


BROTHERS OF CHARITY SERVICES IRELAND

GOOD PRACTICE GUIDELINES ON END OF LIFE CARE

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Ethos

'We are committed to working with people with an intellectual disability to claim their rightful place as valued citizens. Inclusion is a fundamental principle that underlies all aspects of our work. We believe in the intrinsic value of every person and we aim to further the dignity of all associated with our services.'

'We continue the Brothers of Charity Services' tradition of being open to the best contemporary influences. We want to be inspired by the most creative ideas ...and to ask how we give them concrete expression.'

The Brothers of Charity Services Ethos (2001), Going Forward Together.

1.0 Introduction

The Brothers of Charity Services Ireland endeavour to offer services/supports in local communities. This enables each person who is supported by our services to positively engage in the social and economic life of their local towns and villages and in doing so, develop a range of relationships that enhance their quality of life.

Our responses are based on the recognition of each person (who is supported by our service) as an individual, an equal citizen with equal rights and an absolute respect of that status. We, therefore, support each person to live their lives based on their own personal visions and choices, to identify and select their personal goals in life and to develop their personal plan to achieve those goals.

2.0 Guidelines Statement

The Brothers of Charity Services Ireland aims to support individuals who use our service at the end of their life from the point of the diagnosis of illness to their death. The duration of end of life care may be days, weeks, months or in some cases years depending on the individual and their condition. The Brothers of Charity Services Ireland aims to ensure that each person receives care at the end of his/her life which meets their physical emotional, psychological, social and spiritual needs and respects their dignity and autonomy.

3.0 Purpose

In Ireland the number of people with intellectual disability who are living into old age has almost doubled in the past 25 years (Kelly et al. 2007). The medical and social advances that has extended the longevity of the general population has included individuals with intellectual disabilities. The most recent National Intellectual Disability Database report recognises that older individuals availing of services require a

higher degree of support including increased medical services to cater for their specific needs (Kelly 2015). Similarly the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging (IDS-TILDA) acknowledges that life expectancy among adults with intellectual disability is increasing too and with it notes an increased prevalence of dementia (Burke et al. 2014)

Both in Ireland and abroad the challenge of supporting individuals with age related care needs has been acknowledged and the need for further staff training in palliative care interventions has been identified (Ryan et al. 2010; McCarron et al. 2011; Read and Thompson-Hill 2009).

4.0 Scope

'End-of-life care' is being increasingly used as a generic term in preference to palliative care when considering the needs of people with conditions other than cancer, particularly in community and long-stay care settings. It applies to people with a variety of conditions and involves a longer time-period than the days or weeks immediately before death.

5.0 Legislation and related policies

- Assisted Decision-Making (Capacity) Act 2015.
- Bereavement Policy, Brothers of Charity Services, Ireland., 2017.
- Care of the dying adult: draft guideline consultation NICE in development [GID-CGWAVE0694] (NICE 2015).
- Guidance on Dementia Care for Designated Centres for Older People (HIQA 2016).
- Health act 2007 (care and support of residents in Designated centres for persons (children and adults with disabilities) regulations 2013.
- Health Information and Quality Authority (2016) Supporting people's autonomy: a guidance document.
- Health Information and Quality Authority (HIQA) National Standards for Residential Services for People with Disabilities (HIQA 2013).
- HIQA 2014 guidance document- provider self-assessment questionnaire on End-of-Life.
- HIQA 2016- provider self-assessment questionnaire dementia.
- National Consent Policy (HSE 2013).
- Palliative Care Competence Framework Health Service Executive (2014).
- Quality Dementia Care Standards (McCarron and Reilly 2010).
- Statutory Instruments 2013 Health Act 2007.
- The National Quality Standards for residential settings for older people.

6.0 Glossary of Terms and Definitions

6.1 End of Life Care

End-of-life care has been described by HIQA (2009) as care in relation to all aspects of end of life, dying, death and bereavement, regardless of the individual's age or diagnosis or whether death is anticipated or unexpected. It includes care for those with advanced, progressive, incurable illness. End-of-life care includes the management of pain and other symptoms and provision of psychological, social, and other supports.

6.2 Palliative Care

Palliative care aims to improve the quality of life of people with life-limiting conditions and their families, not only by treating their physical symptoms but also by attending to their psychological, social and spiritual needs. Palliative care is applicable for people of any age and may be integrated at any point in the disease trajectory from diagnosis through the continuum of care to bereavement (HSE 2014).

In Ireland Palliative care services are structured in three levels of increasing specialisation. The levels of service refers to the expertise of the staff providing the service.

- Level one – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals and many people with a progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care services.
- Level two – General Palliative Care: At an intermediate level, a proportion of individuals and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.
- Level three – Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care (Department of Health and Children, 2001)

Since 2001 the Department of Health and Children has recommended that specialist palliative care should be made available to individuals with progressive and advanced disease of non-cancer aetiology including individuals with intellectual disabilities (Department of Health and Children, 2001). This was reiterated in 2008 with particular reference to Chronic Obstructive Pulmonary Disease (COPD), dementia and heart failure as these diseases are among the highest mortality rates in Ireland and research has indicated that people with these diseases have palliative care needs that are at least equal to those who have a cancer diagnosis (Irish Hospice Foundation and Health Service Executive 2008).

While the terms palliative care and end of life are defined similarly, for the purpose of this policy end of life care will be used as this is the term used by the Health Information and Quality Authority (HIQA 2016; HIQA 2013).

7.0 Roles and Responsibilities

It is the responsibility of each local region to develop procedures which are in adherence with these guidelines.

Care planning in palliative care is characterised by coordinating and integrating person-centred care in order to promote quality of life for people with life-limiting conditions and their families. It involves assessing need, promoting and preserving choice, predicting likely problems and planning for the future in the context of a changing and deteriorating disease trajectory (HSE 2014).

The Palliative Care Competence Framework, developed by the HSE in 2014, places a focus on the person with a life-limiting condition and their family. It helps in determining what health care staff can do to alleviate distress, pain and discomfort whether this is physical, emotional, spiritual or psychological. Applying the core and specific competences in practice, will help all health care staff (based in a hospital, hospice, GP practice, primary care centre or a community based setting) working with social care partners, to recognise their role in palliative care and to develop their own quality improvements.

When caring for an individual who has been diagnosed with an advanced life threatening illness multidisciplinary team guidance and collaboration with outside agencies may be necessary to support staff. There may be uncertainty around the timing and necessity for specialist services particularly when individuals are diagnosed with conditions other than cancer. In the past resistance to and uncertainty around the need to involve specialist services in intellectual disability services prevented collaborative working both in Ireland and abroad (Read and Thompson Hill 2009; McCarron et al. 2009; Ryan et al. 2010).

Effective care planning ensures that multiple disciplines and agencies can be accessed and referred to as required in a timely manner (HSE 2014). An individual's personal plan may, where an individual wishes to give consideration to these matters, take account of and record their wishes in relation to end of life care and the distribution of their property and personal effects after their death (HIQA 2013).

The HIQA standards advocate that each person receives a timely, comprehensive multidisciplinary assessment of their health needs which is regularly updated and reviewed. Individuals with life threatening or life limiting conditions and their families receive care and support, which meets their physical, emotional, social and spiritual needs and respects their dignity (HIQA 2013).

The information derived from healthcare assessments and options for care are explained to and are discussed with the individual and/or their

family and in accordance with the person's needs a referral may be made to specialist palliative care services to ensure that there is an integrated multi-disciplinary approach to end of life care.

8.0 Process

8.1 Capacity and Decision Making on Issues Relating to End of Life Care

Decision-making may be required in a number of areas to decide a number of issues including the need for further treatment e.g. artificial nutrition and hydration, continuance of current medical treatment, further treatment of infections and if a Do Not Attempt Resuscitation (DNAR) order is to be put in place (HSE 2014).

The plan for end-of-life care should be responsive to the individual's needs values and expressed preferences where applicable. Individuals with intellectual disabilities are presumed to be capable of making informed decisions unless an assessment of capacity finds otherwise and their consent is obtained from them, prior to any medical treatments or intervention.

The procedure for obtaining consent is consistent with current legislation the HSE policy on consent and guidance issued by professional and regulatory bodies (HSE 2013; HIQA, 2016).

8.2 Competent Individuals

When an individual in the service has capacity they should be facilitated to consent or refuse treatment as they wish. It is their right to refuse treatment or stop treatment that has already started. If an individual makes an advance healthcare directive then this should be honoured, as long as the directive is considered valid and is applicable to the situation that has arisen (HSE 2013).

8.3 Communication

Effective communication is essential to the application of end-of-life care principles and to the delivery of care (HSE 2014). Communication is also important where circumstances are ambiguous or uncertain and when strong emotions and distress arise. Specific consideration should be given to communication as a method of:

- Supporting and enabling therapeutic relationships with the person with a life-limiting condition and her/his family;
- Ensuring that the person and her/his family understand and participate in decision-making regarding care to the extent that she/he is able to and wishes to be involved
- Enabling inter-professional teamwork.

Indicators suggest that as a health care professional you should:

- Understand the different types of communication e.g. verbal, non-verbal, visual, written, and interpersonal interaction (either one-to-one or with a group or team)

- Be able to modify your own communication style to facilitate communication with individuals with a range of communication impairments or seek facilitation in this area if required (BOC Policy on Communication and Information to Residents 2015).
 - Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, clarifying statements, inviting questions
 - Demonstrate an ability to be attentive to the person through careful listening to help the person and their family feel they have been heard
 - Support individuals (or parents in the case of children and minors) to make informed decisions regarding the level of information they wish to receive and want to share with their family.
- Further information available in the Palliative Care Competence Framework (HSE 2014).

8.4 Care Management

A more comprehensive plan of care is necessary at end of life. The care plan will encompass the person's physical, psychological, emotional, religious, spiritual and cultural practices and will include the involvement of families.

8.5 Place of Care

The preferred place of care and place of death (if expressed) should be acknowledged and discussed with the person and their family and staff and measures are taken to comply with these preferences, wherever possible. Specialist palliative care services may be required to support individuals at this time.

The place of care may need to be revisited as an individual's condition deteriorates and may be determined by factors other than individual or family preference.

The decision to transfer an individual from a residential setting to an acute setting will be decided by the general practitioner in consultation with the person, their family and the multidisciplinary team as appropriate.

8.6 Pain and Symptom Management

The experience of pain is unique for each individual, including individuals with intellectual disabilities, and has been described as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (Scottish Intercollegiate Guidelines Network, 2008).

Pain can be classified into three modalities physical, psychosocial and spiritual.

Physical pain may be related to the underlying disease or to treatment. Physical pain may also be due to associated factors e.g. constipation, pressure sores etc. Co-morbidities such as sensory or motor impairments, contractures and postural problems and other chronic conditions e.g. osteoarthritis may also be sources of physical pain.

Psychosocial factors can influence the individual's perception and experience of pain and how the sufferer responds emotionally and behaviourally. Spiritual distress may be experienced by individuals suffering from chronic and unremitting pain. It is important to identify spiritual needs in order to offer appropriate support (Watson et al. 2011).

The individual should be involved in pain assessment where possible. Simple straightforward language that the individual understands should be used during pain assessments. Individuals with severe and profound intellectual disabilities may be unable to articulate their pain or distress verbally and will use other non-verbal indicators to communicate their pain. The use of pictures, photographs and or body charts may assist with diagnosis and treatment.

The key worker and care team should make themselves aware, through the person's care plan and medical notes, of longstanding conditions that can predispose the person to pain e.g. arthritis, gastric reflux or constipation. Challenging behaviour may be an expression of how an individual communicates that they are feeling unwell (Kerr 2006; Watson et al. 2011). This information may be available in the person's PCP, Behaviour Support Plan or care plan. Staff need to be educated on pain assessment and management and should liaise with the specialist palliative care team and general practitioner for advice.

Pain assessment tools may be also be useful particularly with individuals who have difficulty communicating that they are in pain and the nature of pain e.g. the DisDaT (Regnard et al. 2007) or the Abbey Pain Scale (Abbey et al 2004).

Specific symptoms may need to be treated e.g. oral care and preventative nursing care is paramount for comfort e.g. the use of appropriate mattress and prevention of pressure sores. The person's dignity will be maintained throughout their final days. Planned interventions may be cancelled e.g. hospital appointments planned investigations, blood tests etc. a decision may be taken not prescribe any further antibiotics. Catheterisation may be considered.

8.7 Feeding Eating, Drinking and Swallowing Difficulties (FEDS)/Dysphagia

MDT members, medical and specialist palliative care may be required to support Feeding Eating, Drinking and Swallowing Difficulties (FEDS) in end-of-life care.

A risk feeding decision (a comfort care approach) if indicated may result in a plan which balances safety and quality of life as equally as possible, taking fully into account the personal, cultural and religious beliefs of the individual.

8.8 Care in the Final Days of Life

The goal of care in the last days of life needs to focus on maximising comfort and providing physical, emotional and spiritual support to the person and their family to ensure that care is peaceful and dignified

and in doing so make the memory of the dying process as positive as possible.

Staff will need ongoing support from the Person in Charge and members of the multidisciplinary team when the person is dying and it may be necessary to roster additional staff to care for the individual in the final days.

8.9 Signs and Symptoms of Approaching Death

In order to care for the dying person it is important to diagnose that the person is dying. All members of the MDT must work collaboratively to recognise when death is imminent. The clearest signs of approaching death are picked up by the day-by-day assessment of deterioration.

The process and timescale of dying varies depending on the individual's disease and the person's underlying robustness or frailty and individuals with stroke or dementia may spend several weeks or months in a gradual decline (NICE 2015).

The following signs and symptoms may alert staff that death is approaching (usually this occurs over a number of weeks):

- Profound tiredness and weakness
- Diminished intake of food and fluids
- Drowsy or reduced cognition
- Gaunt appearance
- Difficulty swallowing medications (Watson et al. 2011)

8.10 Care of the Dying Individual

It is important that there is a plan to manage symptoms that may arise in the last hours so that symptom management is optimised. Some people are without pain or distress even when death is imminent. The focus of assessment in the last hours is to discover what the individual perceives to be his or her problems, and to try and find out which concerns are a priority to be addressed. Individuals often under-report their symptoms and the person's symptoms can be misinterpreted.

The following symptoms may be experienced in the dying phase including:

- Respiratory tract secretions ("noisy rattle")
- Restlessness
- Pain
- Breathlessness
- Nausea/vomiting
- Delirium (Irish Hospice Foundation and Health Service Executive, 2012).

Staff, depending on their clinical training and experience, may have the skills and knowledge to effectively manage many of the symptoms of dying however the input of specialist palliative care service may be required particularly if symptoms prove refractory or difficult to control.

The Specialist Palliative Care Service may offer advice regarding pain, nausea, respiratory tract infections, agitation and any other presenting symptoms of concern. The need for continuation of current medication will be assessed and non-essential treatment may be discontinued.

8.11 Psychological, Emotional and Spiritual Care

Staff rotas should be planned to enable staff significant to the person to be on duty so the individual is supported in their final days. Efforts should be made to ensure that family and significant others are present during the person's dying and peers facilitated to spend time with them. The individual will be cared for in a comfortable environment where it is possible to give care with dignity and comfort at the end of life.

Anticipatory bereavement support should be given to the individual in accordance with their understanding of their decline in health and well-being and opportunities given to the person to express grief reactions as they decline (refer to the Brothers of Charity Services Ireland, Bereavement Policy). Staff should endeavour to support the individual and their family with any fears and anxieties they may have. Religious and cultural needs will continue to be supported.

Staff should be aware that they often just need to be present without saying anything. Although the person may not be able to talk they may still be able to hear so it is important that staff, families the multidisciplinary team and all visitors are aware of this (and made aware of this) and only discuss issues in the company of the person that would take place if the person was fully conscious.

Being present with the person and their family can be a great support to them. Someone should hold the hand of the person who is dying and reassure them that there is no need to be afraid that you are there and name whoever else is present.

8.12 Family

The individual's family should be facilitated to be with their loved one when he/she is very ill or dying. The individual and their family should be offered support from a priest/minister/other according to their faith. When the individual dies, time and privacy is to be allowed to family, friends and carers. An atmosphere of peace and calm is to be maintained at this time. See Appendix II for End of Life Care Family Booklet.

8.13 Following the Death of an Individual

8.13.1 Care of the Body (this occurs after the death is certified)

The deceased body is to be treated with respect and dignity in accordance with his/her wishes if stated or in accordance with the wishes of his/her family or representative and in accordance with the individual's cultural and religious belief and best practice.

8.13.2 Procedure Following the Death of an Individual

A procedure should be in place for staff to follow on the death of a resident including when an individual's death is not anticipated (see Appendix I).

8.13.3 Family

The person in charge will inform the individual's family if they are not present at the time of death. This should be done sensitively particularly when the death is sudden or unexpected. Families should be told of the death of their relative while in our care quickly, accurately, and, unless circumstances prevent this, in a face-to-face interview. Ideally, the family should be visited by a familiar member of staff and a member of the management or support team competent in offering the necessary support and advice required. Those informing the family of the death should be prepared for a range of possible grief reactions, which may include guilt or anger.

8.13.4 Other Individuals

The deceased peers and friends should be facilitated to attend and/or participate with the funeral rites. Support may be necessary for some individuals in the management of their grief. Staff should refer to the Brothers of Charity Services Ireland, Bereavement Policy and the person in charge for advice on the need to support individuals if needed.

8.13.5 Staff

Caring for individuals at their end-of-life is difficult for staff particularly if the staff have worked with an individual over a long period. All staff involved in the care of person should be informed that the death has occurred.

Support, formal or informal should be given to staff in the aftermath of the death of an individual, this may include informal peer support. Staff will be facilitated to attend the funeral services during their rostered shifts to support them with the grieving process.

An end-of-life care, post death audit and review meeting is useful to support staff through reflection and learning following a death. This promotes a culture of continuous improvement in end of life care delivered to residents. Guidance and training from the Irish Hospice Foundation is available to support services at end of life (IHF 2015).

Staff may consult with the relevant Employee Assistance Programme if they feel further support is necessary at this time.

8.13.6 Remembrance Services

Consideration should be given to organising a memorial service in memory of the deceased person as this helps to support families, peers and staff of the person who died. This may be organised in collaboration with the person's family and there may be more than one

service and may incorporate a religious service, in keeping with the person's faith, and/or a secular service.

9.0 Review

A review of these Guidelines will be carried out after 3 years unless for example, an audit, serious incident, organisational structural change, scope of practice change, advances in technology, significant changes in international best practice or legislation identifies the need to update these Guidelines.

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Appendix I Procedure following the Death of an Individual Who Uses the Services

Who to contact

- When an individual dies in their place of residence the staff will inform the Person in Charge on duty at the time.
- The Person in Charge will immediately inform the General Practitioner/or their designate of the death. This will ensure that the death is verified and certified correctly. Usually the doctor on duty will wish to know the person's date of birth, their diagnosis and any recent medical history. If the individual dies outside general practitioner hours the out of hour doctor providing cover will forward details to the person's general practitioner.
- The medical practitioner, pronounces the individual's death and documents, the date and time of death in the individual's medical notes. The resident's body should not be washed until this takes place.
- If the death is sudden or unexplained the Person in Charge will report the death to the Gardaí who will inform the Coroner. A Post Mortem may be requested when the death is sudden and unexpected.
- Expected deaths are also notifiable (only) to the coroner as soon as possible after the death by the the Person in Charge.
- The Person in Charge will inform the individual's family, if they are not present at the time of death. This will have to be done sensitively particularly when the death is sudden or unexpected. Families should be told of the death of their relative while in our care quickly, accurately, and, unless circumstances prevent this, in a face-to-face interview. Ideally, the family should be visited by a familiar member of staff and a member of the management or support team competent in offering the necessary support and advice required. Those informing the family of the death should be prepared for a range of possible grief reactions, which may include guilt or anger.
- The Person in Charge also notifies the priest/minister and their line Manager on the death of an individual.
- If the individual dies at night the Person in Charge can wait until early in the morning to inform the priest if they have recently been seen by their priest or minister. Similarly the relevant Senior Manager can be told early in the morning when a individual dies at night.
- The staff on duty at the time of death records the death in the individual's notes.
- The Person in Charge notifies HIQA of the death in one of the following ways.
 - When the resident dies unexpectedly, including the death of any resident, following transfer to hospital from the designated centre, the death is notified to HIQA within 3 working days.

Or

- Quarterly notification to HIQA of the death of any resident and cause of death.
- The death is notified to the HSE.
- The local hospital is informed of the person's death to ensure there is no further correspondence to the residential or family address.
- The Person in Charge informs the Department of Social Protection of the death of the resident.

Last offices

Last Offices also known as "laying out of the dead" refers to the care of the person's body after they have died. This is an ancient ritual providing an opportunity for people to offer a final mark of respect to the deceased (IHF & HSE, 2010).

Last Offices are carried out with regard to the wishes expressed by the person before death (if expressed) and the wishes of their family following death.

If the person dies in hospital last offices will be done there.

The undertaker may carry out last offices.

The following procedures apply to the deceased individual when the individual is not the subject of a post mortem, and is of a Christian faith. Further advice may need to be sought if the individual is of a non-Christian faith.

Laying Out Procedure-(if being performed)

N.B This is not to be completed until the death has been certified.

- Two people should carry out the procedure-usually one is a nurse and is competent to do the procedure.
- Usual hygiene procedures should be followed.
- The individual's body is washed
- Limbs are straightened
- Remove jewellery unless requested by the family or you are physically unable to remove it.
- All wounds including pressure sores should be covered with a waterproof dressing
- Dentures should be left in situ or inserted if possible
- The individual should be dressed in suitable clothes in accordance with their wishes or that of their family

Adapted from the Irish Hospice Foundation and Health Service Executive End of Life Care 2nd edition 2012.

Funeral Arrangements

- Upon the death of an individual the family are offered practical information. Families will usually look after the funeral and burial arrangements. If there are not any relatives the funeral arrangements will be organised by the services.
- When individuals die in their place of residence staff collaborate with families regarding funeral rites and ceremonies as requested.
- The deceased resident's removal from their home is completed in a dignified and respectful manner.
- The Person in Charge will circulate an internal notification of funeral notification once the arrangements become available.

Death Certification

Procedures for the civil registration of a death in Ireland are set out in the Civil Registration Act of 2004.

- The registered medical practitioner who attended the deceased during their illness must complete and sign Part 1 of the Death Notification Form, stating to the best of his or her knowledge and belief the cause of death. Part 1 of the form concerns general details of the deceased and incorporates the medical cause of death details.
- The Death Notification Form is passed on by the general practitioner to the individual's relative (or civil partner) who signs Part 2 of the form, which concerns additional personal details of the deceased. Upon completion of Part 2, the relative (or civil partner) must give the form to any Registrar of Births, Deaths & Marriages as soon as possible but no later than three months from the date of death.
- In order to complete the registration, the relative is required to sign the Register of Deaths in the presence of a Registrar.
- If the deceased was not seen by a doctor prior to the terminal illness or if s/he died as a result of an accident or in violent or unexplained circumstances the death must be referred to the Coroner, in which case the death will be registered on foot of a certificate issued by the Coroner to the Registrar containing all the details to be registered.

Estate of the Deceased

A Death Certificate is required to administer a deceased person's estate in Ireland. Once death certification has been completed the Person in Charge will advise the individual's next of kin to contact the finance department with regards to the deceased person's estate. Refer to the local procedures to be followed in the event of the death of an individual who uses the services.

Belongings of the deceased resident

The Person in Charge will discuss with the deceased person's next of kin regarding their wishes for the individual's personal belongings. This will be dealt with in a sensitive manner and may be completed by the keyworker or staff that have supported the family.

Records of the Deceased Residents

The records of the deceased residents are archived in accordance with local policy and procedures.