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Policy on End of Life Care

1. Dying Death and Bereavement Training Film.
2. End of Life Person Centred Care Film.
3. Co-ordination of Care at the End of Life Film.
4. Dementia and End of Life Care. Film.
5. Policy on CPR
6. Activities Policy

Please read summary version

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Policy on End of Life Care. Michael S McCaul PIC

Revised May 2020.Revised October 2021, revised Sept 2023 Please note that anticipatory prescribing in relation to COVID 19 has now been removed and is now recorded as anticipatory prescribing.

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1.0. END OF LIFE CARE

Although death is a natural part of life, the thought of dying understandably still frightens many people, including residents, relatives and staff. For residents we have to imagine the pain and loneliness, spending their final days far from family, friends and away from all that they know and love. However, the care we provide should represent a compassionate approach to end-of-life care, enhancing the quality of remaining life and enabling our residents to live as fully and as comfortably as possible.

Emphasis doesn't stop with just living well. Strategies have to be devised for the resident in our care about dying well. Practitioners within this service need to recognize end of life care early. This can be difficult, but we do get clues, frequent transfers to acute hospitals before and after admission to this service, PEG feeding, regular prescribing of antibiotics, regular chest and urinary tract infections and loss of appetite

Ensuring that End of Life is recognized involves a holistic person centred assessment. This needs to examine the:

- **Spiritual Needs of the Person**
- **The Religious beliefs and needs of the person**
- **The Physical Needs of the Person**
- **Supports required by Family and Friends.**

End of Life Care can start at anytime but traditionally begins in this service on the day a resident is admitted here The End of Life Care we provide, and involves palliative care (pain and symptom

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relief) rather than ongoing curative measures, enabling the resident to live their time to the fullest, with purpose, dignity, grace, and support. The aim of End of Life Care enables the resident to spend their final days in a familiar, comfortable environment, surrounded by their friends, family and staff who can focus their attention on and support the resident through this time.

2.0. The Traffic Light System

On admission, we use the Traffic light system. This is a very simple tool to use. It uses different colours of stickers placed on the outside of each residents chart which displays to all staff at what stage the person is at with End of Life Care.

The Following are the colour codes used within this service.



Blue. Attached to the chart of an individual who has just been admitted.



Green when staff notice a deterioration in the person's condition

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Orange or Amber when the person's condition has deteriorated



Red When the Person are in the final stages of life.

All Staff need to be aware of the stage a resident is at. Orange and Red Stages become nurse's priorities in terms of care

Understanding the needs of people at any stage is crucial

Staff are required to be knowledgeable and skilled in dealing with end of life care at all stages. We need to remember that admission to our services is a major transition for a person in their lives and we should not be surprised if anyone of our residents were to die suddenly or become ill quite quickly. This is why it is important that end of life care is central to all the care we deliver.

Key messages for practice

1. Personalised care for people at the end of life requires a planned and coordinated approach to care.

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2. Recording the likes, dislikes and preferences of a person at the end life in one place is a simple but important step towards achieving personalised care, whether from health or social care services. In this service we use “ **My Preferred Priorities for Care**”.
3. People who receive care which reflects what's important for them helps to make them feel more in control and more secure.
4. An understanding of what's important for a person at the end of life means staff will have better ideas of how to support and reassure them.
5. A simple tool which records people's preferences is also useful if they have to change care setting and can facilitate better working between health and social care. In this service we use a “**Key to Me**”



3.0. SOME KEY MESSAGES ABOUT CARDIO-PULMONARY RESUSCITATION (CPR)

The survival rate after CPR is only about 13-20% in hospital, and lower if the cardiac arrest happens out of hospital. When a resident is in the final stages of an incurable illness and death is expected within a few days, the success rate of CPR is very low (various studies have suggested it is less than 5%).

A decision not to attempt CPR (known as a DNAR—Do Not Attempt Resuscitation) only applies to resuscitation and does not apply to any other treatment and care, e.g. IV antibiotics, oxygen therapy, dialysis.

There should always be a Care Plan in place which has been developed and reviewed in discussion with the resident. CPR decisions must always be made in the context of advance care planning. Advance care discussions could include:

- The resident's concerns
- Their values and expectations for care
- Their understanding of their illness and prognosis
- Their preferences for the future including wishes regarding treatments and place of care.

A DNAR DECISION IS MADE ONLY BY THE MEDICAL OFFICER IN CONSULTATION WITH THE MULTIDISCIPLINARY TEAM AND THE RESIDENT AND/OR THEIR REPRESENTATIVE.

It is the responsibility of the most senior healthcare professional: a consultant/ registrar in the hospital, or the person's GP in the home/ nursing home. The doctor should consult with other

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healthcare professionals who will have into the per-son’s condition. The doctor may also consult with the person’s family but, in doing so, needs to make sure that the family is aware that it does not have the right to make the decision.

A person is not obliged to put a DNAR order in place to gain admission to a long-term care setting, e.g. nursing home.

CPR decisions must always be made on the basis on an *individual assessment*. When making a decision regarding DNAR, clinicians need to consider:

- (1) **The likelihood of CPR being successful**
- (2) **The balance of benefits and risks**
- (3) **The individual’s goals and preferences.**

There will be some individuals for whom no formal DNAR decision has been made but where attempting CPR is clearly inappropriate, for example in relation to a person who is in the final stages of a terminal illness. In these circumstances it is reasonable for healthcare professionals not to commence CPR.

Unethical and inappropriate practices such as ‘slow coding’ and ‘sham resuscitations’ where a full resuscitation is deliberately not attempted must not be performed.

[See Policy on Cardio Pulmonary Resuscitation](#)



4.0. What is End of Life Care

Care homes are the normal place of residence for a large proportion of people as they approach the end of their lives. They also provide shorter-term care for people who can no longer cope independently because of a terminal illness. End of life care is care that helps all those with

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advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Good End of Life Care is designed to help the care team provide:

- **the right care at the right time for the right person**
- **care that is person-centred and carer-centred**
- **care that plans ahead rather than simply reacting in an emergency or critical situation**
- **care closer to where the older person and the person with dementia wants to be cared for and to reduce unnecessary admissions to hospital**
- **Partnership working so that the older person and the person with dementia receives good care in all care settings.**



5.0. End of life care is underpinned by:

- **An active and compassionate approach to care that ensures respect for and dignity of the individual and their family**
- **Partnership in care between the person, family and health and social care professionals**
- **Regular and systematic assessment of person/carer needs incorporating the individual's consent at all times**
- **Anticipation and management of deterioration in the individual's state of health and well-being**

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- **Advance care planning in accordance with the individual’s preferences using Priorities for Care**
- **Individual’s choice about place of care and death**
- **Sensitivity to personal, cultural and spiritual beliefs and practices**
- **Effective co-ordination of care across all teams and providers of care (in statutory, Voluntary and independent sectors) who are involved in the care of patient and family.**

The words ‘end-of-life care’ mean caring for someone as they near the end of their life. However, in the case of dementia, it can be difficult to predict when a person is nearing death. They may present with signs that suggest they are very close to death, but in fact can show these signs for many months or even years. Or they may seem near to death and then improve and live for many months longer.

In addition, a person with dementia may die from another medical condition, for example cancer or heart disease. They may also have infections and minor illnesses on top of these ongoing conditions. Having these other conditions and illnesses may mean the person is cared for, or ultimately dies, in a hospital or a facility that does not specialise in dementia care.

For all these reasons, while knowledge about end-of-life care has increased greatly over the past ten years, particularly in areas such as cancer care, many people with dementia still do not receive good quality end-of-life care. Overall, good end-of-life care is generally not complicated, but simply just good person-centred care – that is, care that responds to the needs of the person.

Dementia is not always recognised as a terminal illness or the actual cause of death, often because there may also be other health problems, such as cancer or heart disease, which may be the main health concern. Dementia is, however, a terminal illness.

The majority of care home residents will have some form of dementia and often have a combination of basic and complex health care needs. Typically, when a person with dementia moves into a care

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home they die within two years of admission, so care home staff can develop a lot of experience caring for people at the end of life.

Different pattern of dying - most people die over a longer period than in the traditional cancer/palliative care pattern and there can be great difficulty in recognising the end of life phase. The 'end of life' phase finishes in death. Definition of its beginning is variable according to the individual and professional perspectives.

In some cases it may be the person who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the person. In all cases, subject to individual's consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

Professional judgement may be informed by use of a range of indicators. They include:

- 1. The surprise question: Would you be surprised if this person were to die in the Next 12 months?**
- 2. Choice: The person with advanced disease makes a choice for comfort care only.**
- 3. Need: The person with advanced disease is in special need of supportive/palliative care.**
- 4 Clinical indicators: Specific indicators of advanced disease for each of the three main groups – people with cancer, organ failure, elderly frail/dementia.**

End of life does not normally begin earlier than one year before death and for most individuals it may come much later than that. However, in some cases discussions with individuals about end of life may start much earlier – for example, at the point of recognition of incurability, such as at the time of diagnosis if made.

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6.0. Questions all staff should ask themselves about End of Life Care?

- How many of our residents die each year either in our care home or after transfer to acute care?
- Do all our residents have up-to-date care plans including care at the end of life?
- Can you identify the residents who are nearing the end of their lives? How do we know/
- Do you talk with your residents about where they would like to live and die?
- What are the main disease groups among the residents in our care home?
- How many GP practices provide medical care to our residents?
- What links do we have with specialist palliative care
- Do you know what the priorities of our organisation is in relation to end of life care?

7.0. Challenges and Solutions to End of Life Care within this Service.



Out of Hours (OOH) access to medical help and drugs. While we utilise out of hours Doctor on Call Services, there should be a plan in place and agreed between all members of the multidisciplinary team including our Medical Officer as to what plan of care is in place in a

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situation that occurs out of hours. This should be clearly discussed with the resident themselves and/or their representative. Often, acute illness occurs at night. In these situations, an on-call doctor may have to make a difficult decision about whether to admit the person to hospital. But typically they won't know whether or not the person has asked to be cared for and made comfortable only (that is, to have palliative care), and whether or not the person has elected to have any active treatment, such as resuscitation or intravenous antibiotics. This can lead to the distressing and relatively common situation where a person with advanced illness is transferred to the acute hospital where they then die in unfamiliar surroundings. In order to reduce these difficult decision stressors for nurses and doctors during out of hour's services, a plan should be clearly in place for these scenarios.

- Anticipatory prescribing – the ability to hold some drugs in stock and have access to the commonly used drugs in palliative care. As a public residential service, we are authorised to hold commonly used drugs used in palliative care.
- Specialist palliative care nurse involvement is variable. All Residents who may be nearing End of Life Care, should have a specialist palliative care Referral sent. The Specialist Referral form is located in Appendix Two.
- Advance care planning – In this service we utilise My Priorities for Care in relation to communicating with residents, their current perceptions of their current health status and also is used as a tool to facilitate communication between residents and staff and/or representatives with regards to their wishes and preferences.

It can also be used to start a conversation around end of life care and any concerns/questions people may have

- Resuscitation issues - local policies are developed for this service giving clear guidance. Resuscitation status is a medical decision, made in conjunction with the multidisciplinary. However it is strictly a Medical Decision and the Medical Officer must document all

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discussions with all parties within the Medical Notes. Resuscitation Status must be reviewed on a six to 8 monthly basis.



8.0. Key Messages

End-of-life care requires good person-centred care.

Living well with any illness or dementia also includes supporting a person with an illness or dementia to die well, or as they would have wished.

Be aware of the range of symptoms that an older person or a person with dementia may experience at the end of life.

Support family carers and help them to understand what is happening at the end of life.

ALWAYS INVOLVE FAMILY IN THE CARE PLANNING PROCESS. FAMILIES NEED TO BE KEPT INVOLVED AND INFORMED

DISCUSS WITH FAMILIES USING MY PREFERRED PRIORITIES FOR CARE WHERE THEY THINK THEIR RELATIVE IS AT CURRENTLY

ASK IS THERE ANYTHING THAT WE COULD BE DOING THAT WE ARE NOT

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9.0. Talking about End of Life Care

For many death remains a taboo subject. Consequently, many residents and their families remain reluctant to even discuss the possibility of end of life care. While most people would prefer to die in their own homes, the norm is that many residents admitted to this service will die within this service. Some residents who are admitted to this service may be terminally ill, and some may have received treatment that is either unwanted or ineffective. Their loved ones may only ever had limited access and often miss sharing their last moments of life. The policy of this service is that families are involved in the care of their relatives from the moment of admission.

Some families who do choose nursing home care often do so only when everything else has failed them, and many grieve and feel guilty about their decision to move their relative into nursing home care. To ensure that we deliver good end of life care it is important that both the resident and the family are made to feel as welcome as possible and that they are supported throughout this period. It is important that residents and families are given the opportunity to discuss their feelings with loved ones before a medical crisis strikes. When residents and relatives are clear about their preferences for treatment, they're free to devote their energy to care and compassion. From this perspective this service uses My Preferred Priorities for Care as an aid to discuss important end of life care decisions. (See **Appendix One**)

[My Preferred Priority for Care document is an aid for Nurses Residents and Relatives to assist in discussing End of Life Decisions with Residents and Relatives. If a resident or relative wishes to fill out this form, or use this form in communicating their wishes they are welcome to do so This does not replace resuscitation Policy, nor does it replace a Nurses judgement in relation to end of life care.](#)

The Preferred Priorities for Care (also known as PPC) can help a resident and/or their family to prepare for the future. It gives the resident an opportunity to think about, talk about and write down

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their preferences and priorities for care at the end of their life. They do not need to do this unless they want to. But they should be given that opportunity to do so. The decision is theirs.

The PPC can help the resident and carers ((family, friends and professionals) to Understand what is important to the resident when planning care. If a time comes when, for whatever reason, the resident is unable to make a decision for themselves, anyone who has to make decisions about their care on their behalf will have to take into account anything the resident and/or family may have written in their PPC.

Sometimes people wish to refuse specific medical treatments in advance. The PPC is not meant to be used for such legally binding refusals. If the resident decides that they want to refuse any medical treatments, it would be advisable to discuss this with medical doctors.

Remember that a resident’s views may change over time. They can change what they have written whenever they wish to, and it would be advisable to review the PPC regularly on a three monthly basis as part of the care planning involvement process to make sure that it still reflects what the resident wants.

The document also allows nurses to discuss with the resident and/or their family how they think the resident is progressing, stabilizing or deteriorating. It allows an opportunity to discuss in full all aspects of care and how they can be more involved in all care decisions regarding end of life care.



10.0. End of Life Care is Good Care.

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End of Life care focuses on all aspects of a resident's life and well-being: physical, social, emotional, and spiritual. There is no age restriction; anyone in the late stages of life has entered end of life care. While there is not an end of life care team within this service, end of life care involves everyone, that includes the resident's doctor, , registered nurses and care assistants, , a dietician, physiotherapists, occupational therapist, pharmacologist, social workers, a minister of different religions, and various volunteers.

The medical and nursing team will develop a care plan tailored to a resident's individual need for pain management and symptom relief, and provides all the necessary palliative drugs and therapies, medical supplies, and equipment.

It is **not** time for palliative care instead of curative treatment if a resident is currently benefiting from treatments intended to cure an illness. For some terminally ill residents, though, there comes a point when treatment is no longer working. Continued attempts at treatment may even be harmful, or in some cases treatment might provide another few weeks or months of life, but will make them feel too ill to enjoy that time. While hope for a full recovery may be gone, there is still hope for as much quality time as possible to spend with resident's, as well as hope for a dignified, pain-free death.

There is not a single specific point in an illness when a person should be provided with palliative care; it very much depends on the individual. The following are signs that nurses may want to explore options with the resident, their families and with the multidisciplinary team:

- The Resident has made multiple trips to the emergency room, their condition has been stabilized, but their illness continues to progress significantly, affecting their quality of life.
- They have been admitted to the hospital several times within the last year with the same or worsening symptoms.
- The resident wishes to remain in the centre or may express a wish not to be readmitted to the acute services.
- The resident has decided to stop receiving treatments for their illness/ disease.

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11.0. Co-ordination of Care

Many people have a role to play in end-of-life care – a GP, nurses, care staff, speech and language therapists to name a few – so the network can be large. But one of the most critical aspects to good end-of-life care is making sure that each member of the care team communicates reliably with others in the team. Without good information-sharing, a person is less likely to receive the care they need.

In particular, often the care team can forget to make sure that family understands what is happening and are updated regularly. This can be distressing for the family at what is already a very difficult time.

- Key messages for practice**
- It is vitally important to keep the person who is dying at the heart of communication between health and social care services.
- Social care can be overlooked when medical care takes preference.
- People at the end of life who do not have family and friends to support them are particularly vulnerable to receiving poorly coordinated care.
- Clarity about coordination – who is responsible for doing what – creates an environment of trust and security around the person who is dying.
- Having a single point of contact for the person who is at the end of life helps to coordinate care packages and communication. The person responsible within this service for coordinating services and care practices at Unit Level is the Clinical Nurse Manager.

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Personalised care for people at the end of life requires a planned and coordinated approach to care.

Recording the likes, dislikes and preferences of a person at the end life in one place is a simple but important step towards achieving personalised care, whether from health or social care services.

People who receive care which reflects what's important for them helps to make them feel more in control and more secure.

An understanding of what's important for a person at the end of life means staff will have better ideas of how to support and reassure them.

A simple tool which records people's preferences is also useful if they have to change care setting and can facilitate better working between health and social care.

12.0. Late Stage and End-of-life Care. Care giving in the Final Stages of

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Life

1. Holistic assessment is about the physical, social, psychological and spiritual needs of a person at the end of life.
2. Holistic assessment can result in a plan which records the wishes and decisions of a person at the end of life. This may be useful for family and everyone involved in their care.
3. Holistic assessment is an ongoing process which can be updated and changed as the person's choices and preferences change.
4. The process of making a holistic assessment may increase the confidence and trust of a person at the end of life.

Many families and friends want to support a person at the end of life whether that person is dying at home or in a care setting.

Health and Social care staff should be able to offer support not only to the dying person, but also to their relatives.

Support for relatives may be needed while their relative is dying, as well as after the death when the relative is grieving.

Relatives can find support helpful in dealing with the death of a loved one

In the final stages of many terminal illnesses, care priorities tend to shift. Instead of ongoing curative measures, the focus often changes to palliative care for the relief of pain, symptoms, and

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emotional stress. The complex and often disorderly progression of terminal diseases such as Alzheimer's requires complete care 24 hours a day, 7 days a week, which can be uniquely challenging for caregivers.

Ensuring a final months, weeks, or days are as good as they can be requires more than just a series of resource and care choices. Learning to anticipate the specific demands of end-of-life caregiving can help ease the journey from care and grief towards acceptance and healing.



12.1. Pain.

Pain in older people and with people with advanced dementia is a common symptom.

Older People and People with dementia experience pain just as much as anyone else.

Pain in older people and people with dementia is often poorly recognised and undertreated, and yet it is not difficult to treat.

Caregivers need to work hard to understand a person's verbal and non-verbal signs that they are in pain.

Uncontrolled pain can seriously affect a person's quality of life.

The Pain Assessment Tool of Choice used within this Service is the Abbey Pain Scale. The Abbey Pain Scale is used primarily with those residents who cannot verbalise that they have pain, but where pain is suspected by non verbal communication such as twitching, restlessness, difficulty with breathing, sweating. (See Appendix Three).

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13.0. Understanding late stage care

In the final stages of life-limiting illness, it can become evident that in spite of the best care, attention, and treatment, the resident is approaching the end of life. The resident's care continues, although the focus shifts to making the resident as comfortable as possible. Depending on the nature of the illness and the resident's circumstances, this final stage period may last from a matter of weeks or months to several years. During this time palliative care measures can provide the resident with medication and treatments to control pain and other symptoms, such as constipation, nausea, or shortness of breath.

Even with years of experience, caregivers often find the last stages of life uniquely challenging. Simple acts of daily care are often combined with complex end-of-life decisions and painful feelings of bereavement. End-of-life caregiving requires support. This support is accessible from members of the multidisciplinary team and well as specialist palliative care teams.

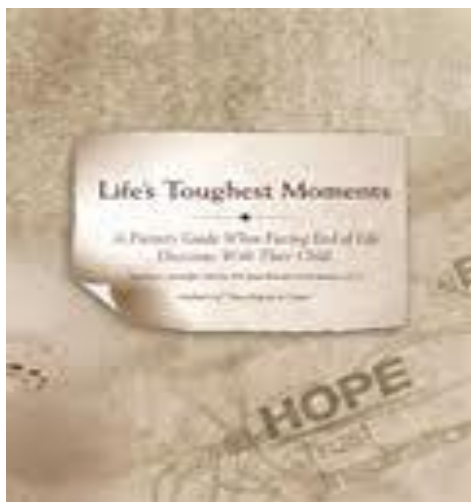
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13.1. Resident and Family needs in late stage care

- **Practical care and assistance.** Perhaps the resident can no longer talk, sit, walk, eat, or make sense of the world. Routine activities, including bathing, feeding, toileting, dressing, and turning may require total support and increased physical strength on the part of the care team. These tasks will be supported nursing staff who will plan most of the care for this group of residents.
- **Comfort and dignity.** Even if the resident’s cognitive and memory functions are depleted, their capacity to feel frightened or at peace, loved or lonely, and sad or secure remains. Regardless of location—the most helpful interventions are those which ease discomfort and provide meaningful connections to family and friends
- **Grief support.** Anticipating a resident’s death can produce reactions from relief to sadness to feeling numb. Nursing staff should assist in preparing a family and offer any supports available in order to assist a family prepare for the coming loss.

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13.2. End-of-life planning: decisions in late stage care



When caregivers and family members, are clear about the resident's preferences for treatment in the final stages of life, they're free to devote their energy to care and compassion. To ensure that everyone understands the resident's wishes, it is important that everyone on the team is aware of these preferences

Prepare early. The end-of-life journey is eased considerably when conversations regarding placement, treatment, and end-of-life wishes are held as early as possible.

- **Focus on values.** If a resident did not prepare a plan while competent to do so, act on what you *know* or *feel* his or her wishes are. Make a list of conversations and events that illustrate his or her views with all members of the resident's family. To the extent possible, consider treatment, placement, and decisions about dying from the resident's vantage point.
- **Address family conflicts.** Stress and grief resulting from a resident's deterioration can often create conflict between family members. If you are unable to deal with these issues, seek advice from the Director of Nursing Office who will assist in these matters or who will seek assistance for you.
- **Communicate with family members.** Choose a primary decision maker who will manage information and coordinate family involvement and support. Even when families know their loved one's wishes, implementing decisions for or against sustaining or life-prolonging treatments requires communication and coordination.

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- If children are involved, make efforts to include them. Children need honest, age-appropriate information about their relative's condition and any changes they perceive in you. They can be deeply affected by situations they don't understand, and may benefit from drawing pictures or using puppets to simulate feelings, and hearing stories that explain events in terms they can grasp.



14.0. Providing emotional comfort

As with physical symptoms, every resident's emotional needs in the final stages of life also differ. However, some emotions are common to many residents during end-of-life care. Many worry about loss of control and loss of dignity as their physical abilities decline. It's also common for resident's to fear being a burden to you yet at the same time also fear being abandoned.

Late stage caregivers can offer emotional comfort to the resident and to their families in several different ways:

- **Keep the resident company.** Talk to the resident, read to him or her, watch movies together, or simply sit and hold their hand.
- **Refrain from burdening the resident with your feelings of fear, sadness and loss.** Talk to instead to someone else about your feelings.
- **Allow the resident to express fears of death.** It can be difficult to hear a resident talk about leaving family and friends behind, but communicating their fears can help them come to terms with what's happening. Try to listen without interrupting or arguing.
- **Allow them to reminisce.** Talking about their life and the past is another way some resident's gain perspective on their life and the process of dying.

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- **Avoid withholding difficult information.** If they're still able to comprehend, most residents prefer to be included in discussions about issues that concern them.
- **Honor their wishes.** Reassure the resident that you will honor their wishes, even if you don't agree with them. If you are uncertain, discuss with your manager
- **Respect the resident's need for privacy.** End-of-life care for many people is often a battle to preserve their dignity and end their life as comfortably as possible.



15.0. Caring at the end-of-life

The *end-of-life period*, when body systems are shutting down and death is imminent typically lasts from a matter of days to a couple of weeks. Some resident's die gently and tranquilly, while others seem to fight the inevitable. Reassuring the resident that it is okay to die can help both of you through this process. Decisions about hydration, breathing support, and other interventions should be consistent with the resident's wishes, and should be communicated sensitively to all family member's present.

After the resident has passed away, some family members and caregivers draw comfort from taking some time to say their last goodbyes, talk, or pray, before proceeding with final arrangements. Give yourself that time if you need it.

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Always inform staff who may be off duty

Comfort colleagues who may have known the resident for a long time

Always refer to the person who has died by their name, and DO NOT USE TERMS SUCH AS REMAINS OR BODY.



16.0. Resident's Support-

Different things dictate how the other residents are involved. In general they should be kept informed of someone's impending death and be encouraged to visit him or her if they so wish. Cultural or religious practices may be appropriate such as prayers, vigils, playing favorite music or welcoming relatives. The extent to which this will depend on how far it accords with the dying person's wishes and the family wish. Other residents should be told of another resident's death and whether they would like to visit the person or attend the funeral.

Other residents will grieve and must be supported during this grieving period.

Staff should be alert to the impact the death of individual residents may have on those remaining in the home. In the case of people with dementia, changes in their behaviour may indicate the impact the death of a fellow resident has had on them and staff should be ready to offer comfort and support.

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Within the Unit, the loss of one of a couple, or of a close friendship needs special and sympathetic support. Particular sensitivity will be needed in some practical matters such as any change of accommodation or disposal or handing over to relatives of clothes and other belongings.



17.0. Supporting Staff

- When a resident in a care homes dies, care staff are very likely to feel affected and bereaved.
- Good practice lies in acknowledging staff may be affected by a death and need time to reflect on and deal with feelings of bereavement.
- Staff need to be able to talk openly about their feelings and emotions. Managers can support staff to do this in one to one meetings as well as group settings.
- This acknowledges the importance of staff to the care and confirms how important and valuable their contribution to good care is.
- It is important to recognise that grief may take some time to surface in staff following a death.

All staff who have had any involvement with the dying resident and this includes managerial and ancillary staff as much as it does nursing and care staff should be kept informed when someone is dying. Those who wish should be given time to spend with the dying resident. This is one way of

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ensuring that there is always someone present. Support should be given to staff who have been closely involved with the resident and their emotional needs should be recognised and catered for, particularly in the case of staff who are witnessing death for the first time

Staff after all deaths within the Centre should discuss the following amongst others:

What was good about the person's death?

What went well for the person during their death?

What didn't go so well/

If we had the opportunity to experience the person's death again, what would we do differently/

18.0. Terminal Care as Part of end of Life Care. Considerations for care planning.



Anticipatory Prescribing in the Last Hours or Days of Life

Introduction

- If a resident is in the last hours or days of life it is helpful if 'anticipatory medication' for symptom control is considered at the end of life (EOL).
- It is essential to review the effect of any PRN medicine after it has been administered.
- There should be a review of the treatment plan within one hour to assess if the administered medication has had the desired effect/ no effect/ a partial, but inadequate, effect on the symptom.
- There should be a review of the treatment plan within 24 hours when the administered medication:
 - Is effective for an appropriate and expected time,

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- Has had a limited duration of effectiveness that has necessitated three or more repeated doses.
- As part of the review, the doses of regular medication, such as modified release tablets, transdermal patches or those given by syringe pump, should be considered. If there are signs of toxicity, a dose reduction, or drug switch, may be required. Advice from specialist palliative care should be sought if needed.
- Consider starting a syringe pump if symptoms persist (see syringe pump information).
- Adherence to guideline recommendations will not ensure a successful outcome in every case. It is the responsibility of all professionals to exercise clinical judgement in the management of individual patients. Palliative care specialists occasionally prescribe or recommend other drugs, doses or drug combinations. For more detailed guidance, visit <https://www.palliativecareguidelines.scot.nhs.uk> AND/ OR contact specialist palliative care team for advice.

What medications?

4 symptoms commonly require medications for relief at the EOL:

Pain and/ or breathlessness

Anxiety or agitation

Respiratory secretions

Nausea or vomiting

Updated (HSE, 25/03/2020).

Opioid for pain and/ or breathlessness

For opioid naive patient

Morphine sulphate injection (10mg/ml ampoules)

- Dose: 2.5mg SC repeated at hourly intervals as needed for pain or breathlessness
- If 3 or more doses have been given within 4 hours with little or no benefit seek urgent advice or review
- If more than 6 doses are required in 24 hours seek advice or review

Note: Patients who are severely distressed may require rapid dose titration and urgent palliative care advice should be sought to guide management in these cases.

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For resident already on regular opioids

If the resident is on a regular opioid, the prn dose is 1/6th of the 24-hour dose of the regular opioid and converted to SC dose, which is half of the oral dose, e.g. MST 30mg BD = 60mg of morphine sulphate in 24 hours. PRN dose is 10mg oramorph PO or morphine sulphate 5mg SC.

Anxiolytic sedative for anxiety or agitation or breathlessness

Midazolam injection (10mg in 2ml ampoules)

Dose: 2.5mg SC, repeated at hourly intervals as needed for anxiety/distress

- If 3 or more doses have been given within 4 hours with little or no benefit seek urgent advice or review
- If more than 6 doses are required in 24 hours seek advice or review
- Note: if on large background doses of BZDs, a larger dose may be needed (if they are frail, a smaller dose may be enough)

Levomepromazine or haloperidol can be used in agitated delirium.

- Levomepromazine 3.125 to 6.25mg SC, hourly as needed OR haloperidol 0.5 to 1mg hourly as needed if levomepromazine not available
- If 3 or more doses have been given within 4 hours with little or no benefit seek urgent advice or review
- If more than 6 doses are required in 24 hours seek urgent advice or review

Updated 25/03/2020

Anti-secretory for respiratory secretions

Hyoscine butylbromide injection (Buscopan®) (20mg/ml ampoules)

- Dose: 20mg SC, hourly as needed. (Maximum dose 120mg in 24 hours)

OR

Glycopyrronium injection (200mcg/ml ampoules)

- Dose: 200mcg SC, hourly as needed (Maximum dose 2.4mg in 24 hours)

Updated 25/03/2020

Anti-emetic for nausea or vomiting

Levomepromazine injection (25mg/ml ampoules)

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- Dose: 3.125 to 6.25mg SC, 12 hourly as needed.

OR

Haloperidol

- 0.5 to 1mg SC, 12 hourly as needed if levomepromazine not available.

Updated 25/03/2020.

Recognising that a person is dying

Imminently dying is a term used to describe patients who are rapidly approaching end of life. The prognosis is expected to be some hours or short days and the patient is likely to be unresponsive. A senior and experienced Clinician and Senior Nurse, as part of a team, will determine that there is no prospect of achieving reversibility and now the focus is exclusively on ensuring comfort.

The diagnosis of dying can be challenging and if any doubt persists the team should be open to reviewing it at any stage.

Communication

Clear and sensitive communication should take place between staff, the person who is dying and those identified as important to them. A diagnosis of dying must be shared sensitively with close family as appropriate. Once a diagnosis of dying is made the decision must be recorded in the clinical record and disseminated with the multidisciplinary team.

Involve

The dying person and those identified as important to them are involved in decisions about care to the extent that the dying person wishes.

Signs and symptoms

Diagnosing dying is not easy, there is no one feature that can diagnose dying, a range of symptoms may be present, but varies from individual to individual.

Consider the response to supportive therapies and if there is a meaningful and sustained response to supportive treatments.

Predicting when somebody is going to die is often complex.

Signs of approaching death are picked up by the day-to-day assessment of deterioration, some but not all of the signs listed may occur:

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Diminished intake of food and fluids
 Difficulty swallowing medications
 Decreased level of consciousness
 Bed-bound/full nursing assistance required
 Apnoeic periods
 Peripheral cyanosis
 Cheyenne-Stokes respirations
 Audible respiratory secretions
 Impalpable radial artery
 Mandibular movement on respiration
 Oliguria

Should symptoms develop suddenly, it is important to exclude a reversible cause of the deterioration such as infection, hypercalcaemia or adverse effects of medication changes.

Support

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible. It is important to be sensitive to the patient and/or family's beliefs. If in doubt, ask a family member to avoid offense.

Clear guidance (based on visiting policy currently in place) should be offered to the family. Visits should be facilitated as per the guidance.

Do

An individual plan of care is agreed, coordinated and delivered with compassion.

There can be challenges and difficulties but reassure families that the exclusive focus is on comfort measures.

In the event of a patient unexpectedly stabilising / improving, reconsider the diagnosis of 'dying'.

Goal a: Ensure the resident does not have pain

Verbalised by resident if conscious, pain free on movement. Observe for non-verbal cues. Ensure need for positional change.

Use a pain assessment tool to assess pain on a continuous basis.

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Use Abbey Pain Scale for those with dementia or who cannot verbalise

Consider prn analgesia for incident pain.

The involvement of the palliative care team

Goal b: The resident is not agitated

Ensure resident does not display signs of restlessness or distress, exclude reversible causes e.g. retention of urine, opioid toxicity if resident is on opioids.

Goal c: The resident does not have respiratory tract secretions

Consider positional change. Discuss symptoms & plan of care with resident, relative or carer
Medication to be given as soon as symptom occurs.

Goal d: Ensure The resident does not have nausea

Verbalised by resident if conscious.

Goal e: The resident is not vomiting

Goal f: The resident is not breathless

Verbalised by resident if conscious, consider positional change. Use of a fan may be helpful.

Goal g: The resident does not have urinary problems

Use of pads, urinary catheter as required. Record same and frequency of changes.

Goal h: The resident does not have bowel problems

Monitor – constipation / diarrhoea. Monitor skin integrity Bowels last opened: Record in Care Plan

Goal i: The resident does not have other symptoms

Record symptom in care plan

If no other symptoms present please record N/A

Goal j: The resident's comfort & safety regarding the administration of medication is maintained

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If Continuous Sub Cutaneous Infusion in place – monitoring sheet in progress

S/C butterfly in place if needed for prn medication, Record location in Care Plan

The resident is only receiving medication that is beneficial at this time. *If no medication required please record N/A.*

Goal k: The resident receives fluids to support their individual needs

The resident is supported to take oral fluids / thickened fluids for as long as tolerated. Monitor for signs of aspiration and/or distress. If symptomatically dehydrated & not deemed futile, consider clinically assisted (artificial) hydration if in the resident’s best interest. If in place monitor & review rate/volume. Explain the plan of care with the resident and relative or carer. Discuss need for continuation of fluids with Medical Doctor and Palliative Care Team

Goal l: The resident’s mouth is moist and clean

See mouth care policy. Relative or carer involved in care giving as appropriate. Mouth care tray at the bedside.

Goal m: The resident’s skin integrity is maintained

Assessment, cleansing, positioning, use of special aids (mattress / bed). The frequency of repositioning should be determined by skin inspection and the resident’s individual needs. *Waterlow score: Please continuously record in Care Plan*

Goal n: The resident’s personal hygiene needs are met

Skin care, wash, eye care, change of clothing according to individual needs. Relative or carer involved in care giving as appropriate.

Goal o: The resident receives their care in a physical environment adjusted to support their individual needs

Well fitting curtains, screens, clean environment, sufficient space at bedside, consider fragrance,

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silence, music, light, dark, pictures, photographs, nurse call bell accessible.

Goal p: The resident’s psychological well-being is maintained

Staff just being at the bedside can be a sign of support and caring. Respectful verbal and non-verbal communication, use of listening skills, information and explanation of care given. Use of touch if appropriate. Spiritual/religious/cultural needs – consider support of the chaplaincy team.

Goal q: The well-being of the relative or carer attending the patient is maintained

Just being at the bedside can be a sign of support and caring. Consider spiritual/religious/cultural needs, expressions may be unfamiliar to the healthcare

Professional but normal for the relative or carer – support of chaplaincy team may be helpful. Listen & respond to worries/fears. Age appropriate advice & information to support children/adolescents available to parents or carers. Allow the opportunity to reminisce.

Offer a drink

Goal 10: last offices are undertaken according to policy and procedure

Achieved **Variance**

The resident is treated with respect and dignity whilst last offices are undertaken. The appropriate religious leader should be contacted as well as the Pastoral Care Worker.

These phone numbers are available at Unit Level.

Universal precautions & local policy and procedures including infection risk adhered to

Spiritual, religious, cultural rituals / needs met

Organisational policy followed for the management of Infection control policies, where appropriate

Organisational policy followed for the management & storage of resident’s valuables and belongings

19. Formal notifications and documentation

Depending on who is responsible for making the arrangements, the manager should do what is necessary or give whatever help is required to support the relatives. Whatever the position the home is likely to have a central role.

Things to do will include:

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- obtaining the death certificate from the doctor;
- informing the coroner if the death was unexpected;
- registering the death;
- Contacting the undertaker and making funeral arrangements.

The manager should also inform the registration authority and follow any other agreed organisational procedures

20.0. Announcing a death

News of a resident's death should be announced in a dignified and gentle way. It may be best to announce it quietly to individuals or staff groups to begin with but some more public announcement may also be appropriate in due course. Some people may find this public recognition comforting. It should never be assumed that people with dementia do not understand when someone has died. Some of the following possibilities might be appropriate:

- a minute's silence at an appropriate time;
- a photograph or some other personal tribute in a suitable place;
- opportunity to visit the dead person and pay last respects;
- a memorial or thanksgiving service or some other religious or cultural ceremony held annually. Unit Manager's will organise this on a yearly basis and will invite all family member's of those who have died during the year.;
- lighting a candle;
- playing a favourite piece of music or reading a poem;
- a plant, picture or piece of furniture in memory of the person.

21.0. Funeral

Residents and staff should be able and helped to attend the funeral or other ceremony if they wish. Transport should be arranged and staff rotas should be adjusted either to provide escorts for residents or so that staff can attend in their own right. It may also be appropriate for the funeral cortege to leave from the home, or for it to pass the home during its journey so that residents unable to attend the funeral can pay their last respects. Depending on relatives' wishes, it may be possible for the home to offer refreshments to those who have attended the funeral so that the whole of the resident group can be involved. Alternative space and activities should be provided for residents who do not wish to be involved.

22.0.: The relative or carer can express an understanding of what they will need to do next

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and are given relevant written information

Conversation with relative or carer explaining the next steps

Grieving leaflet given yes No

Information given regarding how and when to contact the general office / funeral director to make an appointment – regarding the death certificate and patient’s valuables and belongings where appropriate Wishes regarding tissue/organ donation discussed if arises.

Discuss as appropriate: viewing the body / the need for a post mortem / the need for removal of cardiac devices / the need for a discussion with the coroner

Information given to families on bereavement services where appropriate – national & local agencies.

Booklet given to family as developed by these services.



23.0. Handover Bag.

The principle of the family handover bag is to promote a dignified and sensitive way of returning the deceased patient’s personal belongings to the family. A high quality bag should be used in place of a plastic bag. All Units are supplied with these bags and must be used to handover personal items belonging to the resident to relatives. Contact Person in Charge if you have not a supply of these on your Unit.

24.0. The primary health care team / GP is notified of the patient’s death The primary health care team / GP may have known this patient very well and other relatives or carers may be registered with the same GP. Telephone or fax the GP practice.

25.0. The resident’s death is communicated to appropriate services across the organisation
 E.g. Director of Nursing Office, General office / palliative care team / district nursing team / Multi disciplinary teams (where appropriate) are informed of the death. The acute hospital should be notified so that no further correspondence is received.

The resident’s death is entered on the organisations IT system and the death is recorded within the

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hard copy data book on each nurses station which should include the name, time, date and cause of death as known.



End of Life Spiral

This spiral is displayed in the clinical area whenever a person is very close to death or has died. It is a signal to all staff that an intensely personal and profound event is happening for the patient and their family.



Ward Altar. This wooden locker can placed at the patient’s bedside. It contains articles to support spiritual and cultural care before and after death.

26.0. Mortuary.

POST MORTEM CARE

PURPOSE

To prepare the person for viewing by the family and to prepare the person for transfer to the mortuary. These procedures are offered as a resource for use by staff as they attempt to determine how best to achieve the goal of providing each resident with appropriate health care. This policy is not intended to replace the informed judgment and professional discretion of individual nurses, physicians, and other clinicians. GENERAL GUIDELINES

1. Do not perform post mortem care until the resident has been pronounced dead.
2. Should a resident of the Catholic faith die without seeing a priest, the Staff/Charge Nurse must

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summon a priest to the room before releasing the deceased resident to the mortuary.

3. Do not perform any post mortem care on residents of Jewish faith. A representative of the Chevra Kadisha, Jewish Burial Society, will come and perform the service. Wait for this representative. The family or the Staff/Charge Nurse will inform the society of the death. **Please refer to guidelines on dealing with persons of different beliefs and faiths.**
4. Unless otherwise instructed, remove all jewellery from the deceased resident. If jewellery cannot be removed, or the resident's family requests that the jewellery remain on the resident, inform the Staff/Charge Nurse of such request so that this information can be recorded in the resident's medical record.
5. Pack and give all belongings to the resident's family. If the resident's family cannot pick up the resident's personal belongings at time of death, store such items until the family members can do so). Use End of Life Care Personal Belongings bag only.
6. Close the resident room doors and clear the hallways before transporting the deceased resident through the corridors. Invite all residents to view the removal of the person if they wish. Support other residents.
7. Treat the deceased resident with respect and dignity.
8. Handle the deceased resident carefully to prevent distortion, discoloration, or other harm to the body.
9. Do not leave the deceased resident's body alone. Remain with the resident until the deceased is released to the mortuary.

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EQUIPMENT

Disposable tags

Dressings and adhesive strips

Bath towel and wash cloths

Wash basin filled half full with warm water

Cotton balls

Syringe for removing Foley catheter

Brush and comb

Shroud (PURPLE END OF LIFE)

Red bag (if necessary)

Solvent (for removing old adhesive tape residue)

End of Life Care Bag for personal belongings

Personal protective equipment

PROCEDURE

1. Wash and dry your hands thoroughly before beginning procedure.
2. Obtain equipment and supplies needed to perform the procedure and take to the resident's room.
3. Obtain additional assistance as necessary.
4. If family members or visitors are present, ask them to wait outside the room until the procedure has been completed. If possible, the resident's roommate (if any) should be assisted out of the room.
5. Close the door to the room.
6. Lower the head of the bed.
7. Put on gloves.
8. Remove all pillows except one. Place the one pillow under the resident's head.
9. Place the deceased resident in the supine position. Unless otherwise instructed, disconnect all tubes,s/c fluids lines, catheters, etc.
10. Straighten the arms and legs. Handle the resident gently to avoid bruising the skin.
11. If the resident's eyes are open, close them by gently taking the eyelashes and pulling the eyelids down over the eyes. Avoid touching the eyelids as this may cause an unnatural appearance.
12. Bathe and cleanse the body avoiding exposing the resident. Keep the resident's body covered as much as possible.
13. Close the resident's mouth by cupping your hand under the resident's chin and applying light pressure. If the resident wore dentures, reinsert them. If the mouth will not stay closed, place a

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rolled towel under the chin.

14. Comb the resident's hair as necessary.
15. Remove all soiled dressings and bandages and discard into designated containers.
16. Cover all wounds with clean dressings. Use adhesive tape to hold them in place.
17. Unless otherwise noted, remove all jewellery and give to Staff/Charge Nurse.
18. Cover the resident with a sheet. Place the sheet up over the chest for family viewing and place end of life shroud over the person up to their chin..
19. Position the resident's arms in a joined way or to their sides.
20. Remove all post mortem care equipment, supplies, and trash from room.

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21. Pour the bathwater and all other used liquids down the toilet and flush.
22. Unless otherwise instructed, invite the family back into the room and leave them alone with the resident.
24. Strip the bed and discard all laundry and linen into the soiled laundry hamper. Red bag as necessary.
25. Clean, disinfect, and return all reusable equipment to designated storage areas.
26. Return the cubicle curtain to the open position.
27. Permit the roommate to return to the room.
28. Wash and dry your hands thoroughly.
29. Document as follows:
 - Date and time care was given.
 - Name and title of the individual(s) performing the procedure.
 - What was done with the resident's personal effects, especially jewelry and dentures.
 - Signature and title of the person recording the data.
 - Report any other information in accordance with facility policy and professional standards of conduct.



Bed/Trolley Drape

This is a special drape to be placed over the body of the deceased person to promote a dignified ceremony as the deceased patient is transferred off the ward/out of hospital. This is available on all Units.

If the person is been taken to the Service Mortuary, then they should be accompanied there by two staff.

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There is a Mortuary where the person is registered, outlining name, date of birth and time removed to Mortuary.

The Mortuary should be prepared and warmed for welcoming visitors and visitors will be welcome to view the person who has died.

Where the person is been taken to the mortuary of the undertaker, then arrangements and times should be taken by staff so that all family and relatives are aware of the arrangements.

26.0 Registering a Death in Ireland

It is a legal requirement in Ireland that every death that takes place in the State must be recorded and registered. Records of deaths in Ireland are held in the General Register Office, which is the central civil repository for records relating to Births, Marriages and Deaths in Ireland. A relative can apply for a copy of a death certificate to any Registrar of Births, Marriages and Death or to the General Register Office.

A death can be registered with any Registrar, irrespective of where it occurs. Deaths must be registered as soon as possible after the death and no later than three months. It is usually registered by the next of kin. Alternatively, it may be registered by a person who was present during the death or final illness of the deceased, or by a near neighbour or, failing that, by the undertaker.

27.0. *How to register a death*

To register a death, you must bring a Death Notification Form stating the cause of death to any Registrar. You can get this from the doctor who attended the deceased during his/her last illness. You must complete Part 2 of the Death Notification Form. You must then sign the Register in the presence of the Registrar. This registration is free.

A doctor must be satisfied about the cause of death before he/she can certify it. If he/she didn't see the deceased at least 28 days before the death occurred, or if he/she isn't satisfied about the cause of death, he/she must inform a [Coroner](#) who will decide if a [postmortem](#) is necessary. If the deceased died as the result of an accident, or in violent or unexplained circumstances the coroner must be informed. There may be a delay in registering a death where a postmortem is carried out

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Rates

There is no charge to register a death that occurs in Ireland. Fees are charged for a copy of a death certificate.

A certificate is issued for social welfare purposes at a reduced cost. Evidence it is for social welfare purposes is required, such as a note from the Department of Social Protection.

The fees charged for a certificate are as follows:

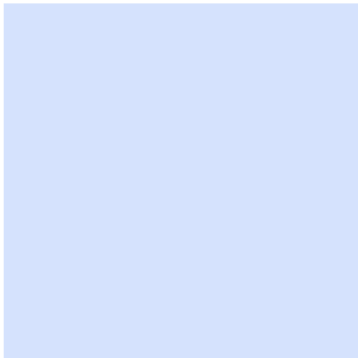
- €20 for a full standard certificate
- €1 for a copy for social welfare purposes (letter from Department of Social Protection required)
- €4 for an uncertified copy of an entry in the Register

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Appendix One. My Preferred Priorities for Care

[My Preferred Priorities for Care.](#)

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This document is an aid for Nurses Residents and Relatives to assist in discussing End of Life Decisions with Residents and Relatives. If a resident or relative wishes to fill out this form, or use this form in communicating their wishes they are welcome to do so This does not replace resuscitation Policy, nor does it replace a Nurses judgement in relation to end of life care.

Director of Nursing Office 2023

My Preferred Priorities for Care.

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<p>Your name:</p> <p>Address:</p>

What is this document for?

The Preferred Priorities for Care (also known as PPC) can help you prepare for the future. It gives you an opportunity to think about, talk about and write down your preferences and priorities for care at the end of your life. You do not need to do this unless you want to.

The PPC can help you and your carers (your family, friends and professionals) to understand what is important to you when planning your care. If a time comes when, for whatever reason, you are unable to make a decision for yourself, anyone who has to make decisions about your care on your behalf will have to take into account anything you have written in your PPC.

Sometimes people wish to refuse specific medical treatments in advance. The PPC is not meant to be used for such legally binding refusals. If you decide that you want to refuse any medical treatments, it would be advisable to discuss this with your doctors.

Remember that your views may change over time. You can change what you have written whenever you wish to, and it would be advisable to review your PPC regularly to make sure that it still reflects what you want.

Should I talk to other people about my PPC?

You may find it helpful to talk about your future care with your family and friends, although sometimes this can be difficult because it might be emotional or people might not agree. It can also be useful to talk about any particular needs your family or friends may have if they are going to be involved in caring for you.

Your professional carers (like your doctor, nurse or social worker) can help and support you and your family with this.

When you have completed your PPC you are encouraged to keep it with you and

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share it with anyone involved in your care. Unless people know what is important to you, they will not be able to take your wishes into account.

What should I include in my PPC?

You should include anything that is important to you or that you are worried about. It is a good idea to think about your beliefs and values, what you would and would not like, and where you would like to be cared for at the end of your life.

People who should be asked about your care if you are not able to make a decision for yourself.

Name: Address: Telephone number: Relationship to you:
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Name:

Address:

Telephone number:

Relationship to you:

Name:

Address:

Telephone number:

Relationship to you:

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Your preferences and priorities

In relation to your health, what has been happening to you?.

(Please write in here your understanding. If you are the Nurse you may wish to write in here discussions you have had with the resident and family or alternatively you may record within your care plan).

Thinking ahead....

1. At this time in your life what is it that makes you happy or you feel is important to you?

2. What elements of care are important to you and what would you like to happen in future?

3. What would you NOT want to happen? Is there anything that you worry about or fear happening?

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4. *Do you have a Legal Advance Decision to Refuse Treatment document?*

5. Proxy / next of kin

Who else would you like to be involved if it ever becomes difficult for you to make decisions or if there was an emergency?

Contact 1 Tel.....

Contact 2 Tel.....

6. Preferred place of care

If your condition deteriorates where would you most like to be cared for?

Where would you like to be cared for in the future?

(If you are a Nurse you may write in here discussions you have had with resident on this issue, or within your care plan.)

1st choice

2nd choice

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Comments

7. Do you have any special requests, preferences, or other comments? **What are your preferences and priorities for your future care?**

(Write in here summary of discussions you had with resident, or within your care plan).

8. Are there any comments or additions from other people you are close to?

If in the event that you're heart suddenly stopped, would you like to be resuscitated?

(Write in here what it is the resident says. You may have used different language to the language used here. You will probably have used language appropriate for the resident, or alternatively write in Care Plan)

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Please record any changes to your preferences and priorities here

(Please sign and date any changes. These should be recorded each time resuscitation status is discussed with the resident or with families, either using this document or within the care plan. This will also be recorded in the Medical Notes by Medical Officer who will have discussions with each resident on each review date)

Further information

You can use this page to make a note of any further information you need or Questions you might want to ask your professional carers (like your doctor, nurse or social worker. Nurses can also use this page to make extra notes on end of life decisions for their resident).

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This document was given to me by:

Name:

Organisation:

Tel:

Email:

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OR I am A Relative and I am happy with what has been discussed with me and know I can change my opinions and my wishes in the interest of my relative at any stage. Please sign and date each time a discussion is had with families.

Signed _____

Date _____

Signed _____

Date _____

Signed _____

Date _____

Signed _____

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Date _____

Signed _____

Date _____

Signed _____

Date _____

Signed _____

Date _____

Signed _____

Date _____

Signed _____

Date _____

Please note that this information will be recorded by Nursing and Medical Staff within their own records.

Appendix Two. Referral to Specialist Palliative Care

Referral Form: Network Service for Adults The Village Residence <i>To be completed by Doctor/SLT/Allied Health Professional</i>	POLICY NO:	
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Name: Date of Birth:/..../.....

Address:

Telephone:/.....

Medical Card No. (if applicable)

Client and/or N.O.K. has consented to referral: Yes No

Is the client bed-bound (not independently mobile)? Yes No

If you have answered no, is the client willing to attend & participate in therapy? Yes No

Is there adequate support to help this person implement any recommendations? Yes No

Has the client previously attended SLT – if so please give details? Yes No

Is the referral considered **urgent** or **standard**? Urgent Standard

Medical Diagnosis/Relevant Medical History/Medication/Risk Factors:

.....

Reason for Referral: (please tick)

Assessment required for: Communication Swallowing

Is the client alert and co-operative? Yes No

Concerns/anxiety/distress expressed by client/family Yes No

Is the difficulty impacting the client's functioning in a negative way? Yes No

Signs of aspiration observed (e.g. coughing, choking, throat clearing) Yes No

Recurrent chest infections Yes No

Compromised nutrition/hydration status Yes No

On a modified diet Yes No

Referral considered: Urgent Non-Urgent

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Referred by:	Profession: <i>p.t.o.</i>
Address:	
Signature:	Date of Referral:...../...../.....

- Please send the fully completed form and copies of relevant reports to:
- **North Louth Network:** SLT Services, Primary Care, St. Alphonsus Road, Dundalk
 - **South Louth Network:** SLT Services, Ardee PCT Clinic, St Brigid's Hospital Complex, Ardee

Appendix Three. Abbey Pain Scale.

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident:

Name and designation of person completing the scale:

Date: **Time:**

Latest pain relief given was.....athrs.

Q1.	Vocalisation eg. whimpering, groaning, crying <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q1	<input style="width: 40px; height: 25px;" type="text"/>
Q2.	Facial expression eg: looking tense, frowning grimacing, looking frightened <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q2	<input style="width: 40px; height: 25px;" type="text"/>
Q3.	Change in body language eg: fidgeting, rocking, guarding part of body, withdrawn <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q3	<input style="width: 40px; height: 25px;" type="text"/>
Q4.	Behavioural Change eg: increased confusion, refusing to eat, alteration in usual patterns <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q4	<input style="width: 40px; height: 25px;" type="text"/>
Q5.	Physiological change eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q5	<input style="width: 40px; height: 25px;" type="text"/>
Q6.	Physical changes eg: skin tears, pressure areas, arthritis, contractures, previous injuries. <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q6	<input style="width: 40px; height: 25px;" type="text"/>

Add scores for 1 – 6 and record here ➔ Total Pain Score

Now tick the box that matches the Total Pain Score ➔

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe
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Finally, tick the box which matches the type of pain ➔

Chronic	Acute	Acute on Chronic
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Dementia Care Australia Pty Ltd
 Website: www.dementiacareaustralia.com

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
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Policy on End of Life Read and Understood Form

Please print and sign your name below to confirm you have read and understand the Guidelines on the Management of Care of the Dying and Deceased Patients

	Print Name	Sign Name	Job Title	Date
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