

Subject	End-of-life care requirements
Audience	Service providers

Standards and guidance relevant to this guidance include:			
Standard	No.	Regulation	No.
<i>National Quality Standards for Residential Care Settings for Older People in Ireland, Revised December 2015</i>	2.4 2.5	Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013	13

This guidance contains explanations of concepts which may assist in implementing Standards and meeting regulations. There may be other requirements relevant to a particular service that are not addressed in this guidance. People providing residential services for older people should identify the regulations, Standards and best available evidence relevant to their service. This guidance is current at the time of printing. Please check www.hiqa.ie for the latest version of this guidance.

Outcomes expected in a high quality service include:

- ensuring that all residents with palliative and end-of-life care needs are identified and assessed
- care plans are in place to meet the end-of-life needs of residents and their families
- the resident's needs are communicated and coordinated clearly within the residential centre and other healthcare settings
- healthcare professionals and non-clinical staff possess an appropriate level of knowledge, skills, competence and confidence to care for residents approaching end of life.

Governance and policy infrastructure

High quality services have:

- clearly defined responsibilities in planning and managing end-of-life care
- evidence-based end-of-life policy infrastructure in place, which is reviewed at least every three years. It should be accessible and understood by all clinical and non-clinical staff and reflected in care practices
- established structured linkages to medical and allied health services

- robust processes for monitoring and audit to ensure provision of high quality care
- planned programmes of training and education to underpin policy, protocols and practice.

Recognition and assessment

Recognising when a resident is approaching the end of her or his life can be difficult and uncertain. Many older people have an advanced, progressive, life-limiting illness whose condition deteriorates over an extended period of time with a long lead time to death. However, the General Medical Council (2010) defines approaching the end of life as when a person is likely to die within the next 12 months. In that context it may be worth considering the question 'Would I be surprised if this person died in the next 12 months?'

If the answer to this question is no, the next question then is 'What do I need to do now for this person?'

It is worth considering whether advice from specialists is needed, e.g. gerontology, psychiatry of old age and palliative care services. For some conditions, it may be worth considering evidence-based prognostic indicators, where available. These are specific clinical indicators related to certain conditions and are designed to help with the earlier identification of people nearing the end of their life and/or who may need additional support (refer to the UK's GSF Prognostic Indicator Guidance).

Good end-of-life care is flexible, contemplative and responsive to residents' needs in order to capture the uncertainty associated with increasing dependency, dying and death. The 12-month time frame provides a guide as to when people might be recognised as approaching the end of life. However trajectories of dying are not always linear, as older people move in and out of the zone of 'living and dying'. Therefore, the tidy view that end-of-life care is a defined period when palliative care services can be introduced and administered is not realistic (O'Shea et al 2008). The need for end-of-life care can arise far away from actual death, depending on the physical, mental and emotional state of patients and their families.

Assessment

Once a resident has been recognised as approaching the end of life, he or she should undergo an initial holistic assessment. Once commenced, assessment is an ongoing and proactive process which is both planned and responsive. A holistic assessment includes physical, social, emotional, spiritual and cultural considerations. These should relate to the preferences and needs of the resident as well as associated treatment, care and support. When a resident has problems in communicating his or her wishes and preferences, or lacks functional capacity, all reasonable steps should be taken to maximise his or her ability to participate in the decision-making process.

These steps are clearly outlined in the National Consent Policy (Health Service Executive 2013).

If a resident has a condition which will progressively impair their capacity, or is otherwise facing a situation in which loss or impairment of capacity is a foreseeable possibility, they should be sensitively encouraged to think about what they might want for themselves should this happen, and to discuss their wishes and concerns with members of their healthcare team.

Care planning

Advance care planning is the process of discussion between the resident and his or her care providers about future medical, social, emotional and spiritual preferences, in the event that the person cannot speak for him/herself due to serious illness or emergency. Residents should be given opportunities to engage in advanced planning but should not be placed under undue pressure if they choose not to engage. Each resident should have appropriate information to make informed decisions and supported by someone who understands the complexities of the process as well as the clinical implications of the decisions. It is a proactive approach which provides timely access to safe and efficient care which meets the individualised needs and preferences of residents approaching end of life. Advanced care planning offers a number of benefits:

- As care often involves multidisciplinary teams working across acute, secondary and primary care services, advance care planning facilitates timely access to coordinated, safe, effective care delivery to meet the resident's needs
- The emotional distress and other pressures inherent in situations in which residents are approaching the end of their life sometimes lead to misunderstandings. However, this can usually be avoided through early, sensitive discussion and planning about how best to manage the resident's care.

The care plan should be documented and regularly reviewed with the resident. It may include:

- the resident's wishes and choices regarding end-of-life care, which should be implemented **as far as possible**
- the resident's values, concerns, fears and personal goals for care
- the resident's understanding of their illness and prognosis
- the resident's physical, social, emotional, spiritual and cultural needs
- the resident's preferred place of care and death including the option of a single room or returning home – depending on services available to support this

- what do to if there is a change in the resident's condition which should include:
 - when a resident should or should not be transferred to an acute hospital
- interventions which may be considered or undertaken in an emergency, such as antibiotics, if an resident has an accident or sustains a fracture and cardiopulmonary resuscitation (CPR)
- any other matter which the resident considers important.

Coordination

It is important that end-of-life care is coordinated. Good communication systems and clear documentation are key to the consistent delivery of quality end-of-life care. Meetings between medical and nursing staff and the input of any external professionals must inform any review and be reflected in the care plan. Audits of care (McKeon et al. 2010) revealed that interdisciplinary team meetings lead to better communication and significant improvements in residents' care and family support.

The focus of care should be "living life to the end". Systems in place to provide effective end-of-life care should be informed by a palliative care philosophy. Palliative care is an approach which improves the quality of life of residents, and their families and includes the goals of enhancing the quality of life for patient and family, optimizing function, helping with decision making and providing opportunities for personal growth. It can be delivered concurrently with life-prolonging interventions or as the main focus of care. The World Health Organisation advises the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and physical, psychosocial and spiritual needs (WHO, 2004). Palliative care can be provided at different locations and at different levels of specialty, based on the needs of the resident and family and on the level of expertise of the staff providing the service, as follows:

Level 1 – Palliative Care Approach: palliative care principles should be appropriately applied by all health and social care professionals in the centre.

Level 2 – General Palliative Care: at an intermediate level, a proportion of residents and families will benefit from the expertise of health professionals who, although not engaged in full-time palliative care, have had some additional training and experience in palliative care.

Level 3 – Specialist Palliative Care: specialist palliative care services are those services which are limited, in terms of their core activities, to the provision of palliative care. Refer to 'Eligibility Criteria for access to Specialist Palliative Care

Services' published by the Palliative Care Clinical Programme, Health Service Executive, 2012.

Spiritual needs and care

There is perhaps no other area of healthcare where spirituality takes on greater significance than in end-of-life care. Spiritual care is not necessarily religious; religious care, at its best, is always spiritual. The UK's National Health Service (NHS) defines spiritual care as, 'That care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires' (NHS Education for Scotland, 2009).

Spiritual care and support helps people approaching the end of life, and those close to them, to:

- explore how they might understand, make sense of or find meaning in what is happening to them
- identify sources of strength they can draw on and decide whether those sources are helpful during this period in their lives.

Spiritual support is tailored to the needs, beliefs and values of the person approaching the end of life. It requires assessment and the provision of resources to support the person and those close to them. Some residents may have no spiritual needs and this position should be respected. However, many residents benefit from referral to a chaplain or religious minister or arranging for the person to attend religious services. The provision of complementary therapy, music therapy and opportunities to engage with nature can also meet spiritual needs. Milligan (2011) identifies some of the practical ways in which carers can identify, support and assist people to meet their spiritual care needs. This can be applied to staff in residential care settings.

Being present and accompanying

Perhaps the most fundamental spiritual care intervention is that of being present. The potential benefits for residents include a sense of not being abandoned, of being valued and of being cared for. For many people the journey towards death is a lonely one and the final part of the journey will inevitably be made alone. However, for much of that journey, the nurse or key worker may be the patient's closest companion. Accompanying the resident can create a sense of shared humanity.

Harmonising the environment

Spiritual comfort may be achieved through the modification of care environments to create opportunities for peace, quietness and contemplation. Access to light, music or nature may also be uplifting.

Family members can be encouraged to replace professionals in the 'inner circle' of care if they wish. Teaching the family member simple skills such as hand massage and basic oral/mouth care, if permitted by local policy, will encourage a sense of purpose and intimacy.

Encouraging reminiscence and life review

Death in modern Western society often takes place remote from a person's ordinary life. There may also be a personal separation, between the person who is dying and the person they once were. Being able to recover a sense of personhood, and being able to contemplate death in the context of a life lived have been found to be beneficial.

Funeral planning

Consciously preparing for death, usually centred on the resident planning his or her own funeral, requires considerable courage on the part of the dying person and great sensitivity on the part of the care professional. However, there is evidence that patients receive spiritual as well as practical benefits from carrying out such planning (McSherry 2011).

Death

An atmosphere of peace and calm is required for residents at end of life. Symbolic resources are used to enhance dignity and respect for residents at this point (e.g. end-of-life spiral to advise staff and visitors that a calm quiet atmosphere is required).

The presence of relatives at the time of death can be important for the dying person as much as for the family members. Research indicates that relatives were more likely to be present at the time of death if the resident had a single room or if privacy and dignity were valued in a ward environment. The availability of facilities for families'/friends' use could include:

- comfort basket (containing items such as towel, toothbrush, toiletries etc.)
- refreshment facilities
- family room
- sleeping facilities.

Individualised end-of-life care plans for dying residents are helpful in coordinating and delivering safe and effective care in the last days of life. Continuous monitoring and documentation of the physical, spiritual, psychological, social and communication needs of the dying person should be ongoing. Local procedures should be followed to ensure rapid access to equipment and administration of medications to ensure optimal comfort and pain relief. Clear communication and response to the needs of family members are essential at this time.

Providing relief from distress will facilitate a comfortable death, and one that is remembered with peace and comfort by family and friends. (An Bord Altranais 2009.)

After death

Caring for the remains of a deceased resident is one part of the overall continuum of care given to people at the end of life and those close to them. At all times dignity and respect of the deceased person should be maintained.

Before the removal of the deceased by the funeral directors, local procedures should be in place and followed to ensure that staff members care for the remains of the person who has died in a culturally sensitive, dignified and safe manner. The needs of family members should be elicited and responded to. Family members should be contacted if not already present. They should be offered sympathy and support, and any queries they may have should be clarified.

Timely verification of death should include information for families and carers on when, where and how to register a death. Information of the role of the coroner (if coroner involvement is likely) should also be provided.

Procedures for the return of personal possessions which uphold the dignity of the deceased should be followed. Staff members need to exercise sensitivity when informing other residents living in the centre about the death of any resident. They also need to identify people who require support to cope with the death. People should be facilitated to pay their respects and participate in requiem services as appropriate before the removal of the deceased from the centre.

The person in charge should liaise with the nominated funeral director to ensure the removal of the deceased is carried out with dignity, respect and in accordance with the Safety, Health and Welfare at Work Act regulations.

Monitoring and audit

High quality services carry out regular monitoring and audit. Monitoring documentation allows for change to be measured easily. For example, the quality of care provided as documented in a care plan.

Audits allow staff to reflect on current practice and identify aspects that require attention by comparing to best practice guidelines. They also provide useful baseline data to measure any future changes implemented against. Audit criteria might include assessment and communication, resident and family support, use of or compliance with care plan, and quality of care linked to a specific disease.

Resources[‡]

Competence and Compassion, End-of-Life Care Map, (2013). The Irish Hospice Foundation/HSE. See: <http://hospicefoundation.ie/wp-content/uploads/2013/04/End-of-Life-Care-Map-2013-version.pdf>

Hospice Friendly Hospitals Programme publications and resources:

<http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/resources-publications/>

<http://www.hospicefriendlyhospitals.net>

<http://hospicefoundation.ie/wp-content/uploads/2012/07/Palliative-Care-For-All-report.pdf>

Professional Guidance for Nurses Working with Older People, Dublin: An Bord Altranais:

<http://www.nursingboard.ie/en/news-article.aspx?article=a647ffb6-7874-4c80-bb4d-6a292477dac8>

HSE National Consent Policy:

http://www.hse.ie/eng/services/list/3/nas/news/National_Consent_Policy.pdf

HSE Palliative Care Clinical Care Programme:

<http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland>

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

References

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[‡] All online resources and references were accessed at the time of preparation of this guidance.

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Health Act 2007. Dublin: Stationery Office; 2007.

Health Information and Quality Authority. *National Quality Standards for Residential Care Settings for older People in Ireland*. Health Information and Quality Authority: Dublin; Revised, December 2015.

Health Service Executive. *National Consent Policy*. Health Service Executive: Dublin; 2013.

Health Service Executive and Irish Hospice Foundation. *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks. Joint HSE and IHF Report of the Extending Access Study*. Health Service Executive and Irish Hospice Foundation: Dublin and Naas; 2008. Available online from: <http://hospicefoundation.ie/wp-content/uploads/2012/07/Palliative-Care-For-All-report.pdf>.

Martins C, Basto ML. *Relieving the Suffering of End-of-Life Patients: a Grounded Theory Study*. Journal of Hospice and Palliative Nursing; 2011;13(3):161-171

Medical Council. *Guide to Professional Conduct and Ethics for Registered Medical Practitioners* (7th Edition 2009). Medical Council: Dublin; 2009.

McKeon K, Hasse T, Pratschke J, Twomey S, Donovan H, and Engling F. *Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life, Report 5, Final Synthesis Report*. Irish Hospice Foundation: Dublin; 2010.

McSherry CB. *The Inner life at the End of Life*. Journal of Hospice and Palliative Nursing; April 2011. 13(2), pp112-20.

Milligan S. *Addressing the Spiritual Care Needs of People near the End of Life*. Nursing Standard; 2011 28 Sept; 26(4): pp 47-56.

Murray E, McLoughlin K, Foley S. *Access to Palliative Care Services and Place of Death in Ireland: What the Data tells us. IHF Perspectives Series: No 2*. Irish Hospice Foundation: Dublin; 2013. Available online from: <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

