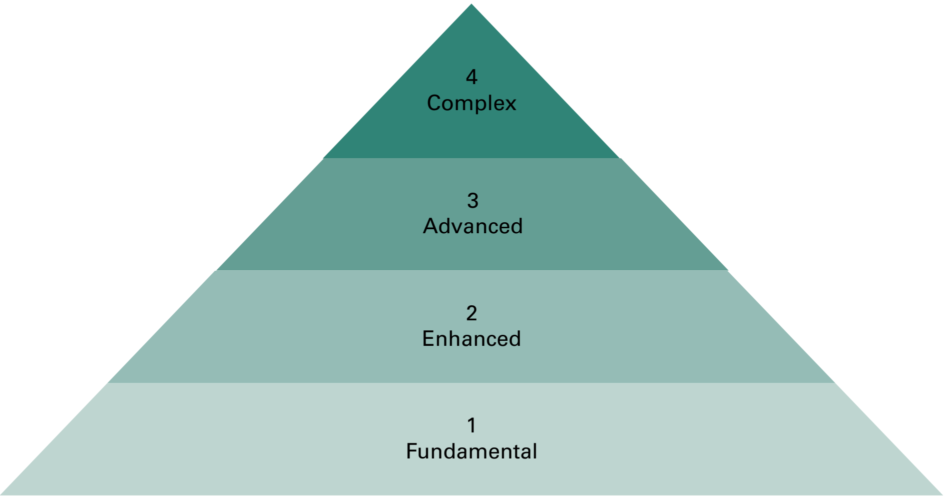
Without self- and professional recognition of the changing needs of older people in hospitals and long-stay settings, it is difficult for older people and their family members to have their needs met. That is why developing knowledge is so important. Patients require confidence and ‘language’ to express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

Currently, the Irish Hospice Foundation is engaged in developing a new approach that seeks to change the culture of care and organisation with regard to dying, death and bereavement in hospitals called the Hospice Friendly Hospitals Programme. This work is being carried through in a partnership programme with the HSE. It focuses on four key themes each with associated projects: integrated care; communication; design and dignity; and patient autonomy. Clearly, there are potential overlaps and learning between these four themes and the dimensions we propose which warrant further research and investigation.

9.4 Levels of Care and Service Provision

A tiered model of service provision is required to meet the varying needs of people at end-of-life in different care settings (Figure 9.3). Older people require different levels of service provision depending upon the complexity of their needs. We see these 'levels' of care as building blocks, that is, as complexity increases so does the need for additional service provision, rather than alternative and separate elements.

Figure 9.3: Levels of End-of-Life Care for Older People



We suggest that all older people in hospitals (acute and community) and in nursing homes will require good quality 'fundamental' care, such as attention to their comfort, dignity, safety and respect for their wishes. As their needs become greater and their levels of distress become more difficult to address, some may require 'enhanced', 'advanced' and ultimately 'complex' care. Complex care may involve specialists in palliative care, but it might equally involve experts in psychological or spiritual well-being, if that is where the need exists. Therefore, while to some extent this model reflects familiar notions of nursing 'dependency', it is more complex than this. This is because levels of care need to be assessed holistically in relation to four domains – physical, psychological, social and spiritual – as well as in relation to the extent of distress reported by the older person and/or family, or observed by others.

This model of service provision is based upon complexity of need rather than a diagnostic category such as cancer or heart failure. It is also not dependent upon prognostication of 'dying' that is known to be unreliable and difficult for professionals, and widely resisted by patients themselves. It is a model based upon the recognition of need – defined as 'distress' (aspects of patient's experience that they or their families report as distressing for whatever reason). It is predicated on the ability of patients and family to report or display distress and/or of staff to recognise this. For example, an older man with some experience of pain may not find this distressing and does not require an intervention such as medication, perhaps because to him minor pain indicates that he is 'alive' or is congruent with his meanings of stoicism, fortitude and/or religious expression. Alternatively, an older person with dementia may be in pain but be unable to tell anyone about the pain, where it is and how severe it is. In this instance, family members and staff need to work together to use known patterns of communication by the older person, such as behaviours or movements that indicate discomfort, to identify that there is a need to be met.

In Table 9.2, we have started to define the service resources and workforce requirements implied by our model and operationalised in the framework. We see careful, regular and comprehensive assessment and recognition of the fluctuating nature of dying in old age (across the zones proposed above) as integral to the implementation of this model. We have defined the staff involved, assessments and interventions required to deliver support and care, the skills and competencies required by staff and the areas where staff training and education is needed to offer care at each of these levels. We realise that there is more to do here in defining the environments of care and the resources required for each level of care, which will require empirical research. The following description offers a starting point.

Level 1: Fundamental

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

Level 2: Enhanced

A nominated end-of-life care 'champion' or 'advocate' should be identified from amongst the regular staff in each ward or long-stay facility. They will need additional training and expertise but will have high credibility and a good understanding of cultural and organisational practices. They will need skills in assessment of need across all domains and an ability to elicit the concerns of older people and their families. This person needs to have organisational backing to ensure they can release resources (equipment, staffing) to support the older person and their family at specific points of distress and need during end-of-life care. They will need training to know the limits of their abilities and when to refer on.

Level 3: Advanced

Staff will be practising at a highly skilled level – such as a clinical nurse specialist or senior social worker – and may be part of a team covering a number of institutions (perhaps based at a hospice) or part of a specialist palliative care service located within a hospital. Typically, the care provider will attend the older person in their normal institution and/or provide advice and support to the normal care staff. This professional will require advanced and specialist assessment skills (for example in pain management, symptom control, psychological screening) and be able to advise on management strategies and deliver interventions. They will be able to support other staff in delivering elements of the specialist care planned. They will need regular supervision and opportunities to update their clinical and specialist skills.

Level 4: Complex

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

Table 9.2: Service and Workforce Requirements for Implementation of the Framework

	Workforce Group	Assessments for Support and Care	Supportive Care Interventions	Skills/ Competencies	Training/ Education Focus
Level 1: Fundamental	All health and social care workers (volunteers).	Recognition of changing needs in all domains of a person's life for older person and family.	Effective compassionate communication and infomation-giving in all 'care' interventions. Maintenance of comfort, dignity safety and respect for wishes for the older person and family.	Ability to provide supportive and competent fundamental care in all domains. Awareness of impact of changes and losses. Listening and communication skills. Ability to refer on as needed.	Fundamentals of care. Listening skills. Models of loss and change. Ageing and dying.
Level 2: Enhanced	'In-house' health and social care workers with additional expertise.	Recognition of changing needs in all domains and ability to engage with consequences for older person and family.	Appropriate problem-solving techniques to meet changing needs in all domains.	Provision of support and enhanced care for all needs. Greater understanding of complex loss and impact on individuals and family relationships. Ability to refer on more complex situations.	Enhanced communication skills and care delivery.
Level 3: Advanced	'In-house' and / or external health and social care professionals.	Recognition and formal assessment to address specific needs within domains of expertise.	Delivering elements of care to meet specific needs in specific domains.	Ability to assess, plan and deliver care. Support to usual care staff as they provide the care planned. Refer on to specialists as needed.	Advanced communication. Assessment skills. Care planning. Providing care using usual care team.
Level 4: Complex	Specialist health and social care professionals with expertise specific to current situation.	Assessment of complex needs and diagnosis with reference to the MDT.	Specialist problem specific interventions / treatments and liaison across MDT.	Ability to assess, plan and deliver complex interactions using a variety of frameworks in liaison with the MDT.	Critical ability to integrate provision of care across settings and disciplines. MDT working.

In each location, we think there will need to be educational input to develop staff skills and competencies in each of these areas. A potential educational framework could be provided through the Senses Framework (Nolan *et al.,* 2001). This framework was developed in the UK care home context but this would need further work to modify it to the Irish cultural context and more importantly to end-of-life care. We think there may be value in developing and testing this in a further study.

9.4.1 A Case Example

Figure 9.2 (page 167) can be interpreted as a hypothetical trajectory of an older person with heart failure admitted to a nursing home. Over time the older person is living with losses, including possibly the loss of their own home. The line shows that the person experiences fluctuation in their condition and two acute episodes where additional care is required. This may be precipitated by acute exacerbations of the main illness, acute infections, falls or a psychological crisis such as bereavement or dementia. There may be a rapid decline in function as shown in the shaded zone where there is uncertainty about the status of the person as they move into the *Living and Dying* zone. At this time, levels of care need to be increased to deal with the distress and this is ideally provided within the nursing home, but if unavailable the older person may need to be transferred to a hospice or hospital. However, once they start to recover, discharge from the hospice should be planned.

In the case illustrated, we have shown there are two periods of rapid decline and subsequent recovery, with the older person finally dying unexpectedly without requiring complex care. Alternatively, the older person may have died when complex care was being provided in a hospice or hospital.

The actual trajectory of dying does not really matter. Rather, what is important is that end-of-life care is reactive and reflective, and responds to the immediate needs of patients in the most appropriate setting. While the distinction between gerontological care and end-of-life care can become blurred in such circumstances, this may enhance care rather than diminish it, as providers integrate end-of-life philosophies into normal patterns of care and quality of life into dying and death.

9.5 Conclusion

The models outlined in this chapter are based on the view that, while older people should be at the heart of decision-making with respect to end-of-life care, institutional structures and processes and social relationships also matter. Thus, while autonomy and independence for older people are important, so too are issues of understanding, empathy, information and communication.

The models attempt to provide a more complex level of understanding of how older people can be helped to negotiate their way through changing circumstances at end-of-life. Four key dimensions are identified as critical for good end-of-life care: knowing and revealing needs; expressing values and preferences; interacting with others; and developing knowledge. These dimensions are important whether the care provided is fundamental, enhanced, advanced or complex.

End-of-life care must be flexible, contemplative and responsive to need in order to capture the uncertainty associated with dying and death. Trajectories of dying are not always linear, as older people move in and out of the zone of *Living and Dying*. Neither are losses confined to individual dying and death; older people have to come to terms with many ‘absences’ within long-stay care and bereavement is a constant feature of life in such settings. Therefore, the neat separation of end-of-life into a defined period when palliative care services can be mobilised and administered is not possible. The need for end-of-life care can arise far away from actual death, depending on the physical, mental and emotional state of patients and their families. Meeting that need when and where it arises is the essence of good quality care.

Chapter Ten

Conclusion and Recommendations

Chapter Ten

Conclusion and Recommendations

10.1 End-of-Life Care

When people think of end-of-life care in Ireland, it is usually in the context of palliative care provision. The hospice model of care has been recognised as a potential model of excellence, not only for people with cancer, but for non-cancer patients as well, in all types of care settings. Despite its importance, investment in hospice and palliative care services in Ireland is relatively low. Service coverage is incomplete geographically and concentrated on people with malignant diseases. The impact of the palliative care approach on older people has therefore, not surprisingly, been weak. Palliative care is generally not available to older people at end-of-life, particularly for older people approaching death in long-stay care settings.

Recently, the focus internationally has begun to shift to a broader understanding of dying and death that goes beyond palliative care provision for cancer patients to embrace a compassionate approach that supports people who are living with, or dying from, progressive or chronic life-threatening conditions. The new approach is holistic and comprehensive and allows a longer lead time to death. It also takes into account the potential uncertainty surrounding dying and death, including the possibility that some people follow complex and non-linear pathways to death. While it may not be possible to know with certainty when people are likely to die, it may be possible to locate them on a pathway to death, along which they need differential care and support that draws on the palliative care model, but goes beyond it as well. In such circumstances, end-of-life care may be a more appropriate term to describe the needs of such patients.

End-of-life care is intimately bound-up with quality of life issues for older people living in acute and long-stay care settings. Loss and decline are common and recurring features of life in long-stay care settings, from admission, through ongoing care, to death, both of which impact on quality of life. This raises complex issues about the meaning and remit of quality of life for older people living in long-stay settings. The publication of the *National Quality Standards for Residential Care Settings for Older People in Ireland* (HIQA, 2008) has given an overdue recognition of the importance of quality of life in long-stay facilities, incorporating important elements such as autonomy and independence, choice, social contacts, care environment and the physical environment, and includes an explicit end-of-life care standard which embraces a holistic, person-centred approach to the care of the dying in long-stay settings. The real challenge for the future will be to find an equilibrium between the care of the living and dying in long-stay care settings from the perspective of both patients and staff. This report provides a potential framework for the development of an integrated care structure for end-of-life care in acute and long-stay settings that embraces living and dying as part of the normal care structures and processes in such settings.

10.2 Methodological Issues

We do not have very good data in Ireland on how people die in acute and long-stay settings. This study sought to elicit the views of patients and staff about their experiences of end-of-life care in the various settings in order to fill the current knowledge vacuum in Ireland on dying and death. The views of patients are particularly important given how often the needs of the dying patient are defined and filtered through the views of family and healthcare professionals. There is a significant literature on the methodological problems associated with doing research on people who are dying and/or close to death. These problems are well documented and include ethical concerns about interviewing people at such a vulnerable stage of their life and dealing with highly sensitive material that arise from such interviews.

In this study, the major methodological issue was the task of identifying older people to participate in the study. Great care was taken to select participating facilities in a random way and within sites to work with staff to select suitable patients for interview. However, even with direction, it was not always easy for staff to select patients for the study. This reflected an ambiguity about the meaning of end-of-life care among staff and a tendency to equate end-of-life care needs with palliative care needs. The majority of older people had conditions other than cancer which were not always recognised by staff as giving rise to palliative care needs. Staff also tended to understand end-of-life care as a point in time rather than as a continuum, which in turn influenced their approach to the care process and to the selection of patients for interview for the study. Even when they knew that particular patients were on a pathway to death, they did not always equate that journey with the need for end-of-life care. In addition, nurses, found it difficult to identify end-of-life trajectories for some patients more than others, particularly those with multiple co-morbidities.

There were also concerns about the risk that the interviewers might reveal or emphasise the terminal nature of their condition to patients who might not otherwise be aware. While this was a particular issue for nursing staff, the

Ethics Committee for the study also requested that the terminology used in the interviews with patients should not overtly refer to dying and death. This meant that the discussions with patients about end-of-life were more indirect than initially envisaged, with interviewers directed to let respondents take the lead in raising end-of-life care issues and only then follow up with more explicit questioning. While the sensitivity of explicitly raising issues about dying and death for people at end-of-life is recognised, it is not always clear who is being protected by such an approach. Older people may be more willing to talk about dying and death than is currently acknowledged and it may be staff more than patients who fear open communication about these issues. Finding out more about older people's attitudes to, and expectations of, end-of-life care, and how they die, may require a more robust and explicit approach to interviewing than is currently allowed and practised. Certainly older people do need the opportunity to engage in discussions around end-of-life issues at a personal and wider service planning level if future resource allocation is to be based on their preferences and needs. Utilising vignettes or peer interviewing might be potential methodologies for use in any future research.

10.3 Legal and Ethical Issues

The key challenge in enhancing quality of life for older people at end-of-life is the preservation of the person's surviving autonomy and dignity balanced against inevitable paternalism. Respect for the person's dignity and autonomy is at the core of their human rights and the law on consent upholds these rights. The current law on decision-making at the end-of-life is based on the principles of autonomy and self-determination. But if these principles do not hold during all of their time in care, beginning at admission, it is difficult to give them meaning at the end stage of dying and death. The first challenge therefore is to involve older people directly in all matters related to their care. This means more information and enhanced communication among providers of care, families and patients. Significantly, any studies have shown that patients want much more information than doctors believe they do.

In Ireland, there is a need for legislative reform in relation to vulnerable older people and the key issue of capacity. In the meantime, it should be possible to have guidance in the form of codes of practice that would incorporate these issues until legislation is enacted. Beginning with the transition from home, and having regard to the least restrictive alternative, the person's wishes should be considered, including whether residential or hospital care is unavoidable. The assessment prior to admission must address the broader needs of the person along with their view of their care. This information is relevant to forming a substitute judgement in future decision-making, if required, based on the best interests of the person. An expansion of the best interest test to include the broader aspects, as in other jurisdictions, would result in a more individualised approach. The difficulty in accessing patient views while in long-stay care should not be underestimated but can be supported by positive relationships with the medical and nursing staff.

Disclosure of information for consent must be individualised in order to enhance decision-making capacity. There is a role for an independent advocate in assisting the person to make a decision about their care and treatment, if and when required. In this regard, knowledge of the patient's wishes or any advance directive made prior to the onset of incapacity should be considered. While there is no legislation at present to underpin advance directives, either formal or informal, they are a means of ensuring wishes are respected following the onset of incapacity, and not just at the end-of-life. It would seem that there is legal support for the common law advance directive based on the right to consent to treatment and respect for the person's wishes. While there is no decision to date on this matter in Ireland, decisions in the English courts will likely have some influence. Where there is diminished capacity, it is important to have a robust system in place to provide alternative decision-making and safeguards.

The human rights principle of age-indifference in policies and practices requires that each person is entitled to the same respect and regard as any other person. There is evidence of ageism in the Irish health and social care system. This results in negative attitudes and behaviour towards older people that can have a profound impact on their quality of life at end-of-life. Information and education is a powerful antidote to ageist tendencies within the health and social care system. Currently, little attention is paid to matters of private and public education in relation to dying and death – an anomaly that serves to underpin ageist attitudes and discrimination at end-of-life. We need to provide education and information for older people on all matters relating to end-of-life decision-making including: advance care planning; living wills; consent; communication; bereavement and loss; and spirituality and faith. Some people will use this information to support a more direct and personal involvement in end-of-life decision-making; others will not, preferring to delegate decision-making responsibility to family members, nurses or clinicians.

Circumstances surrounding end-of-life are poorly understood, leaving many people to struggle through this life event. Ageism can exacerbate the situation for many older people at end-of-life; education and information can help people make better decisions earlier and act as a counterforce to ageist policies and practices.

10.4 Facilities, Services and Procedures

The majority of older people in Ireland die in acute and long-stay settings. The evidence from the quantitative survey suggests that the majority of older patients in private nursing homes die in single rooms. Somewhat surprisingly, nearly three quarters of HSE extended care units responded that their patients are usually cared for in a single room at the time of death. Multi-bedded ward location at time of death is more prevalent in acute hospitals and psychiatric hospitals. There is some conflict between the generally high figures for single rooms reported by the quantitative study and the evidence gleaned from the six site visits, where it seems that having a single room at time of death was much less frequent and, even when available, actual use depended on the capacity of the facility at that particular time. The problem is that the quantitative survey instrument sought information on usual location at time of death rather than actual location for specific patients/residents, which may have resulted in some over-estimation by nurse managers of single room location, reflecting an idealised scenario in the absence of other demands. In reality, pressure on space dictates that single rooms, even when available, are used for other purposes.

The number of designated palliative care beds in the system is extremely low. While all settings provide end-of-life care, with some patients transferred specifically for that purpose, there are very few designated palliative care beds available for patients who need such care. However, the majority of facilities have the full range of equipment available for end-of-life care including suction machines, oxygen, nebulisers, pressure-relieving equipment and hoists. Syringe drivers, TENS machine and oximeters are less available, particularly within the private and voluntary sectors. Acute hospitals have the highest availability of end-of-life care equipment.

The majority of care staff across all facilities have not received any formal qualifications in palliative care, with less than one third of all facilities reporting that their qualified nurses hold a post-registration qualification in palliative care. A higher proportion of all facilities contain qualified nurses with significant experience working in a palliative care setting, or have nurses who have attended short courses/training in end-of-life care. Most nurse learning is facilitated through attending short courses/training in end-of-life care rather than through attaining formal credentials. In relation to other staff, only one third of all facilities responded that their care/support staff had attended short courses in end-of-life care and only 12 per cent replied that doctors/consultants in their facility had received any form of specialised training in palliative care/medicine. These figures suggest a significant education and training gap in relation to palliative care provision.

There are generally low levels of access to consultant-led palliative care teams, especially within long-stay facilities, where only two fifths of respondents indicated that they are connected to the service. Access to 24-hour advice on resident/patient care from specialist palliative care services is higher, as might be expected. Routine visiting/service provision within long-stay settings from geriatricians, PHNs, social workers, psycho-geriatricians, phlebotomists and counsellor/psychologist/CPNs is very low. These providers are likely to visit only when asked or not at all. Such low levels of provision reflect existing resource constraints but may also reflect the sequestration of dying people from living people by healthcare professionals. Older dependent people receiving end-of-life care may not only be physically separated from the rest of society through their admission to long-stay care facilities, but they may also be further isolated through the work practices and patterns of healthcare providers. The priest/clergy/minister of the faith is the most regular visitor to people receiving end-of-life care across all long-stay sectors, reflecting the enduring importance of spirituality for people. There is also significant visiting by volunteers across all long-stay facilities.

Overall, there is a low provision of formal bereavement support structures available before and after death within acute and long-stay settings in Ireland. Less than one third of acute hospitals have a bereavement officer/family liaison nurse in place to engage with families following bereavement. Bereavement support structures for families following death are also weak in the long-stay sector. The availability of private space for engaging in confidential consultations with relatives and friends is scarce in all settings. Similarly, there is very little internal accommodation available for family and friends wishing to stay overnight with their loved ones when death is imminent. Private nursing homes generally have better physical facilities available for families and friends visiting residents/patients who are dying.

The availability of written policies and guidelines on end-of-life care ranges from 85 per cent in acute hospitals to 40 per cent in voluntary welfare homes. Written guidelines are generally more available in the private long-stay sector than in the public or voluntary long-stay sector. Care in the last hours of life, last offices and contacting a patient’s priest/minister/spiritual adviser appear to be well covered by written guidelines, achieving 80 per cent coverage or above in public, private and voluntary facilities. Symptom control and informing other patients of the deaths of relatives are less well covered. The existence of written policies on advance directives is low overall, particularly in public long-stay facilities. Similarly, coverage in relation to written policies/guidelines covering the needs of residents from ethnic minority groups is low across all sectors.

10.5 Living and Dying Experiences in Acute and Long-Stay Settings

The term ‘end-of-life care’ is a relatively new term in the Irish healthcare setting, and opinions on its definition and meaning are quite broad and cover a wide range of factors. However, end-of-life care is generally perceived by staff to be different to other types of care such as terminal care or palliative care. Staff recognise end-of-life care as a continuum, even if they are not always able to identify where people are on that continuum, or the significance of various points on the continuum for care provision. Staff showed an awareness of patient needs, particularly in relation to pain management and their desire for company, particularly at the time of death. There was a strong emphasis in the sites visited on supporting patients at a psychological and spiritual level, with some staff showing clear evidence of having specific skills in addressing the reality of life closure with patients. There was also evidence that the nature and intensity of relationships at the time of death were mutually sustaining for both patients and direct care staff.

The qualitative interviews showed that older people were capable of conceptualising dying and death but were less willing to talk about their own position on the end-of-life continuum. There was recognition of loss and transition upon admission to long-stay care, but no overt willingness to engage in discussion about dying and death. Most patients retained a strong capacity for living in the face of their physical frailty. There was a strong sense of hope permeating many of the interviews with residents and patients. Some participants appeared unaware that they were close to death and simply didn’t discuss their own dying at all as a matter for concern. Instead they focused on recovery and renewal and how they would manage following discharge from their current setting. Many people talked about home and family and were focused on the needs of others as much as themselves when they were asked questions about the future.

It is impossible to know if this kind of response was self-deception or self-protection, or some combination, on the part of patients or whether they were genuinely unaware of their own impending death, even if, for some, the latter was imminent. Information and openness around dying and death were certainly contentious issues in all of the sites visited. Only a small number of staff regarded it as part of the patient’s rights to be informed of their prognosis, in keeping with the general belief that discussion of death was unsettling for residents and therefore not to be encouraged. The majority of staff only discussed death and dying if the resident brought up the topic first and acknowledged that they were dying. Inhibitory factors against open communication included a perceived lack of knowledge and skills among staff and finding the right time to raise the subject with them. The ethos of end-of-life care was to make people as happy and comfortable as possible, which generally was understood to mean not telling people that they were dying. Strategies such as keeping cheerful, reassuring the resident that they would be fine and distraction were used to steer staff-patient discussions away from death.

When death was explicitly acknowledged by patients, being able to achieve a sense of closure over their life was important. Patients often rationalised their deaths either through a belief in God as an external influence on the time and manner of death or as a normal and inevitable pattern of the life-cycle. Some patients reported that they not only accepted but actually looked forward to death as a way of meeting again with family members who had pre-deceased them. This belief appeared to sustain them in the face of death. In all cases, death was perceived to be beyond their control, contributing to a largely fatalistic attitude towards their future and the likelihood of death. A ‘good’ death, when articulated, was described generally as one which was neither protracted nor painful but allowed for reconciliation with family and friends. Most participants were aware of the need to balance physical care with the spiritual dimension of life closure. This was often framed by discourse surrounding faith (predominantly the Catholic faith) as providing hope and meaning at end-of-life, supported by sensitive end-of-life care ritual and practice.

The vast majority of staff described care within their facility as person-centred, individualised and based on resident choice. However, staffing shortages sometimes prevented the realisation of this model of care. Staff did not always have the time to give dedicated personal care to patients who were dying. Staff in all sites referred to low staffing levels as a barrier to spending time with patients, though there were significant differences in staff-patient ratios across the sites. Staff had to balance the needs of dependent older people with multiple nursing needs, the totality of end-of-life care and administration, all of which required scrupulous attention to detail, not only in relation to the patient but for the family as well. There was some recognition of the emotional labour involved in caring for people at end-of-life, making it difficult for staff to move seamlessly between care of the dying and care of the living. However, although this was evident in some facilities, for others, the ethos was to ‘carry on’ and contain emotions, with little support or understanding given to staff who might be emotionally distressed. The value of education and training in end-of-life care was a constant refrain in discussions with staff during the site visits as a counterbalance to the physical and emotional needs of the job.

The physical environment was highlighted by staff as a real issue in end-of-life care. Sometimes the lack of physical space meant that patients and their families could not always have privacy at the time of death. Staff talked about the effect of this on the dignity of patients and on the feelings of families and fellow-patients. Few of the facilities that we visited had a single room that could be used when a resident was at the final stage of their life. Where single rooms were available, they were prioritised in relation to clinical need (e.g. MRSA infection). Most staff valued the single room as a resource that created privacy for the patient and enabled relatives and friends to stay with the person in their final days and hours. However, an alternative viewpoint suggested that a single room may not always be appropriate where patients had formed a friendship with fellow patients or where a private room might be frightening if patients had become used to living in shared accommodation.

10.6 Conceptualising New Models of Care

Conceptualising new models of care for people at end-of-life in acute and long-stay settings is a complex process. The key is the development of a broader view of end-of-life care and its integration into everyday life and work within the facility. We need a longer-term perspective beyond the death of patient or the time period immediately preceding this. Living and dying occur in the same space in long-stay settings and staff are required to care for all residents, whatever their position on the continuum of life and death. Therefore, end-of-life care needs to be reconstituted within long-stay facilities as a key strand in all care provided. All care in long-stay care settings is potentially end-of-life care and residents do not have to be dying for end-of-life standards to be assessed and implemented.

Accepting this philosophy implies that transferring the palliative care model into long-stay settings is not enough. It may be a necessary condition but is not likely to be sufficient to nurture and support a person-centred approach to care involving well-trained, educated and supportive staff who are aware of end-of-life needs of patients from an early stage of the process. Making the patient aware of their prognosis and encouraging them to make decisions regarding the type of care that they would like is an important aspect of care in long-stay settings, not only when people are close to death but from the time of admission to care. Similarly, taking the time to listen to patients and comfort them on their ‘final journey’ is an essential component of any communication strategy, which must begin at the early stages of the process. Involving family in the care of the patient is also a priority which means keeping relatives informed of the condition of the patient, allowing frequent and flexible visiting and having appropriate facilities for relatives to use while visiting.

There are many barriers to the development of new conceptual approaches that seek holistic, person-centred solutions over a longer time horizon than the current *ad hoc* approach allows. There are resource constraints, capacity problems, infrastructural weaknesses, education deficiencies and poor attitudes and expectations in relation to quality of life for older people at end-of-life. Ageism within society generally, and within the health and social care system in particular, makes it difficult to sanction investment in end-of-life care for older people. There has, until recently, been little engagement with quality of life issues for older people in long-stay settings. For decades, neither the living nor the dying within long-stay settings generated much interest among policy-makers, mainly because older people in residential care were outside the moral compass of society. This is now changing in response to greater information on living conditions and quality of life within long-stay settings, but there is no room for complacency. An unwillingness to engage with dying and death at all levels of society, both personally and socially, makes it difficult to develop and sustain solutions to the problem of end-of-life care for older people. What is understood as 'good' end-of-life care is a moral issue but is also the outcome of individual reflection, cultural and social interactions, political deliberations and resource distribution.

The conceptualisation of dying and death for older people in this study is an attempt to address some of the issues raised above. It is not a complete model, but it is based on certain key premises that have been evident and debated throughout this report. These premises require end-of-life care provision to be:

- Respectful of the dying person
- Supportive of families and friends
- Supportive of staff, including training in end-of-life care and emotional support
- Integrated across the various health and social care providers.

Although our approach is focused on the care of older people in particular health and social care settings, the wider social and cultural context is recognised to shape the values and practices in such organisations. Death is by definition personal, but it is also social and public. We therefore present a framework to ensure the development of good end-of-life care for older people that meets their needs and aspirations and is located within social, cultural and institutional realities.

The frameworks outlined in the previous chapter are based on the view that, while older people should be at the heart of decision-making with respect to end-of-life care, institutional structures and processes and social relationships also matter. Thus, while autonomy and independence for older people are important, so too are issues of understanding, empathy, information and communication. An understanding of the human condition is central to good quality care for older people at end-of-life. It is essential that ways can be found to help older people negotiate their way through changing circumstances at the end-of-life. Four key dimensions are identified as critical for good end-of-life care: knowing and revealing needs; expressing values and preferences; interacting with others; and developing knowledge. These dimensions are important whether the care provided is fundamental, enhanced, advanced or complex. Each of the four dimensions have information-generating needs and properties which will have to be examined and articulated. Making progress on each dimension will, therefore, require further research. Institutional reform will also be required for real change to occur. Public attitudes and expectations will also have to be managed if the system is to embrace real change.

End-of-life care must be flexible, contemplative and responsive to need in order to capture the uncertainty associated with dying and death. Trajectories of dying are not always linear, as older people move in and out of the zone of *Living and Dying*. Neither are losses within long-stay facilities confined to individual dying and death; older people have to come to terms with many 'absences' within long-stay care and bereavement is a constant feature of life in such settings. Therefore, the neat separation of end-of-life into a defined period when palliative care services can be mobilised and administered is not possible. The need for end-of-life care can arise far away from actual death, depending on the physical, mental and emotional state of patients and their families. Changing the focus of regulation within the long-stay sector away from care and towards quality of life is an essential element of reform and has already begun in Ireland. A good death should follow a good life; both can only happen if the culture of care within the long-stay sector in Ireland is transformed for all patients and staff.

10.7 Recommendations

There are many practical recommendations that could follow from the analysis contained in this report, particularly since we have identified a clear overlap between gerontological care and palliative care within acute and residential settings. Many of these coincide with previous recommendations made by some of the authors of this report to enhance quality of life for both the living and the dying in long-stay care settings and will not be repeated here. Many of the latter have already been incorporated into the *National Quality Standards for Residential Care Settings for Older People in Ireland* (HIQA, 2008) which, of itself, is an important first step in the reform process. Similarly, the Hospice Friendly Hospitals Programme contains the seeds for real change to occur in the culture and organisation of hospice care in hospital settings and, not surprisingly, influenced our thinking about future needs and priorities. For this report, however, we focus on the following six broad recommendations for potential change covering many different dimensions of dying and death.

Consultation with Older People

Greater consultation with older people to establish Irish domains for quality of life at end-of-life. There is a need for much more dialogue with older people about their needs and preferences, including the moral and ethical perspectives that older people regard as important in end-of-life care and their views on 'the good death'. Focus groups, consumer panels and citizens' juries are three ways to elicit preferences from older people about their preferences for end-of-life care. People need to be given information on the legal aspects of dying and death, including material on rights and responsibilities. There is also a need to explore the relationship between a desire for information on the part of older people and their willingness to assume responsibility for decision-making at end-of-life. Advance directives should be promoted as a means of ensuring that people's wishes are respected from the onset of incapacity and not just at the end stage of life. New legislation is required to provide support for older people with diminished capacity.

Investment in the Physical Environment

The physical environment has a major role to play in the management of death, dying and bereavement in hospital and long-stay care settings. Almost all participants recognised the need for privacy and physical space at the time of death and their importance for the dignity of patients and families alike. The reality is that the physical environment of many of our hospitals and long-stay facilities are disabling rather than enabling for care provision at end-of-life. Regulations and standards are required to ensure that the physical environment provides the optimal circumstances for a comfortable and dignified death. HIQA can play a major role in ensuring enabling environments at time of death in the form of single rooms and proper facilities for family and friends.

Improved Cultural Awareness

Emphasising choice and autonomy is of little value if people find it difficult to talk about dying and death. Attitudes and expectations about dying and death need to be developed and challenged through public education and information campaigns. This is particularly important in the context of greater ethnic diversity in Ireland, particularly within the social care system. The need for parity of esteem between younger and older deaths should be debated. So should the prioritisation of deaths from some diseases more than others.

Policy Reform

Policy reform is required to ensure that end-of-life care is recognised as an important public health issue, separate to palliative care but inclusive of many of its key elements. End-of-life care embraces so many tasks and disciplines across the public health spectrum. The major task is to ensure that the best practice elements of palliative care get transferred into end-of-life care, but that the latter is also intertwined with gerontological care. Increased resources are necessary to develop end-of-life care as an embracing philosophy within all acute hospitals and long-stay care settings, including greater specialist provision, improved services, universal provision of basic equipment and facilities, and investment in physical infrastructure. The inclusion of end-of-life care in the national standards for long-stay care is an important development in this regard.

Practice Development

Practice development that brings real change to the care process is needed. Palliative medicine and geriatric medicine should move towards greater coordination with shared training posts and joint education initiatives. Communication and integration across disciplines should be facilitated through joint initiatives and integrated care structures designed to keep patients at the appropriate level of care. Older people should not be transferred into acute hospitals for end-of-life care unless for clinical reasons. Guidelines and procedures are necessary but not sufficient to ensure quality improvements in dying, death and bereavement services. Regular information and comprehensive monitoring systems are also required for optimal care at end-of-life. All staff should be provided with regular training and education in end-of-life care. Training is necessary to provide knowledge and confidence to staff in respect of long-term care of the dying. Bereavement support for families, staff and patients should be central to the culture of care within acute and long-stay care settings.

Models and Piloting

Testing models is an essential part of the reform process. This report contains the building blocks for the reform of end-of-life care in this country. The next step is to apply some of the lessons of this research on a pilot basis in selected acute and long-stay settings across the country. This is both a methodological and practical task that will require cooperation among researchers, policy-makers and practitioners to bring about a fusion between gerontological care and end-of-life care in the various settings. Information is key to this process. We need to develop more robust information systems linking need to resources at end-of-life. Current innovations within practice development and acute care settings (through the Hospice Friendly Hospitals Programme) need to be evaluated and enhanced through the development of new initiatives in end-of-life care within long-stay care settings.

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