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| **Review Sheet** | |
| Last Reviewed Last Amended Next Planned Review in 12 months, or  09 Jun '20 09 Jun '20 sooner as required. | |
| Business impact | Changes are important, but urgent implementation is not required, incorporate into your existing workflow.  **MEDIUM IMPACT** |
| Reason for this review | Updated in line with Max and Keira's law |
| Were changes made? | Yes |
| Summary: | This policy outlines how to support a service user who is at end of life, detailing their wishes and preferences. It has been updated in light of Max and Keira's Law in relation to organ donation and new 'Further Reading' references have been added that staff should familiarise themselves with. |
| Relevant legislation: | * The Care Act 2014 * The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 * Mental Capacity Act 2005 * Mental Capacity Act Code of Practice |
| Underpinning knowledge - What have we used to ensure that the policy is current: | * Author: GOV.UK, (2016), *Government commits to high quality end of life care*. [Online] Available from: [https://www.gov.uk/government/news/government-commits-to-high- quality-end-of-life-care](https://www.gov.uk/government/news/government-commits-to-high-quality-end-of-life-care) [Accessed: 9/6/2020] * Author: The Leadership Alliance for the Care of Dying People (LACDP), (2014), *One Chance to Get it Right*. [Online] Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/323188/One\_](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf) [Accessed: 9/6/2020] * Author: National Palliative and End of Life Care Partnership, (2015), *Ambitions for Palliative and End of Life Care*. [Online] Available from: <http://endoflifecareambitions.org.uk/>[Accessed: 9/6/2020] * Author: National Institute for Health and Care Excellence, (2017), *End of life care for adults*. [Online] Available from: <https://www.nice.org.uk/guidance/QS13>[Accessed: 9/6/2020] * Author: NICE, (2018), *Decision-making and mental capacity (Guideline NG108)*. [Online] Available from: <https://www.nice.org.uk/guidance/ng108>[Accessed: 9/6/2020] * Author: SCIE, (2016), *Safeguarding adults - End of life care*. [Online] Available from: <https://www.scie.org.uk/adults/endoflifecare/index.asp>[Accessed: 9/6/2020] * Author: NICE, (2019), *End of life care for adults: service delivery NICE guideline [NG142]*. [Online] Available from: <https://www.nice.org.uk/guidance/ng142>[Accessed: 9/6/2020] * Author: NICE, (2020), *NG163 COVID-19 rapid guideline: managing symptoms (including at the end of life) in the community*. [Online] Available from: <https://www.nice.org.uk/guidance/ng163>[Accessed: 9/6/2020] |
| Suggested action: | * Encourage sharing the policy through the use of the QCS App |
| Equality impact Assessment: | QCS have undertaken an equality analysis during the review of this policy. This statement is a written record that demonstrates that we have shown due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations with respect to the characteristics protected by equality law. |



**1. Purpose**

* 1. To provide a framework to guide best practice in the care and support of a Service User who has been identified as nearing the end of their life.
  2. To support Holbeach Hospital & Nursing Home in meeting the following Key Lines of Enquiry:

## Key Question Key Lines of Enquiry

|  |  |
| --- | --- |
| CARING | C3: How are people's privacy, dignity and independence respected and promoted? |
| EFFECTIVE | E1: Are people’s needs and choices assessed and care, treatment and support delivered in line with current legislation, standards and evidence- based guidance to achieve effective outcomes? |
| RESPONSIVE | R1: How do people receive personalised care that is responsive to their needs? |
| SAFE | S3: How does the service make sure that there are sufficient numbers of suitable staff to support people to stay safe and meet their needs? |
| WELL-LED | W1: Is there a clear vision and credible strategy to deliver high-quality care and support, and promote a positive culture that is person-centred, open, inclusive and empowering, which achieves good outcomes for people? |

* 1. To meet the legal requirements of the regulated activities that Holbeach Hospital & Nursing Home is registered to provide:
     + The Care Act 2014
     + The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014
     + Mental Capacity Act 2005
     + Mental Capacity Act Code of Practice



**2. Scope**

* 1. The following roles may be affected by this policy:
     + Registered Manager
     + Nurse
     + Care staff
  2. The following Service Users may be affected by this policy:
     + End of Life Service Users
  3. The following stakeholders may be affected by this policy:
     + Family
     + Advocates
     + External health professionals



**3. Objectives**

* 1. To provide an opportunity to understand the wishes, needs and preferences around the end of life care of a Service User and to assure the Service User that they will have access to end of life care when needed.
  2. To give guidance and stimulate considerations when supporting a Service User to think about the end of their life.
  3. To enable staff to work in a multidisciplinary team to provide high-quality, person-centred care to people who are felt to be in their last year of life, and to ensure that family and people important to the Service User are supported and kept informed, enabled and empowered throughout a Service User's illness.



**4. Policy**

* 1. Holbeach Hospital & Nursing Home will model the Government's commitments to end the variation in end of life care across the health system. These commitments include:
     + Having honest discussions between care professionals and dying Service Users
     + Dying Service Users making informed choices about their care
     + Personalised Care Plans for all
     + The discussion of personalised Care Plans with care professionals
     + The involvement of family and carers in the dying Service User's care
     + Having a main contact so that dying Service Users know who to contact at any time of day
  2. This policy is dovetailed with the National End of Life Care Programme, elements of which are consistent with the best practice identified within the review, in particular, the individualised assessment and person-centred Care Plans.

Holbeach Hospital & Nursing Home will carry out Advance Care Planning where it is assessed that the Service User is nearing the end of their life, or as the Service User discloses. The Service User will be comfortable and as pain free as possible and spiritual and emotional support will be available for all Service Users to access if they wish.

* 1. Where it applies, end of life care will be in accordance with the Deprivation of Liberty Safeguards Policy and Procedure, the Mental Capacity Act 2005 Policy and Procedure as well as Care Planning policies and procedures.



**5. Procedure**

## When to Initiate End of Life Care Planning

Service Users will respond differently to being able to discuss end of life wishes. Holbeach Hospital provides end of life care in line with the Gold standards Framework that is accredidted.

For Service Users who openly disclose their views, information can be gathered, when offered, from the point of service commencement and ongoing.

Registered Nurses must have access to a recognised prognostic indicator to assist with identifying the right time to initiate a conversation. Registered Nurses must ask themselves, 'Would you be surprised if the Service User died within the next 6-12 months?' If it would be a surprise that they were to live longer than 6- 12 months, they are a high priority for talking and planning.

The presence of any of the following must trigger concern when associated with advanced age and/or disease:

* + - Limited self-care and interest in life: in bed or a chair for more than 50% of their time
    - Breathless at rest or on minimal exertion (MRC scale 4/5)
    - Progressive weight loss (>10% over last six months)
    - History of recurring or persistent infections and/or pressure ulcers

Care staff must have access to literature and signpost to recommended sources to support the Service User when considering end of life Care Planning.

Registered Nurses will adhere to the Mental Capacity Act 2005 and Best Interest Decision Making in accordance with the Mental Capacity Code of Practice for those Service Users who are unable to participate in end of life discussions.

## Care Setting

It must be the preference of the Service User and their loved ones where they would like to receive end of life care and this must form part of the Advance Care Plan. Decisions about preferred locations for end of life care will be respected and all measures taken to try and accommodate the Service User's wishes by use of a multidisciplinary approach in complex cases.

## Step by Step End of Life Care

There are generally considered to be six steps in providing effective end of life care which staff must be familiar with and competent in:

* + - Step 1: Discussions as the end of life approaches
    - Step 2: Individualised Assessment, Care Planning and review
    - Step 3: Co-ordination of care
    - Step 4: Delivery of high-quality services in different settings
    - Step 5: Care in the last days of life
    - Step 6: Care after death

## Step 1 - Discussions as the end of life approaches

A planned approach to Advance Care Planning can be effective and the approach staff must take is to:

* + - Raise the topic and give information
    - Facilitate a structured discussion
    - Bring prior wishes to bear on actual decisions
    - Complete the Care Plan
    - Periodically review and update the Care Plan (as per Care Planning policies and procedures) Discussions about end of life care require revisiting and regular review, as Service Users can change their minds - particularly when they are faced with new fears, concerns and/or symptoms on a daily basis.

Care Plan reviews will be completed in accordance with local policies and procedures - refer to the Service

User Care Planning Policy and Procedure and the Advance Care Planning Policy and Procedure.

## Step 2 - Individualised assessment and Care Planning

The steps for individualised assessment and Care Planning, as structured within the Care Planning system are:

* + - Assess
    - Document
    - Develop
    - Discuss
    - Choose
    - Plan
    - Record
    - Review

Registered Nurses responsible for Care Planning must be trained to implement fully personalised and individual assessments and Care Plans.

## Care Plan Content

Registered Nurses must consider the following areas when formulating an Advance Care Plan:

* + - Assessment and communication
    - Management plan
    - Preferences and choices
    - Family and significant others
    - Symptom control
    - Ongoing assessment

## Step 3 - Co-ordination of care

Registered Nurses will ensure that all the staff involved in the coordination of care are appropriately trained to achieve a quality outcome for the Service User.

To this end, staff must:

* + - Be alerted by a healthcare professional if an End of Life Care Plan has been created for a Service User
    - Request a copy of the End of Life Care Plan and assessment
    - Review the Care Plan ensuring that the detail reflects the healthcare professional’s plan to ensure that a cohesive service is provided
    - Ensure that an appropriate person on behalf of Holbeach Hospital & Nursing Home attends all multidisciplinary review meetings
    - Ensure that practical and emotional support is offered to the Service User's family and Care Workers at all times whilst supporting Service Users with end of life care

## Step 4 - Service delivery

Service Users and their families may need access to a complex combination of services across a number of different settings and they must be able to expect the same high level of care regardless of the care setting.

It is the responsibility of the Registered Nurse to ensure that effective co-ordination takes place. Essential practical, day-to-day procedural matters include:

* + - The Service User has access to a medical specialist in palliative care
    - Pain management measurement is ongoing
    - The Service User has comfort needs attending to (e.g. chair, bed etc.)
    - The Service User has diversional therapy (e.g. music, radio etc.)
    - The Service User has a key Nurse with whom they can spend some one-to-one quality time each day
    - The Service User's environment is clean, odour free and comfortable
    - The Service User will have a Nurse to sit with them if they are alone at the end of their life or if they request it
    - The Service User’s family are treated with empathy and offered support and refreshments according to their needs
    - Families will be informed about any changes in the condition of the Service User
    - Families will be informed of the death of a Service User at a time to minimise distress, e.g. in the morning after a death in the night, unless otherwise requested by the family
    - Families will be given an appropriate length of time to remove belongings from the Service User’s room
    - Other Service Users will be informed of the death by a senior member of staff

## Step 5 - Last days of life

When a Service User enters the dying phase, it is vital that care staff can recognise that this Service User is dying, so they can deliver the care that is needed. How someone dies remains a lasting memory for the Service User’s relatives, friends and the care staff involved.

Individualised planning, individualised assessment, further planning, recording and review and providing information are essential components of delivering care and support during the last days of life.

Effective documentation, such as detailed Care Planning and review are essential supports for effective delivery. Some form of Care Planning may be carried out by each of the healthcare professionals responsible for elements of the total package of care. It is the responsibility of Registered Nurses to ensure that effective co-ordination takes place, particularly during the final days. It is also important that Registered Nurses ensure that Care Plans are individualised.

A template End of Life Care Plan can be found within the 'Forms' section of this policy.

## Step 6 - Care after death

Good end of life care does not stop at the point of death. When someone dies, staff need to follow good practice, which includes being responsive to family wishes. The support and care provided to families will help them cope with their loss.

Care after death includes:

* + - Honouring the spiritual or cultural wishes of the Service User and their family/carers, whilst ensuring that legal obligations are met
    - Preparing the Service User for transfer to the mortuary or the funeral director’s premises
    - Offering family members who are present the opportunity to participate in the process and supporting them to do so
    - Ensuring that the privacy and dignity of the Service User is maintained
    - Ensuring that the health and safety of everyone who comes into contact with the Service User is protected
    - Honouring the Service User's wishes for organ and tissue donation
    - Returning the Service User’s personal possessions to their family

An effective end of life Care Plan will also contain four elements of care which must be present throughout the six steps listed above:

* + - Support for carers
    - Information for Service Users and carers
    - Spiritual care
    - Social care

Staff must refer to the Royal Marsden Manual of Clinical Nursing Procedures for best care practice for care after death (last offices), paying particular attention to any religious, spiritual, cultural or medical requirements or preferences.

## Training and Education

Extensive, comprehensive and detailed training in the issues involved in end of life care is essential for all staff within a service providing end of life care.

Staff must be competent in the following areas in order to deliver effective end of life Care Planning:

* + - Communication skills
    - Care Planning and assessment
    - Stages of end of life
    - Supporting Service Users and families
    - Accessing support services and timely referral

Education methods will be via formal training, mentorship support, supervisions and group discussion.



**6. Definitions**

## Palliative Care

* + - The World Health Organisation (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem 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

## End of Life Care

* + - End of life care is for people who are considered to be in the last year of life but this timeframe can be difficult to predict. Its aims are to help people live as well as possible and to die with dignity. It also refers to treatment during this time and can include additional support, such as help with legal matters. End of life care continues for as long as it is needed

## Advance Care Plan

* + - Advance Care Planning is making decisions about the care people would want to receive if they become unable to speak for themselves. These are the decisions to make, regardless of what they choose for their care, and the decisions are based on their personal values, preferences and discussions with their loved ones

## Healthcare Professional

* + - A healthcare professional is an individual who provides preventive, curative, promotional or rehabilitative healthcare services in a systematic way to people, families or communities

**6.5 Gold Standards framework**

* Gold Standards Framework improves the quality, coordination and organisation of care leading to better patient outcomes in line with their needs and preferences



**Key Facts - Professionals**

Professionals providing this service should be aware of the following:

* + - Good end of life care is based on the understanding that death is inevitable and a natural part of life
    - Shared decision-making between staff, Service Users and their families is possible when all have an awareness that the Service User is approaching death as well as an awareness of the Service User's wishes
    - Advance Care Planning aims to encourage people to consider, discuss and document their future wishes for care well in advance
    - The most effective end of life care is provided when there is skillful communication with Service Users and families about realistic goals of care and where attention is given to understanding the concerns of Service Users and families



**Key Facts - People affected by the service**

People affected by this service should be aware of the following:

* + - Staff supporting you will have the knowledge, skills and ability to provide resources and specialist support when needed
    - Letting the family know about your wishes could help them if they ever have to make decisions about your care. Knowing that they are acting in accordance with your wishes can remove some of the stress from a very difficult situation
    - Even though you may not be approaching the end of life, you may still want to think about your wishes for your own end of life care
    - Staff are on hand to support you to talk about your views and wishes



**Further Reading**

As well as the information in the 'underpinning knowledge' section of the review sheet we recommend that you add to your understanding in this policy area by considering the following materials:

**Government - opt-out organ donation:Max and Keira's Bill Passed into Law:** <https://www.gov.uk/government/news/opt-out-organ-donation-max-and-keira-s-bill-passed-into-law> **NHS - Max and Keira's Law, the Organ Donation Act:**

<https://www.organdonation.nhs.uk/get-involved/news/max-and-keira-s-law-comes-into-effect-in-england/> **Dying Matters - Resources: understanding death and dying:** <https://www.dyingmatters.org/page/resources-understanding-death-and-dying>

**RCGP - Palliative and End of Life Care:** <https://www.rcgp.org.uk/endoflifecare> **Training:**

**End of Life Care (Free e-learning)**

Macmillan training materials - you will need to register to use the site (there is no charge): [Lessons Learned - Interactive e-learning from Macmillan Cancer Support](https://www.macmillan.org.uk/information-and-support/resources-and-publications/training)

## CARESEARCH - A collection of tutorials:

<https://www.caresearch.com.au/caresearch/tabid/607/Default.aspx>

Training materials for home care and residential care hosted by the Dignity in Care Network and SCIE, two collections of dignity-specific training resources designed for health and social care: <https://www.dignityincare.org.uk/Resources/Training_resources/>

Skills for Care has worked in partnership with e-Learning for Health to provide free access to e-ELCA, End of Life Care for All, for adult social care employers registered with the National Minimum Data Set for Social Care (NMDS-SC):

<https://www.e-lfh.org.uk/programmes/end-of-life-care-for-all-public-access/>

## Formally Recognised Training

Staff should access their local hospice in the first instance for training. Gold standards framework:

<https://goldstandardsframework.org.uk/>

**Skills for Care - Six steps training is hosted by local hospices:** [http://www.skillsforcare.org.uk/Document-library/Skills/End-of-life-](http://www.skillsforcare.org.uk/Document-library/Skills/End-of-life-care/NationalendoflifequalificationsandSixStepsprogramme.pdf) [care/NationalendoflifequalificationsandSixStepsprogramme.pdf](http://www.skillsforcare.org.uk/Document-library/Skills/End-of-life-care/NationalendoflifequalificationsandSixStepsprogramme.pdf)



**Outstanding Practice**

To be ‘ outstanding ’ in this policy area you could provide evidence that:

* + - Staff are trained, competent and knowledgeable in end of life care and this is evidenced in daily practice through communication and documentation
    - All Service Users are offered an opportunity to have an Advance Care Plan in place
    - A learning culture is embedded in Holbeach Hospital & Nursing Home where staff follow best practice, promote national end of life initiatives and have a host of resources available for staff, Service Users and their loved ones when needed
    - Holbeach Hospital & Nursing Home undertakes thematic audits to ensure that practice is benchmarked against the best, recommended practice and that it is reviewed and changed to meet need and provide high-quality, current care
    - The wide understanding of the policy is enabled by proactive use of the QCS App



**Forms**

The following forms are included as part of this policy:

|  |  |  |
| --- | --- | --- |
| **Title of form** | **When would the form be used?** | **Created by** |
| End of Life Care Plan - CRN09 | Following discussion with medical professionals and family members, once identified that the Service User is entering the last days of life | QCS |

Name:

Date of Birth:

NHS Number:

Place of Care:

Specialist Healthcare Professionals:

|  |  |  |
| --- | --- | --- |
| GP |  |  |

# Summary of Medical Condition:

**Name:**

**Role:**

**Contact Number**

**Local Hospice Contact Number**

Does the Service User have a pacemaker? YES/NO Where it applies, has it been deactivated? YES/NO/NA

**Significant Other Details:**

|  |  |  |
| --- | --- | --- |
|  |  |  |

**Rationale for Commencing the End of Life Care Plan**

**Name:**

**Relationship**

**Contact Number**

**Contact Out of Hours?**

**Signatures as agreed for the commencement of this end of life care plan:**

Name: Signature: Designation:

**Preferred Place**

Include here: Where possible, with the involvement of the Service User, ability including capacity. Who is involved in their care planning and decision making? Any decisions re advance statements?

**Communication**

Include here: Where possible, with the involvement of the Service User, ability including capacity. Who is involved in their care planning and decision making? Any decisions re advance statements?

**Interventions in Changing Needs**

Include here: Where there is not current specialist healthcare professional support in place, is there a need for a referral?

Is there a DNACPR documented? Where is it located? Is there an opt-out of organ donation decision in place?

Where any medical interventions are stopped, record here the rationale for discontinuing them whilst confirming that this has been communicated to the Service User/significant other.

**Medication**

Have anticipatory medications been requested and are they available?

Record that symptom control is available that includes for pain, agitation, respiratory tract secretions, nausea and vomiting, dyspnea. Consider assessment tools to aid medication administration.

Plan for alternative methods of administration (such as syringe drivers) - who will manage this and how will it be managed?

**Significant Issues**

Record any significant concerns or issues as raised by any parties involved in their care (professional or personal)

**Review** - Ongoing medical support should continue for the period of the care plan. However, staff will seek medical advice/support if:

* The Service User shows signs of improvement
* Any concerns are expressed by significant others

**End of Life Care Plan**

Content should include:

* + Types and means of achieving diet and hydration - clearly document this will be continued and supported for as long as possible
  + Monitoring for symptoms (pain, agitation, respiratory tract secretions, nausea, vomiting, dyspnoea) and management
  + Continence –continence aids, frequency of continence care
  + Oral hygiene – what provision is available? Frequency of offering. Is the family/carer able to maintain adequate oral hygiene needs?
  + Personal Hygiene – how will needs be met, balanced with comfort and management of symptoms?
  + Skin Integrity – is skin intact? Is the current pressure relieving regime appropriate and required?
  + Environment – is current environment appropriate to maintain respect and dignity for the Service User and their family? Is privacy available? Ambience requests, e.g. music, light/dark etc.
  + Psychological support – Ensure the Service User and their family feel supported and are given the opportunity to discuss fears/concerns as needed
  + Ensure organ donation is considered where the Service User has not opted out

**Care After Death Plan**

Content should include:

* + Chosen funeral directors
  + Ensure that last offices (care after death) are performed. Significant others should be allowed to express their grief and to participate in ‘last offices’ if they so wish.
  + Ensure that death has been confirmed appropriately (either verified by a Nurse or confirmed by a Doctor)
  + Provision of support/information for significant others
  + Provision of booklet *‘What to do after death in England and Wales’*
  + Ensure that the Service User's death is communicated appropriately across the service
  + Consider religious and cultural needs
  + Consider any infection control management required
  + The Service User is cared for in a culturally sensitive and dignified manner
  + Verification of death should be carried out in a timely manner
  + The medical certificate of cause of death should be completed in a timely manner

**Daily Assessment and Communication**

Where the answer is ‘Yes’ to any questions, please document the action that the staff member has taken and the outcome for the Service User.

**Date: / /** Day:

# Has the Service User experienced any…

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**Pain?**

Staff initials and signature

**Nausea/Vomiting?**

Staff initials and signature

**Agitation?**

Staff initials and signature

**Respiratory secretion discomfort?**

Staff initials and signature

**Dyspnoea?**

Staff initials and signature

**Nutrition and Hydration Concerns?**

Staff initials and signature

**Time Time Time Time Time Time**

**Communication** – use this space to include any conversations and who was present for these

**Time**

**Date: / / Day:**

**Time**

**Any Care Delivery Problem and Management**

**Outcome**

**Signature and Initials**

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| **Conversation Content** | **Signature and Initials** |
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**Service User Name:**

**After Death Notification**

**Date of Birth:**

Date of Death:

Time of Death:

Place of Death:

Persons present at the time of death:

Last offices performed by:

Were significant others contacted at the time of death (if not present)? Please provide detail:

Name and role of person verifying death:

Date and time of verification of death:

Does the Coroner need to be informed or involved? If ‘yes’, provide detail:

Detail when the GP and, where applicable, other healthcare professionals were informed of the death:

Form completed by:

Role:

Signature: