

# IMPROVING QUALITY

**CARING FOR PEOPLE LIVING AND DYING  
IN LONG-STAY SETTINGS**

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for the Project Steering Group*



St. Francis Hospice



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# Preface

This report describes a Quality Improvement Initiative to improve the care of people living and dying in residential care settings. The study was a joint initiative between St Francis Hospice and three public community units in North Dublin, Claremont Residential and Day Services, and Cuan Aoibhinn and Lusk Community Units. Funding was awarded by the Irish Hospice Foundation. A steering group of experienced practitioners in care of the elderly and palliative care was established to oversee the project.

The nature of community units, which provide care for the frail elderly is different to that of hospitals or hospices. Residents may live in a setting for a number of months or years, and relationships are established between staff, residents and families which are different to the transient, but no less significant relationships in hospitals or hospice.

Residents of these units typically have multiple co-morbidities, rather than a single disease, and frequently have cognitive impairment. The lack of clear legal guidance about health care decision-making for adults who lack capacity leads to challenges in planning and providing appropriate care.

This initiative took the form of a literature review which informed a base-line review of care and documentation in the units. This was followed by an educational needs assessment for staff. Interviews and group discussions were held to elucidate the attitudes, views and knowledge about end of life care in the units.

A number of initiatives were undertaken, including the development of death reviews, which were designed specifically for this population; the development of an education programme for staff; the development of a link nurse role and the provision of an education resource folder in the units.

A review of the project, using an end of life care evaluation tool, showed an improvement in the care provided. Areas of continued need for development, especially in the area of the evaluation of interventions were identified.

This project has shown how to improve end of life care in residential and long-term care setting

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# Chapter 1: Introduction and Overview of Project

This chapter provides an overview of the project aim and objectives, together with a description of the tools used to elicit the data in order to meet the project outcomes.

## Rationale for the Initiative:

The Report of the National Advisory Committee on Palliative Care, adopted as Government policy in 2001, outlines the requirement to provide appropriate levels of palliative care to patients with any illness, not just cancer (DOHC, 2001). Appropriate palliative care for older people has been recognized as a vital challenge internationally by the World Health Organisation. The Health Information and Quality Authority (HIQA) has developed standards for residential homes including Standard 16 on End of Life Care (EOLC). In light of these, this quality initiative to develop strategies with staff in participating units to improve the provision of EOLC was developed, and an application for funding was successfully made to the Irish Hospice Foundation.

Following the successful grant application, a Project Steering Group was set up. A project nurse was employed.

## Primary Aim:

The primary aim of this project is to develop a quality initiative for residents in three residential care units to improve End of Life Care (EOLC). The three residential units are Lusk Community Unit, Cuan Ros Community Unit and Claremont Residential and Day Services.

## Objectives:

The objectives of this initiative are:

- a. To identify the structure, process and outcomes of EOLC in three residential care units.
- b. To identify staffs' perceptions of EOLC in their organisation, including areas they regard as being done well and areas that require improvement.
- c. To assess staffs' knowledge regarding EOLC, including symptom management, EOLC standards as outlined in the National Quality Standards for Residential Care Settings for Older People (HIQA), the use of syringe drivers, the use of automatic external defibrillators (AED), genograms and normal bereavement.
- d. To assess staffs' attitudes to care of the dying in their unit, with specific emphasis relating to nutrition and hydration at end of life, end of life decision-making, advance care planning and the family as the unit of care.
- e. To develop an action plan arising from the above.
- f. To implement the action plan.
- g. To develop a palliative care link nurse role in each unit

## Description of the Units:

Three north Dublin long stay community units providing long-term care for elderly residents requiring full-time care participated in this project. Unit 1 has a bed capacity of 42 beds, unit 2 has 119 beds and unit 3 has 50 beds. While most of the beds are occupied by long-term residents, a number of beds are used to provide respite on a rotational basis to

elderly people living at home. Many residents have some level of cognitive impairment.

Each unit is staffed by members of the multidisciplinary team. In some units a designated medical officer is responsible for the medical care of residents. In other units the resident's general practitioner remains responsible for that care and visits the unit when a resident requires a medical assessment. Each unit is managed by a director of nursing with the support of assistant directors of nursing and nurse managers. Single rooms are available on each unit, however the majority of residents are accommodated in two-, three-, or four-bedded rooms. Dining rooms and central recreational areas ensure opportunities for socialisation for able residents. All units have outside garden areas for recreational purposes. Rooms are available on the units for families to visit with residents who are sharing a room to allow for privacy during visits. A team approach to nursing care is the model of choice in all the units. Each registered general nurse works with a health care assistant caring for a maximum of 8 residents. There is a strong emphasis on multidisciplinary involvement.

## Method

In order to meet the above aims and objectives, a part time project nurse with experience in specialist palliative care was employed to undertake the project activities. The project nurse conducted a base line review in all three care of elderly units. This review was threefold in its approach, including an examination of documentation, multidisciplinary team perceptions regarding EOLC, and patient review.

### Documentation:

The examination of documentation planned to include:

- Review of charts of all patients who died in the units, or within six weeks of transfer to an acute hospital, using a recognized End of Life Chart review tool (Teno, 1999).
- Review of all documentation relating to EOLC in each unit. These included policies, procedures and guidelines regarding EOLC, for example, pressure area care, activities of living, physical care, psychosocial and spiritual care and last offices.
- Review of documentation related to Cardio Pulmonary Resuscitation (CPR), the use of Automated External Defibrillators (AED), and hospital transfer.
- A review of all complaints from patients/families or other health care providers about care in the previous year.
- A review of all drug errors.

### Multidisciplinary Team Members' Perceptions Regarding EOLC:

Group discussions and individual interviews were conducted with staff in each of the units. The aim of these interviews was to elicit their views regarding the influences of structure (physical environment, management structure) and process (care provided, protocols, policies and guidelines) on EOLC.

### Individual Interviews:

Members of the multidisciplinary team were invited to attend to meet with the project nurse in an interview format to discuss their experiences of providing EOLC in the unit.

The invitation was by telephone and team members were assured that they would not be identified individually in the transcription of the information. They were also allowed the opportunity to withdraw from the interview if they wished. Thirteen individual interviews were recorded; each interview was transcribed and analysed. The interviews took place in an office away from the main clinical area in a place of choice of the interviewee.

### **Focus Group Interviews:**

A general invitation to attend a focus group discussion in each unit was posted in the nurses' stations and other staff areas. The sample attending the focus group were those staff available and willing on the day and time of the scheduled focus group. Six to eight staff attended each group; a total of eight focus group discussions were conducted. The participants included nurses, healthcare assistants, porters, a complementary therapist, and a recreational therapist.

All interviews and focus groups were transcribed. Content analysis was used to establish the main themes which developed.

### **Cultural differences:**

An additional series of individual interviews and group discussions were held to learn about end of life care in different cultures.

### **Questionnaires:**

An anonymous questionnaire survey of nursing and care staff, with discipline appropriate questions regarding symptom management, use of equipment (for example AED, syringe drivers), normal bereavement and EOLC standards was distributed and returned, and analysed, using Statistical Package for Social Sciences (SPSS).

### **Patient Review:**

Patients were afforded the opportunity to be reviewed by the project nurse (a palliative care specialist). It was explained to the patients (or families if the patient was unable to understand) that this was part of a quality improvement project.

At the request of a clinical nurse, four residents were reviewed during the project. Two residents were reviewed with respect to psychological support and one for pain management issues. The fourth resident was under the care of the specialist palliative care home care team and the project nurse was asked to review her on transfer to the unit from hospital. On other occasions, staff of the units contacted the project nurse seeking advice with regard to syringe driver regimens. These issues were followed up on subsequent visits to the units.

### **Intervention Phase:**

Following the initial base line and staff questionnaires and interviews, the intervention phase commenced.

**This consisted of the following activities:**

#### **(a) Staff Education**

An education plan was developed for staff. While there was potential for the focus of education to be different for staff within each of the units, common themes

emerged from the three sites. The education was delivered by the project nurse in the most appropriate format, usually small group teaching during work time, to minimize staff disruption.

#### **(b) Death Reviews**

Formal death reviews were undertaken within each unit following the death of a resident.

The purpose of the death reviews were to:

- Support staff;
- Explore events that went well and what should be changed;
- Normalize reflection on death in the organisation.

These reviews took place when the death occurred in the unit, or within six weeks of a hospital transfer.

#### **(c) Documentation Development**

Arising from review and education, documentation was developed. Some documentation is common to all three units, some specific to each unit. The documentation takes account of the HIQA end of life care standards.

#### **(d) Policy and Planning Development**

The project nurse contributed, as requested, to policy and budget planning and development.

#### **(e) Link Nurse Development**

The opportunity was offered to registered nurses in each unit to become a palliative care link nurse. The registered nurses were encouraged to undertake additional training and education. This additional training provided the participants with an opportunity to develop knowledge, skills and competencies with regard to the principles and philosophy of palliative care, pain and symptom management, and psychosocial issues in palliative care.

While the registered nurses were undertaking this education, funding for locum cover for replacement was provided.

### **Continuance:**

- An EOLC education and resource folder has been developed and is available to staff on each unit.
- All documentation, policy and procedures from St. Francis Hospice are made available to the units.
- Staff will be provided with the opportunity to participate in specialist education in pain management, within a WebCT programme, being developed at St. Francis Hospice.
- Death reviews will continue at each setting.
- The link nurse post will be developed, at least one at each care setting.

### **Summary**

This project was a collaboration with three public long stay units to identify current practice in relation to end of life care (EOLC) and to develop a programme including education, death reviews and the link nurse role to improve EOLC.

# Chapter 2: Literature Review of End of Life Care in Nursing Homes

## Introduction:

EOLC may best be described as a continuum, rather than a point in time. The term "End of Life Care" is used as a generic term when considering the needs of people with conditions other than cancer, particularly in community and long term care settings (Seymour et al., 2005). Lorenz et al. (2005) regard end of life as an indefinite period of time of life when patients and their caregivers struggle to varying degrees with advanced chronic illness. The World Health Organisation (WHO) promotes holistic palliative care that is relevant to all those with chronic illness and their families in different care settings from the early stages of disease. The WHO (2002) defines 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 the achievement of the best quality of life for patients and families. Many aspects of palliative care are applicable earlier in the course of illness in conjunction with other treatments."*

The Department of Health and Children (DOHC) (2001: 157) regards specialist palliative care as:

*"...those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs, and, consequently, require a greater degree of training, staff and other resources."*

Additionally, non-specialist palliative care practice is considered by the DOHC (2001: 517) to be:

*"...the practice of palliative care principles by all health care professionals with a focus on quality of life, which includes good symptom control, a holistic approach that takes into account the person's life experience and current situation, care that encompasses both the dying person and those that matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues."*

This implies that palliative care should be a core skill of every clinician at hospital and community level.

## Deaths in Ireland:

Almost 30,000 people die in Ireland each year; of these, just over three quarters are aged 65 years and over (CSO, 2006). Forty per cent of these older deaths occur in the acute hospital setting while a further 20% of older people die at home. Additionally, up to 15% of people die in private nursing homes, while the remaining 25% die in other settings, mainly public long-stay care facilities. While various frameworks have been proposed that depict the nature of dying (Corr, 1993; Copp, 1999), three stages associated with EOLC in long stay settings has been identified by Froggatt (2004). These consist of *"the living and losses experienced in the care home"*; *"the actual death and dying"* and *"the*

*bereavement that follows a person's death"*. This suggests that EOLC needs to be integrated as a key element of all care provided from admission to bereavement. The National Quality Standards for Residential Care Settings for Older People in Ireland, (HIQA, 2008), outlines an *"End of Life Standard"* which highlights the necessity for regular review and assessment of each resident's palliative care needs. It recommends that referrals be made to specialist palliative care services when necessary in order to initiate an integrated multidisciplinary approach to EOLC. These standards require that each residential setting has facilities in place to support residents' end of life care, in order to avoid unnecessary transfer of residents to an acute setting except for specific medical reasons, or in accordance with the resident's wishes.

## Residential Nursing Home Care Settings:

In keeping with the principles and philosophy of palliative care and the principles and philosophy of older person care, there is evidence to support the argument that the provision of palliative care in nursing homes improves the quality of care received by residents (Baer and Hanson, 2000). The dying trajectory of older people, however, is often characterised by lack of certainty which is common to long term conditions (Field and James, 1993), especially in the absence of a significant medical event to mark the terminal phase of illness. George and Sykes (1997) highlight key differences between older people and others receiving palliative and terminal care, including the presence of multiple disorders; being diagnosed as dying much closer to death; and a tendency for older people to have poor communication skills and social isolation. These differences pose a challenge to the manner in which palliative care is currently practised (Addington-Hall et al., 1998).

Patient profiles in long term settings differ in a number of ways from patient profiles in specialist palliative care settings. Those differences include: a lower prevalence of cancer; a higher prevalence of dementia; greater variability in prognosis; a greater reliance on nursing assistants to provide care; and greater limitations on resources such as on-site pharmacy services (Zerzan et al., 2000). Despite these differences, a broader acceptance of palliative care requires a shift in the culture of long-term care (Kristjanson et al., 2005). Advocates have identified a number of organisational and cultural barriers to providing adequate EOLC in nursing facilities. Those include inadequate support of staff caring for the dying residents, emphasis of regulations on restorative care and a reluctance to collaborate with outside hospice providers (Froggatt et al., 2002). In addition, studies suggest that nursing facilities incorporating care of the dying into daily care processes and organisational and clinical policies provide optimal palliative care (Travis et al., 2002). Although nursing staff in long term care are at the forefront of end of life services for individuals with dementia, they may not have received relevant education and training enabling them to adopt palliative care practices in older person care settings (Phillips et al., 2007). Applegate and Morse (1994) suggest that health care assistants are an invaluable resource for administrators seeking to integrate individualised palliative care into the culture of an institution; it is important to recognise opportunities for health care assistants to utilise their knowledge of individual residents and their families,

leading to positive resident outcomes, particularly in terms of engagement in the life of the facility and personalised care.

Providing care to the terminally ill demands the qualities and skills that arise from compassion, reciprocity, professional commitment, and the ability to communicate with patients and their families (Pusari, 1998). In addition, nurses need to be competent in their assessment skills and possess up to date knowledge and skill to provide treatment to alleviate symptoms, engage in communication and provide a family-centred approach to care. Cohen et al. (2002) report that palliative care nursing is believed by many nurses to be a distinct manner of practice that is dependent on the attributes of the person who provides the care. Despite recognition of these specific attributes, palliative nursing is practiced in a range of environments and settings including acute hospitals, nursing homes, hospices and residential care settings (Taylor, 2004; Samson Katz, 2004).

## Education and Training in EOLC:

While staff in long-term facilities have a variety of experiences in dealing with death and dying, they may lack formal training in palliative and EOLC practices. According to Brazil and Vohra (2005), the acquisition of such experiences is recognised as a prerequisite to the provision of good quality care in long term facilities. Froggatt (2000) concludes that nursing home residents may benefit from care staff receiving palliative care education, particularly in enhanced physical and psychological care, pain management and communication skills. Stillman et al. (2004) suggest that a palliative care programme within a nursing home potentially increases carers' general knowledge of the problems faced in caring for the dying. Watson et al. (2006) identify barriers in a nursing home to implementing an integrated care pathway for the last days of life. These barriers include a lack of knowledge symptom management, lack of preparation for approaching death, not knowing when someone is dying or understanding the dying process, lack of multidisciplinary team working, lack of confidence in communicating about dying, and unwillingness or inability of staff to change. Froggatt and Payne (2006) advocate the reframing of the EOLC issues as a key strand of work within care homes so that death is not seen as the sole focus for EOLC.

In spite of the numbers of deaths in nursing homes, there appears to be limited knowledge among care staff regarding the nature and quality of these deaths. In a study by Goodridge et al. (2005), nurses identified the importance of on-going symptom assessment and coordination of care, but said that their assessment was made challenging by the lack of diagnostic test results. Nurses needed to rely on their prior knowledge of the patient and of the dying process in order to determine the point at which to inform family members of the impending onset of death. The management of physical symptoms, including repositioning, mouth care, incontinence and skin care were highlighted as core components of EOLC. The ability of staff to provide this care afforded staff the most personal job satisfaction. Staff were very familiar with each resident, the usual pattern of behaviour and his/her likes/dislikes by virtue of their long-term relationship and could thus individualise their care. In addition, education of family members was an important part of EOLC, particularly with regard to symptoms of

dying. Families valued the teaching that occurred during this period; it was equally important, however, that nurses were sensitive to the family's ability to cope with information.

## Dementia and EOLC:

Dementia is a progressive terminal disease. More than 95% of patients will require 24-hour care either in long stay hospital wards or in nursing homes at the end of life (Lloyd-Williams and Payne, 2002; Burgess, 2004). Dementia is a major public health problem with 6.4% of Europeans aged 65 and over affected by it; its prevalence increases with age, from 0.8% of those aged 65-69 to 28.5% of those aged 90 and older (Lobo et al., 2000). It is envisaged that the aging of the European population will lead to a rapid increase in people with dementia, from 7 million in 2000 to an estimated 16 million in 2050, posing a challenge to the organisation of EOLC for these patients across Europe (Houttekier et al., 2010).

According to Mitchell et al. (2004), individuals with a diagnosis of dementia receive sub-optimal EOLC, particularly in terms of the palliation of their symptoms. Cox and Cook (2002) point out that people with dementia may die, at some point on their pathway, of another identifiable disease or die with the complications of end stage dementia. The National Council for Palliative Care (NCPC, 2002) conference on dementia highlighted the need to understand that palliative care for people with dementia is different to that of cancer patients. The specific needs of these patients arise not only because of a prolonged disease trajectory and uncertain prognosis but also because poor cognition impairs their ability to express their wishes or verbalise their feelings of pain, discomfort and emotional anguish. The NCPC (2002) suggests that three areas require special attention when caring for patients with advanced dementia:

- Holistic assessment of pain and symptoms in end-stage dementia
- Burdens and strain experienced by carers of dementia patients
- Decision making with regard to EOLC

The UK NICE (2006) guidelines on supporting people with dementia and their carers agree that dementia care needs to incorporate palliative care from the time of diagnosis up to the time of death. The guidelines specifically state that the aim should be to support the quality of life of people with dementia, enabling them to die with dignity and in a place of their choosing. In addition, the guidelines recommend that carers should be supported during their bereavement (UK NICE, 2006).

Sachs et al. (2004) suggest that the role of the family in decision making and communication with health care providers is the element that most strongly distinguishes EOLC of persons with dementia from those without a cognitive impairment. According to Sloane et al. (2008), decisions to initiate and utilise a palliative care approach in long term care were more common among persons who had dementia. Thus, persons who were cognitively intact living in long term care were more likely to have died in the hospital and to have emergency services called on the day of death. However Mitchell et al. (2004) suggest that palliative care to the cognitively impaired population is not

optimal in the care home setting for a variety of reasons. These include the lack of recognition of impending death, infrequent hospice referrals, hospitalisations, burdensome treatments, and potentially treatable distressing symptoms which are common prior to death. This may be attributed to the fact that advanced dementia is often not recognised as a terminal illness.

It is accepted that palliative care should be included in the care pathway for people with dementia, and that a person-centred approach advocated for people with dementia integrates well with palliative care principles. However, a number of challenges in implementing this approach have been identified. These include: the timing of the introduction of palliative care, clarity with regard to the role of specialist palliative care team, addressing the ethical dilemmas that may present at end of life for people with dementia, the ability to communicate with individuals with a cognitive impairment and the role of advance directives in care pathways. From a person-centred perspective, the key challenge facing people living with dementia is the threat of not being considered to be a person (Kitwood, 1997). In many respects, the assumptions and implications of a person-centred approach parallel the development and aim of the palliative care approach (Hughes, 2004). Both these approaches are concerned with care for the whole person, including their physical, emotional, social, occupational and spiritual needs. They are also both concerned with quality of life and living until one dies. In addition, such an approach incorporates a family-centred approach to care as advocated by Nolan et al. (1996). Person-centred dementia care adds a central concern with a belief in the person's capacity for communication regardless of his/her degree of impairment (Kitwood, 1997; Downs, Small and Froggatt, 2006).

## Challenges in Providing EOLC in Nursing Homes:

Wilson (2001) suggests that the intensity of care required by residents has increased as more people enter nursing homes as a result of early hospital discharge. Nursing home staff have identified that residents admitted to nursing homes are becoming more dependent; they have expressed concern about the rising number of residents being admitted in the later stages of terminal illness. Such changes in trends potentially result in problems for residents and their relatives in adjusting to a new environment at a particularly stressful time and for the nursing home in trying to assess and care for the resident (Wilson, 2001).

The National Council for Palliative Care UK (2006) highlights a number of issues which may need to be addressed with respect to EOLC in care homes. The nature and extent of those issues may vary, depending on how services have developed locally. In terms of GP support, the key issues that arise include: out of hours access, anticipatory prescribing, numbers involved in care homes, verification of death and resuscitation issues. In relation to nursing home staff, the issues most commonly arising include: staff education with regard to EOLC and advance care planning, staff retention, cultural and language differences and involvement of specialist palliative care nurses. Additionally, the ability to hold some drugs in stock and have access to the commonly used drugs may promote the initiation of therapeutic pharmacological interventions for this patient group.

Challenges that staff encounter in providing EOLC to residents with cognitive impairments are numerous. Findings from a study by Ersek and Wilson (2003) suggest that residents with pain were less likely to receive analgesia if they had a cognitive impairment, were older than 85 years or were members of a racial minority group. Lack of physician involvement in care, lack of educational preparation and staff shortages were also factors that impacted on the care provided to those individuals. Carpenter (2004) suggests that one of the challenges in the management of patients with dementia is that cognitive impairment may hinder treatment because of limited ability to either consent to or adhere to treatment.

Certain attributes of nursing homes and their staff form a strong foundation for care of the dying, including the long term close relationships that develop with residents, ethnic diversity of staff and the long tradition of providing care to dying residents (Ersek and Wilson, 2003). Long-term, daily contact may also promote knowledge and understanding regarding residents' values, personal goals and care preferences. Bowers et al. (2000) found that staff delivering day to day care described the quality of this care in terms of the relationships they were able to develop with residents.

Brandt et al. (2009) suggest that while physical aspects of palliative care management - for example, pain and other symptoms - were adequately addressed in nursing home residents, most shortcomings occurred in the more subjective, less observable psychosocial (resident anxiety) and spiritual (support, life worthwhile and self-worth) aspects of care. In the context of spiritual care, it appears that this is a common element of practice that is frequently unaddressed. Literature suggests that nurses' reluctance to involve themselves in spiritual care may well be the result of little or no insight into their own spirituality (Govier, 2000). Several barriers to providing spiritual care, including the lack of clarity among nurses regarding the nature of spirituality, role ambiguity with the assumption made that it is not a nursing role to provide spiritual care and lack of educational preparation for the role have been identified by Narayanasamy and Owens (2000). This may in part be related to the complex nature of spiritual care and in particular spiritual pain and spiritual distress among residents during the dying process. Greater attention needs to be focused on the psychosocial and spiritual aspects in the dying process of nursing home residents. General competencies for spiritual care have been identified; including nurses' availability and actual presence to patients, active listening, showing empathy and compassion which may instil hope; facilitation of religious practices to patients belonging to a religious affiliation (Taylor, 1995; Baldacchino, 2002); helping patients to have quiet time or space; helping patients with unfinished business; and referral to chaplains and other professionals (Halm et al., 2000). The inclusion of such competencies as a component of educational programmes and continuing education for nursing home staff may, in some way, address these deficiencies in spiritual care.

## GPs and Nursing Home Care:

GPs have a vital role in the provision of palliative care to the residents of nursing homes by providing medical support services (Katz, 2003). In order to support the implementation of palliative care to dying residents in

nursing homes, it is necessary to establish and maintain good working relationships between GPs, nursing home staff and the palliative care team (Maddocks and Parker, 2001). Lack of physician presence in the nursing home care environment, with limited contact with staff and residents is seen as a barrier to providing palliative care. According to Hanson et al. (2000) physicians are rarely onsite yet they remain responsible for medical treatment.

## Death and Dying in Nursing Homes:

It has been reported that between 67% and 90% of residents will die in the nursing home, however, many nearing the end of life are transferred to hospital (Katz et al., 1999). Kayser-Jones et al. (1989) identify that 48% of residents were transferred due to social-structural factors, i.e. lack of support services, insufficient trained staff, poor nurse-physician communication and family pressure, rather than for clinical reasons. However Travis et al. (2002) suggest that it may take a hospital admission for the nursing home staff, resident and family members to understand, recognise and agree that the resident is truly in the terminal phase of life. Less than 15% of older people in care homes die of a specific terminal disease such as cancer; many more die following a slow deterioration (Goodman et al., 2003). According to Hanson et al. (2002) the challenge lies in the fact that the slow trajectory towards death for these residents is often punctuated by acute and apparently reversible illnesses. These common illnesses include pneumonia, sepsis and dehydration. Furthermore, episodes of acute illness may occur repeatedly prior to death. According to Katz et al. (1999), nursing home managers found it difficult to identify the beginning of the terminal phase of illness in residents and classified their residents as chronically ill and likely to die at any time. Nursing home staff are challenged with providing care for residents with diseases that have various trajectories, consisting of slow decline with periodic crises and less defined terminal phases.

While it may be ideal to extend the availability of specialist palliative care services to patients with non-malignant conditions, such aspirations appear to be idealistic particularly in terms of the availability of resources, and current specialist palliative care service provision in Ireland. O'Leary and Tiernan (2008), in a survey of specialist palliative services in the Irish context, identify perceived barriers to extending the service to non-cancer patients. They include the unpredictable disease trajectory of non-cancer patients, lack of definition of referral criteria, lack of disease expertise, services already being overwhelmed with cancer patients and limited resources.

Additionally, Wowchuk et al. (2007) identify internal factors affecting the provision of palliative care in nursing homes. These are varied and include: lack of knowledge regarding the principles and practice of palliative care; care provider attitudes and beliefs about death and dying; staffing levels and lack of available time for dying residents; lack of physician support; and lack of privacy for residents and families; families' expectations regarding residents' care, and hospitalisation of dying residents. The medical management of elderly people in care homes remains poorly defined, and residents are located somewhere between primary and secondary healthcare and social services (Black and Browne, 1997). Farquhar et al. (2002) found that GPs were not always

able to identify when patients had palliative care needs and were reluctant to refer residents to specialist palliative care services. Ellershaw and Murphy (2005) state that in order to transfer hospice culture to long stay care, there may be a need for compromises to be made. Partington (2006) suggests that current research and previous published work tends to focus on shortfalls that occur in the care homes rather than addressing why these issues arise. The work is often undertaken by external bodies who review the systems within homes, while little is done by internal personnel within the nursing home. More collaborative work needs to be undertaken to address the issues from within the home setting in order to ensure that quality EOLC is in place for residents.

It is evident from the above that the provision of palliative care to residents in nursing homes has various challenges; however, it may be argued that some of these may be overcome through the provision of multidisciplinary education to staff within the care homes.

## Education of Nursing Staff in Nursing Homes:

The dying experience of a nursing home resident can be significantly affected by the interventions of the care staff (Goodridge et al., 2005). In investigating the possibility of delivering palliative care training to nursing home staff, Katz et al. (2000) conclude that in order to deliver care to dying residents effectively, staff need to understand how older people experience dying. Additionally, there is a need for staff to acquire skills in communication, recognise the dying process, and understand the basic principles of pain control, symptom relief and bereavement care. Knowledge regarding the access to palliative care services for equipment, advice, support and training also emerge as a necessity for those staff. A better understanding of symptom management, a greater awareness of the needs of relatives, and highlighting staff members' own need for support are some of the reported benefits of palliative care education (Froggatt, 2000). Such findings support the need for education programmes to be designed, developed and delivered in order to increase staffs' knowledge and skills regarding care of dying residents and their families (Ersek et al., 2000). There appears to be a poor understanding of palliative care principles among nursing home staff and inequitable access to palliative education in nursing homes (Whittaker et al., 2007; Matthews and Finch, 2006). While the provision of education regarding the management of pain and other symptoms throughout the dying trajectory may have a positive impact of care outcomes, it cannot be assumed that education alone is sufficient to generate changes in practice (Froggatt, 2001). Any change in practice stimulated by increased education needs to be supported by the organisational culture in which that change occurs. The acquisition of knowledge is only one aspect of interdisciplinary education in palliative care (Matzo and Sherman, 2001). Palliative care education needs to take cognizance of the beliefs and emotions of nurses, and include explorations of self-care, self-healing, and the resolution of issues of loss and grief and mutual support (Matzo and Sherman, 2001).

## Advance Care Planning or Planning for EOLC:

According to Waldrop and Kirkendall (2009), two critical decisions arise as the terminal phase of an illness commences. These include the decision on whether to hospitalise a dying resident or initiate and support EOLC within the caring facility. The transition from routine care to EOLC may be delayed due to the lack of awareness of the signs of dying or inadequate communication on the part of the key decision makers. While these may pose challenges to the care providers, it appears that those providing care strive to provide a *"good death"* for residents in their care. A *"good death"* in a nursing home has been described as involving individualised care, interdisciplinary teamwork, and advance care planning to avoid inappropriate re-hospitalisation (Happ et al., 2002). The nature of advance care planning is complex. Woodruff (2004) proposes that advance care planning ought to be included as a component of care; however, such a process within the Irish context remains relatively new. Advance care planning includes decisions related to life-extending treatments such as resuscitation and dialysis; quality of life issues such as symptom control; and preferences for the setting of care (Mareiniss and Casarett, 2009). It also incorporates spiritual and emotional issues, as they help define medical decisions, relieve suffering, and provide meaning and dignity (Christakis, 1994). Advance care planning also facilitates the co-ordination and implementation of these decisions through patients, family and health care professionals (Weiner and Cole, 2004).

According to Gillick (2009), residents and families need a comprehensive understanding of the specific disease from which they suffer and their likely trajectory. Additionally, and in the case of older residents, they need a more general understanding of their overall health. Without such an understanding, they overestimate or underestimate the likely outcomes of medical interventions. Approaches to advance care planning are needed to guide physicians and patients through the process of eliciting and prioritising goals. In addition, such planning assists in translating care priorities into pathways of care, specifying an upper and lower bound of appropriate care rather than attempting to decide in advance exactly what interventions are acceptable.

According to Levin et al. (1999) advance directives may offer hope to nursing home residents that their wishes will be known and respected at the end of life. It appears, however, that physician-resident conversations regarding life-sustaining treatments are not common. Additionally, while advance directives appear to increase the likelihood that a resident's wishes not to be hospitalised or resuscitated will be respected, the percentage of compliance may be low. Levy et al. (2008) attribute such issues with compliance to physicians', nurses' and relatives' attitudes, disorganisation or lack of clarity of documentation and inconsistent or vague language in documents.

## EOLC Pathways:

EOLC requires an active, compassionate approach that treats, comforts and supports individuals who are living with, or dying with, progressive or chronic life-threatening illness. Such care is sensitive to personal, cultural and

spiritual values, beliefs and practices. It encompasses support for families and friends up to and including the period of bereavement (Ross et al., 2000).

Bookbinder et al. (2005) suggest that a clinical pathway to improve palliative care for patients who are expected to die from advanced disease offers a systems-oriented approach to induce organisational change, improve patient access to resources, enhance communication, and directly redress deficiencies in care. Integrated care pathways (ICP) are evidence based, structured, multidisciplinary care plans. They detail steps of care designed for patients with particular clinical conditions and can be used as an audit tool. They enhance multidisciplinary communication and care planning, enabling staff to spend less time on paperwork (Campbell et al., 1998).

Jones and Johnson (2005) suggest integrated care pathways (ICP) for the dying patient incorporate a multidisciplinary perspective to patient care, representing a process approach to care management. An integrated care pathway offers continuous quality monitoring and reports the following benefits: patient-focused care, preparation for problems, incorporation of relatives' needs, promotion of multidisciplinary working and documentation, clear definition of roles and responsibilities, development and implementation of guidelines and standards, and provision of evidence of good practice (Jones and Johnson, 2005). Additionally, care pathways clearly document quality care and provide a mechanism for monitoring and evaluating care. The majority of nursing home staff stated that the hardest skill was knowing when to commence the pathway, and successful introduction of the ICP in nursing homes requires staff to extend their generic skills to encompass the principles of palliative care (Jones and Johnson, 2005). Clients in care home settings have been repeatedly reported to have last minute recoveries or to bounce back. For clients already frail with multiple pathologies, it could be questioned whether stopping medications may impede this bounce back (Froggatt, 2001). Forbes (2001) and Costello (2001) found that there is a continued reluctance on the part of staff to discuss death and dying openly and honestly with residents. This may stem from a difficulty in predicting death but may also be due to carers' fear of broaching the topic with residents. There is a potential risk that by using a care pathway for the final few days of life, palliative care will become focussed only on the care given in those last few days.

## Quality of EOLC:

The quality of care provided during the last few months of life can strongly affect the quality of life of both the patients and their loved ones, as well as the length of life of the patients (Draper, 1997). This makes it important to document the quality of care and quality of life experiences of dying patients and their families (Stewart et al., 1999). These authors propose a conceptual model of the quality and outcomes of care of terminally ill patients. The model includes three categories: patient and family factors affecting healthcare and its outcomes; the structure and process of care; and patient and family outcomes of care. Based on the premise that palliative care is patient-focused and family-centred, the framework considers the patient, family and loved ones to be important.

Structures and process of care include access to care within a system, organisation of care, formal supports available (Stewart et al., 1999). Kristjanson (1989) found that the most important processes of care that family members of dying patients perceived as being helpful to patients and themselves pertained to prompt and thorough medical care. The top five processes rated in three different settings were: pain was relieved quickly, the patient's needs were responded to quickly, the patient had trust and confidence in the physician, the doctor referred the patient to a specialist promptly, and the patient knew it was acceptable to call for help at any time. While these processes appear reasonable, it may be argued that achieving them all may not be possible without transfer to an acute hospital setting.

Stewart et al. (1999) suggest that the quality of a person's life is determined both by the nature of his or her experiences and by the values and meaning that person attaches to those experiences. Persons confronting death, and their loved ones, may thus define quality of life differently to those not facing imminent death.

Dying is an inevitable part of human life that holds the potential for suffering as well as important opportunities for personal growth. It is a period when medical care ought to be patient-focused and family-centred. Patient-focused care reflects that patient preferences ought to shape the timing of transitions of the goals of care, i.e. from treatment that emphasises life extension to care that focuses on comfort and preparation for death. Family-centred care acknowledges the important role played by the family and other loved ones in the patient's final days (Byock, 1996).

Teno et al. (2001) identified 14 domains relating to high quality care of the dying including: providing physical comfort, helping the dying achieve control over decision making, educating families and providing grief and bereavement counselling. Singer et al. (1999), in a study of patients with chronic illness, identified five domains of good quality EOLC, including, receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burdens, strengthening of relationships with loved ones.

It appears that the ability to deliver high quality EOLC is contingent upon the health professionals' education regarding issues of both symptom and psychosocial care (Sherman, 1999). Important to achieving good quality care at the end of life is the provision of highly individualised care that acknowledges the values and preferences of patients and their families and is achieved through a process of shared decision making and clear communication (Steinhauser et al., 2000). Thompson and McClement (2002) suggest determining and measuring quality in EOLC provision is a complex issue. Many different dimensions of the construct exist and knowing how best to capture the determinants of quality care is difficult. Munn and Zimmerman (2006) interviewed family members of residents who died in long term care about care during the residents' last month of life. Important issues such as emotional support and symptom management, staffing adequacy, training and consistency and facility environment and size were among factors that were identified as influencing quality EOLC.

## Concept of a Good Death:

According to the WHO, in order to improve care of older people, the philosophy of palliative care should be integrated into older person's care. Froggatt (2001) questions the tendency to automatically transfer into the nursing home culture the model developed within specialised palliative care. One way in which they differ is that death as a natural ending is the focus in nursing homes and in palliative care units death cuts short life in middle age and maybe younger. It is therefore important to adapt the palliative care philosophy so that it supports the unique needs of older people. Schwartz et al. (2003) suggest that a number of factors have been found to influence one's concept of a good death: having witnessed someone else's death; one's own cultural heritage; having an accurate understanding of life-sustaining treatments for one's actual situation; and having engaged in advance care planning.

The US Institute of Medicine describes a good death as *"one that is free from avoidable distress and suffering for patients, families and care givers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural and ethical standards"* (Field and Cassel, 1997:4). Steinhauser et al. (2000) identifies process-oriented components of a good death; pain and symptom management; clear decision making; preparation for death; completion; contributing to others; and affirmation of the whole person. Brazil et al. (2004) conducted focus groups with long term care provider groups and identified themes that contribute to quality EOLC: responding to residents' needs; creating a home-like environment; support for families; providing quality care processes; recognising death as a significant event; and having sufficient institutional resources.

Ternstedt and Franklin (2006) reveal three main themes relating to death from the perspective of older people living in nursing homes: zest for life, indifferent attitudes, and longing for death. The participants were aware they were close to death and they were reconciled with this fact. Zest for life was characterised by the residents' interest in life outside the nursing home; this appeared to contribute to retaining a positive self-image and self-respect. An indifferent attitude was a more passive approach to life in the unit; it indicated a sense of handing over one's life to staff in the unit. Longing to die was indicated by those residents who explicitly expressed a wish for their lives to end; they did not experience a sense of dignity and that was part of the reason they wanted to die.

It is reasonable to assume that advance care planning potentially promotes older peoples' sense of dignity, since care planning focuses on the older person's needs and desires (Seymour et al., 2004). However, intervention studies are needed that focus on how to promote older people's self-determination and participation in EOLC. Organisational changes are needed to create as high a standard of conditions as possible for palliative care. In integrating the palliative care philosophy into the nursing home context, however, Froggatt (2002) points out the importance of facilitating the knowledge and experience that already exists in the nursing homes.

Palliative care is above all based on the idea of reinforcing factors that improve quality of life, and decreasing the

impact of factors that may reduce quality of life; this seems adequate as a concept for the long term care of older people (Halberg, 2006). Baltes and Baltes (1993) suggest that successful aging depends on strategic optimisation and compensation; this also implies that factors which may be regarded as important at one point in life may be less important or not at all important in another point in life.

Apart from having to face the fact that life is going towards its end and the reality of their dependency on others, older people also have to deal with significantly more health problems of various kinds. Thus, providing care to older people in this phase of life is not just a matter of addressing their diseases and the practical problems of daily living; the existential problems related to loss of autonomy, maintaining their social relationships and the issues related to life and death with which they have to deal must also be addressed (Hallberg, 2006).

Knowledge of the meaning of the very last phase of life, and older people's wishes in that last phase is needed in order to provide high quality care at this stage. The fact that most people die at an older age indicates that dying and death, as well as EOLC, are of especial concern for older people. Despite this, research has not focused on older people to the extent it has focused on premature death (Hallberg, 2004). Providing high quality EOLC to older people not only requires knowledge of palliative care, but also knowledge of the meaning, the views and fears, if any, that older people hold about death and dying.

Interventions to improve advance care planning and documentation of patients' wishes in collaboration with the patients in nursing homes led to an improvement of documentation of patients' wishes, and to greater concordance between patients' stated wishes and the care they received at the end of their lives (Morrison et al., 2005). However, more research is needed to ascertain older people's views of how palliative care might be provided, as well as their views of death and dying, so that they experience a good death. Like palliative care, symptom management is vital to older people's quality of life, and so too is maintenance of the social network. The management of health problems may be more complex in older people and it may thus be beneficial to view them from a more holistic perspective. The older person's awareness of approaching death and fear of dying puts demands on nursing care, which must include talking about these issues and learning what is in the best interest of the older person (Hallberg, 2006).

Gibson et al. (2008) used an adapted version of the concept of good death scale (Schwartz et al., 2003) in order to establish staff opinions about the components of a good death in long-term care. The majority of care providers agreed that over half (12/20) of the attributes were important or essential. The 12 items identified as essential to a good death included symptom control items as well as items reflecting the psychosocial and spiritual aspects of death. Given the general support for these attributes, they could be used as indicators in a quality improvement project aimed at enhancing the likelihood that deaths that occur in long term care homes have these essential and/or important attributes (Gibson et al., 2008). Three attributes identified as not being necessary included that death be sudden and unexpected, that there be mental alertness until

the end and that there be control of bodily functions to the end. These findings may be explained by considering the nature of the long term care environment and its resident population.

Understanding what it means to live with impaired functional ability in old age is important for how care is provided. It is known that the transition from living a life independent of others to becoming dependent and having to ask for help to manage daily living is a true challenge for the older person. It is not only associated with having to give up activities that may mean a lot and changing routines in life, but also a reminder that life is now going towards the end and there is no return (Janlov et al., 2005).

## Cultural Considerations in EOLC:

Cultural competence is the incorporation of one's cultural diversity experience, awareness and sensitivity into everyday practice behaviours (McGee and Johnson, 2007). It combines knowledge, attitudes, acquired skills and behaviour. Culturally competent healthcare providers are willing to learn and ask questions, keep an open mind and avoid making assumptions and judgements. They learn from mistakes, appreciate differences in people, and recognise that building relationships takes time (Zoorenbos and Schim, 2004).

The high labour turnover rates at the start of the last decade in the care sector, coupled with gradual ageing of the population (CSO, 2006) has meant that the older adult care workforce has undergone a demographic and cultural transformation (McCarthy et al., 2002). The increase in the number of migrant health and social care workers in the sector has become increasingly evident over the years. 49% of nursing staff and 36% of all staff in private nursing homes are from another country (Annual Private Nursing Home Survey, 2007). The public sector has also seen an increase in migrant care workers.

A report by Walsh and O'Shea (2009) on the role of the migrant care workers in ageing societies, written in the Irish context, aimed to:

- Analyse the factors that determine the current and future demand for migrant carers in the health and social care of older people in Ireland
- Examine the migration and work experiences of care workers: the means and motivation for migration, the role of recruitment agencies, choice of employment and working life
- Explore the current and future role of migrant carers in health and social care and their impact on the structure of care and independent living of older people
- Investigate the impact of employing migrant care workers on older people, their families, the quality of care and the carer-care recipient relationship
- Explore the most effective and ethical policies to regulate the admission, employment and integration of registered nurses and care assistants in the older adult care sector.

Some advantages stated by employers in the report included the willingness of foreign national workers to work all shifts, a willingness to learn new skills, a respectful and caring attitude toward older people and a good work ethic.

Challenges identified by unit managers were poor knowledge of the Irish culture, poor proficiency in English and the requirement of extra training, lack of assertiveness and decision making skills and lack of acceptance of migrant workers by older people.

Migrant workers themselves identified two forms of discriminatory experiences in long term care of the elderly units, in the form of both explicit and subtle discriminatory experiences. The more explicit included selective rostering, work team isolation, increased workloads and favouritism. Skin colour appeared to introduce an additional layer of prejudice, with a number of African participants mentioning the overt favouritism shown not only towards Irish carers, but towards European Caucasians. In term of relationships with the older people, a number of carers recounted occasions where residents, or clients, openly favoured Irish workers, while dismissing the assistance of foreign national staff (Walsh and O'Shea, 2009).

According to Hughes and Lapane (2006), changing organisational culture to create a work environment where problems arising from racial and cultural differences can be addressed and where employees are supported in their professional development is a difficult task. Creating a comfortable work environment and developing and maintaining organisational cultural competency is an

important managerial strategy for increasing job satisfaction and improving staff retention. To achieve this, the focus must include: improving cross-cultural communication, developing and training employees in procedures to respond to perceived unfair treatment of residents/co-workers due to race/culture, involving all levels of staff and the residents in culture change activities and ensuring that employees are supported in their professional development and receive regular feedback on their performance (Allensworth-Davies, 2007).

Culturally appropriate EOLC requires nurses to demonstrate recognition and acceptance of others' culture, ethnicity and race. Three elements of EOLC which vary culturally are: communication regarding a terminal illness or end of life issues; decision making within the family unit; and attitudes to life-sustaining treatment (Doolen and York, 2007).

### **Conclusion:**

EOLC requires an active, compassionate approach that treats, comforts and supports individuals who are living with, or dying from, progressive or chronic life threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices. It encompasses support for families and friends up to and including the period of bereavement.

# Chapter 3: Documentation Review

## Introduction:

This chapter provides an overview of data that emerged from the review of charts of patients who had died and of documentation about EOLC.

## Chart Review:

A modified version of the Teno (1999) Toolkit of Instruments to Measure EOLC (TIME) was used to review the charts of the 37 residents who died in one of the units or within 6 weeks of transfer to hospital, in the previous year. The Toolkit of Instruments to Measure EOLC is a research initiative with the goal of creating measurement tools to allow healthcare institutions to evaluate whether care is patient focused and family centred (Teno, 1999). The tool attempts to capture the care delivered to dying individuals, both from person and family centred perspectives. The tool is divided into four parts. Part 1 addresses *Demographic Details*, Part 2 is a *Diagnosis and Status* section. Part 3 addresses *Sentinel Decisions*, with regard to resuscitation decisions and interventions, nutrition interventions, mechanical ventilation status and transfer to ICU. Part 4 is an exploration of *Symptoms / Problems*, treatments administered and diagnostics. For the purpose of this project, the presence and management of five symptoms (pain, respiratory secretions, breathlessness, agitation and fever) in the last forty-eight hours of life were used to evaluate EOLC. Other domains assessed included the evidence that discussions around EOLC planning had taken place, and if resuscitation status was documented. Interventions carried out in the last 48 hours including enteral feeding, blood tests, IV or subcutaneous fluids, intravenous medication, the prescription and administration of opiates and the use of syringe drivers were also assessed in the charts. The presence of documented communication with and emotional support of families, recent medical reviews, involvement of a chaplain or pastoral care and the need for transfer to an acute hospital and the necessity of post mortem examination were also assessed.

## Collecting Data from the Deceased Residents' Charts:

Charts of deceased residents were made available to the project nurse by the directors of nursing. Anonymity was maintained, as patient identities were not used in importing the data into Microsoft Excel.

All electronic and hard copy data was stored securely during the project and subsequently destroyed.

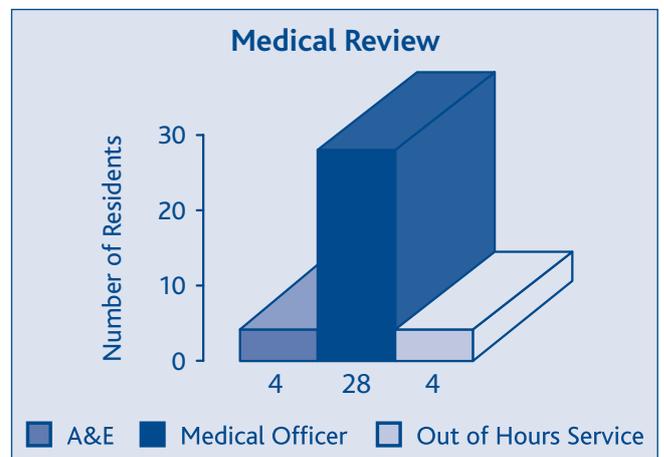
## Demographic Details of Residents whose Charts were Reviewed:

|           | Male  | Female |
|-----------|-------|--------|
| Gender    | 20    | 17     |
| Age Range | 75-95 | 80-104 |

Of the residents, 24 had a documented significant cognitive impairment, using the terms Alzheimer's, Severe Dementia and Cognitive Impairment. Only one resident had a documented history of malignant disease; however this was not a significant contributor to his death.

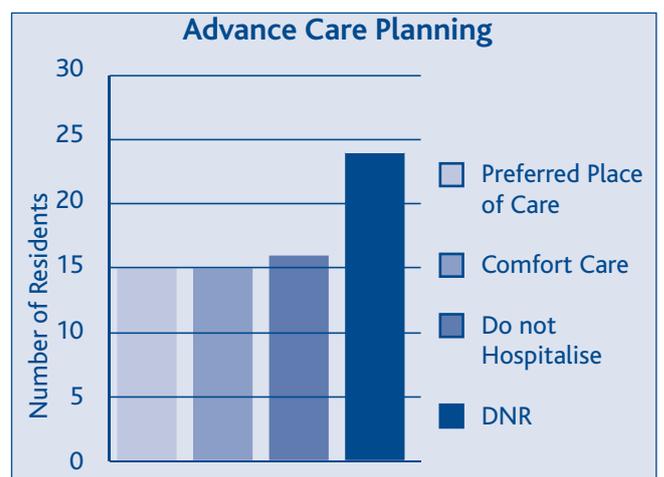
## Recognition of Approaching Death:

Seventeen charts had documented evidence of recognition that death was approaching. This may have included resuscitation status documentation or simply documentation that the resident was deteriorating and including notifying the family of a significant change in the resident's condition. Medical reviews were undertaken in a variety of ways. Four residents had an Accident and Emergency visit in the last 48 hours of life; 28 residents were seen by the medical officer or GP affiliated with their own unit in the last 48 hours of life and 4 were seen by the Out of Hours Doctor Service.



## Advance Care Planning:

Fifteen residents had established that the unit in which they were currently resident was to be the preferred place of care should a change in condition occur; 16 residents had a *Do Not Hospitalise* order. These were stated by the residents' families and documented in the residents' charts. Twenty-four residents had a documented *Do Not Resuscitate* order. In one instance, the resuscitation order was discussed with the patient, in all other cases it was discussed and agreed with the family or next of kin.



### ***Symptom Management:***

The assessment of symptoms and the subsequent initiation of a treatment plan, if required, with respect to pain, agitation, respiratory tract secretions, shortness of breath and fever were also reviewed. Pain was specifically assessed in 10 residents – 9 had a treatment plan documented and 8 had the plan implemented – however, only 2 residents had a written evaluation on the effectiveness of the intervention. Sixteen residents were receiving opiates. One resident had a subcutaneous syringe driver in use; this was used to administer an opiate.

### ***Respiratory Symptoms:***

Fourteen residents had problems documented with respiratory secretions; all 14 had a treatment plan documented, 12 had the plan implemented, and the effectiveness was documented in five. Sixteen residents had shortness of breath documented; all had a treatment plan documented, 15 had the implementation documented and the effectiveness was documented in three charts.

### ***Agitation:***

Agitation was identified as a symptom assessed on three patients. There was evidence of a treatment plan initiated and implemented, however, effectiveness was not documented.

### ***Fever:***

Nine residents were reported to have a fever; 8 had a treatment plan documented, and for 7 residents it was implemented and the effectiveness recorded.

### ***Subcutaneous Fluids and Other Interventions:***

Twenty residents were receiving subcutaneous fluids; no intravenous fluids were administered. Blood tests were done for one resident and one resident has a urinary catheter in situ.

### ***Spiritual Care:***

Six residents had a chaplaincy referral in the last forty-eight hours.

### ***Families and EOLC in Older Persons:***

The main reason that families were included in the documentation was communication with respect to a change in condition of the resident and this was noted in

12 charts. There was very little documentation of emotional support to the family.

### **Other documentation relating to EOLC:**

Policies and guidelines with respect to EOLC in the community units were included in the chart review. While EOLC was implicit in documentation, there were no specific EOLC plans in use, although last offices and care of the body were clearly documented in all units.

Staff education and training was also reviewed. All units illustrated a commitment to providing quality EOLC.

All staff possessed current CPR certification and this is renewed every two years. An automated external defibrillator (AED) is available in all of the units and all staff are trained in its usage.

There were no drug errors recorded and there were no complaints about EOLC recorded, so no reviews could be carried out.

### **Conclusion:**

**The most pertinent findings from the documentation review were:**

- 17% of residents died in one year
- Common symptoms were documented and care plans put in place, but documentation of symptom evaluation and monitoring was less frequent
- There was little documentation of emotional or spiritual support for the patient.
- There was evidence of information sharing with the family, including advance care planning, and informing family of patients' deterioration, but less evidence of emotional support for the family.
- It was evident that there was good involvement in family care.
- There appeared to be a lack of spiritual care documented as part of care as death approached.
- There were no guidelines or policies specifically for EOLC in the units

## Chapter 4: Palliative Care Education Needs in Long Term Community Units

A questionnaire developed by McDonnell et al. (2009) was modified (with permission) in order to establish the experience and educational needs of staff with respect to palliative care and EOLC. The questionnaire consisted of 37 items for registered nurses (RN) and 26 items for healthcare assistants (HCA).

The HCA questionnaire consisted of five sections. Section one recorded respondents' demographics, including title, age, ethnic origin, length of work in a care of the elderly setting and education. Section two was about education and training in palliative care. As well as recording the education and training respondents had previously undertaken in this area, this section asked about interest in future education programmes. Section three examined respondents' understanding of palliative care and the information and resources available to them on palliative care. Section four was concerned with HCAs' confidence in their abilities, and areas in which they felt extra support or training was needed. Finally, section five addressed further examined support needs for the HCAs.

The RN questionnaire consisted of five sections. Sections one, two and three were similar to the HCA questionnaire. Section four dealt with palliative care in the workplace, specifically addressing themes such as referring patients, syringe driver use, discussing death and dying with patients and relatives, and communication issues. Section five presented a series of questions concerning support, skills development and education.

### Completion Rates:

One hundred and two questionnaires were sent to RNs and 74 to HCAs, with 60 (58.8%) RNs and 25 (33.7%) HCAs returning completed questionnaires.

|       | Sent | Returned | Completion Rate |
|-------|------|----------|-----------------|
| HCAs  | 74   | 25       | 33.7%           |
| RNs   | 102  | 60       | 58.8%           |
| Total | 176  | 85       | 48%             |

The first stage of data analysis involved transferring the data from the 25 HCA and 60 RN questionnaires to a data file. Statistical Package for the Social Sciences version 14 (SPSS) was used to combine all the information and perform statistical analysis.

### Number of Questions Left Blank:

Among HCAs on average, 2.5 respondents left a mandatory question blank, for a non-completion rate of 10%. Among RNs on average, 8.3 respondents of the 60 left a mandatory question blank, for a non-completion rate of 13.8%.

## HCA Section One: Demographics:

### Title:

Respondents in this first section were asked for their working title. Forty per cent (n = 10) described themselves as "*Health Care Assistants*", with the remainder indicating their title was "*Care Assistant*", "*Carer*" or "*Care Staff*".

### Age Groups:

The largest age group was the 40-49 years bracket, with 40% of survey respondents being drawn from this group.

| Age Group     | Frequency |
|---------------|-----------|
| 20 - 29 years | 3         |
| 30 - 39 years | 8         |
| 40 - 49 years | 10        |
| 50 - 59 years | 1         |
| 60 - 69 years | 3         |

### Ethnicity:

Respondents were asked about their ethnic background; 56% (n = 14) of respondents indicated they were Irish. The remainder were migrant workers.

### Language:

Ninety two per cent of respondents (n = 23) indicated that English was their first language.

### Length of Work in Care of the Elderly Setting:

Respondents worked in a care of the elderly setting for 11 years on average.

### Educational Qualifications:

Respondents were asked to state their educational qualifications from a list of six options. The majority (88%, n = 22) had at least one of these qualifications.

| Qualification                 | Frequency | Percentage |
|-------------------------------|-----------|------------|
| FETAC Qualification           | 15        | 60%        |
| Leaving Cert Completed        | 11        | 44%        |
| Junior / Inter Cert Completed | 11        | 44%        |
| Second Level Education        | 6         | 24%        |
| Other                         | 5         | 20%        |

Those qualifications noted in the "*Other*" category included beauty therapists, registered general nurses, and student in third level education.

## RN Section One: Demographics:

### Age Groups:

The largest age group was the 30-39 years bracket, with almost 50% of survey respondents being drawn from this group.

| Age Group     | Frequency |
|---------------|-----------|
| 20 - 29 years | 2         |
| 30 - 39 years | 28        |
| 40 - 49 years | 14        |
| 50 - 59 years | 15        |
| 60 - 69 years | 1         |

### Ethnicity:

Three main groups of ethnicities were identified amongst respondents: Irish, Asian and Filipino. While the largest single ethnic group was Irish, the majority of respondents (57%) were foreign, from Asian countries including the Philippines, India and China. The fourth category, "Other" contained respondents who were African or from continental Europe.

| Ethnicity | Frequency |
|-----------|-----------|
| Irish     | 25        |
| Asian     | 21        |
| Filipino  | 9         |
| Other     | 3         |

### Language:

55% (n = 33) indicated that English was their first language.

### Current Position:

73% (n = 44) indicated they worked as staff nurses and 27% (n = 16) of respondents described their current position as a nurse manager. Respondents were allowed describe their position in further detail; these titles consisted of senior nursing positions, such as 'Director of Nursing' and 'Clinical Nurse Manager 2' (CNM2).

### Length of Work in Care of the Elderly Setting:

Respondents worked in a care of the elderly setting for an average of 9.4 years. The mean length in care of the elderly setting for nurse managers was 12.7 years, while for staff nurses it was lower, at 7.8 years.

| Length        | Frequency |
|---------------|-----------|
| 0 - 5 years   | 17        |
| 5 - 10 years  | 23        |
| 10 - 15 years | 7         |
| 15 + years    | 10        |

### Length of Work in Current Position:

Respondents were asked how long they had been working either as a Staff Nurse or Nurse Manager. Staff Nurses

responded on average that they had been working as such for 15.7 years. Nurse Managers indicated they had been working as such for 7.8 years on average, and prior to that had been working as Staff Nurses for an average of 22.2 years.

| Years as a RN | Staff Nurses | Nurse Managers |
|---------------|--------------|----------------|
| 0 - 5 years   | 3            | 0              |
| 5 - 10 years  | 8            | 0              |
| 10 - 15 years | 14           | 4              |
| 15 - 20 years | 12           | 3              |
| 20 - 25 years | 3            | 2              |
| 25 - 30 years | 1            | 4              |
| 30 + years    | 3            | 3              |

| Years as a Nurse Manager | Nurse Managers |
|--------------------------|----------------|
| 0 - 5 years              | 6              |
| 5 - 10 years             | 6              |
| 10 - 15 years            | 2              |
| 15 + years               | 2              |

### Qualifications:

Respondents qualifications were grouped into four categories: Registered Nurse (RN), Higher/Post Graduate Diploma, Bachelor Nursing Science/Nursing Studies, and Other. 56 respondents (91.8%) had completed registered nurse qualification; the remaining completed registration through a bachelor of nursing degree. The Other category allowed respondents to include any other qualifications they had attained. This category included qualifications in Midwifery, MSc in Nursing and Healthcare, Diplomas in First Line Management and Public Management, Gerontological and Neonatal care. Many had more than one qualification.

|                                     | Frequency | Percentage |
|-------------------------------------|-----------|------------|
| RN                                  | 56        | 91.8%      |
| Bachelors Nursing Science / Studies | 25        | 41.0%      |
| Other                               | 18        | 29.5%      |
| Higher / Post Graduate Diploma      | 17        | 27.9%      |

Nearly half of respondents in this study had two or more qualifications.

| Qualifications | Frequency | Percentage |
|----------------|-----------|------------|
| 1              | 19        | 31.7%      |
| 2              | 29        | 48.3%      |
| 3              | 10        | 16.7%      |
| 4              | 2         | 3.3%       |

## HCA Section Two: Palliative Care

### Training:

Health Care Assistants were asked if they had attended any in-service, study, or lecture days in relation to palliative care in the last two years. Forty per cent of HCAs (n = 10) responded that they had. These courses ranged in duration from one hour to six weeks, and were located in venues such as the local specialist palliative care education centre, university or local long stay community unit. The majority (58%) of these respondents indicated that they attended courses in work time; the remainder attended in their own time.

When asked if the respondent would be interested in a planned education course in *"Palliative Care of the Older Person"*, 100% (n = 25) of respondents indicated they would have an interest in such an educational opportunity. To gauge incentives to attend this programme, respondents were asked if there was anything that would encourage them to attend. The majority of respondents (88%) indicated that they would attend simply to improve their knowledge of palliative care and issues surrounding care of patients at the end of life. Evidence of this is as follows:

*"I would like to know more about caring for a resident near their end of life."*

*"To know more about palliative care for the dying and support for families and staff."*

The remaining respondents indicated that they would either be interested in attending regardless of additional incentives, or if the location of the training was convenient to them.

On this point, HCAs were also asked their preferred location for palliative care education to take place. Sixty-two per cent of respondents (n = 16) indicated they would prefer their place of work, 32% (n = 8) indicated they would prefer the local specialist palliative care education centre, and one respondent had no preference. Reasons respondents gave for preferring their place of work were that the HCAs were used to their own patients, and their workplace was more convenient. Those who favoured the local specialist palliative care education stated that it would be good to receive the education in a hospice setting, or that they had previously attended courses at the centre.

When asked about the timing of education, HCAs would prefer a potential training in palliative care, no clear majority decision or consensus was reached. Results are displayed below, showing a marginal majority favouring the afternoon time.

| Time        | Frequency | Percentage |
|-------------|-----------|------------|
| Afternoon   | 7         | 28         |
| Morning     | 6         | 24         |
| Working day | 6         | 24         |
| Day off     | 5         | 20         |
| Evening     | 1         | 4          |

## RN Section Two: Palliative Care Training:

Registered nurses and nurse managers were first asked if they had any specific qualification in palliative care or palliative nursing. Eight per cent (n = 5) indicated they had this training. None had a higher diploma in palliative care, but five had additional training, and three of these had completed a five-day course at the local specialist palliative care education centre.

RNs were then asked if they had attended any courses or study days in relation to palliative care during the last two years. Thirty per cent (n = 18) had attended study days, with the majority of these (n = 14) having attended 3-8 day courses in *"Introduction to Palliative Care of the Older Person"* at the local specialist palliative care education centre. Other courses listed were one and two day courses in other venues. These courses were Syringe Driver workshops and Palliative Care of the Elderly.

Respondents were asked if they had attended any formal palliative care training in various aspects around end of life and care of the elderly, with the following results:

| Area  | Frequency | Percentage |
|---|-----------|------------|
| Pain Management                               | 22        | 36.7%      |
| Pain Assessment                               | 22        | 36.7%      |
| Constipation                                  | 21        | 35.0%      |
| Communication Issues                          | 21        | 35.0%      |
| Pain Assessment in the Elderly                | 18        | 30.0%      |
| Shortness of Breath                           | 18        | 30.0%      |
| Care in the Last Days of Life                 | 17        | 28.3%      |
| Oral Problems                                 | 17        | 28.3%      |
| Nutrition and Hydration Issues at End of Life | 17        | 28.3%      |
| Dementia and EOLC                             | 16        | 26.7%      |
| Restlessness                                  | 15        | 25.0%      |
| Bereavement Support                           | 15        | 25.0%      |
| Nausea and Vomiting                           | 15        | 25.0%      |
| Assessment of Other Symptoms                  | 15        | 25.0%      |
| Ethics at End of Life                         | 13        | 21.7%      |
| Multidisciplinary Team Working                | 13        | 21.7%      |
| Fatigue / Cachexia                            | 12        | 20.0%      |
| Other Gastro-Intestinal Symptoms              | 11        | 18.3%      |
| Non - Malignant Conditions                    | 10        | 16.7%      |

Of those who attended such courses and study days, 33% attended courses in their own time, and 84% attended courses in work time.

96.7% (n = 58) indicated they would be interested in attending planned education in *"Palliative Care of the Older Person"*. When asked if there was anything that would encourage respondents to attend this training, 20 responded that they would like to attend to improve their skills and knowledge.

*"To update my knowledge base and apply that knowledge to my work setting."*

*"It would give me more knowledge and to be able to deliver [better] quality of care for the older people through updates and education."*

Eight respondents indicated they would be interested in attending without encouragement and two respondents indicated they would attend if the venue was conveniently located or timed for them.

*"I would love to attend the course anyway; I wanted to do it in my own time."*

When asked where respondents would prefer this training to be held, 67% (n = 40) indicated they would prefer it to be held at their place of work. The remaining 33% (n = 20) would prefer the training to be held in the local specialist palliative care education centre. When asked for comment on this decision, those respondents who preferred their own place of work mostly mentioned convenience and shorter travel distances, while some of those who favoured the local specialist palliative care education centre did so owing to the availability of resources there.

Respondents were also asked what time of the day would they prefer the training to be held. The majority favoured office hours, while very few respondents would like to complete the training as an evening course.

| Time         | Frequency | Percentage |
|--------------|-----------|------------|
| Office Hours | 34        | 57.0%      |
| Morning      | 26        | 43.3%      |
| Afternoon    | 14        | 23.3%      |
| Evening      | 7         | 11.7%      |

### Health Care Assistants Section Three: Understanding of Palliative Care:

Health Care Assistants were asked what they understood by the term *"Palliative Care"*. Palliative care is described by the World Health Organisation (WHO, 2002) as: *An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."*

This definition was divided into key phrases and words, and the number of respondents who mentioned each, out of a total of 23 who answered this question, is shown here:

|  | n  | %     |
|--|----|-------|
| Patient is Approaching End of Life                         | 21 | 91.3% |
| Relief of Suffering / Pain                                 | 7  | 30.4% |
| Improve Quality of Life                                    | 7  | 30.4% |
| Relief / Prevention of Symptoms                            | 6  | 26.1% |
| Holistic Treatment (Physical, Psychological and Spiritual) | 4  | 17.4% |
| Extend Treatment to include Families                       | 3  | 13.0% |
| Early Identification of Symptoms                           | 2  | 8.7%  |

As can be seen, the vast majority of HCAs include *"End of Life"* in their definition of palliative care.

60% (n = 15) indicated they had received this information on palliative care, either a formal course from an institution such as Dublin City University (DCU), FETAC (Further Education and Training Awards Council) or St. Francis Hospice, or from personal studies or experience.

Respondents were also asked if there was a Specialist Palliative Care Service available to patients in their unit. Only 36% (n = 9) indicated this was available to their patients.

### Registered Nurse Section Three: Understanding of Palliative Care:

RNs were asked what they understand by the term *"Palliative Care"* and the number of respondents who mentioned each part of the above definition, out of a total of 58 who answered this section, is shown below:

|  | n  | %   |
|--|----|-----|
| Patient is Approaching End of Life                         | 50 | 86% |
| Relief / Prevention of Symptoms                            | 22 | 38% |
| Relief of Suffering / Pain                                 | 21 | 36% |
| Improve Quality of Life                                    | 20 | 34% |
| Early Identification of Symptoms                           | 17 | 29% |
| Holistic Treatment (Physical, Psychological and Spiritual) | 7  | 12% |
| Extend Treatment to include Families                       | 6  | 10% |

It is evident that the vast majority of RNs made reference to EOLC; this was the most frequently used definition of palliative care for RNs in this study. A minority of respondents mentioned aspects of holistic treatment (12%) and the inclusion of families in the palliative treatment (10%).

RNs were then asked if they were familiar with the principles of palliative care. Fifty-two responded.

| Palliative Care Principles Identified by RNs | n  | %   |
|--|----|-----|
| Relief from Pain and other Symptoms          | 21 | 40% |
| Integrate Psychological and Spiritual Needs  | 15 | 29% |
| Enhance Quality of Life                      | 15 | 29% |
| Neither Hasten nor Postpone Death            | 13 | 25% |
| Offer Support to Help the Family             | 13 | 25% |
| Affirm Life and Regard Death as Normal       | 12 | 23% |
| Help Patients Live as Actively as Possible   | 11 | 21% |
| Use a Team Approach                          | 10 | 19% |
| Be Applicable Early in Illness               | 10 | 19% |

The answers RNs returned were varied, with the most common response being Relief from Pain and other Symptoms at 40% (n = 21). It is clear from these results that RNs have a varied and broad view of the principles of palliative care.

Only 27% of RNs considered that a specialist palliative care service was available to patients in their unit.

## HCA Section Four: Palliative Care in the Workplace:

### Palliative Care Issues:

Health Care Assistants were asked how confident they felt regarding their ability to address various issues around palliative care/EOLC; 24 responded, as outlined in the table:

| Palliative Care Issue                                     | Not at All |     | Sometimes |     | Always |     |
|---|------------|-----|-----------|-----|--------|-----|
|   | n          | %   | n         | %   | n      | %   |
| Identifying and Reporting Symptoms to the Nurse in Charge | 0          | 0%  | 1         | 4%  | 23     | 96% |
| Pressure Area Care  | 0          | 0%  | 3         | 13% | 20     | 83% |
| Continence Care   | 0          | 0%  | 4         | 17% | 20     | 83% |
| Care of Deceased at Time of Death and After Death         | 2          | 8%  | 3         | 13% | 17     | 71% |
| Washing the Patient                                       | 0          | 0%  | 6         | 25% | 18     | 75% |
| Feeding the Patient                                       | 0          | 0%  | 8         | 33% | 16     | 67% |
| Support of Relatives at Time of Death                     | 3          | 13% | 5         | 21% | 16     | 67% |
| Being with and Supporting the Patient                     | 0          | 0%  | 12        | 50% | 12     | 50% |

These results are positive, with the majority of HCAs reporting that they feel *"Sometimes" or "Always"* confident in their ability to address each of these issues. As can be seen, the area in which HCAs are most comfortable is in Identifying and Reporting Symptoms to the Nurse in Charge, with 96% (n = 23) of respondents saying they were always confident in doing this. The area in which HCAs were least confident overall was in Being with and Supporting the Patient, with only 50% (n = 12) of respondents saying they were always confident in doing this. HCAs were asked if they felt supported by the nursing staff when caring for a patient who is seriously ill or dying, and 92% (n = 22) indicated they felt supported.

### Talking about Death and Dying:

Talking about death and dying is an issue that is central to the palliative care approach. However, many HCAs in this study had a series of difficulties around their ability to do so. When asked if HCAs talk regularly about death and dying, only 8% (n = 2) indicated that they talked about this issue with patients, and 17% (n = 4) indicated they talked about this issue with relatives. When asked what is discussed with patients, one HCA responded:

*"About their wishes and giving reassurance to them that we will respect their wishes."*

HCAs gave these examples of what is discussed with relatives:

*"Sometimes a patient goes downhill health-wise; relatives will ask things like 'How long do they have left'."*

*"Would their loved ones feel any pain when they are dying; if you think there is a heaven."*

These are difficult topics to discuss. When asked if they felt they had enough training to talk to patients about death and dying, only 8% (n = 2) indicated yes, and 13% (n = 3) indicated they felt they were sufficiently trained to talk about these matters to relatives. When asked to elaborate on the specific areas where further training in speaking to patients was needed, the following was a typical response:

*"It is very hard to begin talking about it with patients, as you feel it may upset them. I would like to be trained in how to talk to someone about these issues."*

HCAs who elaborated on their answer all responded in a similar vein, expressing difficulty in being able either to tell a patient that he/she is dying, or talk to patients about death and dying. When asked about talking with relatives, HCAs raised similar issues, mainly expressing uncertainty in their ability to communicate effectively and compassionately with relatives when a patient is dying. Language difficulties were not apparently a significant reason for these communication problems.

HCA's were then asked about awareness of patients dying in their units, with the following results from the 24 who responded:

|  | Never |      | Sometimes |       | Often |       |
|--|-------|------|-----------|-------|-------|-------|
|  | n     | %    | n         | %     | n     | %     |
| Are families aware when their relative is dying? | 1     | 4.2% | 7         | 29.2% | 16    | 66.7% |
| Are other patients informed when a patient dies? | 2     | 8.3% | 9         | 37.5% | 13    | 54.2% |

## RN Section Four: Palliative Care in Your Workplace:

### Specialist Palliative Care Services:

RNs were asked if they had the experience of a Specialist Palliative Care Clinical Nurse visiting their unit, to which 58% (n = 34) indicated they had. Of these, 89% (n = 32) indicated they found this helpful in supporting the care of their patients. When asked to comment on the specific support they found helpful, 13 RNs mentioned the general experience and advice Specialist Palliative Care Clinical Nurses offered.

*"A general overall support when I contacted them, mainly to use them as a 'sounding board' to ensure that I as a health care professional was offering all the care I could, and enquiring if there was anything more we could do."*

Eight RNs indicated they found the support around pain control and the use of syringe driver helpful.

*"Assessment of pain medications, indicated whether to use a patch or syringe driver, and whether what we did was good enough for the patient's comfort or not."*

Seven RNs indicated that the support around either end of life issues or other technical or medical issues was most helpful.

*"In giving us an idea how to support the patients' needs and specifically the type of medication to give and when to give."*

When asked on what occasions RNs considered referring residents to Specialist Palliative Care Services, 53% (n = 23) of RNs who responded mentioned difficulties in controlling symptoms including pain, and 47% (n = 20) indicated when a patient is terminally ill or in the final stages of life.

*"If we fail to keep the client comfortable and pain free."*

*"When we have difficulty in controlling their symptoms at end of life, i.e. for specialist opinion on most appropriate medication in difficult cases."*

*"When they are in their end stage of life."*

RNs were also asked how patients are referred to Specialist Palliative Care Services. Most were by a referral by either the patient's GP, a medical officer, resident doctor or unit manager (44%, n = 19). Thirty-five per cent (n = 17) indicated a referral is made by the RN calling the local

specialist palliative care services or seeking advice from a member of the local specialist palliative care services staff. Twenty-one per cent (n = 9) indicated they did not know how to refer a patient to Specialist Palliative Care Services.

### Syringe Driver Use:

Two thirds of RNs (n = 41) indicated they had experience of caring for a patient with a syringe driver. However, less than half (48%, n = 29) indicated they felt they were competent to assess a patient's need for a syringe driver. Sixty-three per cent (n = 37) indicated they felt competent enough to care for a patient with a syringe driver.

### Discussing Issues Around Death and Dying:

RNs were asked whether issues relating to death and dying were discussed with residents in their units, with 80.7% (n = 46) responding that they were. Ninety-one per cent (n = 54) responded that these same issues were discussed with family members. The following issues were included in these discussions:

| Issues in Relation to Death and Dying | Discussed with Residents |       | Discussed with Family |       |
|---------------------------------------|--------------------------|-------|-----------------------|-------|
|                                       | n                        | %     | n                     | %     |
| Resuscitation Status                  | 53                       | 88.3% | 60                    | 100%  |
| Transfer to Hospital                  | 52                       | 86.7% | 60                    | 100%  |
| Preferred Place of Care               | 41                       | 68.3% | 57                    | 95.0% |
| Hydration at End of Life              | 41                       | 68.3% | 55                    | 91.7% |
| Feeding at End of Life                | 37                       | 61.7% | 49                    | 81.7% |
| Wishes of Resident after Death        | 30                       | 50.0% | 42                    | 70.0% |
| Use of Intravenous Medicine (IV)      | 31                       | 51.7% | 42                    | 70.0% |

While the majority of issues above are discussed in units, it can be clearly seen that every issue is discussed less with patients themselves than with family members. In both cases, *"Use of Intravenous Medicine"* and *"Wishes of Resident after Death"* were the least discussed issues, approximately half of RNs responding that residents' wishes after death were discussed with residents themselves.

When asked why these issues were not discussed with residents, 41.7% (n = 10) of those that responded indicated many of their residents suffered from dementia and were thus unable to discuss such issues. One-third of RNs (n = 8) indicated that issues that were not discussed with residents were instead discussed with family members. Almost 30% (n = 7) indicated either that they were not trained to use an IV or IVs were not used in their unit.

## Education Issues around Discussing Death and Dying:

This section explored whether RNs felt adequately educated to discuss issues around death and dying with residents and their family members. Seventy-two per cent (n = 43) indicated they felt adequately educated to discuss these issues with relatives, but only 55.7% (n = 34) responded that they felt adequately educated to discuss these issues with residents themselves. RNs were then asked if these issues included any of the following; forty five responded:

| Issues which RNs feel adequately educated to discuss with relative or patients | n  | %     |
|--|----|-------|
| Hydration at End of Life   | 45 | 100%  |
| Preferred Place of Care  | 45 | 100%  |
| Transfer to Hospital   | 44 | 97.8% |
| Feeding at End of Life   | 41 | 91.1% |
| Resuscitation Status   | 42 | 93.3% |
| Wishes of Resident after Death   | 36 | 80.0% |
| Use of Intravenous Medicine  | 33 | 73.3% |

The use of intravenous medicine was the area RN considered they had least education which may be related to the unit polices which do not support their use.

## Support in the Last 24 Hours of Life:

RNs were asked if they felt adequately supported to provide palliative care to residents and families in the last 24 hours of life, with 79% (n = 46) indicating they did. When asked to comment where RNs did not feel supported, the most common answer was that this was a specialist area and the unit in question simply did not have either the staff or training to adequately provide this care:

*"Access to a specialist resource to ensure staff are confident with delivering palliative care."*

*"I feel an extra staff member is needed for some parts of the day at this time, also require doctor who is experienced in palliative care."*

Other RNs noted that this care was difficult to deliver due to time constraints and the extra attention that is required to adequately care for residents and their families during this time.

88% (n = 52) of RNs indicated they felt they were competent in communicating with families and providing support to them in the last 24 hours of life. When asked where specifically RNs did not feel competent, five indicated they had difficulty in knowing what to say or how to word it. There was no indication that this was due to language difficulties.

RNs were asked if families were aware when their relatives are dying. No RNs indicated *"Not at All"*, 23% (n = 14) indicated *"Sometimes"*, and 78% (n = 47) indicated families are *"Frequently"* aware their relatives are dying. RNs were then asked how confident they were in predicting

that a resident is dying, with none saying *"Never"*, 49% (n = 29) saying *"Not Always"*, and 51% (n = 31) saying *"Very Confident"*. When asked what aspects needed further development, the majority of RNs expressed uncertainty on this.

*"The dying process is hard to predict; families always ask for time of death."*

*"Our residents have the tendency to recover when you think they are dying; death is unpredictable."*

*"I am confident that I know someone is very unwell but when or how near death they are is difficult to know."*

RNs were asked if they were confident in communicating to families that a family member is dying. The majority of RNs responded that they were, with two-thirds (n = 33) responding with statements such as:

*"Yes, explain gently, clearly, be prepared, active listening to questions. Be available, maintain ongoing support and rapport."*

*"Competent due to years of experience."*

Eighteen per cent (n = 9) expressed uncertainty in their ability to communicate this to families:

*"It is difficult to talk to the family with regards to those issues."*

*"If no manager or chaplain is around I will do it."*

There were a variety of reasons offered:

*"First of all, English is not my first language. Sometimes I am afraid that something I said is not in a pleasant way. Secondly I would like to know more about Catholicism and cultural issues around death."*

*"This is something I don't like doing."*

*"Feel uncomfortable in doing so, sometimes feel inadequate in answering their many questions."*

RNs were asked if other residents were informed when a resident dies, with 4% (n = 2) of those who responded saying *"Never"*, 64% (n = 38) saying *"Sometimes"*, and 32% (n = 29) saying *"Always"*. Their comments on this statement included:

*"Not all residents are informed. Residents who themselves are very ill or cognitively impaired are not."*

*"Most of our residents suffer from dementia/Alzheimer's. I would always be ready to answer questions."*

*"After all, they have shared this nursing home as their own home, so it's good practice to allow all residents be as involved as they are able."*

*"It depends on the residents who are close to the resident."*

When asked if they believed residents should be informed, the majority at 54% (n = 31) responded that residents should be informed:

*"Yes, very important. If residents witness death and dying with dignity and respect they can be assured they will receive the same when their time comes."*

*"I think it's important that all residents are informed of another resident's death; old people are very acceptable of death and seem to deal with it very well."*

*"I believe it is always best to be truthful to residents in our care. However care is taken that a resident is capable of coping with this information."*

Of the RNs, 33% (n = 19), expressed uncertainty at this issue, or responded that telling residents about this would be contingent on other factors:

*"Only if they are very close friends, otherwise I feel the news will make them upset."*

*"I will tell a resident who is asking about the others depending on their condition."*

*"If it was a resident they knew or in bed beside them. It's important to explain any changes in routine so as not to cause concern."*

Thirteen per cent of RNs (n = 7) explained that they would not tell residents if another resident had died:

*"I don't think so, because death is something the no one wants to hear about. Also this information may affect other residents' health status."*

*"Not really, it might create tension."*

*"No. Some of them won't be able for it."*

### HCA Section Five: Staff Support:

Health Care Assistants were asked if support is available to them following the death of a resident in their units; 21 responded.

| Support                  | n  | %   |
|--------------------------|----|-----|
| None Available           | 14 | 67% |
| Yes – Individual Support | 5  | 24% |
| Yes – Group Support      | 1  | 5%  |
| Unknown                  | 1  | 5%  |

As can be seen, two-thirds of HCAs (n = 14) indicated that no support was available in their units. Of those who referred to Individual Support, all referred to some form of clerical or religious worker, or individual counselling that was available in their units.

*"There is a Pastoral care worker available if you feel the need to talk."*

When asked if HCAs felt that support was an area that needed further development, 68% (n = 15) indicated yes. Of those HCAs who expanded on their answer, the vast majority mentioned the need for either time off or for a colleague or professional to be made available, to whom they could speak about the deceased, or how their death has affected them.

*"Staff are expected to go back to their normal duties and no time off to grief if very close to the resident."*

### Additional Comments:

HCAs were given the opportunity to give additional comments at the end of this questionnaire. The following is a sample of their responses:

*"When a client dies the staff would talk to each other about how they feel. I find this is a great help."*

*"Some nationalities are not informed of certain customs Irish people would have in after care of the deceased, i.e. a member opened curtains and windows to a public area with the deceased lying in bed. I was upset by this, and as the staff member was my superior I could not change things even though I explained that we would draw curtain, low light, etc."*

*"It is not always possible for some families to be present around the clock while their loved one is seriously ill or dying. If this is so, a member of staff should be present as I feel very strongly that the patient should never be left alone."*

*"I would like to be more aware of the stages of death or what can be expected when someone is dying."*

### RN Section Five: Staff Support:

RNs were asked what support is available for staff following the death of a resident in their units. The following are the responses of the 57 who answered this section:

| Support                               | n  | %     |
|---------------------------------------|----|-------|
| None Available                        | 16 | 28.1% |
| Formal Staff Support                  | 16 | 28.1% |
| Informal Staff Support                | 11 | 19.3% |
| Chaplain / Pastoral Service Available | 11 | 19.3% |
| Other                                 | 3  | 5.3%  |

The majority of RNs (71.9%, n = 41) indicated that there was some degree of support available for staff. RNs who mentioned informal staff support simply responded with answers such as:

*"We support each other mainly by discussing and including each other."*

*"We can speak to each other or a close colleague."*

When asked if this support was something that required further development, 56% (n = 34) responded that it was. When asked for comment on this, nine indicated they would like some form of counselling, bereavement time or support for dealing with the loss of a patient. The remaining RNs who commented on this gave a wide variety of answers, including:

*"More regular sessions which would allow more staff to attend."*

*"To continue yearly commemoration activities in our unit for the service users who passed away and their families will attend and have continuing bonding with the staff and families here."*

RNs were asked how they felt their palliative care skills and knowledge can be further developed, with the following results:

|  | Number | Percentage |
|--|--------|------------|
| Lectures   | 41     | 68.3%      |
| Workshops  | 36     | 60.0%      |
| Supernumerary Clinical Placement in Specialist Palliative Care Setting | 24     | 40.0%      |
| Other  | 3      | 5.0%       |

Finally RNs were asked what topics about which they would wish to receive education:

| Topic                        | Number | Percentage |
|------------------------------|--------|------------|
| Pain Assessment              | 57     | 95.0%      |
| Cultural Issues around Death | 56     | 93.3%      |
| Supporting Families          | 56     | 93.3%      |
| Symptom Management           | 55     | 91.7       |
| Communication                | 52     | 86.7%      |
| Advance Planning             | 51     | 85.0%      |
| Resuscitation                | 40     | 66.7%      |
| Others                       | 6      | 10.0%      |

Those who indicated "**Others**" mentioned Staff Support, Religious Practices at Time of Death, Feeding and Hydration at End of Life, Dyspnoea, Challenging Behaviour and Constipation.

### Summary:

This chapter presented the findings from a survey which established the educational needs of RNs and HCAs with respect to a palliative care approach to EOLC in long stay community units. Participants' interest in palliative care education was highlighted, while their confidence in their abilities in providing EOLC was also presented. Areas for further support as perceived by the participants were also presented. All staff who responded were interested in receiving further education and training in aspects of palliative care. Staff, HCAs more than RNs, also identified a need for more staff support.

## Chapter 5: Death Reviews as support and education

This section presents an overview and evaluation of death reviews that were undertaken as a part of the EOLC initiative. A brief overview of reflective practice as a framework within which death reviews were undertaken is presented. A description of the process and outcomes of the death reviews is presented together with recommendations for practice.

### Reflective Practice:

According to Schon (1983), reflection enables an individual to uncover knowledge in and on action. In the context of learning, reflection is a generic term for intellectual and affective activities, in which individuals engage their experience to create and clarify meaning in terms of self, and which results in a changed conceptual perspective (Boud et al., 1985). Ghaye and Lillyman (2000) consider that reflection enhances caring practices. It enables participants to free up their thinking with regard to themselves and their clinical practice and to discuss what they are actually doing and why in terms of patient care (Graham et al., 2005). According to Gustafson and Waterberg (2004), encouraging nurses to reflect upon nursing situations, in order to promote the nurses' professional development, contributes to more effective and comprehensive nursing care for patients. Reflective practice should not be perceived as a means to identify deficiencies in practice but rather as a means to advance individuals' understanding of the art and knowledge embedded in the care of individuals who are dying patients and their families (Howell, 1999).

### Reflecting on Experiences of Providing EOLC:

To assist staff in long stay community units to reflect on EOLC, death reviews were introduced. For the purpose of this quality initiative, death reviews are described as a reflective process on the EOLC provided by residential care staff to residents in the last weeks of life. The reviews were provided in respect of all residents who died in the units. A modified version of Gibb's (1988) model of reflection was used to guide the review process. This includes (1) description of the experience; (2) Feelings (What were you thinking and feeling?); (3) Evaluation (What was good and bad about the experience?); (4) Analysis (What sense can you make of the situation?); (5) Conclusion (What else could you have done?); (6) Action Plan (If it arose again what would you do?). Throughout the course of the project, a total of death 35 deaths were reviewed in three units over a 12 month period.

Following the death of a resident, the project nurse was notified by a staff member from the residential care unit. Death reviews took place following a review of the documented EOLC provided to residents in the last forty-eight hours of life. The death reviews occurred within two to three weeks of the resident's death and were attended by 6-10 staff.

The purpose of the death reviews was to evaluate EOLC delivered to residents prior to death in long stay community units or within 6 weeks of transfer to a general hospital. The review also helped to create an awareness of individual needs of dying residents and their families. Additionally, the death reviews facilitated staff in reflecting on EOLC skills in order to evaluate best practice in EOLC in the long stay community units. Finally, death reviews helped staff to appreciate the complexity of EOLC in a specific patient population.

### Process of Death Review:

The death reviews were facilitated by the project nurse, who commenced by inviting staff within the residential care unit to assemble in a comfortable room. The project nurse welcomed all those who attended the review, and provided an overview of the review process. Staff attending the death review were informed of the deceased resident's name, and the date of the resident's death. All staff – including nurses, carers, members of the multidisciplinary team, catering staff and porters – were invited to remember the resident and share memories of the resident during a short reflection. This included occasions that stood out for the staff, for example, a birthday, Christmas or a family occasion, or any other memories they wished to share. This was followed by a reflection and discussion on the care activities provided to the resident within the last forty-eight hours of life. Invariably, the discussion of EOLC provided to the resident extended beyond this time frame, as staff regarded EOLC to include more than the last two days of life.

### Themes Arising from Death Reviews:

While death reviews varied in duration and attendees, a number of themes arose from the reviews and the reflections on the EOLC residents received. These include staffs' ability to: (1) value all care as part of EOLC; (2) the value of the relationship between staff and the residents; (3) face challenges in recognising dying; (4) understand the role of advance care planning and how this impacted on EOLC; (5) recognise and understand the need for transfer to hospital; (6) be aware of the need for spiritual care of the residents; (7) appreciate communication challenges in addressing end of life issues; (8) meet the needs of residents with cognitive impairment (9) understand the central role of the family in providing EOLC. These formed the basis of discussion with staff arising from the death reviews. These will be discussed in the following section.

#### 1. *Valuing All Care as Part of EOLC:*

In the reviews, staff commented on the value of all care that was provided as a component of EOLC. From their comments, it was apparent that EOLC extended beyond the last few hours, days and weeks of life. Some of those who attended the death reviews acknowledged the value of all care they provided to the residents from the time of admission to the residential care unit – in other words, they regarded EOLC as having a long trajectory, in some cases, a number of years. Those caring activities included supporting the residents in undertaking their activities of daily living, providing companionship to the residents and treating them with respect and dignity. Also, staff commented on the value of the care they provided nearer the time of death, which included

comfort measures, providing pain relief or making some difference to the residents' quality of living. Irrespective of when the care was provided, staff valued the care they provided to the resident and acknowledged that such care made a difference to the residents' stays in the long stay community units.

## **2. Relationship between Staff and Residents:**

Relationships that staff formed with the residents were highly valued and considered to be central to the caring processes. Many of those who attended the reviews commented on how relationships developed with the residents over a period of time in the long stay community units. There appeared to be differences in the extent to which this relationship developed. This was influenced by the grade of staff, length of stay in the long stay community units, willingness of the resident to develop the relationship and finally, the cognitive status of the resident. Staff attending the reviews also indicated that developing the relationship with residents was in part influenced by the amount of time they spent with the resident during his or her stay in the residential unit. In cases where the resident had not spent a long time in the unit, there may not have been the opportunity to get to know the resident. The intensity of the relationships varied; for some staff, the intensity of the relationship enhanced their intuitive knowledge of the resident – they commented that they "*just knew*" what the resident wanted or the resident's wishes without the resident needing to express this verbally.

## **3. Challenges in Recognising Dying:**

The majority of deaths that occurred in the residential care units involved in this quality initiative were expected. Despite this, staff who attended the death reviews recounted the challenges they faced in terms of recognising the onset of dying. While nursing staff were knowledgeable regarding the physical and physiological changes that occur throughout the dying phase, they were frequently challenged to be definite as to when death may occur, particularly when asked by residents' relatives about the likely time of death. Staff encountered occasions when they contacted family members to come to the residential care unit because they considered their relative was dying. On some occasions, when family members arrived at the unit, the resident did not die at that time; some lived for a number of days or even weeks. On other occasions, families had requested to be called when death was imminent; however, for some residents, death occurred without family members being present, as it was not recognised or anticipated that death would occur.

## **4. The Role of Advance Care Planning:**

For many of the staff who attended the death reviews, the role of advance care planning was a common focus of reflection. While advance care plans infer a variety of meanings, staff recalled how the provision of advance care plans mainly centred on the resident's resuscitation status and wishes of the resident with regard to the place of death. In situations where there were clear directives with regard to resuscitation status, it provided a sense of security for staff. In some instances, there was a lack of clarity with regard to this status. Staff recounted how they experienced difficulties in obtaining clarity around

this issue, creating ambiguity that caused uneasiness for care staff.

The residents' preferred place of death was generally the residential care unit. While staff made every effort to support the residents' wishes, there were occasions when acute medical episodes warranted the transfer of residents to an accident and emergency department for active management. In some cases, the residents died in the emergency department, while others were transferred back to the residential care unit. Where a resident's death occurred in an emergency department, staff expressed a heightened sadness.

In addition to resuscitation status, there were situations where there was clarity about the resident's wishes with regard to nutrition and hydration status. For some, there was a clear indication whether a percutaneous endoscopic gastrostomy tube (PEG) was to be inserted for nutrition and hydration purposes. In those situations, this meant the procedure was carried out in a general hospital, with subsequent management in the residential care unit. While this was not problematic in terms of management of nutrition and hydration, staff recalled occasions when there were difficult decisions that needed to be made about whether to continue with PEG feeding, or when to cease it, particularly when it was evident that the resident was dying. In situations where the decision was made to cease the PEG feeding, and where staff were in agreement with this, the challenge of discussing the care of the resident with families was eased.

## **5. Understanding the Need for Transfer to Hospital:**

Staff were frequently challenged within the care units about whether a resident ought to be transferred to a general hospital for further medical management. There were occasions when there was a definite need for transfer, particularly when residents suffered an acute condition superimposed on the chronic conditions and this needed active management – for example, haemoptysis. There were also situations when staff considered that decisions to transfer residents to an acute service were made by doctors who may not have known the resident as well as the staff in the residential care unit.

## **6. Awareness of and Addressing of Spiritual Needs:**

Understanding the nature of spirituality formed an important aspect of EOLC. Many residents in the residential care units wished to attend Mass and the sacraments on a regular basis; however, this was dependent upon a local priest being available. Staff also considered that many residents would appreciate visits by priests, but this was not always possible.

It was also highlighted at a number of death reviews that many residents placed high value on the rituals of their religion as an expression of their spirituality. These included prayers, masses, the use of holy water and religious artefacts. Participants ensured that these were available to residents during their dying moments; however, they felt that the presence of minister of religion or pastoral care staff would have enhanced the spiritual care of the resident, particularly as death approached. In situations where a minister of religion or pastoral care worker was not available in the resident's

dying moments, participants expressed their confidence in leading prayers with residents' family members at the time of death.

Death reviews also provided the opportunity to acknowledge the changing culture of carers and residents within residential care settings. It was acknowledged that there was a need for further awareness around residents' cultural needs and the level of understanding that participants had in relation to this.

#### **7. *Communication Challenges in Addressing End of Life Issues:***

Communication challenges were also recognised during the death reviews as potential challenges in providing EOLC. Participants commented on the difficulties associated with the language and words used to inform family members of a resident's changing and often deteriorating condition. It appeared that on occasions, staff had difficulty in attempting to initiate a conversation with family members and informing them that their relative's condition was deteriorating. This deterioration may be subtly marked, in terms of gradual withdrawal from activities, deteriorating appetite and increasing fatigue. Participants were on occasions reluctant to initiate those conversations as they considered that their judgement regarding the resident's condition may not be correct. In addition, family members regularly witnessed the decline, and wished to speak openly to staff about this. For some, this posed a challenge, as they considered that they did not have the words to express the reality of the resident's situation.

#### **8. *Challenges in Assessing Needs of Residents with Cognitive Impairments:***

It was a common occurrence that residents within the residential care units suffered from a cognitive impairment. In some instances, this was superimposed with multiple co-morbidities. The death reviews provided participants with the opportunity to highlight occasions when they felt that, as a result of knowing the resident, their intuitive knowledge assisted them in identifying the resident's needs and they were in a position to meet those needs, particularly in terms of comfort and symptom management interventions. While participants considered that they had the competencies to address the physiological aspects of EOLC in residents with dementia, the death reviews provided them with the opportunity to address their concerns regarding residents' psychosocial needs.

#### **9. *The Central Role of the Family:***

Leaving a loved one in a unit for long term care was identified by staff as being difficult for families. While developing a relationship with family members took time, such relationships provided valuable opportunities for family members to become involved in caring activities for their relatives in the residential care unit. Participants and family members valued this opportunity, as they considered it enhanced the quality of care provided. Additionally, staff became aware of the residents' various personal preferences as a result of these relationships.

Regular family visits to the unit provided the opportunity for families to get to know other residents and their

families also. It appeared that such visits helped to create a social network among family members, particular throughout the stages of the residents' decline. In situations where a resident had infrequent visitors, other family members provided companionship for these residents. They became surrogate families which, staff considered, added to the uniqueness of the care unit.

The central role of family members around the time of death was acknowledged as being highly valued by family members and staff in the residential care units. Their input and availability at this time assisted in making decisions with regard to meeting the resident's wishes and funeral arrangements.

### **Death Review Evaluation:**

Staff completed an evaluation of the experience of taking part in a death review on completion of each review. Evaluation of the reviews indicated that:

1. Death reviews constitute a meaningful process, which assists staff who are providing EOLC to discuss strengths and limitations of the EOLC they provide.
2. Staff regarded the death reviews as a valuable means of providing staff support. It affirmed the value of their practices, which may not have been recognised without undertaking a death review.
3. Death reviews provided special time for staff to remember a resident who had died and for whom they had cared. This special time also brought a sense of closure for staff, allowing them to move on from the death, and also to sustain the memory of the resident and the resident's family.
4. In conjunction with the previous point above, death reviews assisted staff to recall the value of the care they provided; the process helped them value the contribution staff had made to EOLC.
5. Staff felt supported in what can be a challenging area of care, improving self-esteem in the team by valuing all members of the team.
6. Staff commented that the review process provided a valuable tool for reflective practice, allowing them to discuss their practice in a safe and supported environment.
7. Death reviews were not considered to be an activity used to highlight poor EOLC practice. On the contrary, the reviews assisted staff to develop confidence in practice by highlighting the strengths and limitations of the EOLC they provided to residents who had died. As a result, staff were in a position to transfer the learning towards improving EOLC practice within the residential care unit for future residents.
8. Following a series of reviews in the residential care units, staff acknowledged "*pattern recognition*" with respect to the onset of dying. This in turn contributed to initiating EOLC practices earlier than they normally would have prior to death reviews, improving the quality of EOLC for other residents.
9. The value of multidisciplinary input to EOLC was regarded as an important skill in providing quality EOLC. This was particularly evident when a variety of multidisciplinary team members attended the death reviews.
10. Death reviews assisted in developing a framework for meaningful EOLC documentation and education.

## **Recommendations Arising From Death Reviews in Residential Care Units:**

The following are recommendations arising from death reviews for education, research and practice and management.

1. Staff need to be trained in the structures, process and outcomes of death reviews. The value of using a reflection tool, for example Johns (1995), Kolb (1984), or Gibbs (1988) ought to be used in order to provide staff present at the reviews with a framework within which to undertake the reflection.
2. Senior management in the residential care units need to support staff by providing the time for death reviews to be undertaken.
3. There is a need to encourage continuing dialogue around EOLC among multidisciplinary team members.
4. Staff should be facilitated to attend an education programme, which has been developed to address the needs identified by staff through the reviews around EOLC.
5. Death reviews need to become regular practice for all deaths that occur in residential care units.
6. Additional research needs to be undertaken in order to assess the value of death reviews, in terms of their impact on EOLC practice and documentation.
7. The role of family members in reviewing EOLC needs to be considered.

# Chapter 6: The Nature of End Of Life Care and Palliative Care

## Introduction:

This chapter presents the findings from the focus group and individual interviews conducted over a period of six months. As outlined in chapter one, interviews and group discussions were held in each of the three units. From the analysis of data, it emerges that EOLC is comprised of four inter-related constructs (illustrated in Figure 6.1), which occur in a non-linear fashion and are in a constant state of movement. Each construct is supported by members of the multidisciplinary team, so that quality person centred and family centred care is delivered to residents up to the time of their death. There also appears to be a stage in EOLC when the threshold is crossed and EOLC is considered to be *"palliative care"*. This section presents the constructs that compose EOLC.

EOLC is regarded by the participants as being holistic in nature and extending across the *"time for planning"*, the *"time of transition"* and at a time when EOLC is *"timeless"*.

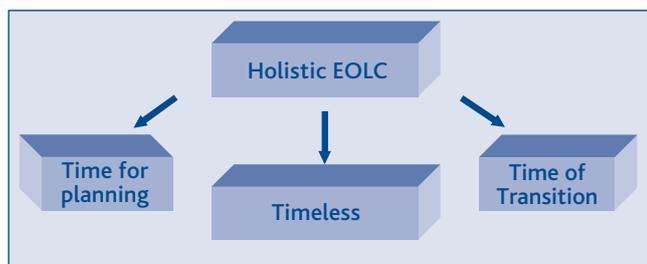


Figure 6.1: The Nature of EOLC

## EOLC as a "Time for Planning":

EOLC forms part of the normal component of planning that exists in the residential homes.

*"EOLC is something as a team we address on admission."*

EOLC is whole person care.

*"It looks at the whole person, their life story and they are cared for medically for whatever they need.."*

*"I would think it's a more holistic approach for us in care of the elderly, almost preparing people for the journey to death. It's a continuous process."*

EOLC is regarded as a time for planning. There were a number of important issues that participants felt that needed to be considered throughout this time. This is evident from one participant who commented:

*"It's a time to establish their resuscitation status and whether they should be transferred to a hospital or not. Time to establish with families what they would like, what their wishes would be."*

In addition, involving residents in making choices with regard to their care was seen as important, so that their choices are considered and taken into account as part of their care planning.

*"It is important to give residents choices where possible."*

Keeping the resident informed of the nature of his/her care was considered to be a component of EOLC.

*"You need to tell residents what's going on, so they can be involved."*

While planning appeared central to the initiation of EOLC, the actual trajectory of EOLC appeared to occur within a continuum. Staff considered that EOLC was care that was delivered as residents' conditions changed and fluctuated throughout their stay in the residential care home.

## EOLC as a "Time of Transition":

Transition appeared to be a component of EOLC. In some cases, it was difficult to recognize the stages of transition, as there appeared to be no entry point to EOLC; however subtle changes in residents appeared to mark this time. For one respondent, the point of entry to transition to EOLC commenced once the resident was admitted to the residential care home. This is evident from the following quote:

*"Being in a long stay unit all of our clients are just waiting to die in some ways."*

It appears also that, throughout this transition phase, EOLC and supportive care were synonymous. As one respondent commented:

*"When someone, a patient or a resident in a nursing home, comes to a stage where they are at an advanced age with associated medical problems, the care they need is not to prolong life, but to give basic support. It's the care that we give someone when they reach a certain age that we don't want to prolong their life terribly."*

EOLC was also regarded as a form of care that spanned an extended period of time. Its nature was determined by the resident's condition at various stages throughout that time. This is evident in one participant's comment:

*"Residents are sometimes here for 5 to 6 years, care changes over the years. Sometimes there's acute episodes then chronic again, so the residents and the nature of care changes over the years."*

It appears from the above participant's comment that there was a need to be aware of and attuned to the likely changes that could occur throughout the resident's stay in the care home. As it was not uncommon for residents to experience acute episodes of illness in addition to having a chronic illness, these acute illness episodes were actively managed. As many of the residents in the residential care homes had multiple co-morbidities, this required a variety of pharmacological interventions in order to manage symptoms associated with their conditions. In some instances, EOLC was signalled when an overall review of the resident's was carried out in response to a resident's deteriorating condition.

It appears from the above participant that such a review formed a significant part in signalling a change in the resident's medical status and required a review of the care being delivered.

## EOLC as “Timeless”:

It was evident from individual and focus group interviews that staff found it difficult to depict a point in time that signalled the delivery of EOLC. It appeared that, for some, EOLC was timeless, and an aspect of care that was holistic in nature, irrespective of whether the resident was actively dying, or progressing through the normal stages of living. One participant commented:

*“It’s about caring for someone as they’re coming towards the end of life in elderly settings, it’s not always time specific.”*

For one RN, EOLC was a component of all care delivered to residents, and was difficult to consider as beginning a point in time. She comments:

*“Caring for someone at the end of life in a unit like this isn’t always the last weeks or days, but maybe a year beforehand, it can be a longer period of time.”*

On the other hand, it appears that EOLC was also regarded as care that was specific to the latter stage of living. It was initiated when it became evident that death was approaching. One participant suggested that EOLC:

*“...is that last stage, there isn’t a time, it’s a stage we feel the change where someone is going to die.”*

Similar sentiments were expressed by another respondent who commented:

*“Clients who the medical team has realized they are nearing the end of their life, there is no time limit to it, but we know that the problems they have are terminal.”*

It was acknowledged by participants that, while it was not possible to predict the moment of death, some respondents regarded EOLC being more focused on the time prior to the actual occurrence of death.

*“End of life care is really that period shortly before someone dies.”*

Similar comments were expressed by another participant with regard to EOLC as is evident from the following quote:

*“Caring for them during the immediate dying process as they would like, but you can’t put a time on it.”*

## The Nature of Palliative Care:

From the analysis of data, the nature of palliative care is seen as composed of three interrelated entities. These are *“Palliative Care as an End Point”*, *“Palliative Care as an Intervention”* and *“Palliative Care as Support”*. There appeared to be a period of time when EOLC crossed the threshold from being *“EOLC”* to being regarded as *“Palliative Care”*. The subtle differences between the two forms of care were not always evident; however, the acquisition of specific knowledge related to EOLC appeared to be a pre-requisite to the delivery of palliative care to residents within the residential care units.

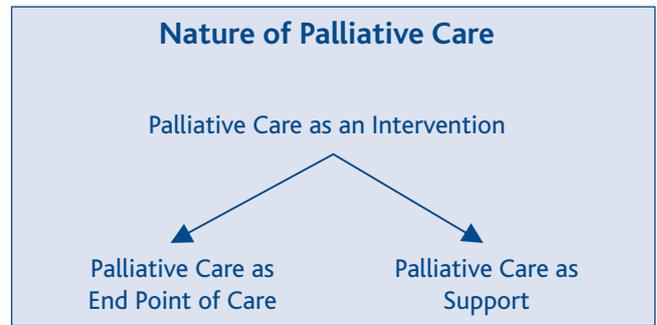


Figure 6.2

## Palliative Care as Supportive Care:

It appeared that the central element of support for residents was to address their pain and symptoms. Staff focused here on good symptom management as the key to ensuring patient comfort. They considered that this was a central component of palliative care:

*“Palliative care involves pain relief, control of nausea and other symptoms. I think it’s all about comfort. Palliative care is a more active type of care. You intervene to control symptoms.”*

*“Symptom management through teamwork.”*

*“Palliative care is about keeping the resident pain free and comfortable.”*

Palliative care was considered synonymous with the acquisition and possession of advanced skills and knowledge with regard to the caring process. It appeared that it was regarded as being a type of care that was *“special”* in terms of when it was initiated and by whom it was initiated. As one participant commented:

*“I suppose we often believe palliative care is a more specialised care even though a lot of the care we would do here like pain relief, nutritional supplements, control of symptoms, would be regarded as EOLC but because it’s not done by a specialist we don’t term it palliative care.”*

Central to the provision of palliative care was the ability to provide support for the resident and for the resident’s family. Person-centred and family-centred care are not exclusive to palliative care; it was evident from the participants that this approach to care was also practiced in the residential care homes. Staff were cognizant that the probable eventual outcome for the resident was death. There was a sense of supporting families in preparation for this inevitability so they were somewhat prepared for the event when it occurred.

*“Palliative care was also seen to be delivered with a focus on families and being prepared for the inevitability of death.”*

Healing was central also in dealing with family members. It appears that there was an awareness in staff that there may not always have been harmony between residents and family members and they regarded this time as an opportunity to revisit those occasions in order to facilitate some healing in relationships. This is evident as follows:

*“...a time – opportunity to make peace with an estranged family member – a common experience in long stay units.”*

Facilitating residents to revisit their past provided them with the opportunity to be more prepared for the inevitability of death. As one participant commented, palliative care is when:

*"Healing during living and at a time when it is preparation for dying."*

Spiritual care formed a central role in the provision of palliative care to residents in the residential care homes.

*"Palliative care involves helping the person find peace in their journey, look back on their lives and be able to talk about it, look at the good and the bad, and come to accept where they are at and go forward with confidence."*

Another component of spiritual care that was evident as part of palliative care was the availability of staff to be present with the resident.

*"I would see it as somebody remaining in the room with them, sit with them. I would sit with them if it was a quiet time for me, and maybe say nothing, maybe hold their hand."*

Another participant commented:

*"... time and opportunity to say what's on their mind."*

In addition, spiritual care as a component of palliative care was providing support to the resident so they could:

*"Look forward to the best is yet to come, that is what our faith teaches."*

The inevitability and recognition of the onset of dying could cause distress to residents. It was regarded as being important to support the residents on such occasions, as part of the palliative care provision.

*"Responding to a resident who was scared – I remember she said, 'I am frightened, what happens when you die?'. I didn't know where it was coming from but I knew she loved her sleeps especially after lunch, so I said, 'You know the way you love your sleep, that's probably what it's like, you just go for a lovely sleep' and she was fine with that."*

### Palliative Care as an End Point:

For some participants, palliative care was considered to be initiated at a time when death was imminent and there was no further indication for active measures. It was considered to be a time for ensuring that comfort was a key focus of care.

*"Seen as more at the very end stages, when the decision has been made that someone is at the end of life and we must ensure that they are comfortable."*

*"Palliative care and EOLC have the same 'end point', and that is the support they need to keep them comfortable."*

Palliative care was seen as doing as much as possible to make the last days and hours comfortable.

*"Time you know when you are not able to heal someone, just make their time the best possible."*

*"Care when there are only days to death."*

Staff seemed able to differentiate between "phases" of dying, in terms of "terminal care" and "actively dying", both of which are times when palliative care is delivered. As one participant commented, palliative care is a way of:

*"...dealing with symptoms really, at times when the resident has gone down a 'no recovery road'."*

### Palliative care as Intervention:

Palliative care consisted of interventions that attempted to address symptoms and distress. This is evident as these participants suggest:

*"I would refer to palliative care as when we alleviate all symptoms and distress and just good quality of life as long as they are here."*

The delivery of palliative care appeared to be synonymous with the stage of "active dying" by some of the participants.

### The Merging of Palliative Care and EOLC:

From the analysis of data it appears that a "mergence" occurred between "Palliative Care" and "EOLC". There appeared to be no point at which residents' care switched from EOLC to palliative care. Both philosophies of care were interrelated and complemented each other. In essence, they were in "aposition" as opposed to being in "opposition". This is depicted in the figure below.

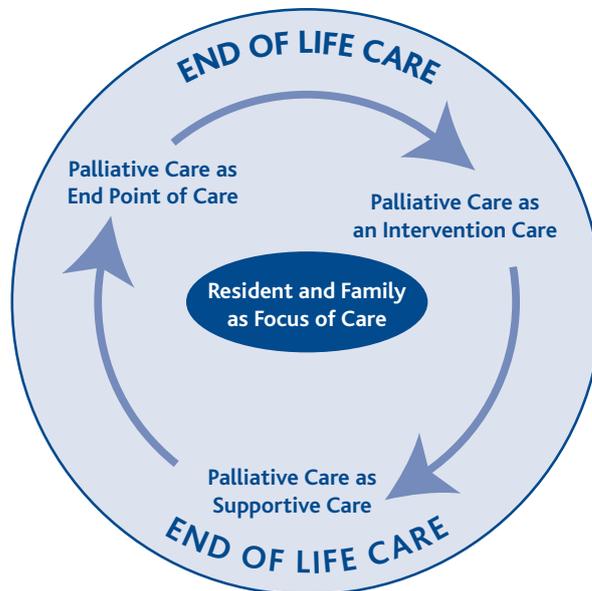


Figure 6.3: The Emergence of EOLC and Palliative Care.

### Summary

This chapter presents an overview of the nature of EOLC and the nature of palliative care as perceived by staff. While both were considered to have distinct characteristics, there were also commonalities between them. It appeared that there was no "crossing point" between EOLC and palliative care. Staff endeavoured to promote a person-centred and family-centred approach to care, in which the physical, psychological, social and spiritual needs of the residents were addressed.

## Chapter 7: Contributors to Good End Of Life Care

### Introduction:

This chapter discusses the views of staff about what constitutes good EOLC. While staff had some difficulty in describing the differences and similarities between palliative care and EOLC, they were able to describe the constituents of good EOLC and poor EOLC.

### Coordination of Care:

Participants recognised that the time of approaching death was a special time, not only for the dying resident, but also for his or her family members. They considered that an important factor in facilitating good EOLC was care that was well coordinated. As one participant commented:

*"It is something that is coordinated, something everyone knows they should be doing, know what the client's expectation of them is, involving family, just making sure things run smoothly, that it is not too stressful or too traumatic. I think it needs to be controlled and calm and people are comfortable in their role providing care."*

In order for effective coordination of care to take place, it was essential for staff to have a plan of care in place that took account of the resident's and family members' wishes.

*"Knowing a plan of care and including the wishes of the family means we can give the best care by addressing all the issues here, keeping in contact with the family all the time. In the absence of a family member we would always assign a staff member to be with the resident."*

It seemed to the participants that involving patients in planning and offering them choice was a component of the skills that staff ought to have in order to facilitate good EOLC. One participant said:

*"It's about choice, the person's final choice and comfort and knowing they are happy at the end, important to give them comfort and happiness so that they can go peacefully."*

The centrality of person-centred and family-centred care is a component of the philosophies of both palliative care and older person care. In this study, it was important that staff caring for the dying resident at end of life had already established some form of connection or relationship with the resident. As one participant commented:

*"Main thing is staff, having the staff is so important for the person to know someone is there, just someone with you, which would be my biggest thing, you can feel they want to be there."*

It was also important that staff members involved family members at this time, while treating them with dignity and respect.

*"Staff attitude, dignity and respect, not just caring for the patient but the family as well, trying to give the best quality of life, caring for them like they are your own."*

Participants commented comfort care is multidimensional.

*"I would see apart from treating their symptoms, ensuring their comfort and assigning, as death is imminent, to have somebody to stay with them."*

While comfort care transcends all aspects of the dying process, participants highlighted the importance of possessing the skills to be able to recognise that death was approaching. This recognition facilitated more effective and efficient co-ordination of care, so that the best possible EOLC could be provided for the dying resident.

*"Recognising the fact that somebody's life is coming to an end helps make it good, allows time to do everything possible."*

The coordination of care needed to include spiritual care. Spiritual care was not an element of care that could be initiated at a late juncture of a resident's illness; it needed to begin at a time following admission. One participant highlighted the importance of this practice, and commented:

*"It's important for pastoral care to begin when a resident enters here – it takes time for people to build up trust. It becomes deeper and closer as the relationship develops."*

### Communication:

Communication skills were regarded as being important. It was not uncommon for residents to be suffering from dementia. The importance of knowing the patient was acknowledged as a component in good EOLC provision, particularly when caring for residents with dementia. As two participants commented:

*"In a resident with dementia it's about the nursing staff and carers who have the relationship with the resident who can tell if the resident is in pain or comfortable."*

*"A good communication pathway is vital, helping families know what to expect, especially when the resident has dementia."*

The presence and support of families and preparedness of the family was also seen as important in contributing to good EOLC. It was considered that family members' presence provided the dying resident with a sense of security, as is evident from the following:

*"Very important to have families involved, the dying person has to sense their family are all right."*

Another participant commented, with regard to the central role of communication in providing good EOLC:

*"Effective communication and the ability to engage with families and assist them in exploring any difficulties with respect to the resident is an important aspect of good EOLC."*

There were occasions when participants struggled about when to call a resident's family, so they could be present with him or her as death approached. There were times when staff felt they got the timing right, and on such occasions, they considered that this contributed to providing good EOLC. However, it appeared that getting the timing right was dependent on possessing good clinical decision making skills, and also having the awareness of the importance of preparing family members for the impending death.

Some of the participants acknowledged their lack of confidence on occasions in their ability to communicate effectively with family members of residents with respect to EOLC. In part, a lack of knowledge as to what to say appeared to cause challenges in terms of effective communications. As some participants commented:

*"Most important aspect of care is communication. There is always room for improvement."*

*"Some staff are very good at this; others avoid it because they don't know what to say or don't have the confidence."*

In order to enhance staffs' communication skills, it was acknowledged that there was a need for staff education in how to deal with different communication issues.

Informing a family member of the death of their relative in the care home was acknowledged as being a challenging communication situation, however, it was acknowledged that this skill could be developed over time. This is evident as one participant commented:

*"Not knowing the language to use, communication can be very difficult for staff, how do you say 'your parent has died' over the phone. I suppose you get better with more exposure."*

Diversity of culture in long term care of the elderly units was also seen as an important factor that impacted on communicating with families around EOLC.

*"Communication is a huge thing and the influence of different culture groups, they have different ways of communicating about death and dealing with the dying resident and their families."*

It was acknowledged by some non-Irish nationals that they experienced difficulty in communicating on occasions. A number of participants agreed that knowing the actual language to use was difficult and this was particularly relevant to staff whose primary language was not English.

## **The Role of Advance Care Planning:**

Participants agreed that there was a need to engage residents in advance care planning activities. While there was much value in supporting residents in engaging in this activity, it was also considered important to engage family members in such discussions. Participants were cognizant of the need to engage in those discussions at an early stage following admission, so that person-centred care could be planned.

While involving residents in decision making with regard to advance care planning seemed to be the ideal, there were situations when this was not always possible. This occurred mostly in situations where the resident suffered from cognitive impairment, which was usually dementia.

*"Sometimes the choice to discuss wishes for end of life is taken away from people by the nature of their illness, especially dementia."*

*"If a patient has dementia and can't decide for themselves if they want transfer to hospital. We as the doctors and nurses must know how the resident was before the infection; it is not unreasonable to send a resident out to hospital for IV antibiotics if you feel it will improve their condition."*

Staff had a function in advance care planning in establishing that there are choices around care and enabling families and residents to understand this. Through family meetings and open communication, family members were advised about the choices they had in terms of the care their relative received. In one care unit, there appeared to be a clear structure in place with regard to this form of care.

*"We offer three care streams just introduced 3 months ago, the registrar meets with families and agrees where the resident is at the moment. Interventional is where everything is considered a go. Comfort is things like antibiotics and Palliative would be recognising that maybe more intervention would be of no benefit at all."*

*"From admission we are planning with families; we have a family meeting on admission and then give updates as necessary for two main reasons: to discuss CPR or in case of the need to transfer to hospital."*

*"If the patient is compos mentis, I would certainly ask the patient, but it is very important to ask the families because different family members have different views, they may not agree with a lot of things."*

*"We find most families have not had this discussion (about resuscitation) when they arrive; we let them off to think about it, we talk also about hospitalisation and palliative care, and we only have three patients out of fifty for resuscitation. Some decide to go to hospital, others we watch and wait, treat certain things but then have to decide when to stop, and inform families."*

Another participant commented about decisions that may need to be made, irrespective of the family members' wishes or the resident's wishes.

*"We address this from admission but advise families there may be times when a resident must be moved, e.g. x-ray."*

Such discussion came as a surprise to people, who were reluctant to make such decisions without involving other family members.

Another participant described her unit in this way:

*"What we offer in the unit is maximum comfort; having input from palliative care is very important to help us make decisions re syringe drivers etc. It helps us give maximum comfort."*

Each resident and family was unique in how this matter was dealt with and it required the understanding and support of staff. Being admitted to a residential care unit did not automatically infer that the resident would not be transferred to a general hospital or, in the event of suffering a cardiac arrest, would not be resuscitated.

*"You can't say everyone is not for resuscitation; it is on an individual basis."*

*"It is important to know some residents can make their own decisions and they can surprise you."*

Participants acknowledged the right of a resident or family member to change their minds with regard to advance decision making. This appeared to happen in different situations, either over a period of time, or in the case of sudden deterioration in the resident's condition.

*"When you talk about advanced planning it doesn't always work; a 92-year-old resident after deciding one care stream changed her mind and now wants transfer to hospital as she feels they might have drugs there to help her that we couldn't use here."*

Families may also decide not to transfer a resident for further care to an acute hospital. In many situations, family members were satisfied with the care their relative received in the residential care unit, and their wish was for them to remain there. This decision may be related to the quality of care they received, the relationship they had developed with the care staff, or their wish not to have their relative exposed to a busy emergency department.

*"A lot of relatives would prefer to see them remain here in the unit for care and comfort."*

*"Ninety per cent of residents/families would choose to stay here for end of life care."*

There were occasions when a transfer to hospital was necessary and families needed to understand the need for such interventions. In such situations, participants provided them with the relevant information, to assist them.

Sometimes families experienced difficulty in decisions regarding EOLC, particularly in situations where there was disharmony among family members. Participants were acutely aware of those situations and used their skills to assist family members to overcome those differences.

*"I would encourage families to have open communication and put any grievances they have aside to deal with the issue at hand. To help them look at the parent and do the things they would have wished for rather than let squabbles colour what they do."*

## **The Surprise Element of Death:**

Staff were sometimes surprised by the death of a resident and equally as often surprised that a resident recovered from an illness they thought was terminal. Some staff, however, felt that with experience, they came to recognise the changes that signalled the inevitability of death.

*"We all know when they are here they are at an advanced age. It's inevitable they will end their life here; what I have seen so far is usually within 5 years once they have moved here, most of them will slowly deteriorate before they die."*

*"I would generally say that no, a death never surprises me; you usually see the deterioration."*

On the other hand, despite knowing the residents throughout their stays in the unit, there were occasions when staff were surprised by a resident's death.

*"Sometimes we are taken by surprise, because of an acute event, like a Pulmonary Embolus (PE), it might occur out of nowhere, without warning, that's a bad situation."*

It was not uncommon for residents to experience fluctuations in their conditions, which could lead to their deaths or recoveries, albeit temporary. Such situations may result in staff not having the opportunity to inform family members of the change in the resident's condition.

*"There is an element in a unit like this that someone's time has come. We have had situations where residents have episodes of acute illness, recover, and then die suddenly, even without family [because] it happened so quickly."*

The fact that the occurrence of some deaths took staff by surprise did not infer that they were considered to be bad deaths. Rather, for some, a sudden death was seen as a positive event.

*"Sometimes it doesn't surprise you but it's just quite nice if somebody goes off quickly and peacefully without any pain or suffering; not so much a surprise but just not planned or anticipated at the time."*

## **Religious and Spiritual Care:**

Part of the challenge encountered by participants in the residential care unit was the provision of "religious care" as a component of spiritual care. It was evident that participants had developed comprehensive skills in providing spiritual care to the residents in the care units, while also facilitating religious activities with residents and their families. They considered this to be important from the residents' and families' points of view.

*"Prayers and rosary very important."*

*"Staff saying a prayer can mean a lot to families."*

*"Depending on their religious beliefs we offer them, if they think it would be comforting to their mum or dad or themselves, if they would like us to say the rosary, would you like prayers. We also have nice music here; we do whatever the family wants."*

The limited availability of chaplaincy and pastoral care staff within the residential care units was acknowledged as limiting the range of religious care that participants provided to the residents. Staff considered that having a chaplain would ensure a more regular attention to the residents' religious needs.

*"It's hard when there are so few priests available, we have mass usually twice a month, it depends on the availability of the priest, it could be three in a row and then not for ages."*

In situations where there was a priest available in the residential care units, participants acknowledged the importance of their presence as a resident was dying.

*"We always call the priest if someone is dying. In the past if you forgot to call the priest or if you left it a minute late you would be so disappointed."*

There was a sense by some participants that having a priest present was part of the "ritualized care" at end of life.

## **Relationships:**

Participants highlighted that the uniqueness of the care they provided in the residential care units centred on the nature of the relationship with the residents, relationships with fellow staff and the nature of the relationship with residents' family members.

### **Relationship with Residents:**

Participants were very aware of the need to involve residents in making decisions with regard to their care, in so far as this was possible. This openness was centred on respect for the residents; it enhanced the residents' autonomy, as they able to make choices about their care.

*"You need to tell residents about what is going on, they can see it."*

*"Important to give residents choices where possible."*

The longevity of residents' stay in the care units was acknowledged as being a common occurrence. This provided participants with the opportunity to connect with the residents and it was acknowledged that they became like family to the participants, rather than just residents in a care unit.

*"Residents are sometimes here for 5-6 years, care changes over years, sometimes acute episodes then chronic again so the residents and nature of care change over the years."*

*"That's the difference between here and general hospitals, you get to build up relationships over time, it's like you are one family."*

For some residents, staff in the residential care units were "surrogate families", and this type of relationship impacted on staff, in terms of impending loss and grief for staff.

*"You feel sad when somebody is coming to the end of their life, and you see them every day, so you remember them."*

*"You build up relationships with family as well and you have great contact. When they [residents] are dying you feel empty, it's hard to think of letting go."*

The impact of a resident's death frequently extended beyond the resident's family and the staff. Many of the residents were in the residential care homes for an extended period of time, therefore the death of a fellow resident was likely to impact on them. Death was a reality in the units; it was difficult for long term residents when this occurred and they were aware of the death. As one participant commented:

*"Residents feel sad when someone dies; we try to shield them a little by closing doors when a body is going out. There are some residents you would tell and some you would not."*

### **Relationship with Families:**

Staff in the units provided family-centred care throughout the resident's stay in the units and they acknowledged the importance of being available to family members, particularly around the time of the resident's death. Their role at this time, in particular, appeared to centre on family preparation for the death, and also to inform family members what was happening around the time of death.

*"Ninety-nine per cent of the time families are here [at the time of death], families sometimes beat themselves up if they are not here when their family member dies. They want to be here but they want the reassurance of a staff member never to be far away, because as soon as mum takes that extra breath they are calling come quickly. So I think it is important to be available to them too because even if the family are all around, they want somebody to look up to, to say what's happening now."*

Recognising and respecting each family's uniqueness and respecting their wishes regarding their dying family member was supported where possible. Taking notice of the actual environment and doing anything possible to create a peaceful ambience was considered to be an important support strategy for family members.

*"Some families have asked us not to move residents to a side room to die as they are happy in the room with their roommates; this has been facilitated but we must always think of the other residents. A family once requested no screens around the bed; this could be frightening for others, we have to work with each family."*

*"Families are glad when we can move a resident to a single room at the end of life, it's hard in the middle of a four-bedded room."*

These comments illustrate the importance of having a relationship with families so the residents and those of the family may be respected if possible.

Support for family members did not cease after the death of a resident. It was not uncommon for staff members to provide a guard of honour as the resident's body was being removed from the care home. Support for families was also evident in terms of providing guidance in preparation for a resident's funeral service. Family members' involvement at this time was considered an important aspect of the grieving process.

Some units provided a family support group for families; this was acknowledged as being a supportive measure to families in their grieving process. Giving family members the opportunity to return to the residential care unit was considered to be important, so that family members could maintain a connection with the unit, even after the death of their family member occurred.

*"The first time families come back to visit the unit after a death is hard, they look into the room, they always want to see the room, and they look at the bed, ah that part really gets to me, they look in maybe have a little tear and then they compose themselves. I am sure they get used to visiting the unit, we are all part of the family really, and you get to know all the faces."*

The units acknowledge the need for residents to be remembered and how important this is to families. Participants highlighted how they attempted to keep the memory of the deceased residents in the units.

*"A memorial mass is held once a year in the units; families appreciate this."*

*"One unit has a garden of remembrance."*

### **Relationship with Fellow Staff:**

Providing care to residents in long stay residential units required a commitment to care. Frequently, this care involved a high degree of physical activity, in terms of assisting residents in undertaking their activities of living. In addition, such care also required staff to address residents' psychosocial, cultural and religious needs.

Participants were cognizant of supporting fellow staff members when they experienced bereavement. This was particularly so when the death of a parent of a staff member

occurred. Understanding the difficulties of staff returning to work after a family bereavement was seen as important in a unit like this.

*"It's very important when staff lose a parent in a unit like this, they really need support to be able to come back and deal with residents and families. People have been out for months after the death of a parent, it's hard to come back to a unit like this, because you know the majority of them will die too."*

Despite the absence of a formal staff support system, the initiation of death reviews following the death of a resident provided the opportunity for staff to reflect on the EOLC which the resident had received and also the type of death they experienced. Death reviews were considered to be important in fulfilling this role. As one participant commented:

*"Death reviews have been very helpful as a debriefing and something we should sustain, an opportunity to learn and also to have the social and emotional space they need given the kind of relationship staff have with residents."*

## **Cultural Discussions:**

As part of the review processes concerning EOLC in long stay community units, cultural differences were highlighted on a number of occasions with respect to the manner in which non-Irish nurses and carers may approach care provision to dying residents and their families.

To gain some insight into the different attitudes, beliefs and experiences regarding EOLC in other cultures, nurses and carers from countries outside of Ireland were invited to discuss the range of issues that emerged for them in their current caring roles. There was a positive response and over a period of 3 months a number of individual interviews and group discussions took place as follows:

- Five individual interviews with nurses and four individual interviews with carers.
- Two group discussions including nurses and carers and representing the Philippines, Nigeria and India.

The discussions took place at different times, including night duty, in order to capture a wide variety of staff. The main points which emerged from the interviews are presented below.

### **Indian Staff (Christian Tradition):**

The staff had no experience of elderly care units in India. Working in an elderly care unit was a new experience. Deaths occur mostly in the acute setting or at home, as culturally, the elderly are normally cared for by family members. In India, a central aspect of caring is to attend to the spiritual needs of the patient, always calling a priest if necessary. These nurses thought that the spiritual needs and religious aspects of care are not as well attended to here. However, it was considered that people in Ireland are more open to talking about death and dying. This willingness provided the opportunity to explain things to families and prepare them for the dying process and death. It was considered important to fulfil the wishes of a dying person. Sharing / breaking bad news to families was something regarded as being a very difficult component of their role here.

Giving little sips of water is considered to be very important, as culturally, this is regarded as an indication that the dying person was a *"very good person"*.

In their experience in India, last offices and dressing of the patient are carried out by the staff on the ward where the patient dies and body removed to home usually within two hours, which is not what happens in Ireland. The dead person is dressed in new clothes, and all married women are buried in their wedding sari. There are no funeral homes. There is no television or cleaning of the house during this period. Once the body is taken from the home, all family members take a shower and change their clothes. The family stays together for seven days. A body is never left alone; a family member stays until the body is removed to home. The Bible is read and songs are sung the night before a burial. The coffin is left open for the funeral service. Prior to the burial, all close family kiss the body and then place a white cloth over the person's face before closing the coffin. This ritual is usually designated to the eldest male member of the family.

### **The Philippines:**

As there are no nursing homes, death occurs in the hospital or at home. Dying at home would be unusual, as most dying people transferred to hospital. There is a very high expectation of care on the families; if they cannot do it and can afford it, they will hire someone to be in the hospital with the sick person. Nurses initiate care and then teach the families to do it; nurses rely on the family to care for the patient in hospital. The nurse's main duty is to carry out the doctor's orders. The role of the nurse described as being more professional in the Philippines and it is important to distance oneself from the dying patients and their families.

The immediate family take responsibility to care for the elderly, with a hierarchy in families which decides who makes decisions in the family regarding the patient.

Spiritual aspects of care are regarded as being very important.

Following death the body is never left alone or unattended by a family member until the body is transferred to the funeral home for embalming, with all preparation if the body, including washing, carried out by the undertaker. No cleaning, washing or work goes on in the home before the burial. Funerals are very family oriented. There is a novena for 9 days after the death.

### **Eastern European:**

Eastern European staff described EOLC quite similar to that seen in Ireland. Death very much seen as part of life.

No nursing homes/care of the elderly units are available, resulting in individuals with dementia usually being cared for in psychiatric hospitals. The care for those individuals who are admitted to those hospitals is not considered to be of a high standard. The long stay community units in Ireland units are viewed as being *"a good idea where families are guaranteed that their loved ones will be cared for"*.

### **Nigeria:**

In Nigeria, there are more than 200 tribes and 300 languages. Tribal beliefs may influence the manner in which a person is cared for. The importance of asking family members

about issues they consider to be important around EOLC was highlighted. Very family oriented time, which the participants considered differed to their experiences here.

Prior to death, family members would not usually give sips of water in case this caused the death. (In contrast to Indian Christian practice).

Some Eastern Nigerians believe in reincarnation and this may influence who can come when a person dies.

Communication around dying is difficult; staff could be attacked by families after telling them their loved one is dying. Parents of a child are not allowed to go to the child's funeral. Crying and expression of emotions are very important.

Elders in the family usually attend to a body, not nursing/hospital staff, with females carrying out the washing of the body. A widow shaves off her hair and dresses in black for 6 months, during which time, she is never left alone. They are looked after by family and celebrate after this time.

At death, no candles are used and windows are opened to let spirits out.

### **Discussion re Cultural Issues:**

Staff thought that previous experience plays a large part in one's ability to provide good EOLC. Many interviewed had little experience of death in Ireland or on the unit. Knowing what to do is important; all knew of the existence of the last offices protocol but still felt they needed guidance around this. Communication and confidence in communicating with families and residents was identified as something that non-Irish staff had difficulty with; sometimes they felt they didn't have the skills and/or language necessary to initiate a discussion around EOLC.

Different groups felt that dying here is less personal, less family oriented and that it is hard to see families come and go at the bed of a loved one. Leaving the body alone is a practice that the majority of staff had great difficulty with.

Staff from the different cultural groups have a vast amount of experience in very diverse cultural situations. Utilising this range and depth of experience may enhance intercultural care in the community care units.

### **Perceptions of Bad EOLC:**

While participants were acutely aware of their role in providing good EOLC and articulated their perceptions of such care, they were also invited to share their views with regard to the nature of bad EOLC. Participants aware that EOLC was not always considered "good", however, there were occasions and events that were beyond their control in their endeavour to deliver good EOLC. Perceptions of bad EOLC may be regarded as occurring under three themes: transfer of resident to hospital, patient and family influences, and pain and symptom management issues.

#### **Transfer to Hospital:**

One of the key reasons for bad EOLC was perceived by the participants to be the transfer of residents to a general hospital, as the resident neared death. Situations arose when there was no option but to transfer the resident, however, there were times when it was felt that the resident could be managed in the residential care home.

*"Difficult when a resident has to be transferred for something new and acute to hospital and it becomes EOLC and they die off the unit, that is very difficult but sometimes unavoidable."*

Participants were acutely aware that the resident may be cared for on a trolley in a busy emergency department, and this caused participants to feel sad that such events occurred at such a stage in patients' lives, particularly as they were dying. As one participant said:

*"Waiting on a trolley in an accident and emergency department – it's very sad to see them like that at such a time of their lives."*

Transfer to a general hospital was like breaking a connection, or ending a relationship that participants had with residents, and they expressed the desire to have them back in the residential care unit, so as to complete the residents' "journeys" with them. This is evident from the following comment:

*"You really want them back because you have that connection, you bring somebody on a journey and feel sure you will be there when they die and then it all changes, that is very difficult for staff."*

The decision to transfer residents to an acute setting also impacted on family members, who had equally built up a relationship with the staff in the units. In some situations, participants felt under pressure to send a resident to an emergency department, particularly if medical cover was not available. Families' reactions to the transfer varied, in some situations, families were distraught as a result of the transfer, and in others, families demanded hospital transfer.

#### **Patient and Family Influences:**

The majority of residents had been in the residential care units for a long period of time.

Generally, participants had developed a relationship with a resident's family over a period of time. In these situations, families were regularly involved in discussions regarding EOLC about their family member, particularly in cases where the resident suffered from a cognitive impairment. However, in some instances, there were family members who influenced participants' experiences of EOLC negatively, resulting in perceived bad EOLC.

*"Lack of communication between families; often you get a family member who is least involved in the care of the resident who suddenly becomes involved and might change decisions already made."*

The importance of staff caring for residents to engage in a family-centred approach, especially as residents neared the end of their lives was discussed. This was influenced by the relationship staff had with the residents and their families, and also their ability to engage with them. The degree of "connecting" with residents and their families varied between staff, however, there was a perceived need for staff to have a positive attitude towards connecting with families, in order to promote good EOLC.

*"Staff attitude and willingness to engage in a family-centred approach to care affects this quality."*

It became apparent that staff were aware of the need to

allocate time to the residents and their families, in order to deliver person-centred and family-centred care. In some situations, this was not possible, due to the lack of staff or staff work load. One participant commented:

*"Lack of time. Sometimes you just want to sit and hold their hand because their relatives aren't there, you feel guilty. You would like to stay but the other residents need you."*

### **Pain and Symptom Management:**

Effective pain and symptom management invariably impacted on the perception of a good and bad death. While staff and participants were knowledgeable with regard to pain and symptom management, there were situations when it was acknowledged that it was not always possible to effectively manage pain and symptoms as the resident was approaching death. Those situations were highlighted by participants as "bad EOLC", because the comfort and quality care they provided to the resident was impacted. It is expressed by one participant as follows:

*"Pain and wishing there was something we could give them, they are like family here and you hate to see them suffering especially if they have been content for a few years."*

Pain management in particular required staff to have the necessary knowledge and skills with regard to the appropriate pharmacological approach. It was not uncommon for opioids to be used in EOLC; however, this required staff to be confident in their use.

*"A lack of confidence in using opioid analgesics and other medications can affect the quality of EOLC."*

*"Staff might be slow to give medications, very important to have a balancing act."*

The use of subcutaneous medications is not uncommon in caring for dying individuals as a means of delivering necessary medication. This requires that those caring for individuals for whom this type of medication is being delivered, particularly through a subcutaneous continuous infusion, have the knowledge, skills and competencies in order to deliver those medications.

### **Improving EOLC of the Older Person:**

While staff provided a high standard of care to the residents and their family members, there was an acknowledgement that this care could be improved. Interventions suggested by participants in order to enhance care may be considered in terms of organisational and educational.

### **Organisational Interventions:**

Participants acknowledged that the residential care homes were well supported from a managerial perspective; however, they considered that, in order to provide one to one care to residents who were dying, and to their families, there was a need for additional staff to assist with the care of the residents.

*"Sometimes we have to leave families for long periods to attend to other residents; it would be great to have one dedicated staff to the person who is dying, to be able to reassure the family that you are the main person to be there available to them all day, that would be just great."*

Participants felt challenged as they attempted to provide high quality person-centred and family-centred care, particularly in situations when residents with a cognitive impairment, especially dementia, were being cared for in the same location as residents without a cognitive impairment. Participants acknowledged the difficulties this posed, and in some cases, they did not have a solution to offer. This is evident from the following comments:

*"Everything has to be different in dementia care, person-centred not a medical model, and we need a special unit."*

*"We have a mixture of clients here, some with dementia and some with physical illness; it's two philosophies of care really, it can be very difficult. There can be a kind of heightened activity around the place and it's not always conducive to a calmer environment for someone who is very unwell. I don't know how you address that, more staff, a quiet room?"*

*"A specialist dementia care unit; it's so difficult to take care of them in a regular unit because their needs are different."*

While it was not possible to predict when the death of a resident would occur, in many instances families were spending long periods of time in the units. The availability of a family room or a single room for the resident was considered one solution that may overcome the situations that participants encountered in some of the residential care units. As some of the participants suggested:

*"A single room, where families would have the privacy to be with their loved one, take the clinical look off the room, allow some peace and quiet."*

*"More rooms, the privacy thing is major; we have had people here for nights on end, they start bringing in all their own food, they don't want to bother you and the place is just packed with stuff."*

There was a awareness of the need for privacy for family members following the death of a resident within the care homes. It was considered that a designated location within the residential care homes ought to be available, to provide this privacy, while also attempting to avoid other residents being excluded from using the chapel when a resident's body was lying in repose there.

The valuable contribution of a pastoral care worker was also acknowledged as a means of enhancing the care of the residents in the face of impending death and their family members.

*"I would love a pastoral care person, sometimes more so than a priest as they can just be oriented to the job in hand. If we had a pastoral worker, that person could be on hand for staff, families and the resident – maybe even on call."*

While staff were confident and competent in managing residents' medications, there was an acknowledgement of the need for greater scope to administer medications, particularly in the absence of a full-time medical officer.

This could have potentially been addressed through the residents' prescription orders for example by the use of some standardised prescriptions and the availability of as required medications.

The extension of registered nurses' scope of practice was also considered to be a means of enhancing the EOLC provided within the residential care homes. As organisational policies did not extend to allowing the administration of intravenous antibiotics, residents had to be transferred to a general hospital in order to receive those.

### ***Education Interventions:***

There was an expressed need for additional education. While the residential care units are not considered to be specialist dementia units or specialist palliative care services, it was recognised that staff required knowledge of both dementia specific and palliative care specific approaches to care.

## **Summary**

The qualitative part of the project, interviews and focus group discussions identified similar issues about EOLC as had been identified in the death reviews, including the importance of good communication, advance care planning, the nature of relationships between patients, families and staff which are different to relationships in acute care settings, because of the duration of care, and challenges when patients have cognitive impairment. A striking feature is the responsibility placed on families to make current and future decisions about care of patients with cognitive impairment, despite there being no legal proxy decision making, or enduring power of attorney for healthcare decisions in Ireland.

Staff gave consideration to why EOLC may be poor and to ways to improve EOLC including environmental change, staffing and education.

## Chapter 8: Interventions to improve EOLC

During the course of the project a number of interventions were undertaken. Death reviews were introduced, and these have been discussed in chapter 3. Other interventions will be discussed below.

### **Link Nurse:**

A link nurse initiative was established with the objective of improving EOLC. Eight nurses within the 3 units were identified by the Directors of Nursing as being interested and suitable for the role of link nurse for EOLC.

### **Background:**

A link nurse initiative comprised of support, training and development, has been identified as a potential way to enhance clinical effectiveness and to benefit patient care, as well as enabling communication and information sharing between specialist nurses and clinical staff (McKeeney, 2003). Positive outcomes related to the role of the link nurse reported by Cotterell et al. (2007) include: influencing ward colleagues; improving palliative care practice and raising the profile of palliative care. Barriers reported included lack of time and support on the unit. Suggested requirements of effective link nurses include having background knowledge of the appropriate speciality, being able to pass on information, and being in a position to implement change at ward level (Charalambous, 1995). However difficulties were also identified with the role including: difficulties in leaving their clinical areas to attend link nurse meetings, difficulties in distributing information and low levels of enthusiasm.

Link nurses fulfil a resource role for colleagues, assist in dealing with challenging/complex issues around EOLC, raise awareness of palliative issues, and emphasize palliative care needs (Grigg and Parker, 2004). Enabling factors related to the link nurses' ability to influence practice include the following attributes: being motivated and enthusiastic; finding palliative care rewarding; and having confidence to challenge and educate medical colleagues on behalf of patients. Link nurses should be approachable, good at listening, assertive, empathetic, open-minded, non-paternal, diplomatic, calm and enthusiastic.

### **Link Nurses at the Three Units:**

Once the link nurses were appointed in each unit, they were invited to a meeting at the local specialist palliative care education centre, to clarify their expectations of the role and to establish the support role of the project nurse.

Link nurses identified a number of challenging issues which they encounter as part of their role in providing EOLC in the long stay community units:

- The positive experience of the death reviews with respect to valuing care given by staff and also as a formal means to remember a resident.
- The difficulties in helping some families accept that a resident is dying.
- Understanding indications of entering the dying phase of an illness trajectory.

- Communication difficulties related to a resident with cognitive impairment.
- Communication difficulties with families.
- Helping residents in the dying phase of illness to express wishes, talk about fears, hopes and dreams including those with and without cognitive impairment.
- The importance of knowing the previous life of a resident so one can talk to them and remember with them.
- The nature of the relationships between residents and staff.
- The complexity of care that, on occasion, makes it difficult to make decisions.
- Difficulties arising with transfer of residents to hospitals.
- Having the confidence to manage pain well with medication and addressing these issues with the medical officers and GPs.

### **Support for Link Nurses:**

An education programme was developed and delivered to the Link Nurses, including education about symptom management and communication skills. Bawn and Matthews (2002) found benefits of a link nurse education programme to include increased confidence, motivation and encouragement to undertake further training in palliative care. A workshop was delivered to train the Link Nurses how to provide education and training for others.

The Link Nurses were trained how to conduct the death reviews, and they carried out the initial death reviews themselves while supported by the project officer.

Each Unit was provided with a folder stating the aims and objectives of the project, the main themes that arose from the death reviews and guidelines for future death reviews on the unit. It was suggested that on each unit that on a monthly basis, time would be set aside to discuss end of life issues. This might include discussing a recent admission, reviewing any issues related to a resident with respect to EOLC, or putting in place a plan to provide the best possible care for a resident identified as in decline. This was suggested as a means to keep issues around EOLC in an open and continuing forum on each unit.

### **Role of the Link Nurse:**

The initial roles of the Link Nurse were identified as:

- Facilitation of interactions in the multidisciplinary team;
- Communication;
- Information giving and sharing;
- Encouragement of staff;
- Conducting death reviews;
- Symptom management;
- Guidance, practice development, support in EOLC;

### **Challenges in the Role:**

Three months after the initiation of the Link Nurse role, a further support meeting was held, facilitated by the project officer. Challenges identified included:

- Time issues around cancellations of Death Reviews and rescheduling them. Being assertive about protected time for death review meetings, including it on agenda at staff meetings
- Giving colleagues support: convincing them of the value,

highlighting the positives, introducing HIQA Standard 16, showing progress, sharing family letters

- Addressing resistance to change: using gentle persuasion, highlighting the outcomes, getting more staff on board, acting as a mentor. Inclusiveness very important, valuing all staffs' good work, highlighting team work
- Questioning quality of care, developing standards/summary sheet of what to stop/start/do differently
- Maintaining momentum/interest of staff: set time to a maximum of 20 minutes, show change in results of care, get more involved
- Inclusiveness: Training up others, giving feedback on performances, engaging with doctors, considering at MDT review;
- Giving responsibility to others: training others on how to do death reviews, the guidelines, template, practice, feedback

To ensure continuity of the link nurse role and to capitalize on the improved care delivery, all participants stressed the need for follow up education and support for themselves and for staff in the nursing home. They stressed the need to update themselves continually in palliative care and also believed it would be difficult to continue their role without the ongoing support of a facilitator.

## Death Reviews

Each link nurse has been provided with a framework to continue the death reviews. Death reviews are documented and available for staff to read as a means of sustaining the profile and interest of the project on each unit and

continuing to improve EOLC. Where possible a death review should be held within 4 weeks of the death and a note written in the ward diary to highlight the date. All members of the multidisciplinary team are to be invited.

## Education Programme:

As part of the questionnaire sent to all registered staff nurses and healthcare assistants, each member of staff identified the areas in which he/she would most like to receive further education to enhance his/her practice in providing EOLC. The main areas highlighted were: Symptom Management, Communication Issues, Spiritual Care, Self-Care, Ethical Issues at End of Life and Advance Care Planning. All of these issues were addressed in a customised education programme which 25 registered nurses and 17 healthcare assistants attended. These included link nurses.

Each registered nurse attended for 3 days over a six week period. A workbook was developed to be completed during the course to assist with applying material learned to their own clinical areas. On the final day each nurse presented his/her completed work to the group. Healthcare assistants attended for one day.

Feedback from the course was very positive. It is hoped in the future to provide further courses that the link nurses may attend as a means of providing regular updates and support.

A total of ten workshops on the indications for use of a syringe driver and management of a resident while receiving medication via syringe driver were carried out by the project nurse in the community units.

## Chapter 9: Evaluation of the Quality Improvement Initiative

To evaluate the impact of the quality initiative to improve EOLC in long stay community units, 10 charts of residents who died on the units were reviewed one year after the project.

The adapted Teno (1999) tool which was used in the original audit of documentation at the commencement of the project was used. The evaluation focused on documentation in the last forty-eight hours of life.

With respect to symptom management, eight residents had evidence of assessment of pain, three had documented pain and five others were described as having no pain. No resident was assessed as being agitated in the last forty-eight hours of life. Respiratory secretions were assessed in four residents, two of whom had a treatment documented and administered but there was no clear evidence of the effect. Five residents had documented shortness of breath, all five had interventions ordered and implemented; only one had the effect documented. Two residents had a fever in the last forty-eight hours of life, with treatments ordered and implemented but no evaluation documented.

Two residents had antibiotics prescribed in the last forty-eight hours of life and one received them intravenously. Three residents had opiates administered, five had them prescribed but not given. In the last two days of life two residents started on a Butrans (Transdermal Buprenorphine) 10mcg/hour patch, while the others had Cyclimorph (morphine and Cyclizine) 2.5mgs-5mgs prescribed, with a maximum of 10mgs administered in 24 hours. No syringe drivers were used.

All deaths were expected and there was evidence in the chart to support this. Family meetings were documented, as were decisions around intervention in the event of a deterioration of the resident's condition. All 10 residents had a not for

resuscitation order. Eight also included a do not hospitalise order, comfort measures only and had identified the unit as the preferred place of care. Nine charts had an EOLC plan documented. Six residents were seen by the unit medical officer and two by the out of hours medical service. There were no transfers to an accident and emergency department.

Family support and inclusion of family in the decision making was evident in all ten charts; there was clear evidence of discussions around any deterioration of the resident and any change in the plan of care. Support of family after the death of the resident was also noted in all charts. Discussions around EOLC and treatment decisions were involving the family and not the resident. Nine out of ten residents were documented as having a cognitive impairment and/or dementia. Four out of ten residents were seen by a chaplain in the last forty-eight hours of life.

### Treatments Received in the Last 48 Hours of Life:

| Treatments/Interventions           | Number of patients   |
|------------------------------------|--|
| Antibiotics                        | 2  |
| Enteral feeding                    | 0  |
| Intravenous or subcutaneous fluids | 4  |
| Blood draws                        | 0  |
| IV Medication                      | 1  |
| Opiates                            | 3 (5 had opiates prescribed)                                     |
| Foley Catheter                     | 0  |
| Syringe driver                     | 0  |
| Total opiate dose in 24 hours      | Butrans 10mcg/hour, Cyclimorph 10mgs (Max) (in 2.5 – 5mgs doses) |

### Symptom Assessment in the Last 48 Hours of Life:

| Symptom                | Assessed | Treatment plan initiated if present | Implementation of treatment | Documentation of evaluation |
|------------------------|----------|-------------------------------------|-----------------------------|-----------------------------|
| Pain                   | 8        | 3 (others noted as no pain)         | 3                           | 1                           |
| Agitation              | 0        |                                     |                             |                             |
| Respiratory secretions | 4        | 2                                   | 2                           | 0                           |
| Shortness of breath    | 5        | 5                                   | 5                           | 1                           |
| Fever                  | 2        | 2                                   | 2                           | 0                           |

## Other Issues:

| Issue                             | Documented | Discussion with Patient and or family documented |
|-----------------------------------|------------|--|
| EOLC plan                         | 9          |  |
| Resuscitation status              | 10         | 10   |
| Do not hospitalise order          | 8          | 8  |
| Comfort measures only             | 8          | 8  |
| Preferred place of care           | 8          | 10   |
| Accident and Emergency visit      | 0          |  |
| GP visit within 48 hours of death | 6          |  |
| Chaplain visit                    | 4          |  |
| Family emotional support          | 10         |  |
| Post mortem                       | 0          |  |

## Discussion of Chart Evaluation:

Evaluation of documentation in the charts of EOLC showed a big improvement since commencement of the project. There was clear evidence of a plan of care and staff had documented recognition of deterioration of the resident's condition. No resident in this sample was transferred to hospital in the last 48 hours of life and all had been managed in the unit. There is still a need to document outcomes of interventions given to allow for continuity of care by all staff. The commencement of transdermal opioids, close to death, may reflect the need to give analgesia to patients who are unable to take oral medication, although the time taken to reach a steady state may make the use of transdermal opioids inappropriate in this setting. The documentation of the psychological and social aspects of care of residents and families had greatly improved. There is still difficulty around chaplaincy visits prior to death and this is directly related to the availability of chaplains in a unit. End of life care plans had been initiated on nine of the residents indicating a real awareness of the impending death of the residents.

## Chapter 10: Discussion and Recommendations

End of life care requires an active, compassionate approach that treats, comforts and supports individuals who are living with, or dying from, progressive or chronic life threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices. It encompasses support for families and friends up to and including the period of bereavement (Ross et al., 2000). All care staff should be ready to listen to people nearing the end of life, address their needs if possible or seek expert help where extra skill or knowledge is required. Steinhauser et al. (2000) in a study examining components of a good death from the perspective of patients, families and healthcare providers identified six major elements of a good death:

1. Effective pain and symptom management;
2. Clear decision making;
3. Preparation for death;
4. Completion (life review, resolution of conflicts, spending time with family and friends);
5. Contributing to others (gifts, time or imparting knowledge);
6. Affirmation of the whole person.

In relation to the quality of EOLC in nursing homes, if dying people are to receive an adequate standard of care based on the principles of palliative care then the following issues must be addressed:

- Adequate staffing, including having a pool of staff who are familiar with residents would be the ideal source of extra help;
- Education and training for all staff to promote a deeper understanding of the principles and practice of palliative care;
- Sufficient resource materials available to care for dying residents;
- Good support from GPs in all settings where older people die (Komaromy et al., 2000).

It has been suggested that there is a need to encourage care of the elderly nurses and healthcare assistants to engage in reflective practice. This will enable them to become aware of, and comfortable with, their own views about pain and analgesic use in order to affect positive resident outcomes (Hicks, 2000; Williams, 2001). There also needs to be greater promotion of the routine use of validated pain assessment tools, particularly for people with cognitive impairment so that pain does not go undiagnosed and untreated (Abbey et al., 2004). Herr et al. (2006, 2010) discuss the value of pain assessment tools and argue that there is a risk of underdiagnosing pain in patients who present with few behaviour changes, or overdiagnosing pain, as behaviour changes may be due to other causes of distress.

The support of families is central to care in these units; as illustrated, many residents have a cognitive impairment and this limits their ability to be responsible for their care. The support of the family through a prolonged disease trajectory to death is a challenge for all staff, and often the ability to recognise a gradual deterioration towards

death can be difficult for staff and families to come to terms with because of the nature of the relationship and prolonged connectedness to the unit and to each other. The importance of respect, attitude, dignity, caring, relationship, connectedness and communication has been supported by all members of the team in relation to EOLC.

The team has also acknowledged that skills, education and support may be needed by staff to facilitate confidence and competence in providing EOLC in these units. Staff members are sometimes surprised by the death of a resident and are more comfortable if they have been able to recognise the decline and been able to provide care that they feel allowed the resident the best quality of care at the end of his/her life. Staff members also recognise the importance, where possible, of preparing a family for the death of a resident and for all members of the team and family to have the same understanding around expectations of care at that time. Resuscitation status is important to the team. However, cardiac arrests are uncommon and discussing different streams and possibilities of care may be a more appropriate course of action in advance care planning.

While family meetings are used for the support of the family and resident, often the primary aim was to discuss resuscitation and to document the status in the chart. Residents and families also need to have an understanding of reasons why a resident might be transferred to hospital. In general, families wanted their loved one to stay on the unit in the event of deterioration, but sometimes there were exceptions and families might change their minds and suddenly request transfer. Family wishes are usually respected, however avoiding conflict around EOLC is important and this is possible through regular updates and team meetings, and sharing information with families.

The high percentage of residents with dementia impacts on EOLC; there is a consensus throughout the interviews that an awareness of the special needs of residents with dementia is essential in providing good care at end of life. This group of residents provides a challenge in providing adequate symptom management and also in the support of families especially in relation to advanced care planning.

The culture of the unit affects how staff members value their work and support each other. In general, staff support was informal; death reviews have been identified as being very helpful in allowing staff time to reflect, remember and value the care given to residents. An awareness of staff who have recently lost parents was important as many find themselves caring for residents in similar age brackets and in similar situations. It was important to acknowledge this and allow changes of schedules/assignments if this would be helpful to staff.

Environment plays a part in providing good EOLC. The availability of single rooms was mentioned by many staff; however sometimes staff felt residents would be isolated in single rooms and on occasion families requested to stay on the ward when death was imminent.

Spiritual care was discussed by many members of the team. The lack of a consistent chaplain or pastoral care worker was identified as a deficit. The units acknowledge the shortage of priests as chaplains but would be keen to explore other possibilities. The units understand the importance of time,

trust, relationship, connectedness in relation to spiritual care and the availability of a person committed to this role would contribute greatly to providing an improved EOLC. Also, the availability of a pastoral worker to assist with bereavement support and the grief process would be a valuable asset.

Spiritual issues were not often documented in the chart and although units have a practice of keeping a book with respect to when a patient was last anointed (i.e. received the Sacrament of the Sick), very few residents had a referral to chaplaincy in the last days of life nor was there evidence in the chart of a visit from chaplaincy. The units have all identified this as an important issue requiring attention. One unit has a lay chaplain who frequently visits patients and families and this may be a possible model to replicate in other units as a shortage in priests available to such units is acknowledged by them all as a real problem.

Only one facility has been in the position to offer bereavement training to staff; this is something staff in other units would welcome.

As many residents in these units have a cognitive impairment, the involvement of families is very important. All units endeavour to include family in the on-going care of residents; one of the units openly acknowledges its deficit with respect to this and has commenced a process to rectify this where patients will now have a 3-monthly review, including a family meeting. Staff frequently described families as being assigned roles as proxy-decision makers, though this role has no legal basis in Ireland, and can be problematic when there are different views within a family, or when the family wishes are not consistent with the patient's previously expressed wishes, or nursing or medical assessment.

Although all units had hospital transfer documentation, there was no clear policy or rationale for transfer to hospital. Some patients did have a 'do not transfer to hospital order'. However, staff members are often required to transfer patients to hospital in the event of deterioration in a resident's condition or if they have called an on call or out of hours doctor for assistance and the doctor called requests this. A rapid access and assessment protocol in emergency rooms for patients from residential care units could be utilized to ensure prompt assessment of patients and return to the unit when appropriate. The lack of available IV access and protocols may impact on this decision and this may be addressed in the initiative to train staff in the units in venepuncture and allow IV access in the community units where IV antibiotics may be required short term to treat a patient with sepsis.

All staff members in the community units have current CPR certification; although many residents are not for active resuscitation and staff members have rarely used these skills on residents, there have been occasions when a member of staff or a family member required CPR. The automatic external defibrillator is available on all units and staff members have been trained in its use.

As a means of providing continued support from specialist palliative care, the community Clinical Nurse Specialists (CNS) in palliative care can potentially take on a number of roles. These include direct care functions working with patients and their carers in the capacity of an expert practitioner, as role model for staff, and as patient advocate.

Indirect roles include acting as a change agent, educator, facilitator and empowering other practitioners to meet the needs of patients and their carers (Bamford and Gibson, 1998). The work of the community palliative care team CNS is limited as it has to be balanced with the demands of the rest of the caseload. In a study by Froggatt and Hault (2002), clinical nurse specialists identified that a lack of education amongst staff shaped the effectiveness of their working in nursing homes and suggested that homes need to be individually targeted for education; this works well when an inpatient unit can be the focus for informal teaching and information giving. Educational initiatives and the use of a link nurse system were part of the work undertaken by some clinical nurse specialists and could be regarded as a means to develop practice and encourage home staff to take responsibility for aspects of the provision of palliative care themselves. However, these approaches were often reactive and a wider vision for a strategy of practice development led by the CNS was generally not present. In terms of this project, the support of the palliative care clinical nurses specialist needs to be considered when complex EOLC challenges occur in the long stay community units.

## Recommendations:

- Continue to support the initiative through development of the link nurse role.
- Use a reflective practice approach to improving care by sustaining the use of death reviews to remember residents who have died, evaluate the care given and improve care for other residents in the future based on experience.
- Continue to provide education and updates for staff on EOLC issues.
- EOLC should be discussed and included on all team meeting agendas.
- Facilitate the development of communication skills that will enhance staff competencies with regard to EOLC discussions with residents and their families.
- Include families and next of kin in planning care, in a way that is compatible with the patient's best wishes and in line with ethical practice and legal requirements.
- Where possible, establish the wishes of a resident with regard to their wishes at the end of life.
- Have a multidisciplinary approach to care, where all members of the team are aware of the plan of care for a resident.
- Continue developing EOLC documentation in each unit that takes cognizance of the residents' EOLC needs.
- There is a need to review the manner in which residents' spiritual care needs are addressed. In the absence of a chaplain, lay pastoral care staff ought to be utilised in the units to assist in providing this care. Staff education, focusing on spiritual care provision, may also be used in order to enhance staff awareness of the nature of spiritual care.
- Support the development of rapid access assessment facilities in accident and emergency units for long term care residents who may require assessment and treatment in the acute hospital setting but who desire to return to their unit as soon as possible.
- Develop routine review and advance planning processes which is guided by patient's wishes, best interests and current ethical and legal best practice.

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