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People
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Palliative and End-of-Life Care Procedure

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Contents

1.0 Introduction	4
1.1 Relevant policies and procedures	4
2.0 Definitions	5
2.1 Palliative and end-of-life care	5
2.2 End-of-life care definition	5
2.3 When does palliative care start?	6
3.0 Capacity	6
4.0 Palliative and end-of-life care principles	7
4.1 PANEL principles	7
5.0 Advanced care planning	7
5.1 Advanced care plans	7
6.0 Multi-disciplinary working	8
6.1 Potential multi-disciplinary team)	9
7.0 Risk & vulnerability	9
8.0 Confidentiality and information-sharing	10
9.0 End-of-life care	10
9.1 Symptoms	10
9.2 Interventions	11
9.3 Preserving dignity	12
9.4 Final hours	13
10.0 Staff training	13
11.0 Implementation and Review	14
11.1 Implementation	15
11.2 Review	15

[Appendix 1 list of related information](#)..... 16

1.0 Introduction

Supported people have the right to receive good palliative and end-of-life care. When a supported person is diagnosed with a life-limiting condition this will trigger the commencement of a palliative care approach by staff.

ARK will work to ensure supported people are supported to “live well” with their life-limiting illness or condition.

ARK will provide care and support which is both person-centred (putting the individual at the heart of all choices and decisions) and relationship-centred (taking into account the significant relationships between supported people, their friends, family and staff).

Individuals will be supported to plan the care and support they wish to receive and plan for the end of their life.

ARK will support individuals to maintain and improve their quality of life by ensuring they continue to have access to information in accessible formats, are enabled to maintain their usual routines, have access to social networks and continue to live lives that are meaningful for them.

ARK recognises that multi-disciplinary team working is vital in providing holistic and effective palliative and end of life care and support.

Care & Support staff will be trained and supported to provide the highest quality palliative and end-of-life care and support where required.

1.1 Relevant policies and procedures

This procedure is aligned with **CS11 Death & Dying**

It should be read and understood in conjunction with:

- CS02 Personal Planning
- CS04 Risk & Vulnerability
- CS11 Death of a Supported Person
- G24 Privacy & Data Protection

2.0 Definitions

2.1 Palliative and End-of-life Care

An approach that improves the quality of life of people and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Planning for care at the end-of-life should be responsive to the person's choice regarding place of care and place of death.

Palliative and end-of-life care are integral aspects of care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition.

(World Health Organisation, 2004)

Palliative care is treatment, care and support for people with a life-limiting illness, and their family and friends. It is sometimes called 'supportive care'.

The aim of palliative care is to help the individual have a good quality of life – this includes being as well and active as possible in the time they have left. It can involve:

- managing physical symptoms such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- support for family and friends.

(Marie Curie 2018)

2.2 End-of-life care definition

End-of-life care involves treatment, care and support for people who are nearing the end of their life. It is an important part of palliative care.

It is for people who are thought to be in the last year of life, but this timeframe can be difficult to predict. Some people might only receive end-of-life care in their last weeks or days.

End-of-life care aims to help individuals to live as comfortably as possible in the time they have left. It involves managing physical symptoms and getting emotional support for the individual and their family and friends.

End-of-life care also involves talking to the individual and their family and friends about what to expect towards the end of your life. Care & Support staff looking after the individual will discuss their needs and wishes with them, and make sure they consider what the individuals want from their care.

(Marie Curie 2018)

2.3 When does Palliative Care Start?

The initial diagnosis of a life-limiting condition should be recognised as a trigger for the introduction of a palliative care approach.

3.0 Capacity

People are presumed to have capacity unless we have evidence to suggest otherwise and in that case it is the responsibility of the Care & Support team to raise these concerns with the appropriate health and social work professionals.

It is a possibility that the supported person could lose capacity as their illness or condition progresses; this is likely to be the case where the person has dementia. In order that the person can ensure their preferences and wishes are carried out if and when they lose capacity they should be supported to consider granting Power of Attorney (welfare and/or financial) to an appropriate person, e.g. a family member or friend. The services of a solicitor are required for this process.

If a person no longer retains capacity it may be that family members (if appropriate) or the local authority have to apply to the courts for welfare and/or financial guardianship. This can be a lengthy process and it may be that the guardian has different views than those of the supported person. If a person has expressed their wishes in the past these wishes must be taken into account. If there is any concern about adherence to the wishes of the individual, the Mental Welfare Commission and/or Office of the Public Guardian can offer advice and guidance.

Supported people who lack capacity must have a Section 47 certificate in place regarding consent to medical treatment, however this certificate does not include any other decision-making powers. Supported people who are receiving palliative care and lack capacity should have a legally appointed representative in place to act on their expressed wishes and/or make decisions on their behalf.

Do Not Resuscitate / Do Not Attempt Cardiopulmonary Resuscitation orders (usually referred to as DNACPR) cannot be made simply on the basis of an individual having a disability and should take account of the individual's, and where relevant, their family's

wishes. Clinical responsibility for this decision rests with the most senior medical professional involved in the person's care, and they are not obliged to attempt CPR against their professional judgment.

4.0 Palliative and end-of-life care principles

4.1 PANEL principles

The PANEL Principles is a human-rights-based approach to palliative and end-of-life care. These are:

- Participation – People should be involved in decisions that affect their rights.
- Accountability – There should be monitoring of people's rights are being affected, as well as remedies when things go wrong.
- Non-Discrimination – All forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.
- Empowerment – Everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.
- Legality – Approaches should be grounded in the legal rights that are set out in domestic and international laws.

5.0 Advanced care planning

Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.

International Consensus Definition of Advance Care Planning (Sudore, et al., 2017)

5.1 Advanced care plans

The aim of advance care planning is to develop better communication and recording of decisions, thereby leading to provision of care based on the needs and preferences of supported people and carers.

Advanced care planning enables supported people to make choices and decisions about the care and support and death they wish to have when they no longer retain the capacity to make such choices and decisions.

ARK will ensure that palliative and end-of-life care plans are developed and implemented with all supported people with palliative and end-of-life care needs as the outcome of a person-centred planning process which takes account of their needs, wishes and preferences at every stage of the journey. The care planning process will involve all the people important to the individual and will be reviewed on at least a 6 monthly basis or more regularly as the individual's needs and wishes change.

Care planning should also take account of any religious, cultural, spiritual or other life circumstances that are relevant to appropriate care. The individual's and their family's beliefs, values and cultural practices should be respected.

Key Issues:

- Information needs
- Being treated as a human being
- Empowerment
- Physical needs
- Continuity of care
- Social needs
- Psychological needs
- Spiritual needs

The advanced care plan should include the supported person's/ family members' views on:

- Resuscitation
- Eating and drinking
- Antibiotics
- Pain and pain-management
- Antipsychotic medication
- Hospital admission
- Medical treatment

6.0 Multi-disciplinary Working

Communication between all members of the multi-disciplinary team is vital if supported people are to receive good quality and effective palliative and end-of-life care. Care & Support staff will work proactively in communicating and planning for the individual's care and support with the multi-disciplinary team.

6.1 Potential multi-disciplinary team

- District Nurse - Primary palliative care provider. Carries out most aspects of the plan of care. Monitors supported person's physical condition, symptoms, pain management, and response to palliative interventions.
- Care & Support staff – In providing direct care, helps district nurse to identify supported person's needs and monitor response to treatment. Delivers many non-medical palliative interventions. Provide individual meaningful activities to enhance the quality of life of the supported person.
- GP or Nurse Practitioner – Monitors physical response to palliative care, orders necessary interventions, discusses prognosis with supported person/family, orders supported person's advance directives
- Local Authority/Social Worker – Helps supported person/family plan for end-of-life issues like finances and funeral arrangements. Ongoing review of supported person's support needs.
- Dietitian – Offers suggestions for appropriate diet at the end-of-life and help families be involved in meals.
- Speech and Language Therapist – Provide support and guidance regarding food textures and potential choking risks for the supported person whilst in of life care.
- Preferred spiritual representative – Provides spiritual and emotional support to supported person, families, and even staff
- Physiotherapist and/or occupational therapists – Provide therapies or supportive devices to maximize supported person's comfort; teach family members, support staff etc. how to assist supported person and/or be involved in supported person's care.

7.0 Risk & vulnerability

As the supported person's illness or condition progresses, there may be increasing risks of harm, see: **G57a Adult Support & Protection**

Staff will carry out or review and amend the Risk and Vulnerability Assessment on an on-going basis. The focus remains on maintaining the supported person's abilities and not focussing on deficits. Good Life Documentation must focus on the outcomes for the individual and balance the health and safety risks with the emotional and psychological risks facing the supported person if they are not enabled to living meaningful and purposeful lives. See: **CS02 Personal Planning** and **CS04 Risk & Vulnerability**

8.0 Confidentiality & information-sharing

As an illness or condition progresses the individual's personality, appearance and/or behaviour may change as a result. These changes can cause anxiety and frustration for other supported people and can have negative impacts on relationships, particularly in group living situations, when there is a lack of understanding of the reasons for the changes.

The supported person's diagnosis can only be shared with other supported people to raise awareness and understanding and to maintain relationships in the following circumstances:

- The individual has given consent
- Where the individual lacks capacity, consent has been granted by the continuing attorney or guardian.

The information should be presented in a format that is accessible for individual supported people e.g. Talking Mats, social stories, visual formats etc. Information provided should be appropriate to the understanding of the supported people.

Where no consent to share the diagnosis is given, an explanation of why someone is behaving in a different way may be discussed; for example, the person is not feeling so well, or is a bit more forgetful.

Supported people may require additional support during this time. This could be due to their emotions regarding the ill -health of a friend or dealing with the realisation of their own mortality. Some people may have little experience or understanding of dying and death and may require specialist support. Person-centred support must be offered to meet the needs of these supported people.

9.0 End-of-life care

9.1 Symptoms

- Pain
- Respiratory symptoms
- Gastrointestinal symptoms
- Psychological symptoms

Pain can be the most common symptom for people in end-of-life and can be difficult to manage for people with communication difficulties. See: **Appendix 1 The Abbey Pain Scale** to help staff to identify pain for people who cannot verbalise.

Research has shown that, despite the common nature of pain, it is often under-addressed and under-treated. A thorough pain assessment (source, level) is critical to ensuring that the person's comfort is maximized through appropriate pain management.

Respiratory symptoms are also very common; for example, shortness of breath, wheezing, and coughing.

Gastrointestinal symptoms are also significant. In some situations, however, if, nausea or constipation is not bothersome to the person, it may not require intervention. If the person is not eating or eating very little, constipation is a natural consequence.

Untreated psychological symptoms can diminish quality of life at the end-of-life, for example depression, delirium and anxiety. Assessment and intervention are appropriate.

9.2 Interventions

Nurses are in the best position to determine whether the person needs around-the-clock versus 'as required' (PRN) medications for pain. A person with one or more chronic painful conditions, such as arthritis, peripheral vascular disease, or a chronic wound, should get around-the-clock medications. These medications may be in the form of a controlled drug, where particular rules apply in terms of storage apply, for example, opioid-based medications like morphine. See: **CS08 Support with Medication**

Care & Support staff are in an ideal position to help assess pain because they spend the most time with the person. Pain assessment observations should include intensity, location, duration, what makes it better or worse, and any changes Care & Support staff may notice from previous observations. Continued assessment of pain relief from medications is critical, because people are often under-medicated. Ensure the supported person is receiving an appropriate dose.

To address respiratory symptoms, interventions such as oxygen, nebulizers, and/or diuretics (if related to heart failure) are often effective. Other options to address respiratory symptoms may include an antitussive with codeine (which may also help if the person cannot sleep due to night-time coughing) or prednisone.

To address nausea, consider both pharmacological and non-pharmacological interventions. Removing dietary restrictions may be both appropriate and helpful.

Psychological symptoms are often the most difficult to treat. If the person is delirious, a GP appointment should be made to determine the cause and alleviate it.

In the case of depression and/or anxiety, the physician or nurse practitioner should do an assessment to determine the diagnosis. Medications such as anti-depressants or anxiolytics (anti-anxiety medications) can be very helpful.

In addition to medications, there are many non-pharmacological or non-medicine interventions that can help the person. Examples include therapeutic touch or massage, reminiscing with the person, playing music, and aromatherapy. The presence of family or comforting/familiar faces often helps relieve a person's anxiety.

Families may want to have a more involved role in caring for the person. Give the family suggestions on how they can support the person. For example, they may want to bring in pictures or comforting personal items, such as a throw blanket or figurines or a pet the person may have liked. Families can also participate by providing mouth care, styling the person's hair, or applying lotion to the skin.

9.3 Preserving dignity

Taking a person-centred approach to preserving dignity is one of the most important aspects of palliative and end-of-life care. As the person may lose their cognitive capabilities and the ability to state their preferences or advocate for themselves, it becomes the responsibility of all members of the team to preserve the person's dignity. This concept overlaps with preventing depression and helping the person feel good. Although dying people may seem unaware, we don't really know how aware of their surroundings they actually are; therefore, it is important to maintain dignity till the end.

This can be done in a variety of ways. First, meticulous attention to cleanliness is critical. As incontinence increases at the end-of-life, frequent perineal care and prevention of odors is critical.

It is just as critical to maintain cleanliness of the face, hands, and feet. For example, if a man were typically clean shaven, he should continue to be shaved.

Do not allow crust to form around the lips, and keep finger nails and toe nails well groomed.

If the person has a favorite pillow, blanket, or even a stuffed animal, be sure those items are on the person's bed or in close proximity.

As the person becomes frailer, the amount of medical equipment in the room may increase, e.g. oxygen tanks, nebulizer machines, etc. To maintain a homelike environment put care-related items away when not in use. Although space may be limited, try not to replace the person's personal items with medical items on room tables or furniture.

9.4 Final Hours

The final hours of life can be distressing for both staff and family to witness. The most common symptoms residents will experience are pain and noisy breathing.

It is important for you to anticipate these symptoms and work with the care team to ensure that the advance care plan incorporates interventions to alleviate pain and respiratory symptoms. Nurses will be in the primary position to teach the family and Care & Support staff about what the person is experiencing, and what is being done to ensure the person's comfort or attend to distressing symptoms. Meticulous attention to hygiene will also be important, especially if incontinence increases.

As the person approaches death, they will not take oral foods and fluids. It is important to educate the family that the person is not starving or thirsty, and that this is part of the natural dying process. Families are often very distressed about the fact that their loved one will no longer eat or drink. Family members may request IV fluids and/or a feeding tube. These interventions do not help a person live longer. In fact, they can worsen respiratory symptoms, making it harder for the person to breathe. They can also increase oedema (water retention or swelling) and overall discomfort, and also increase incontinence.

As previously noted, maintaining dignity during the final hours of life is critical. In addition to the interventions noted previously, you can also continue to talk to the person, letting him or her know that you are there and what you are doing to promote comfort. You can also encourage family members to talk to the person.

10.0 Staff training

There is a range of training that staff can access in relation to palliative and end-of-life care. NHS Education Scotland (NES) and the Scottish Social Services Council (SSSC) developed the framework, Enriching and improving experience. Palliative and End-of-life Care: A learning and development framework to support the needs of the health and social service workforce in Scotland, which identifies the knowledge and skills required by all workers who might come into contact with people who have palliative and end-of-life care needs. The framework has five domains reflecting the core knowledge and skills considered integral to the delivery of high quality palliative and end-of-life care. Each domain presents four levels of knowledge and skills outlining what workers need to know and do. The levels of knowledge and skills workers need may differ across the five domains depending on their degree of involvement in palliative and end-of-life care; and their responsibilities in caring for and supporting people, their families and carers.

Informed Level	Skilled Level	Enhanced Level	Expert Level
Knowledge and skills required by all health and social service workers in relation to palliative and end-of-life care.	Knowledge and skills required by health and social service workers who by virtue of their role and level of responsibility regularly provide care and support to people with palliative and end-of-life care needs, their families and carers.	Knowledge and skills required by health and social service workers who by virtue of their role and level of responsibilities provide, co-ordinate and manage and support care.	Knowledge and skills required by health and social service workers who by virtue of role and level of responsibilities provide expert role in care and support.

Staff will have training in the provision of palliative and end-of-life care and any specific healthcare interventions as agreed by the multi-disciplinary team. District nurses may come out and deliver specific training for staff. Staff may undertake specific SVQ units pertinent to the provision of palliative and end-of-life care.

11.0 Monitoring and recording

In addition to the usual recordings made in respect of supported people, for example daily recording and Medication Administration Recording sheets, additional monitoring and recording will be required to ensure the individual's healthcare needs are being met and that any changes to their medical status is identified as soon as possible. Care & Support staff may be required to record, for example, the following:

- food and fluid intake
- urine output
- turning charts (when the service user needs repositioned to reduce the risk of pressure sores)

- Bowel movement charts
- Pressure charts (recording any areas of concern that could result in pressure sores)

The types and frequency of recording and monitoring will vary according to the individual's needs. Care & Support staff will receive training and guidance in recording and monitoring, provided or sourced by the Care & Support Manager or Registered Operations Manager.

12.0 Implementation and Review

12.1 Implementation

Care & Support Managers / Registered Operations Managers are responsible for the implementation of these procedures by their Care & Support staff teams.

12.2 Review

ARK Area Managers' group is responsible for the review of these procedures, at least every 3 years. Any changes to the associated policy as a result must be submitted to the Board of Management for approval. **Next Review by: April 2023**

Appendix 1 – list of relevant information (see folder)

1. Abbey Pain Scale
2. NHS DNACPR form
3. NES (2018) Informed about palliative care: digital learning resource
4. NES (2018b) Palliative and end-of-life care framework
5. NICE (2004) Improving supportive and palliative care for adults with cancer
6. SSSC (2018) Supporting social care workers who provide palliative and end-of-life care
7. Author unknown (date unknown) End of Life plan
8. Author unknown (2015) When people are dying: an introduction to palliative care