

STANDARD OPERATING PROCEDURE (SOP)

For managing care of dying adults in the last few days

Introduction

The purpose of this SOP is to provide operational guidance to staff working within Department of Health and Social Care and Hospice Isle of Man in relation to the caring for dying, deceased persons, and the people important to them.

The guidance contained within this document has been compiled to assist staff in understanding the issues around death and dying, and to provide them with advice on how to maintain the persons' privacy, dignity and respect.

It aims to help staff improve end of life care for people in their last days of life by communicating respectfully, sensitively and involving them, and the people important to them, in decision making. The guideline covers how to manage common symptoms and maintain hydration in the last days of life.

It is important to recognise that staff, may also be affected at this emotional and stressful time.

Scope

This SOP applies to all health and social care professionals directly involved in the care for the dying person and the people important to them.

This policy provides guidance for staff to ensure the highest possible standard of care for all dying persons and the people important to them before and after death.

The standards of care are based on the following:

- Care of dying adult in the last days (NICE, 2015)
- Priorities for Care of the Dying Person (Leadership Alliance for the Care of Dying people, 2014)
- End of Life Care Strategy (DH, 2008)

Roles and Responsibilities

Care of the dying includes 24-hour care availability to manage pain and symptoms and provide support to the dying person and the people important to them. The Priorities for Care of the Dying Person document (2014) sets out five priorities for care in the last few days and hours of life. It highlights the duties and responsibilities staff to ensure 'the Priorities' are achieved when they are involved in the care of dying people. The way in which we care will vary, to reflect the needs and preferences of the dying person and the setting in which they are being cared for.

Five Priorities of Care:

1. Recognise

The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

- If the person's condition deteriorates unexpectedly the doctor must determine whether the change is potentially reversible, or if the person is likely to die.
- Professionals need to recognise when a person is entering the last days or hours of life.
- A senior doctor should take overall responsibility and the person should be assessed by them or a delegated clinician daily.
- The views of the wider multi-professional team must be taken into consideration.
- Decisions made and actions taken are in accordance with the person's needs and wishes using an advance care plan.
- Consider the person's current mental capacity to engage and actively participate in shared decision-making on their end of life care.
- All discussions must be clearly documented and accessible to all those involved in the person's care.
- Consider whether involvement of a palliative care specialist would be helpful.

2. Communicate

Sensitive communication takes place between staff and the dying person, and those important to them.

- Open, honest and sensitive communication between staff and the person who is dying and those identified as being important to them

- Identify whether the dying person has an advance statement or an advance decision to refuse treatment in place. Included will be their current goals and wishes and whether they have any cultural, religious, social or spiritual preferences.
- Difficult conversations must not be avoided but carried out sensitively.
- Any change in care delivery should be communicated clearly and sensitively to the person where appropriate and to the people important to them.
- Ensure professionals and relevant out of hours services contact details are given to the dying person and those important to them.
- All discussions must be documented and accessible to all those involved in the person's care.

3. Involve

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

- Provide the information needed or are asked for by the person in a manner they can understand.
- Offer support to the person to make informed decisions about treatment and care options.
- Decisions must involve consideration of the potential benefits, burdens and risks of treatment (or non-treatment) for the individual person.
- Provide all the help and support they need to make a decision before a conclusion is made that the dying person cannot make their own decision.
- Actions taken or decisions made on behalf of someone who lacks capacity must be done in their best interests
- Consider carefully which decisions need to be made on-the-spot to ensure the person's comfort and safety, and which can and must wait.
- Openly discuss what would be in the best interests of the person if there are differences of opinion in care and treatment options – seek additional advice, including a second opinion, where there is a continuing difference of opinion or if additional reassurance would be helpful.

4. Support

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

- Regularly assess and address (if possible) the needs of those important to the dying person.
- Ensure those important to the person are welcome and enabled to spend time with the dying person.
- Avoid euphemisms – clear and sensitive communication is best.
- Ensure adequate support is available to the bereaved - allow them to spend time with the deceased person, if they wish.

5. Plan & Do

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

- Offer the dying person the opportunity to discuss, record and update their wishes and preferences as part of individualised care planning.
- Take account of and give weight to the views, beliefs and values of the person in agreeing the plan of care and review this regularly.
- Show those important to the person some simple practical techniques, if they wish to participate in the care (assumptions must not be made about their ability or wish to participate).
- Decisions made must be in the person's best interests if it is established that they lack capacity.

Assess

- The person's physical, social, psychological, spiritual, cultural and religious needs must be assessed to formulate personalised care plans.
- Assessment must be conducted with respect for personal privacy and dignity.
- Ensure all assessments are conducted openly and those important to the dying person are provided with clear and concise explanations.

Food and Drink

- Support the person to eat and drink as long as they wish to do so and as long as there is no serious risk of harm (e.g. aspiration/choking)
- Consider alternative forms of hydration if the dying person is unable to swallow.
- If a dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected.
- Offer frequent care of the mouth and lips to the dying person, and include the management of dry mouth in their care plan, if needed.
- When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:
 - any distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration if inadequate.
 - preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs.
 - the risk of pulmonary oedema.
- Refer to General Medical Council 2010 guidance “Treatment and care towards the end of life: good practice in decision making and relevant clinical guidelines”.

Symptom Management

- When considering medicines for symptom control, take into account:
 - the likely cause of the symptom
 - the dying person's preferences alongside the benefits and harms of the medicine
 - any individual or cultural views that might affect their choice
 - any other medicines being taken to manage symptoms
 - any risks of the medicine that could affect prescribing decisions
- Discuss all changes in treatment/medication, including the use of a syringe pump, with the dying person and to those important to them. Other than in exceptional circumstances, this should be done before used.
- Common side effects, especially drowsiness, must be discussed with the person to enable them to make informed decisions, and explained to those important to them, if the person wishes.
- Clearly document the clinical rationale for prescribing or indeed discontinuing medication e.g. the starting dose, regular review, and adjustment needed for effect.
- Avoid giving intramuscular injections - give either subcutaneous or intravenous injections if unable or have difficulty swallowing.

- Seek further advice from the specialist palliative care team if symptoms are difficult to manage (e.g. initial measures have failed to provide adequate relief within at most 24 hours).
- Just in Case Box protocol is used in the community setting.

Spiritual care

- Discuss with the dying person and those important to them, if they have any cultural or religious requirements, including care after death.
- Contact the relevant chaplain and /or spiritual care provider, if wanted.
- Document wishes/needs in the personalised care plan.

Co-ordinating care

- Provide accurate and timely handover to teams taking over care, particularly regarding the person's wishes.
- After discussion with the dying person a Do Not Attempt Cardiopulmonary Resuscitation Order should be in place. Documentation (according to local policy and procedure) is completed Explanation is also given to the people important to them as appropriate.
- Refer as appropriate to other specialist services for further guidance (i.e an Insulin Dependent Diabetic - contact Diabetes Nurse Specialist; if the person has an Implantable Cardioverter Defibrillator (ICD), contact the person's cardiologist. Refer to ECG technician and to local guidelines re deactivating it).
- Refer to the rapid discharge policy if the dying person indicates they wish to die at home.

Documentation

- Record individualised care plan discussions and decisions in the dying person's personalised care plan and share this with them, those important to them and all members of the multiprofessional care team.
The record of that conversation must include the following:
 - That the clinician explained that the person is now dying and when and how death might be expected to occur.
 - If the persons important to the dying person do not accept that they are dying, the clinician has explained the basis for that judgement.
 - That the persons important to the dying person had the opportunity to ask questions.

- Update any changes in the person's condition at least every 24 hours in the individual care plan.

Care after Death

- When the person dies, verification of death should be recorded according to local guidelines. Death certified and appropriate documentation completed.
- Last offices are undertaken according to policy and procedure.
- Information is given to the persons important to the deceased about what they need to do following the death of their loved one. Ensure relevant written information is also given.
- Ensure the appropriate services across the health organisation are informed. E.g. Palliative Care Team, Social Worker, Occupational Therapist, Physiotherapist, District Nurse etc.
- Bereavement care leaflet/pack is offered to the relatives and referral to bereavement team if wanted and/or necessary.

Audit

- Measurement of end-of-life care through audit and research, which should look into the structure, process and outcome of end of life care.
- Undertake regular audit of clinical work in all care settings.

References

End of Life Care Strategy (DH, 2008)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf.

Independent review of the Liverpool Care Pathway: More Care Less Pathway

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf.

National End of Life Care Programme Website:

<https://www.endoflifecareforadults.nhs.uk/education-and-training/communication-skills>.

National Institute for Health and Care Excellence – care of dying adults in the last days of life (NICE, 2015)

<https://www.nice.org.uk/guidance/ng31>

Priorities for Care of the Dying Person (2014)

<https://www.nhs.uk/endoflifecare>

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Watts, T. (2012) 'End-of-life care pathways as tools to promote and support a good death: a critical commentary', *European Journal of Cancer Care*, vol.21, no.1, pp.20-30.