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General Note

NHS Fife acknowledges and agrees with the importance of regular and timely review of policy/procedure statements and aims to review policies within the timescales set out.

New policies/procedures will be subject to a review date of no more than 1 year from the date of first issue.

Reviewed policies/procedures will have a review date set that is relevant to the content (advised by the author) but will be no longer than 3 years.

If a policy/procedure is past its review date then the content will remain extant until such time as the policy/procedure review is complete and the new version published, or there are national policy or legislative changes.

Definitions

End of Life Care

End of life care should follow from the diagnosis of a patient entering the process of dying, whether or not they are already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.
For the purposes of this Policy, End of Life is defined as; “when the team caring for the person agree that death is expected within hours to days and a natural death is occurring with all possible reversible causes having been considered”. End of Life Care is the care given to patients in the last days and hours of life

Palliative Care

Palliative care seeks to improve the quality of life of patients and their families living with life limiting conditions. Palliative Care aims to:

- affirm life and regards dying as a normal process
- intends neither to hasten or postpone death
- uses a team approach to address the needs of patients and their families
- provides relief from pain and other distressing symptoms
- integrate the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help relatives and carers

Generalist Palliative Care

Generalist palliative and end of life care is an integral component of compassionate care delivered by all health and social care practitioners and is not dependant on diagnosis or place of care. Palliative Care should be delivered alongside active treatment where appropriate.

Specialist Palliative Care

Specialist Palliative Care is provided by specially trained multi-professional specialist teams and seeks to support individuals (and their families) with complex palliative and end of life needs.

1. FUNCTION

1.1 NHS Fife affirms the importance of end of life and palliative care which is person centred and which is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.

1.2 **This policy is informed by;**

- Scottish Palliative Care Guidelines (2019)
- NHS Fife: Clinical Strategy (2016)
- Scottish Government: Strategic Framework for Action on Palliative and End of Life Care. (2015)
- Scottish Government: "Caring for people in the last days and hours of life" (2014)
- Scottish Government: Shaping Bereavement Care (2011)

1.3 The policy recognises that those providing end of life care, including staff, may require support.

1.4 The policy recognises the importance of commencing bereavement care prior to the death, where the death is expected, or at the earliest possible point in the event of sudden or unexpected death.

1.5 This policy seeks to support a new culture of openness about death, dying and bereavement.

2. BACKGROUND

2.1 In 2014 the World Health Assembly the governing body of the World Health Organisation passed a resolution requiring all governments to recognise palliative care and to make provision for it in their national health policies.

2.2 In 2015 the Scottish Government published its "Framework for Action on Palliative and End of Life Care" which clearly articulated a vision for palliative care in Scotland and set out an ambitious set of commitments to ensure that everyone in Scotland receives the end of life care they require.

2.3 In 2016 NHS Fife published its Clinical Strategy which includes a number of recommendations in relation to the development, and provision of, Palliative Care in the Last Days of Life.

3. LOCATION

3.1 This policy applies across all health and social care settings within NHS Fife including domiciliary settings where healthcare professionals provide care.

4. AIMS & OBJECTIVES

4.1 NHS Fife seeks to support end of life care which is person centred and based on neither diagnosis nor prognosis but on the individuals needs.

4.2 NHS Fife seeks to promote an approach which recognises the diversity of life circumstances of people who require palliative and end of life care and which is responsive to these circumstances, whether they relate to age, disability, gender, race, religion/belief or sexual orientation.

5. OBJECTIVES

5.1. The provision of high quality person centred care for the dying person, their family and carers to reduce, where possible, a negative impact for those supporting the dying person in their bereavement.

5.2 To improve the identification of people who may benefit from palliative and end of life care.

5.3 To enhance the contribution of a wider range of health and care staff providing Palliative Care.

5.4 To ensure staff feel adequately trained and supported to provide palliative and end of life care when and where it is needed.

6. RESPONSIBILITY

6.1 Responsibility of Director of Nursing

6.1.1 The Director of Nursing, as executive lead for End of Life and Palliative Care, has overall responsibility to ensure the principles and aims within this policy are met.

6.1.2 Coordinate the development of services that ensure those living with a life limiting illness, have access to best supportive care and palliation as required to prepare for end of life.

6.2 All Staff

6.2.1 All staff should be aware of the uniqueness of the dying process and, of each individual's death, and should respond sensitively and empathetically to people's needs

6.2.2 Ensure that the patient and where appropriate their carer, will be enabled to collaborate in, and manage, their care in partnership with health and social care providers.

6.2.3 Ensure that all care is planned and delivered with the person at the centre; ensuring care reflects their wishes, priorities and goals for treatment including contributing to their own anticipatory care plan.

6.2.4 Ensure that the patient has access to clearly defined point(s) of contact appropriate to their treatment and care plan.

6.2.5 Staff whose duties involve coming into contact with or caring for people with a life limiting condition should ensure they conduct themselves in a respectful and sensitive manner.

6.2.6 Staff should be respectful of the preferences, choices and decisions during the last days and hours of an individual's life.

6.3 Responsibility of Management

6.3.1 Managers have responsibility for the effective implementation of this policy and for ensuring that arrangements are in place within their spheres of responsibility to facilitate the delivery of safe, effective and sensitive care for patients in the last days and hours of life.

6.3.2 Managers should support staff in the development of knowledge and skills that evidence compliance with this policy, ensuring that, staff have access to appropriate education, training, resources and support.

6.3.3 To ensure that services within their area of responsibility have the appropriate workforce and capacity to undertake their commitment on behalf of NHS Fife in relation to generalist and specialist palliative care provision.

6.3.4 Recognise that staff can be affected when working with patients who have life limiting illness or who are dying. Managers should ensure staff are aware of and have access to bereavement support from Staff Health & Wellbeing or the Department of Spiritual Care.

6.3.5 Managers should ensure that staff have access to appropriate support and are cared for in line with Shaping Bereavement Care (2011), according to individual circumstances.

6.4 Medical Staff

6.4.1 Identify people who are likely to be in the last 6-12 months of life, enabling effective anticipatory care planning to deliver a person centred and planned approach to the provision of care to patients who are in the last days and hours of life.

6.4.2 Ensure timely, sensitive and focused conversations for those identified with palliative care needs and their careers. This is aligned with Realistic Medicine and enables person-centred goals for care, including participating and contributing to anticipatory care planning by the patient.

6.4.3 Ensuring Anticipatory Care Planning is in place, is clearly documented and communicated to all health care professionals involved in delivery care to the person and their carer and relatives. This enable a consistent and supportive plan of care is available to meet the persons individualised needs. In particular medical staff should consider and record:

- What active treatments should continue
- Resuscitation status discussed and documented
- Decisions regarding clinically assisted hydration and nutrition are documented
- Anticipatory prescribing of medications for managing pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation and noisy respiratory secretions have been considered and prescribed if appropriate
- Consider the emotional, spiritual and psychological needs of the patient and carer

6.4.4 Establish with the person identified as dying and their relatives, to what extent, they wish to be involved with discussions and decision making. This includes establishing whether there are plans or wishes expressed by the person about their care at this point. It should always be clear when discussing a decision with a person if they are being informed of that decision or if consent is being sought. Documentation of these conversations and outcomes is critical.

6.4.5 Understand that the care of the dying person involves active care and that the person needs ongoing assessment, decision making and tailoring of the care given. Within the inpatient setting the Hospital Anticipatory Care Plan (HACP) is available to support anticipatory care planning for patients during their admission to hospital or hospice.

https://intranet.fife.scot.nhs.uk/atoz/index.cfm?fuseaction=policy.display&objectid=53519CEF-A12A-E87F-5900684899722E0A

6.4.5.1 Carefully consider whether investigations and procedures are appropriate or likely to affect decisions and care when someone in the last days and hours of life.

6.4.5.2 Documentation of decisions, both for and against active interventions, should be made and communicated to the person, relatives and team wherever possible.

6.4.5.3 Document a clear treatment plan, **including DNACPR status** and escalation of treatment.

6.4.5.4 Document conversations with the patient and their family as appropriate, clarifying goals of care and their understanding of current situation and wishes in relation to ongoing care delivery.

6.4.5.5 Review the HACP and document updates.

6.4.6 People who deteriorate and appear to be in the last days and hours of life can improve even when this is not clinically expected. It is therefore essential that ongoing meticulous assessment continues as uncertainty always exists. If a person is thought to be improving this should be communicated to the person, relatives and to the staff involved in their care. Where there is a high level of uncertainty, advice should be sought from an experienced colleague, or the specialist palliative care team.

6.4.6.1 Senior review and decision making is key in caring for a dying person.

If person deteriorates out of hours they should be reviewed by a senior member of their core team as a priority within the normal hours of work.

6.5 Nursing Staff

6.5.1 Care should be delivered in line with the standards as detailed in the NHS Fife 'Nursing Standards: Compassionate Care in the Last Days of Life' (Appendix 1)

6.5.2 Work in partnership with members of the Multi-disciplinary Team to identify people who are at the end of life and depending on role support these discussions with the patient, carer and relatives to provide a multi professional approach to care planning and delivery.

6.5.3 Challenge the appropriateness of care if concerned about inappropriate interventions, and to act as the patient's advocate.

6.5.4 Undertake a holistic assessment of the dying persons needs, involving carers and relatives as appropriate, to ensure care needs are identified and a plan of care is in place to meet those needs.

6.5.5 Ensure that the care delivered is person centred and aligns with the interests of the patient, and that the plan of care is clearly documented and communicated to ensure a consistent approach.

6.5.6 When a person has been identified as dying they should be supported to continue with hydration and nutrition as much as they are able and is safe.

6.5.7 Medication is often delivered subcutaneously by injection or by continuous infusion. Registered nurses using such methods should be adequately trained in the medication that can be delivered this way and the use of such devices.

6.5.8 When a person has died, the wellbeing of their relatives must be considered and adequate immediate support offered in the first instance. People who want to spend time or visit the deceased person must be supported to do so.

6.5.9 Monitor care delivery and respond to any concerns in relation to care of persons with palliative care needs and at the end of life.

6.6 Allied Health Professionals (AHP)

6.6.1 AHP staff have a responsibility to undertake a holistic assessment of need, involving family and carers, as appropriate, for all palliative care patients referred to their service.

6.6.2 AHP staff have an important role to play in the non pharmacological management of symptoms experienced by palliative care patients and in promoting self management. As patients approach end of life, AHP staff have a responsibility to adapt their approach accordingly and interventions may be of a more supportive and educational nature to help maintain dignity and quality of life.

6.6.3 AHP staff are responsible for ensuring that intervention and plans are clearly documented in the patients ward notes and communication with community staff is carried out in a timely manner.

6.6.4 AHP staff have a responsibility to discuss with medical and nursing staff if they identify patients with palliative care needs.

6.7 Spiritual Care

6.7.1 Spirituality relates to the way in which people understand and live their lives in view of their core beliefs and values and their perception of ultimate meaning and is a core aspect of person centred care.

6.7.2 Spiritual, cultural and religious needs vary from patient to patient. Person centred care requires that each individual's needs are respected and met in an appropriate way. Staff should recognise the importance of including these dimensions of an individual's life and death.

6.7.3 Spiritual needs can be an important part of a person's journey at the end of life. Health and social care staff should ensure spiritual needs are identified, recorded in agreed care plans and be comfortable in supporting these needs and

6.7.4 Registered Healthcare Chaplains shall provide expertise and guidance to ensure that the death, culture and beliefs of an individual are recognised, and provided for, when they are dying and in their care after death.

6.7.5 Registered Healthcare Chaplains shall provide quality patient-centred spiritual care for staff, patients, carers and relatives, recognising everyone needs support systems especially in times of crisis and when confronting serious or life-threatening illness or injury. Patients, relatives and staff often require someone to listen to their experience and help them cope.

7. OPERATIONAL SYSTEM

7.1 Scottish Palliative Care Guidelines

Care should be delivered in line with standards as detailed in Scottish Palliative Care Guidelines that is, review and management of reversible causes of deterioration, along with ensuring effective symptom management in particular pain control, appropriate anticipatory prescribing, and effective care planning to meet the individual patient needs.

http://www.palliativecareguidelines.scot.nhs.uk/

7.2 DNACPR

7.2.1 The Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy (2010) provides guidance in Scotland for clinical staff to support people with the right care at end of life, recognising that there needs to be a decision about whether cardiopulmonary resuscitation is appropriate in relation to identifying patients for whom cardiopulmonary arrest represents the terminal event in their illness and for whom CPR will fail and/or is inappropriate.

7.2.3 The DNACPR forms have been embedded in practice for a number of years however their use is often variable. Clinical staff are required to adhere to the guidance, and ensure DNACPR forms are reviewed, decisions respected and communicated effectively with patients and their families. For more specific information and guidance seewww.scotland.gov.uk/dnacpr

7.3 Anticipatory and advance care planning

7.3.1 Anticipatory care planning is when the plan of care considers what matters to the person in relation to managing their future care (including place of care at the end of life) and which recognises people as an individual and requires the need for clearly communicated plans of care. It is important this plan involves the patient where possible, as well as family and carers to allow for realistic goals of care.

7.3.2 Many people move between care settings and ensuring a consistent approach to care, that augment the plan of care rather than rewriting it. It is critical that information is shared and can be accessed at a time when clinical teams require support and direction.

7.3.3 The single repository of information at present is the Key Information Summary (KIS) which can be accessed across acute and community services however can only be added to by the person's general practice. Providing information for entry to the KIS, and accessing a person's KIS on presentation to hospital are important to ensure continuity of care.

7.3.4 As noted in 6.4.5 NHS Fife have a Hospital Anticipatory Care Plan (HACP) for use within the inpatient setting which enables treatment plans to be detailed along with escalations of treatment, and communication with patient and families related to the inpatient stay. The HACP should be reviewed regularly, and at discharge with any relevant information shared with the GP for update in the KIS.

7.4 Referral to Specialist Palliative Care Service

7.4.1 Palliative care is everyone's business and should be provided in all care settings by all clinical staff. Within NHS Fife there is a specialist palliative care team who can provide advice and clinical management support for patients with complex symptoms and care needs.

7.4.2 Ward based staff can make referrals for patients to AHPs on ward teams. Patients with non-pharmacological symptom management needs and complex discharge planning can be referred to the specialist palliative care occupational therapy team. Referrals received by Occupational Therapists for discharge planning for end of life care are responded to as a priority.

7.5 Transfer of people who may be in the last days and hours of life

7.5.1 Wherever possible, in the hospital environment, transfer of patients within the terminal phase should not occur. Where such a transfer is suggested, and where there is no clinical need to move the patient, such transfers should only occur following discussion with senior clinical staff.

7.5.2 People who are recognised as dying may be transferred between care settings to ensure care is delivered in an appropriate place, and where possible reflecting the person and their family wishes. For example a person may wish to go home to die, transfer to a hospice or move to a familiar in patient area if care is being withdrawn from a critical care area.

7.5.3 To ensure safe movement and coordination of care, the transfer should be agreed with the patient and or carer, as well as the medical and nursing staff responsible for delivering care.

7.5.4 Effective communication (that is, direct verbal communication as well as relevant documentation) should be in place to ensure the receiving service have the appropriate information, to prepare for the patients arrival, appropriate accommodation, equipment, medication and staff resource available. Clear transfer documentation requires to be in place, including valid DNACPR form, AWI and copies of relevant care plans and documentation including the HACP.

8 RISK MANAGEMENT

8.1 Awareness of this policy will ensure that patients, relatives and carers wishes are known, reflected in the patients care plan and respected as care is provided at the end of life.

8.2 All NHS Fife staff must follow this policy and local procedures to ensure all patients who have palliative care needs, specialist and generalist, and are at the end of their lives have access to the care and support they need.

9. RFERENCES

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Scottish Government (2016) Strategic Framework for Action on Palliative and End of Life Care

Scottish Palliative Care Guidelines, Health Improvement Scotland and NHS Scotland. http://www.palliativecareguidelines.scot.nhs.uk

The Kings Fund (2010). *Implementing the End of Life Care Strategy – lessons for good practice.* London, The Kings Fund.

The Scottish Partnership for Palliative Care (2016)
https://www.palliativecarescotland.org.uk

World Health Organisation (2016) http://www.who.int

10. RELATED DOCUMENTS

1. Appendix 1 - Nursing Standards: Compassionate Care in the Last Days of Life

2. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy (2010), NHS Scotland

3. NHS Fife Hospital Anticipatory Care Plan Standard Operating Procedure (2018)

4. NHS Fife Spiritual Care Policy (2018)

5. Strategic Framework for Action on Palliative and End of Life Care (2015).

6. Alzheimer Scotland Advanced Dementia Practice Model: Understanding and transforming advanced dementia and end of life care (2015)

http://www.alzscot.org/assets/0001/9474/AlzScot_ACReport_FINAL.pdf

Nursing Standards: Compassionate Care in the Last Days of Life

PRIORITIES

Timely

STANDARD 1

There will be timely identification and communication that the person is nearing the end of life

- Nurses have a role in identifying when deterioration in a patient's condition indicates that there is a potential that the patient may die in the proceedings hours/days or is imminently dying.
- Nurses have a role in participating in the MDT assessment to establish the patient is at the End of Life and that there are no reversible causes identified
- Nurses have a role in the timely communication with the patient / family providing 'time' with the family in order to support the family come to terms with the prognosis
- Nurses have a role in the regular, planned review and documentation of the care plan to ensure that the most appropriate care is given as the patient's condition deteriorates, stabilises or improves
- Nurses have a role in preparing patients and their families of what to expect when the patient deteriorates and dies and in the period following death.
- Nurses have a role in coordinating and ensuring timely referral to other members of the multi-professional team and private sector as appropriate.
- Nurses have a role in ensuring the timely access to necessary equipment
- Nurses have a role in ensuring patients and their families have access to advice and support when they need it

Person Centred

STANDARD 2

Patients and their family will be involved in shared decision making and their needs and preferences will be pivotal to the care they receive

- Nurses have a role in ensuring that the patient's / families wishes are considered and that they are involved in shared decision making with regards to further investigations and treatment
- Nurses have a role in communicating with the patient / family to establish 'What Matters to them' and their personal, Religious, Spiritual and cultural beliefs, wishes and preferences are recognised and used to inform the care that is provided.
- Nurses should prioritise spending time with patients and their family and clarify the aim of care, providing regular updates with any change to the patient's condition or management.
- Nurses have a role in the documentation and communication of Patient's / Family's wishes and any significant conversations
- Nurses have a role in ensuring that patients are cared for in an environment that provides privacy and promotes a feeling of spiritual wellbeing, with the opportunity for the patient / family to personalise the space if desired.
- Nurses have a role in providing comfort and support to families communicating available facilities and refreshments and relaxed visiting times
- Nurses should act as the patient advocate at all times

Fundamentals of Care

STANDARD 3

Patients will receive an excellent standard of holistic and personalised fundamental Nursing Care

- Nurses will ensure regular mouth care and assessment of hygiene needs.
- Nurses will ensure regular Pressure Area Care and positional changes for comfort as appropriate
- Nurses will encourage and support oral food / hydration as patient is able
- Nurses will Check bladder and bowel function and consider catheterisation if appropriate
- Nurses will deliver personal care as per patient and family wishes maintaining the patient's privacy, dignity and respect.
- Nurses will Involve the patient and their families in the provision of personal care where appropriate and in accordance with the patient's/family's wishes and preferences
- Nurses will ensure that the patient is kept comfortable and that their basic needs are met

Symptom Management

STANDARD 4

Patients will receive appropriate and timely treatment and symptom management

- Nurses have a role in participating in conversation with the patient/family with regards to ceilings of care and resuscitation. Where appropriate the nurse will support the timely and accurate completion of the HACP and DNACR paperwork.
- Nurses have a role in ensuring that the patient does not receive any unnecessary treatments or interventions
- Nurses have a role in ensuring appropriate medications are prescribed for anticipated symptoms e.g. pain, nausea, vomiting, breathlessness, agitation, respiratory secretions
- Nurses have a key role in assessing patients symptoms and comfort and reviewing the effectiveness and appropriateness of the patient's treatment plan
- Nurses have a role in considering appropriate changes to the mode of medication delivery to a subcutaneous syringe pump if patients remain symptomatic or are no longer tolerating oral medication.
- Nurses should seek advice and support from other HCP or the Specialist Palliative Care Team as required

Bereavement and Care After Death

STANDARD 5

Patients, their families and the staff's emotional and spiritual wellbeing will be supported during and following death

- Nurses have a role in supporting the family throughout the bereavement process, which can begin pre-death, recognising the different responses to loss e.g. 'Spiritual Distress'.
- Nurses have a role in identifying families that may require additional bereavement support e.g. 'complex grief'
- Nurses should be aware of additional support services that are available for patients and their families and refer or signpost to these as appropriate.
- Nurses have a role in delivering the last offices/Last acts of care whilst maintaining the person's privacy, dignity and respect at all times. Family should be supported to participate in the Last acts of care if relevant.
- Nurses must respect the religious or cultural wishes of the deceased and their family where possible, and ensure legal obligations are met
- Nurses have a role in ensuring the timely confirmation of death and that the death certificate is issued sensitively and is correct, with a clear explanation with regards to registering the death. A bereavement pack and advice should be provided.
- Nursing staff involved in the care of a dying patient should receive support and have the opportunity to discuss their experience with the team and/or their line manager and be signposted to additional support if required.

Frequently assess, action, review and document

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