



# Policy:

## NP 044 End of Life Care, Policy & Procedure

|                                |  |
|--------------------------------|--|
| <b>Executive Director Lead</b> | Director of Nursing, Professions and Quality |
| <b>Policy Owner</b>            | Head of Clinical Quality & Standards         |
| <b>Policy Author</b>           | Resuscitation Officer                        |

|                                |   |
|--------------------------------|---|
| <b>Document Type</b>           | Policy                                  |
| <b>Document Version Number</b> | 02                                      |
| <b>Date of Approval By PGG</b> | June 2023                               |
| <b>Date of Ratification</b>    | 12 <sup>th</sup> July 2023              |
| <b>Ratified By</b>             | QAC                                     |
| <b>Date of Issue</b>           | June 2023                               |
| <b>Date for Review</b>         | November 2025 Extended June 2025 at PGG |

|  |
|--|
| <b>Summary of policy</b><br>End of Life Care, Policy and Procedure |
|--|

|                        |  |
|------------------------|--|
| <b>Target audience</b> | All SHSC Staff and Volunteers working within In-Patient, Community and Care Home Environments.<br><br>All SHSC Staff and Volunteers working with Service Users with a diagnosed life limiting condition. |
|------------------------|--|

|                 |   |
|-----------------|---|
| <b>Keywords</b> | Palliative Care<br>Life Limiting Conditions<br>End of Life<br>Recognised as Dying<br>Actively Dying<br>Advanced Decisions<br>Advanced Decisions Care Plan<br>End of Life Champion |
|-----------------|---|

|   |
|---|
| <b>Storage &amp; Version Control</b><br><br>Version 01 of this policy is stored and available through the SHSC intranet/internet. |
|---|



## Version Control and Amendment Log (Example)

| Version No. | Type of Change           | Date    | Description of change(s)              |
|-------------|--------------------------|---------|---------------------------------------|
| 1.0         | Approval and issue       | 02/2022 | New Policy approved at PGG            |
| 2.0         | Review / approve / issue | 06/2023 | Full review completed as per schedule |

## Contents

| Section |   | Page |
|---------|---|------|
|         | Version Control and Amendment Log   |      |
|         |   |      |
| 1       | Introduction  | 1    |
| 2       | Scope   | 1    |
| 3       | Purpose   | 1    |
| 4       | Definitions   | 2    |
| 5       | Details of the policy   | 3    |
| 6       | Duties  | 5    |
| 7       | Procedure   | 7    |
| 8       | Development, consultation and approval  | 21   |
| 9       | Audit, monitoring and review  | 23   |
| 10      | Implementation plan   | 23   |
| 11      | Dissemination, storage and archiving (control)  | 24   |
| 12      | Training and other resource implications  | 25   |
| 13      | Links to other policies, standards, references, legislation and national guidance                               | 25   |
| 14      | Contact details   | 25   |
|         | APPENDICES  |      |
|         | Appendix 1 –<br>Care Quality Commission’s Fundamental Standards introduced<br>1 April 2015                      | 26   |
|         | Appendix 2 –<br>Human Rights Act (HRA) (1998)   | 28   |
|         | Appendix 3 – How to support eating and drinking with clinical<br>assistance; A summary guide to decision making | 32   |
|         | Appendix 4 – Support Available from Physiotherapy /<br>Occupational Therapy Team                                | 33   |
|         | Appendix 5 – Anticipatory Medication table  | 34   |
|         | Appendix 6 – Bereavement Support Services   | 35   |
|         | Appendix 7 – Referral to Specialist Palliative Care Services  | 36   |
|         | Appendix 8 – Care in the Last Days of Life  | 37   |
|         | Appendix 9 – What to expect when someone is in the last days<br>of life   | 39   |
|         | Appendix A - Equality Impact Assessment Process and Record<br>for Written Policies                              | 43   |
|         | Appendix B New/Reviewed Policy Checklist  | 44   |



## **1 Introduction**

This policy aims to support the implementation of End-of-Life Care for Adults NICE Guidelines (NG142, 2019) and the End-of-Life Standards defined by NHS England and the National Palliative and End of Life Partnership in their paper: Ambitions for Palliative and End of Life Care (2015 – 2020). The development and embedding of a Policy and Procedure to support Healthcare Workers in providing high-quality, person-centred End of Life Care is supported by The Gold Standards Framework (GSF) and the Preferred Priorities of Care Framework (PCC) which provides best practice guidance around decision making in end-of-life care.

This policy is in line with the Trusts legal obligations. The specifics of how legislation is followed is detailed in the course of the policy.

Being able to provide high quality end of life care should be an integral part of every health care worker's role. However, the expected death of a patient in the care of our services is not a regular occurrence therefore it is even more important that staff have the knowledge, skills and support, to deliver effective, quality, care and treatment to patients who are approaching the end of their life. Death is an inevitable part of life and does not necessarily constitute a failure of care. Indeed, caring for those approaching the end of life is one of the most important and rewarding areas of care. Although it is challenging and emotionally demanding, if healthcare professionals have the necessary knowledge, skills and attitudes, it can also be immensely fulfilling.

“How people die remains in the memory of those who live on...” Dame Cicely  
Saunders, founder of the Modern Hospice Movement

Good, person centred, end of life care enables people to live in as much comfort as possible until they die and to make choices about their care, these decisions can be made through advanced care planning with the person and their family in discussion with professionals. It is about providing support that meets the needs of both the person who is dying, and the people close to them, and includes symptom management, as well as provision of psychological, social, spiritual and practical support. Care does not end at death but includes appropriate care of the body, support for family, carers, people important to the individual who has died and other Service Users within the environment who may have been affected.

This policy is solely concerned with caring for those people who have a diagnosed life limiting condition from diagnosis through to death, where required, through planned end of life care and does not apply to unexpected or sudden deaths.

## **2 Scope**

This policy and associated guidelines is relevant to SHSC inpatient, community and care home environments, however it is acknowledged that in the community and care home environments that are part of SHSC will have input from primary care therefore parts of the procedure around management of end of life care will not be the primary responsibility of SHSC staff. However, this policy is written in such a way to cover the diverse inpatient, community and care home environments encompassed by SHSC.

## **3 Purpose**

The main aim of this policy is to provide staff with a framework, clear direction and standards, to deliver planned, compassionate and competent person-centred care for service users and their families as they approach the end of their life.

## 4 Definitions

**End of life** – People are considered to be approaching the end of life when they are likely to die within the next 12 months.

**Palliative Care** - focuses on the relief of pain and other symptoms and challenges experienced in serious illness, to provide comfort even when treatments aimed at cure are no longer possible; the goal of palliative care is to improve quality of life, by increasing comfort, promoting dignity and providing a support system to the person who is ill and those close to them. Palliative care is care provided where a person has a life limiting diagnosis.

**Specialist palliative care** - is the active, total care of patients with progressive, advanced disease and their families; care is provided by a multi-professional team who have undergone recognised specialist palliative care training outside of SHSC.

**Prognosis** – predicting the likely course of a disease or ailment.

**Care planning** - embraces the care of people with and without capacity to make their own decisions. It involves a process of assessment to establish the person's wants, needs, preferences and goals of care, and making decisions about how to meet these in the context of available resources. It can be oriented towards meeting immediate needs, as well as predicting future needs and making appropriate arrangements or contingency plans to address these. This must have been agreed with the person receiving care or by those acting in the person's best interests.

**Mental Capacity** - the ability to make an informed decision about a particular issue at the time the decision needs to be made or to give consent to a particular act and be able to communicate their decision.

**Advance Care Planning (ACP)** - a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record choices or decisions relating to their care and treatment so that these can then be referred to by health professionals and family carers in the event that they lose capacity. ACP can be completed with Lasting Power of Attorney (LPA) for Health & Welfare if the individual has lost capacity, and with family members involved and healthcare professionals through best interest discussions/meetings. A person may also have made LPA provision for Property and Financial Affairs however this only relates to decisions they may want taken regarding property/finances.

**Advance decision to refuse treatment (ADRT)** - a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.

**Advance statements** - are written statements, either written down by the person themselves or written down for them with their agreement. Any such Advance Statement refers to decisions the person might make before losing capacity about their wishes and feelings regarding issues they wish to be considered in the case of future loss of capacity due to illness, such as the type of medical treatment they would want or not want, where they would prefer to live or how they wish to be cared for. Whilst advance statements are not legally binding, professionals **MUST** still have regard to them when determining that person's best interests.

**Best interests** - under the Mental Capacity Act, any decision made or any action done for a person who lacks capacity to make specific decisions must be in accordance with their best interests. Where a best interests determination is being made in relation to life sustaining treatment, the Act states such a decision should not be motivated by a desire to bring about the person's death.

**Holistic assessment** - includes, as a minimum, physical, psychological, social, spiritual, cultural, and where appropriate, environmental considerations; this may relate to needs and preferences as well as associated treatment, care and support.

**Lasting powers of attorney (LPA)** - is a statutory form of power of attorney created by the Mental Capacity Act. Anyone who has the capacity to do so may choose a person or persons to take decisions on their behalf if they subsequently lose capacity. The LPA replaces the Enduring Power of Attorney. LPA decisions are separated for Health & Welfare and Finances & Property.

**Acutely Unwell** – in the context of this policy is a significant unplanned physical health event where there is an element of distress or disruption requiring urgent response and appropriate intervention.

**'Last days of life'/'recognised as dying'** - is the period of time when death is imminent and when the time before the anticipated death is being measured in days.

**Responsible Clinician** - has overall responsibility for care and treatment for Service Users assessed and treated under the Mental Health Act. These responsibilities include, making decisions about treatment, reviewing detentions, granting leave of absence for detained patients. Although the Responsible Clinician has overall responsibility decisions about the patient's care and treatment are made in discussion with the multi-disciplinary team.

**Independent Mental Capacity Advocate (IMCA)** – introduced under The Mental Capacity Act 2005 provide a legal safeguard for people who lack the capacity to make specific important decisions; IMCAs are mainly instructed to represent people where there is no one independent of services, such as a family member or friend, who can represent the person.

**Dysphagia** – a swallowing impairment, symptoms may include: difficulty, discomfort or pain when swallowing. These may be difficulty in the oral preparation for swallowing, such as chewing and tongue movement or in protecting the airway during the swallow itself. Disruption of swallowing can have serious effects, with complications such as malnutrition, pulmonary aspiration (fluid or food going into the lungs instead of the stomach), and the emotional and psychological challenges associated with not being able to eat properly.

**Nutritional Support** - Therapy for persons who cannot get sufficient nutrition through eating and/or drinking.

## **5 Detail of the policy**

Caring for a person in the last days of life is occasionally required within SHSC in-patient environments however providing care for a short time for those in End of Life, last 12 months of life, is likely to be more frequent. It is recognised that raising the topic of end-of-life care with an individual and those important to them at time of 'crisis' may not be appropriate. However, during the course of an admission, as the crisis event is managed, an opportunity should be created for the individual and those important to them to have a conversation about ACP.



If a person who is recognised as dying is not able to be 'Fast Tracked' to a more appropriate, tranquil care setting in the last days of life high-quality, person-centred care, will be provided by appropriately skilled, knowledgeable SHSC staff.

The process for delivering end of life care is based on the following standards:

- End of Life Care Strategy developed by the Department of Health
- National Institute for Health and Clinical Excellence (NICE) End of Life Care for Adults (NG142)
- National Institute for Health and Clinical Excellence (NICE) Quality Standard for End of Life Care
- Five Priorities in the final months/days of end-of-life care created by a coalition of 21 organisations known as the Leadership Alliance for the Care of Dying People
- Ambitions for Palliative & End of Life Care: A National Framework for Local Action. NHSE & NHSI (Renewed 05/21)
- Department of Health and Social Care (2015) One Chance to Get it Right: One Year On Report.

## 5.1 Legislative Framework

Delivery of quality end of life care is guided by a number of National Clinical Standards and Strategies whilst these are critical in the delivery of high-quality, person-centred end of life care the Trust acknowledge that these guiding principles do not sit alone and have taken note of current legislation that has an impact on end-of-life care.

### **Appendix 1 Care Quality Commission's Fundamental Standards, introduced 1 April 2015**

|                       |  |
|-----------------------|--|
| <b>Regulation 9:</b>  | <b>Person-centred care</b>                     |
| <b>Regulation 10:</b> | <b>Dignity and respect</b>                     |
| <b>Regulation 11:</b> | <b>Need for consent</b>                        |
| <b>Regulation 14:</b> | <b>Meeting nutritional and hydration needs</b> |

### **Appendix 2 Human Rights Act (HRA) (1998)**

The Trust, as a state body, is required to develop policy and procedure in line with its HRA obligations. Staff practice must be informed by their obligation to follow the parameters of the HRA. The Trust has an obligation to protect the human rights of those under its care, if those rights are imperilled by another person, group or institution, for example, safeguarding someone whose life right to life (Article 2) may be in danger. Furthermore, the Trust is obligated not only to prevent human rights abuse, but to investigate when such breaches may have taken place.

End of life care will almost inevitably involve human rights dimensions and human rights law will need to be considered at many decision-making points. In cases of absolute rights (Articles 2 and 3) consideration must be given to how these may be potentially breached and how to avoid such breaches. In situations where qualified rights are involved staff interference with human rights is only legal, justifiable, and proportionate in limited circumstances where it becomes absolutely necessary, such as interfering with an individual's rights, with the aim of protecting another's rights.

The rights that are especially pertinent to end of life care situations are **Articles 2, 3, 5, 8, 9, and 14**. Details of which are expanded upon in **Appendix 2**.

## **Mental Capacity Act (MCA) 2005**

The Mental Capacity Act 2005 (MCA) provides legislation to safeguard people who lack mental capacity to make particular decisions. The MCA places a range of statutory obligations on both health and social care professionals along with various laypersons when making best interest decisions.

A Court of Protection was established under the MCA as being a higher court of law where disagreements in relation to mental capacity and best interest decisions can be arbitrated and decided upon, along with it being a Court which can consider more complex and contentious cases relating to those individuals who lack mental capacity. Occasions may arise when the Trust is required to provide information to the Court of Protection, initiate legal proceedings or become a formal legal party to a Court of Protection case.

A core concept throughout the MCA is that all decisions made for a person who lacks mental capacity must be in that individual's best interests. Decisions which are in the best interests of an organisation or easier for professionals are not permitted. Similarly, the Act is clear that any best interest decision in relation to medical treatment must never be undertaken with the underlying motivation being to bring about a person's death.

## **Mental Health Act 1983 (as amended)**

The Mental Health Act 1983 (as amended) (MHA83) makes legal provision for the care and treatment of people suffering from mental disorder. It sets out the statutory grounds which have to exist for a person to be admitted to hospital, potentially against that person's wishes and consent, for assessment and treatment of mental disorder. The MHA83 contains a variety of legal safeguards in relation to when treatment for mental disorder can be given to a person and sets out statutory processes which allow for a person to challenge either the loss of their liberty or restrictions on their liberty.

A person cannot be detained under the MHA83 for physical health problems or to impose a physical health treatment upon a person with mental capacity. There are some occasions however when physical interventions may be permitted under the MHA83 eg. to treat injuries which have occurred following acts of self-harm related to mental disorder.

## **6 Duties**

6.1 The Chief Executive, on behalf of the Trust, retains ultimate accountability for the health, safety and welfare of all service users, carers, staff and visitors, however key tasks and responsibilities will be delegated to individuals in accordance with the content of this policy.

6.2 **The Medical Director and Executive Director of Nursing Operations are required to:**

Ensure that all Medical and Registered Nursing staff are aware of this policy, and other policies and guidance which relate to this policy.

Ensure that adequate training is given to allow medical and registered nursing staff to implement this policy safely.

To inform Senior Management if the policy is not being implemented appropriately.

**6.3 Medical and Registered Nursing and AHP Staff are required to:**

Ensure that they are aware of the contents of this and supporting policies.

Ensure that their physical examination skills are maintained in accordance with General Medical Council (GMC) or the Nursing and Midwifery Council (NMC) requirements.

To identify via relevant pathways appropriate training/development requirements.

Deliver quality care and ensure that the needs of service users and those important to them are identified in accordance with best practice guidance.

To inform via senior management the medical Director and Executive Director of Nursing Operations if the policy is not being implemented appropriately.

**6.4 Unregistered nursing staff are required to:**

Be aware of the contents of this policy and supporting policies and guidance.

Support registered colleagues and medical staff to deliver care in line with care plans linked to this policy.

Request training to develop skills in line with this policy and Trust appraisal.

**6.5 SHSC Chaplaincy**

Chaplains offer spiritual care for any service user with a palliative care diagnosis, their family and those who are important to them. The Chaplain service is available to those people receiving end-of-life care, care during the last 12 months of life, not only in a persons final weeks/days of life.

**6.6 Lead Nurse - Infection Prevention & Control Nurse**

Provide specialist advice on a needs led basis should the service user have, or be suspected to have, a diagnosis that may require barrier nursing. Advise may be in relation to level of PPE, attendance of visitor in the last days of life and procedure to protect visitors.

**6.7 Allied Health Professional (AHP)**

Working alongside the Nursing and Medical Team to provide specialist input around specific areas of need. This includes Physiotherapy, Occupational Therapy, Dietetics and Speech & Language Therapy (SaLT).

See Appendix 4 for more details on Physiotherapy and Occupational Therapy provision.

**6.8 Specialist Palliative Care Team (STH)**

Will provide support, on a need led basis, where service user identified needs are beyond the scope of SHSC staff competence.

## 6.9 **St Luke's Hospice**

Will provide support with training of SHSC staff on a need led basis. This includes supporting training of End-of-Life Champions within in-patient and care home environments.

Will provide support and guidance, on a need's led basis, in circumstances where SHSC staff require discussion/liaison with a specialist end of life care provider.

## 6.10 **Training**

The Trusts overarching policy for training is the Learning & Development Policy and this should be read in conjunction with this policy.

Each in-patient and care home environment will support the training of a nominated Registered Professional to undertake training in Improving End of Life Care and take on the role of End-of-Life Champion within that environment.

AHP's may choose to support the End-of-Life Champion Role in a wider context, providing support as required around local, bespoke, training to meet both service user and staff needs in this subject area.

## 6.11 **End of Life Champion**

This role includes:

Support embedding of End of Life Care Policy & Procedure within local team.

Provide support for colleagues to have difficult conversations, right person, right time, right environment, for the service user and those important to them.

Identifying local training needs and develop training plan around end of life care based on service user and staff needs.

Act as a local point of contact for queries related to high quality, person-centred end of life care.

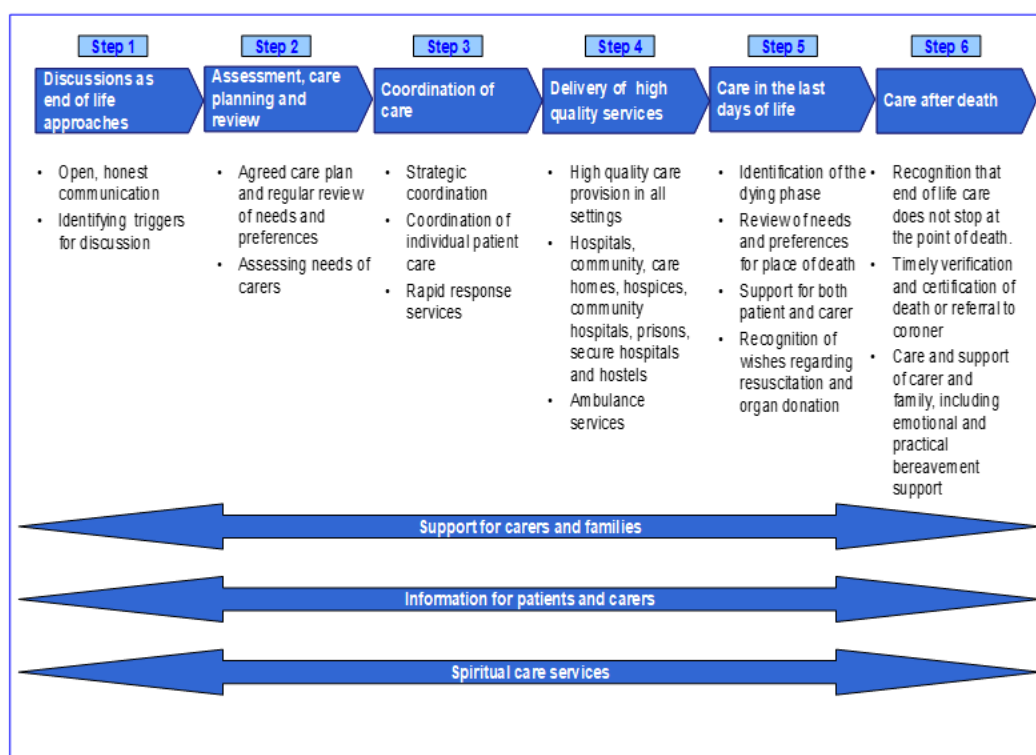
Support monitoring/audit of end of life care planning.

## 7 **Procedure**

Individuals differ in many ways as they approach the end of life. Different factors will impact on individuals needs and preferences for care. These include the nature of the condition, or conditions, from which they are suffering and the different symptoms that they cause.

Different diseases have different trajectories at the end of life. Despite these differences the following key elements of an end-of-life care pathway are recommended:

# The End of Life Care Pathway



## 7.1 Identification

People approaching the end of life must be identified in a timely way. It is important to note that any person with a diagnosis of a life limiting condition must have the opportunity, at a time appropriate for them and those important to them, to discuss Advanced Care Planning, prior to reaching the end-of-life stage of their condition.

Where possible identification should take place with sufficient time to enable provision of high-quality end of life planning, care, and support in accordance with the person's needs and preferences. Ideally this would be a discussion with a GP or other health care professional working with the individual. Rather than within an in-patient environment at a time of mental ill health crisis. Identification needs to be considered on an individual basis.

There are a number of tools available to assist clinicians with timely identification of people approaching the end of life, including the Gold Standards Framework prognostic indicator guidance, extract below:

### Three Triggers that suggest that a person is nearing the end of life

1. The surprise question – would you be surprised if this person were to die in the next months, weeks or days?
2. General Indicators of Decline – deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.

The focus of identification should be on predicting needs rather than exact prognosis hence more about meeting needs rather than giving defined timescales. The emphasis is on anticipating service users' likely needs so that the right care can be provided at

the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

Identification, in this context, may have already been discussed and recorded with the service user and those important to them through primary care services, prior to admission to an inpatient or care home environment. If this has not been the case Responsible Clinician and the wider MDT must consider if the person is likely to be in the last 12 months of life.

## **7.2 Communication and information**

Effective communication, carried out with compassion and sensitivity, is fundamental to the process of providing good quality, person centred care.

Communication and information should be appropriate to the individual, their family and those important to them:

Provided in a way they will be best able to understand, recognising different needs including language, mode of communication, comprehension ability and those of adults with a learning disability.

Must be appropriate to the stage reached by the person who is approaching the end of life.

Provided at a time (not too early or too late) when information is requested or useful to enable the person to make choices/decisions.

Communication with, and information for, families and carers should be considered around the same time as with the person approaching the end of life.

Information should be made available in a variety of accessible formats and languages and be free at the point of delivery. Examples of leaflets on end of life care include those available to download from Dying Matters Coalition using the web link:-

<http://www.dyingmatters.org/page/dying-matters-leaflets>

All communication between care staff the person nearing the end of life and those important to them MUST be clearly documented within the EPR.

## **7.3 Assessment, Care Planning, Advance Care Planning, Plan of Care and Review**

People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment. This will be offered within an appropriate environment facilitated by appropriate members of the MDT.

Within a community setting, including care homes, this is likely to be led by GP, supported by District Nurse with elements of direct care delivered by SHSC staff.

### **7.3.1 Assessment**

Once a Service User has been identified as approaching the end of life, they should receive:

- A prompt holistic initial assessment. Assessment is an ongoing and proactive process that is both planned and responsive. Timing of

assessments should take into account changes in the person's condition or circumstances as well as specific requests from the person approaching the end of life, their families and those important to them.

- The ongoing, proactive assessment process may be transferred between services with the service user therefore needs to be clearly recorded to reduce repetition/duplication and potential delay for the service user.

Assessments must encompass all aspects of end-of-life care, taking into account the preferences of the person, views of their families and those important to them.

The person may have made provision of Lasting Power of Attorney for Health & Welfare and/or LPA for Property & Financial Affairs who must be included in the assessment process if the individual no longer has mental capacity.

In some cases, an individual may have Court Appointed Deputies under the MCA, or an Advocate who will need to be involved in the assessment process.

### **7.3.2 Care Planning**

Care planning is the first step in making care and treatment decisions with a person with life limiting illness, irrespective of their capacity to participate or to decide.

### **7.3.3 Advance Care Planning**

Advance Care Planning discussions and recording can happen at any point in a person's care.

Health Care Professionals involved in the individual's care should provide opportunities for these conversations, discussions and decisions/planning over the course of the person's life following diagnosis of a life limiting condition. However, no pressure should be brought to bear on the individual concerned by health or social care staff, family or any organisation to take part in Advance Care Planning

During the course of discussions, it may become apparent that the person wishes to make an Advance Decision to Refuse Treatment (ADRT). This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act (2005). Specific rules apply to advance decisions to refuse life-sustaining treatment. Advance Care Planning should include asking whether the service user has a Lasting Power of Attorney(s) in place for Health & Welfare and/or Property & Financial Affairs or Court Appointed Deputy has been made in relation to care and welfare decisions for the person should they lose capacity in this respect.

### **7.3.4 Plan of Care**

When a person approaching the end of life has had their needs assessed, their wishes and preferences discussed the agreed, collaborative, care plan should

be recorded, and a copy provided/offered to the individual and family/carer as appropriate.

To enable a person to participate in the planning of their care there may be a need to assess their capacity to participate if there is evidence of reduced or fluctuating capacity.

Assessing capacity and maximising capacity are essential aspects of the care planning process. A person must be given all help that is practicable to maximise their capacity.

This means providing information tailored to their abilities and communicating with them in a way they find easiest.

If a person with capacity chooses not to participate in care planning, their adequately informed consent must be gained in relation to any decisions about their care or treatment that result from care planning.

Care and treatment decision-making by a person with life limiting illness requires that the individual has the capacity to understand, discuss options available, make decisions and communicate their decisions. A person's participation in care planning (including advance care planning) is voluntary.

If a person lacks capacity to participate in their care plan, care planning should involve their relatives, partner, close companions and any other care staff who know them or are responsible for their care. If the person lacks capacity and has no-one to support or represent them staff must seek the assistance of an Independent Mental Capacity Advocate (IMCA) to represent them.

Recommended Summary Plan for Emergency Care and Treatment, ReSPECT, document.

Summary points.

- The ReSPECT plan acts as a summary of key information for future emergency care and treatment at a time when a patient may not be able to express what matters to them. This policy template refers to recommendations about a range of emergency care and treatment options. Life-sustaining treatment could include admission to hospital, antibiotics, fluid resuscitation, admission to Critical Care for intubation and ventilator support, inotropic and other cardiovascular support, as well as cardio-pulmonary resuscitation (CPR).
- Advance decision making about emergency care and medical treatment is a collaboration between a person, their family and their healthcare professionals. In an emergency situation, it is vital that healthcare professionals have a clear understanding of what is important to a person and record realistic care and treatment recommendations including those about CPR.
- All care and treatment recommendations must be clearly recorded on the ReSPECT plan. This could include preferences about Critical Care admission, drug or other treatments. A patient can have a ReSPECT plan and be for CPR.
- **ReSPECT plans are not legally binding.** The ReSPECT plan should be regarded as a summary of an advance clinical assessment with recommendations, recorded to guide immediate clinical decision-making in the event of deterioration in a person's physical health or cardiorespiratory arrest. It constitutes an 'advance statement' under the terms of the Mental Capacity Act 2005, rather than an 'Advance Decision to Refuse Treatment (ADRT)'. The



decision regarding whether or not to attempt CPR or other life-sustaining treatment should be made by the healthcare professionals responsible for the person's immediate care at the time of the emergency.

- A ReSPECT plan complements additional detailed advance care planning documentation, such as ADRT, Ok to Stay documents – it does not replace them. Details of these conversations must be recorded in the healthcare record.
- **Healthcare providers, who are uncertain about the need to give life-saving care, should always presume to save life.** Emergency care should be given until any previously agreed recommendations are clearly understood – this clarity is the purpose of the ReSPECT plan.
- ReSPECT plans must be reviewed when a person's clinical condition or what matters to them during an emergency significantly changes. A review may be considered when they are transferred / admitted / discharged from one healthcare provider to another.
- ReSPECT plans **MUST** stay with the individual so that health and care providers can easily access them. They should, where possible, also be recorded on the patient's digital record.
- DNACPR forms will still be recognised in Sheffield as ReSPECT is implemented across the health and social care system. It is recommended that patients who have current DNACPR forms should have a ReSPECT conversation and a plan created if there is a change in their health conditions.
- Once the ReSPECT process and plan is created, no new DNACPR forms should be completed for patients.

<https://www.resus.org.uk/respect/respect-healthcare-professionals>

Care Plan MUST include:

Any ACP/ADRT – Ceilings of care discussed and agreed with the person and those important to them.

Any spiritual, cultural or practical wishes the dying person and those important to them may have for the time of death or afterwards, particularly regarding urgent release for burial or cremation. This can be done as part of the advance care planning process, or it can be completed nearer the point of death.

Who the person wishes to be present at the time of their death? If this cannot be obtained from the individual try to find out from those important to the person, as well as details of how they wish the news of the death to be communicated if they are not present. Relevant contact details will need to be recorded and readily accessible by all appropriate staff.

Transfer of information from previously recorded, and reviewed, ACP/ADRT.

Wherever possible, assess the dying person's wishes regarding organ, tissue and body donation and possible post-mortem examination, document this in a way that is readily accessible at the time of death.

There should be locally agreed procedures about where care planning documentation is kept and systems in place to enable sharing between the health professionals involved in the care of the individual, including out of hours providers and ambulance services as appropriate.

## Dysphagia or Malnutrition Risk

Service Users should have a care plan that includes mouth care and oral nutrition and hydration that is monitored & reviewed as necessary.

For those Service Users who are not actively dying, specialist assessment and advice concerning swallowing and feeding should be sought for all who have been identified as being at risk of dysphagia or of developing malnutrition.

People who are at the end of life may well not eat or drink enough to prevent malnutrition without support. The decisions on how to support Service Users with their food and drink should be communicated carefully with Service Users, relatives, carers, healthcare workers and advocates to keep them informed and to discuss any difficulties in emotional and contentious areas of nutritional support.

For those Service Users who are actively dying then food & fluid should be offered for comfort. See Appendix 3 for further information.

Ethical and legal principles must be applied when making decisions about withholding or withdrawing nutritional support.

### 7.3.5 Review

The care plan is subject to review by the multidisciplinary team, the service user and those important to them on a planned/schedules basis or as and when a person's condition, or wishes, change, whichever is sooner.

### 7.3.6 Prescribing Best Practice

Prescribing guidance is that in general all medication should be reviewed and rationalised by the multidisciplinary team regularly.

Prescribing at the end of life can include, but is not limited to, pain, nausea and vomiting, breathlessness or infections. Practitioners are reminded that they should only prescribe treatments that are within their routine scope of practice and where they can evidence that they have the most up to date knowledge skills and competency to do so.

Appendix C is a table of Anticipatory Drug table that SHSC Pharmacy department are able to supply in End of Life Care initially.

### 7.3.7 Professional Responsibility for Decisions About Care and Treatment

All members of the multidisciplinary team must carefully consider which decisions need to be made 'on-the-spot' to ensure the person's comfort and safety, and which can and must wait for an MDT review of the person's condition.

The Doctor (Responsible Clinician/GP depending on environment) must ensure that adequate information is available to support decision-making by those involved in caring for the person when they are not available. The plan **MUST** be recorded within the individuals care records, as agreed by the MDT.

## **7.4 Co-ordination of Care**

Co-ordinated care ensures that the person approaching the end-of-life experiences seamless care of a uniformly high standard, regardless of which professionals are delivering the care at the time and the information that the person receives is clear and the content is neither confusing nor contradictory.

As the person's condition may change rapidly it is essential that appropriate support and services are accessible without delay. To support effective end of life care and improve communication through a co-ordination of care, all service users accessing the services provided by the Trust are allocated a named professional to act as their care co-ordinator and be a link for both the person and those important to them. The named professional will link to other clinicians and teams, as appropriate, to ensure that care can and is being delivered appropriately to support the person at the end of their life.

All members of the direct care team should be empowered to report any difficulties that cannot be managed by them to the wider MDT to facilitate a review and update of the plan of care.

## **7.5 Comprehensive Support**

Comprehensive holistic support will include, as a minimum, physical, psychological, social, spiritual, cultural, and where appropriate, environmental considerations. This may relate to needs and preferences as well as associated treatment, care and support.

### **7.5.1 Physical and Psychological Support**

Safe, effective and appropriate symptom and side-effect management at any time of day or night may require co-ordinated input from a number of different professionals and services. As a minimum, essential 24/7 care services should include:

- Medical and nursing services
- Access to pharmacy services
- Access to equipment and adaptations
- Access to specialist palliative care advice on symptom and side effect management

Medical staff are directed to the General Medical Council's comprehensive guidance "Treatment and care towards the end of life: good practice in decision making" and in particular the important issues around clinical assisted nutrition and hydration.

Psychological support encompasses general emotional support and empowerment as well as specialist psychological care. General emotional support can be provided by confident & competent Nursing & Medical staff as well as members of the Chaplaincy Team.

Specific psychological needs are more likely to require psychological interventions this would be provided through specialist services provided by an appropriate Psychologist.

### **7.5.2 Social, Practical and Emotional Support**

Within a hospital or care home environment practical support will be provided by the multidisciplinary team, which may include Occupational Therapists, Physiotherapists, and other Health Professionals.

Effective practical support will require timely and rapid access to appropriate equipment such as commodes, pressure-relieving mattresses and other aids, to meet individual needs and preferences.

A stepped approach to emotional support may be appropriate, which includes, but is not limited to:

- Information about available support services and support to access these.
- General emotional support, such as supportive conversations with medical and nursing staff.
- More specialist support from the Spiritual Care Team or referral to trained counsellors, or specialists in palliative care.

It is recognised that conflict can arise between what professionals may deem appropriate and what the person approaching the end of life wants or prefers, which may also differ with the views of those important to the person approaching the end of life. Appropriate support is support that has due regard to the preferences of the person approaching the end of life and is in their best interests.

### **7.5.3 Spiritual and Religious Support**

Spirituality is a universal human quality that every person can experience independently of religion. It refers to the way individuals seek and express meaning and purpose in life, their sense of relationship to themselves, to others whom they love, to nature, to God and to the sacred. It relates to their identity, values and beliefs. When spiritual needs are acknowledged and addressed it can bring comfort and strength. If they are ignored it can lead to emotional pain and distress.

Chaplains can provide spiritual care for any service user with a palliative care diagnosis, their family and those who are important to them. The Chaplaincy service is available to all in-patient service users, including those people receiving end-of-life care and care during the last 12 months of life, not only in their final weeks/days of life. SHSC chaplains are accessible through regular visits to all SHSC in-patient sites, including Grenoside Grange, Birch Avenue, Woodland View and Buckwood View.

Each service user should be asked whether they would like to see a chaplain, so that the chaplain can introduce themselves and identify any spiritual needs and support that may be desired. Clinical staff can make specific referrals to Chaplaincy, who offer person-centred spiritual and religious care to both service users and their loved ones.

It should be acknowledged that spiritual care is broader than religious care and includes things like purpose, meaning, identity, relationships, grieving over losses, the exploration of a person's life and existential issues relating to the person's beliefs and questions about death and dying. Talking about fears and

worries, painful experiences, loss and grief can lead to a sense of reconciliation, healing, peace and hope.

Spiritual care is an intrinsic part of providing excellent end of life care. It is holistic, personalised, inclusive, responsive and compassionate. Chaplains do not impose religious ritual or practice but sensitively respect the beliefs and values of each individual service user and their families. The Chaplaincy team is multi-faith and represents a variety of faith and non-faith backgrounds (including humanist). They offer support to the service user during their journey towards death and later, bereavement support to family, carers and those important to the person.

If a service user has a religious faith, they can offer prayer and communion, read sacred texts or contact the person's faith leader on their behalf, if they would like this. The Muslim chaplain can offer prayer and support for Muslim service users and their relatives.

Availability: Any member of staff can contact the Chaplaincy team:  
Tel: 0114 271 8022 or [chaplains@shsc.nhs.uk](mailto:chaplains@shsc.nhs.uk), during office hours  
Sunday to Friday.

If a service user requires urgent spiritual or religious care (for example, last rites for a Roman Catholic) staff should contact the person's own faith leader in the first instance.

***Spiritual care is everyone's business and part of the care offered by all healthcare professionals.***

The Chaplaincy Team can offer guidance and teaching sessions for staff in this area as well as supporting staff after a death which may have been distressing, either individually or in a group reflective practice session.

#### **7.5.4 Support for Families and Carers**

The term 'families' is broad and relates to any person who has significant contact with the person approaching the end of life, including children, a partner, or close friends.

'Carers' are defined as informal, unpaid carers or supporters. Sometimes the main carer maybe a young person or a person with their own disability, and services should be sensitive to the particular challenges that this may raise. Support for families and carers may include emotional and psychological support.

Appendix 5 provides a list of bereavement support services.

#### **7.5.5 Prompt, Safe, Effective and Responsive Care**

Urgent care is defined as the range of responses that health and care services provide to people who require, or who perceive the need for, urgent advice, care, treatment or diagnosis. People in receipt of SHSC inpatient, Community Services and Care Home services and their families and carers, can expect 24 hours a day, 7 days a week consistent and rigorous assessment of the urgency of their care need

and an appropriate and prompt response to that need.

### 7.5.6 Specialist Palliative Care

People who may benefit from Specialist Palliative Care are those whose symptoms cannot be managed in a timely way by their usual care team. Specialist palliative care support is available:

|               |   |
|---------------|---|
| In Hours:     | St Lukes Hospice, referral form             |
| Out of hours: | On-call palliative spr via STH switchboard. |

Specialist palliative care support should be used on basis of need, not diagnosis. It should be offered and accessed at the right time for the individual and be appropriate to their needs and preferences at any time of day or night.

## 7.6 Care in the Last Days of Life

'The last days of life' is the period of time in which a person has been medically recognised as actively dying, when death is imminent and when the time before the anticipated death is being measured in days.

The Leadership Alliance for the Care of Dying People Report '**One Chance to get it Right**' identified five new priorities for care to replace the Liverpool Care Pathway as the new basis for caring for someone at the end of their life. The priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person.

5 new priorities Leadership Alliance for the Care of Dying People.

- Anybody who has a progressive life-limiting illness should be offered the opportunity to develop, document, review and update a Personal Palliative Care Plan.
- Care of people in the last days of life must seek to achieve the outcomes set out for care in the last days of life and what this means for people approaching the last days of their life and their families and carers.
- The outcomes and principles set out should be used to guide the care of dying people.
- The discomfort that lies in conversations about dying and care in the last days of life must be acknowledged and should be a recognition that whilst some tasks of caring for dying people can be reasonably straightforward, other aspects of care will be more difficult.
- The quality of care of dying people should be demonstrated through local quality assurance processes, participation in national audits and inspections, and by exploring the experience of the dying person and those closest to them.

**Appendix 7** provides further information to support care in the last days of life.

**Appendix 8** provides information to support communication with the dying person and those important to them around 'What to Expect When Someone is in the Last Days of Life'.

## 7.7 Care after Death

The healthcare professionals' role at the end of life extends beyond death to provide care for the deceased person and support to their family and carers. The term 'care after death' (which has replaced the traditional term of 'last offices') is intended to reflect the differing nursing tasks involved, including the physical preparation of the body itself and on-going support of the family and carers.

Although based on comparatively straightforward procedures, care after death requires sensitive and skilled communication, addressing the needs of family members/carers and respecting the integrity of the person who has died. It is a very difficult time for those who have been bereaved and can be emotionally challenging for the direct care team therefore support should be available for reflection and debrief as appropriate.

Professionals who may be involved in the end-of-life pathway include doctors, mortuary staff, ambulance staff, bereavement officers, social care staff, funeral directors, pathologists, coroners and faith leaders. Co-ordinated working between these individuals and organisations is vital if the process is to run smoothly.

### 7.7.1 Verification and Certification

When death has taken place, the medical practitioner responsible for that person's care must be informed. Verification needs to be completed by a Doctor before the body is transferred from the care setting.

Record verification of death, the date and time this occurred in the notes and/or care pathway documentation, along with the name and contact details of the responsible Doctor (RC/GP depending on care environment).

The professional verifying the death (this may be a Nurse or Dr depending on the care environment) is responsible for confirming the identity of the deceased person using the terminology of 'identified to me as. This must include:

- Name
- Date of birth
- Address
- NHS number

It is good practice for the person verifying the death to attach name bands with this information to the wrist or ankle of the deceased person.

The practitioner who verifies the death must ascertain whether the person had a known or suspected infection and whether this is notifiable.

In such cases, they must then follow SHSC Infection Prevention Control Policy regarding reporting responsibilities.

It is vital that processes are in place to protect confidentiality, which continues after death. However, this does not prevent the use of sensible rules to safeguard the health and safety of all those who may care for the deceased.

Timely verification and certification of death should include information for families and carers on when, where and how to register a death and information on the role of the coroner (if coroner involvement is likely).

The following details are required when reporting a death to the coroner:

- The professional's telephone/bleep number
- The deceased person's name, address, date of birth and GP details
- Family members' names, contact details and relationship to the deceased person
- Date and time of death
- Details of the person who pronounced life extinct
- Details of what happened leading up to the death

Where the death of a detained Service User occurs, the Trust's Mental Health Act Administration Manager must also be informed, to ensure the Care Quality Commission is notified in accordance with statutory requirements.

### **Medical Certificate of Cause of Death (MCCD)**

The MCCD (more commonly known as the death certificate) fulfils a number of purposes including:

- Allowing the relatives of the deceased to register the death.
- Provides a permanent legal record of death.
- Allows the relatives to arrange for the funeral, etc and to settle the estate of the deceased.

Death certificates should be completed by a doctor who has provided care during the last illness and who has seen the deceased within 28 days before death. The Coronavirus Act 2020 provides further guidance around Certification of Death.

#### **7.7.2 Personal Care after Death**

Personal care after death is the term used for the physical preparation of the deceased person. The privacy of the body must be maintained, and no unauthorised persons must be granted access to the body. After death has been certified, the Nurse in charge is responsible for ensuring that the deceased is cared for in a culturally sensitive and dignified manner, so the spiritual and cultural wishes of the deceased person and their families are maintained whilst ensuring legal obligations are met. This responsibility includes preparing the deceased for transfer to the mortuary or the funeral director's premises in full consultation and agreement of family/carers. Family and carers present should be provided the opportunity to participate in 'care after death' with support from the Nurse in Charge and wider MDT where available. The movement of the body and the transfer to undertakers must be fully documented in the deceased Service User's record.

The personal care after death needs to be carried out within two to four hours of the person dying, to preserve their appearance, condition, and dignity.

It is important to note that the body's core temperature will take time to lower and therefore refrigeration within four hours of the death is optimum.

Tasks such as laying the deceased flat (while supporting the head with a pillow) and preparing them and the room for viewing need to be completed as soon as possible within this time.



Some family members/carers may wish to assist with the personal care in acknowledgement of individual wishes, religious or cultural requirements.

The care team must prepare them sensitively for changes to the body after death and be aware of manual handling and infection control issues.

Any in place medical devices should be respectfully removed by competent practitioners and clear documentation must highlight any medical devices that are unable to be removed such as pacemakers.

The privacy and dignity of the deceased on transfer from the place of death is paramount. Each Ward/Unit is responsible for ensuring that the transfer respects the values of personal dignity and that these are incorporated in the design of the concealment trolley and the way the deceased is covered.

Whole body donation can only be agreed by individuals themselves and not by anybody else on their behalf after death. If an individual's wishes regarding organ and tissue donation were not formally recorded before death, consent can be sought from a nominated representative or someone else in a qualifying relationship, if they believe the deceased wanted to donate.

Advice on consent is available from the NHS Blood and Transplant Service - <http://www.uktransplant.org.uk/> Upon death, the nurse/medical practitioner should contact the Specialist Nurse – Organ Donation service (SNODS) who will liaise with the various organisation to facilitate the donation of organs. SNODS can be contact 24 hours a day, seven days a week on: SNODS - 07659591642 The Health and Safety of everyone who comes into contact with the body must be protected.

Guidance on Infection control management can be obtained from the Trust's Infection Prevention and Control Lead.

### **7.7.3 Personal Possessions**

If the next of kin attends the ward/care home following the death, return the deceased's personal possessions to them ensuring that the appropriate Trust documentation is completed for patient's property and valuables. However, if the deceased is known, or suspected, to have an infectious disease then personal possessions need to be placed in appropriate container which is sealed and kept on the Ward/Unit for a minimum of 72 hours prior to transferring into the care of next of kin. This will need to be communicated sensitively to the next of kin providing reassurance that the items are being safely stored. Please refer to Trust IPC Policy.

Evidence suggests that how the deceased's possessions are handled not only has an immediate impact on relatives but also impacts on their subsequent bereavement.

It is important for staff to be both sensitive and procedurally aware during the handover, ensuring a receipt is always obtained to indemnify the organisation against any possible claim.

If the next of kin are not present, or property is found after the relatives have left the environment they need to be notified and it is important that any valuable property is stored in an appropriate safe and documented correctly.

All other personal property should be stored safely before being returned to the next of kin/power of attorney. If property has not been returned to next of kin and, if it is a coroner's case, the property should be transferred to the mortuary with the deceased in accordance with standing financial instructions.

Please refer to the Trust's 'Patients' Monies and Property Policy' for more detailed information.

#### **7.7.4 Bereavement Support**

Bereaved people must be offered support at the time of death that is culturally and spiritually appropriate, immediate, and available shortly afterwards. Bereavement support may not be limited to immediately after death, but may be required on a longer-term basis and, in some cases, may begin before death.

A stepped approach to emotional and bereavement support may be appropriate, which could include but is not limited to:

- Information about local support services.
- Practical support such as advice on arranging a funeral, information on who to inform of a death, help with contacting other family members and information on what to do with equipment and medication.
- General emotional and bereavement support, such as supportive conversations with the Chaplaincy Team or support from the voluntary, community and faith sectors, referral to more specialist support from trained bereavement counsellors can be facilitated if needed.

**See Appendix 5**

### **8 Development, Consultation and Approval**

*This section should include details of:*

*Policy has been developed through End-of-Life Task & Finish Group involving diverse range of professionals.*

*Head of Mental Health Legislation*

*Human Rights Officer*

*Specialist Mental Health Dietician*

*Speech & Language Therapist (Learning Disability/dysphagia)*

*Speech & Language Therapist (Mental Health)*

*Resuscitation Officer*

*Chaplaincy Team*

*Head of Nursing (Acute inpatient & Older Adult Services)*

*Deputy Head of Nursing (Acute)*

*Chief Pharmacist*

*Older Adult Consultant*

*Occupational Therapist*

*Physiotherapists*

*Deputy Ward Manager (Inpatient Older Adult Service)*

*End of Life Champion (Care Home)*

*Guidance followed:*

*NICE*

*Gold Standards Framework*

*DoH*

*Legal Framework*

*MHA*

*MCA*

*Equalities Act*

*HRA*

*CQC*

**Policy Template**

## 9 Audit, Monitoring and Review

*This section should describe how the implementation and impact of the policy will be monitored and audited. It should include timescales and frequency of audits.*

*If the policy is required to meet a particular standard, it must say how and when compliance with the standard will be audited.*

| <b>Monitoring Compliance Template</b>                        |                        |  |                         |   |  |  |
|--|------------------------|--|-------------------------|---|--|--|
| Minimum Requirement  | Process for Monitoring | Responsible Individual/group/committee | Frequency of Monitoring | Review of Results process (e.g. who does this?) | Responsible Individual/group/committee for action plan development | Responsible Individual/group/committee for action plan monitoring and implementation |
| Discussions around DNACPR                                    | DNACPR audit           | Ward/Service leadership team           | Monthly                 | Physical Health team                            | Physical Health team   | Physical Health Management Group   |
| Discussions around ACP                                       | Care plan audit        | Ward/Service Leadership team           | Monthly                 | MHA team  | MHA team   | MHA team with ward nursing leadership team   |
| End of life champion in each inpatient/care home environment | Audit                  | Learning & development                 | Yearly                  | Ward/Service/Care Home management team          | Ward/Service/Care Home management team                             | Ward/Service/Care Home management team   |

## 10 Implementation Plan

| Action / Task  | Responsible Person | Deadline   | Progress update              |
|--|--------------------|------------|------------------------------|
| Upload new policy onto intranet and remove old version | SHSC Comms         | 26/06/2023 | Sent for 2-week consultation |

|  |              |                           |  |
|--|--------------|---------------------------|--|
| Upload new policy onto intranet        |              | 5 days after ratification |  |
| Make teams aware of new/updated policy | Team manager | 5 days after ratification |  |

## 11 Dissemination, Storage and Archiving (Control)

| Version | Date added to intranet | Date added to internet | Date of inclusion in Connect | Any other promotion/ dissemination (include dates) |
|---------|------------------------|------------------------|------------------------------|--|
| 1.0     | March 2022             | March 2022             | March 2022                   |  |
| 2.0     | June 2023              | June 2023              | June 2023                    |  |
| 3.0     |                        |                        |                              |  |
| 4.0     |                        |                        |                              |  |

**12 Training and Other Resource Implications**

**13 Links to Other Policies, Standards (Associated Documents)**

**14 Contact Details**

| <b><i>Title</i></b>   | <b><i>Name</i></b> | <b><i>Phone</i></b> | <b><i>Email</i></b>      |
|-----------------------|--------------------|---------------------|--------------------------|
| Resuscitation Officer | Mo MacKenzie       |                     | Mo.mackenzie@shsc.nhs.uk |
|                       |                    |                     |                          |

## Appendix 1

### Care Quality Commission's Fundamental Standards introduced 1 April 2015

#### **Regulation 9 Person-centred care**

Providers must make every reasonable effort to provide opportunities to involve people in making decisions about their care and treatment and support them to do this. This includes physical, psychological or emotional support, or support to get information in an accessible format or to understand the content. It may include involving people in discussions, inviting them to meetings and encouraging them to ask questions and providing suggestions.

People using the service and/or those lawfully acting on their behalf must be actively encouraged and supported to be involved in making decisions about their care or treatment as much or as little as they wish to be. This includes taking all steps to maximise a person's mental capacity in different ways to make as many of their own choices as possible.

#### **Regulation 10: Dignity and respect**

All staff must treat people receiving care and treatment with dignity and respect at all times. This includes all communication with people using services must be respectful; using or facilitating the most suitable means of communication, for them, and respecting a person's right to engage or not to engage in communication; respecting people's personal preferences, lifestyle and care choices.

#### **Regulation 11: Need for consent**

Where a person lacks mental capacity to make an informed decision, or give consent, staff must act in accordance with the requirements of the Mental Capacity Act 2005 and associated code of practice.

Discussions about consent must be held in a way that meets people's communication needs. This may include the use of different formats or languages and may involve others such as a speech language therapist or independent advocate. Consent may be implied and include non-verbal communication such as sign language or by someone offering their hand when asked if they would like help to move.

Consent must be treated as a process that continues throughout the duration of care and treatment, recognising that it may be withheld and/or withdrawn at any time.

When a person using a service or a person acting lawfully on their behalf refuses to give consent or withdraws it, all people providing care and treatment must respect this.

#### **Regulation 14 Meeting nutritional and hydration needs**

Providers must include people's nutrition and hydration needs when they make an initial assessment of their care, treatment and support needs and in the ongoing review of these. The assessment and review should include risks related to people's nutritional and hydration needs.

Nutrition and hydration assessments must be carried out by people with the required skills and knowledge. The assessments should follow nationally recognised guidance and identify, as a minimum:

- Requirements to sustain life, support the agreed care and treatment, and support ongoing good health.
- Dietary intolerances, allergies, medication contraindications.
- How to support people's good health including the level of support needed, timing of meals, and the provision of appropriate and sufficient quantities of food and drink.
- Nutrition and hydration needs should be regularly reviewed during the course of care and treatment and any changes in people's needs should be responded to in good time.
- A variety of nutritious, appetising food should be available to meet people's needs and be served at an appropriate temperature. When the person lacks capacity, they must have prompts, encouragement and help to eat as appropriate.
- Where a person is assessed as needing a specific diet, this must be provided in line with that assessment.
- Nutritional and hydration intake should be monitored and recorded to prevent unnecessary dehydration, weight loss or weight gain. Action must be taken without delay to address any concerns.
- Staff must follow the most up-to-date nutrition and hydration assessment for each person and take appropriate action if people are not eating and drinking in line with their assessed needs.
- Staff should know how to determine whether specialist nutritional advice is required and how to access and follow it.

Providers must follow people's consent wishes if they refuse nutrition and hydration unless a best interests' decision has been made under the Mental Capacity Act 2005. Other forms of authority such as advance decisions should also be taken into account.



## **Appendix 2**

### **Human Rights Act (HRA) (1998)**

The rights that are especially pertinent to end of life issues are Articles 2, 3, 5, 8, 9, and 14. Details of which are expanded upon below:

#### **Article 2: The Right to Life.**

No health practitioner can deliberately end a patient's life. The right to life is absolute.

It is not lawful to administer medication or make decisions about an individual's care without consent of a person who has capacity and is conscious (as per *Re F* 1990). Likewise, conscious patients with capacity cannot have their care withdrawn against their wishes. (as per *Burke v GMC* 2005).

As per *Ozman v UK* (1998) Health services have a positive obligation to protect life. If there is a real and immediate risk to a patient's life -that health care providers know about or should know about, there is a legal obligation to take steps to protect that person's life.

For example, if someone under the care of the Trust is a suicide risk there is an obligation to protect that person from themselves. Or if there is a reason to believe a patient's life is at risk (such as a family member planning to facilitate an assisted suicide) the Trust is obligated to protect that person from this risk.

When a Service User dies under the care of the Trust, and the Trust's action/inaction may have been a contributory factor, there must be an independent investigation.

Withdrawal of care is a complex area in regard to Article 2 as this will depend on the particularities of the case. The Court of Protection may have to be consulted in decisions to withdraw care. In general, treatment where there is benefit to the patient cannot be withdrawn.

Actively administering drugs to deliberately end life, and have no other pain relief, medical and/or therapeutic benefit would not only be an Article 2 breach (as per *Bland v Airedale NHS* 1993), but also be a criminal matter where individual staff may face serious consequences including prison.

Unconscious Service Users, unable to make decisions, could have their care withdrawn if this is a clinical decision, made in the best interest of the person, concurrent with respectable medical opinion, and where treatment serves no therapeutic or other end. For example, for a person in a perpetual vegetative state there is a potential argument that nutritional substance could be withdrawn – however the Court of Protection would need to affirm such a decision before such an action was taken.

Where there may be conflict with Article 2 is a situation in where life prolongation is inhumane or degrading, as this could be said to be in breach of Article 3 (prohibition of torture, inhuman and degrading treatment). In such a case health care provider are not obliged to prolong life (as per *Burke v GMC* 2005). Administering pain relieving medicine that has the result of hastening death maybe justifiable as a means of protection against inhumane or degrading treatment if the sole purpose is to ease pain. This will depend on circumstances. However, not if the purpose is to end the person's life.

It must be noted that there is no legal 'right to die'. The obligation to prevent Article 3 violations to avoid inhumane and degrading treatment do not extend to assisting a person to die, even where a Service User with capacity has asked explicitly for this (as per *Pretty v UK* 2002). Assisting a person to die is not only an Article 2 breach but is a criminal offence which may result in anyone who has been involved being arrested and subsequently going to court, this can result in lengthy prison sentences.

A Service User could refuse treatment knowing that this would result in death (as per *Re B (Adult: Refusal of Medical Treatment)* (2002) However, there is a clear distinction between passively allowing death and active assistance in suicide.

As with other elements of care and human rights a Service Users family (or those with legal obligations towards the care of an individual under LPA) should be included in any decisions.

### **Article 3: The right not to be tortured or treated in an inhumane or degrading way.**

This is an absolute right thus under no circumstances is it lawful, proportionate or justified to interfere with it.

Broadly this right not only requires that the Trust not act in a way which is torturous, inhumane, or degrading but to also protect patients from this. Key here is protection from both intention (premeditation to carry out such breaches) but also from breaching Article 3 unintentionally through failing to take steps to prevent and protect from inhumane and degrading treatment. The holistic context of the case is vital here to assessing if Article 3 breaches are likely. What may be acceptable to one person may be tortuous, inhumane, and degrading to another. Thus, factors such as age, disability, gender, historical trauma, personality, belief system etc need to be fully considered to assess if any action/inaction may result in a person feeling they are being treated in a degrading or inhumane way. Ultimately inadvertent Article 3 breaches are most effectively avoided by ensuring that plans, decisions, assessments etc are carefully tailored to the individual's circumstances to ensure that anything that may be torturous, inhumane, humiliating or degrading to each specific person is identified and protected against.

### **Article 5: Right to Liberty**

Article five is a qualified right. This means that there are specific circumstances in which a person can be deprived of their liberty. Most commonly for the Trust this would be deprivation of liberty via the Mental Health Act or Mental Capacity Act. Anyone detained under the MHA will be deprived under one of the sections of the Act. Anyone detained under the MCA will have had to have been detained in accordance with the Deprivation of Liberties Safeguards (DOLS). In some situations, authorization from the court of protection may be required.

It should be noted that new arrangements around deprivation of liberty are scheduled to be introduced by the UK government from April 1<sup>st</sup>, 2022, via the new Deprivation of Liberty Safeguards.

A person is said to be deprived of their liberty if they are under continuous supervision and control and are not free to leave (as per *P v Cheshire West* 2014).

If the *Cheshire West* definition describes the situation of a patient placed in a hospital or care home a DOLS authorization will need to be obtained by the local authority. Anyone deprived

of their liberty in a domestic context, for example in supported living, a court of protection order will be required.

Service users must be informed about why they are detained, given the opportunity to challenge that decision, to be facilitated to tell their side of the story and be allowed to see any relevant documentation that pertains to their detention.

### **Article 8: Respect for Private and Family Life, Home and Correspondence**

Article 8 covers not just privacy and confidentiality but also aspects of personal autonomy, involvement in treatment decisions, the ability to be part of a community, to access one's own personal networks. 'Home' can in this regard be considered as such in context of residency in a hospital in-patient environment, a care home as well as one's own personal home.

Article 8 is a qualified right, thus there are limited circumstances in which there may be legal, justified and proportionate interferences in a patient's Article 8 rights. This will be in circumstances in which there is a security, public safety, public health issue or to protect and prevent infringements on the rights and freedoms of other people or to prevent a crime. If one or more of these justifications emerges as a reason to impose a restriction upon a patient's rights that restriction must be proportionate. The restriction imposed must be the absolute minimum restriction available to meet the aim of its imposition.

Blanket restrictions are extremely difficult to justify and should be avoided. The imposition of restrictions should, in most cases, be done on a case-by-case basis that is tailored to the context of the person's individual circumstances.

It is incumbent on care providers to protect Article 8 rights.

It is in the context of Article 8 rights, that respect private decisions, that 'Do Not Resuscitate orders' operate. Decisions on how a person spends the last days of their life falls within the scope of Article 8, as decisions contingent upon personal autonomy, personal integrity, dignity, and quality of life which are protected by Article 8. Hospitals must consider patients' rights before imposing DNACPRs and where possible involve the individuals subject to those orders and inform them of the imposition of a do not attempt cardiopulmonary resuscitation order. It is only permissible that a patient should not be involved in the decision to impose a DNACPR if it would likely to cause serious physical or psychological harm to involve them in that decision (as per Tracey V Cambridge University Hospitals NHS Trust 2014).

### **Article 9: Freedom of thought, conscience and religion**

Article 9 means that someone cannot have their right to hold their beliefs interfered with. The Trust has a duty to protect this right for those under its care. The ability to put one's convictions into practice is also protected except for some limited circumstances- such as to protect public safety, public order, public health and morals or the protection of the rights and freedoms of others.

Restriction of Article 9 rights again can only be lawful, justified and proportionate. In practice this right will be most relevant in terms of ensuring that people's religious and spirituality needs are facilitated as their life ends and practices that are religiously important to patient; but they may also manifest in terms of people's religious beliefs informing their decisions to decline some medical interventions. Another situation may occur when an individual is not happy to abide by religious customs that their families may be very insistent, they follow as

their life ends; this right to choose to not observe religious custom is equally important to Article 9 adherence.

#### **Article 14: Prohibition of discrimination**

Article 14 is mostly deployed in connection with other rights. Article 14 prohibits other rights not being applied to a person due to some characteristic they may possess (sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status). Article 14 enhances the Equality Act 2010, which covers much of the same areas. However, it is in the term “other status” that Article 14 enhances the protections of the Equality Act which covers only 9 ‘protected characteristics’. The inclusion of the term ‘other status’ in Article 14 extends discrimination protection to a much wider range of groups- for example asylum seekers would not necessarily be covered by the Equality Act, whereas they would fall under the scope of ‘other status’ in Article 14.

## Appendix 3

### How to support eating and drinking with clinical assistance; A summary guide to decision making.

| Area                               | Key Points   |
|------------------------------------|--|
| <b>Assessment</b>                  | A complete medical assessment is needed, preferably by a physician experienced in nutrition support. A medically led nutrition support team often includes all the required skills and is most experienced in coordinating the discussions. An understanding of the prognosis of the underlying condition (with and without CANH) and the mechanism of the impaired oral intake will inform these discussions. |
| <b>Communication</b>               | Good communication with patients, relatives, carers, healthcare workers and advocates is essential, both to keep them informed and to discuss difficulties in emotional and contentious areas.<br><br>Verbal and written language should be clear and unambiguous.   |
| <b>Time</b>                        | Adequate time is required for discussion and for decisions to be made effectively. Rushed and poorly informed discussion will lead to unhappy patients and relatives.  |
| <b>Capacity and best interests</b> | The patient's capacity must be determined and, if they lack capacity to make the relevant decision, all actions must be taken in their best interests.   |
| <b>Care</b>                        | Good nursing care that includes attention to mouth care and oral nutrition/hydration will improve outcomes.<br><br>There should be trained staff available to pass a nasogastric feeding tube safely when required (certainly in hospitals).   |
| <b>Oral intake</b>                 | Food and fluid orally have value beyond biological usefulness and should always be offered.<br><br>Patients should always have oral foods and fluids available to them, modified in consistency if necessary.<br><br>Small quantities of fluid can improve mental alertness.<br><br>Dietitians and speech and language therapists can help in supporting this approach.  |
| <b>End of life</b>                 | Most palliative medicine physicians believe that to force fluid into a dying patient does not relieve thirst or hunger as these are not usually felt towards the end of life.<br><br>Tube feeding is therefore rarely required at this stage.  |
| <b>Technical skills</b>            | Technical understanding and skills are essential for the nutrition support team so that they can advise on which methods of CANH are appropriate in individual cases.<br><br>The exact prescriptions of feed should be made by experienced dietitians.   |

Supporting people who have eating and drinking difficulties. A guide to practical care and clinical assistance, particularly towards the end of life. Report of a working party  
Second edition, March 2021. Table 5. Pages 72 & 73

## Appendix 4

### Support Available from Physiotherapy/Occupational Therapy Team

The Physiotherapist can assist in the care of the dying person in a range of ways depending on the individual's goals, physical challenges and moving and handling needs. Some of the areas that a Physiotherapist can support with include:

- Show the service user how to move safely and comfortably.
- Assist in pain control through positioning techniques and assisted exercises.
- Advice on energy conservation techniques and pacing.
- Evaluate the person's ability to move and transfer safely and identify areas of difficulty to focus on to make these work better for the service user.
- Support to achieve a final goal such as one last outing. The Physiotherapist can help problem solve a safe way for the individual to achieve this, for example identifying an appropriate wheelchair and safe transportation method considering the length of the trip and position changes which may be necessary during that time.
- Provide advice to those important to the dying person on ways they can support the dying person with exercises if they wish.
- Provide advice to those important to the dying person on activities they can do with the person to enhance their experience, enabling visiting to be meaningful for the dying person and those close to them.
- Physiotherapists, in collaboration with Occupational therapists can consider the environment that will be most suitable for the individual and their moving and handling needs.
- Assist in transferring such as in and out of bed, toilet transfers and from wheelchair to bed, these assessments are made in collaboration with the Occupational therapist.
- Physiotherapists and Occupational Therapists are able to make referrals for and order equipment such as wheelchairs, they can recommend different types of equipment to support the service users transfer needs and postural needs for example specialist seating, and postural cushions.
- Recommend equipment needs and adaptations for the home environment as well as provide advice to family members and carers if the service user wishes to be discharged home, the Physiotherapist will, in these circumstances, refer on to therapists in the community who can provide appropriate continuity of care.
- Positioning to prevent contractures, pressure sores, as well as aiding respiration and digestion.
- Provide exercise programmes which maintain functional but comfortable range of movement.
- Falls prevention strategies and advice to the wider MDT about how to support the individual to reduce risk of falls.

## Appendix 5

Below is a table of the medications recommended by SHSC for end-of-life care. This is not an exclusive list, but a guidance of what the trust uses and keeps in stock. For further information contact pharmacy (01142718632) or the palliative care team (0114 2714940).

| Indication   | Anticipatory Drug  | Dosing and frequency for PRN use (Subcutaneous)  | Max doses over 24 hours  | Further information  | Compatible Diluent: Water for injection  |
|--|--|--|--|--|--|
| Pain<br>(If on a patch continue patch & administer oral or SC for breakthrough pain)<br><b>Use lower doses if opioid naive</b> | Morphine Sulphate (1 <sup>st</sup> )   | 2.5mg to 5mg hourly PRN (Older adult 1.25mg to 2.5mg) PRN  | No maximum however review if reach 120mg/ 24 hours (not including patch) | If requiring more than 3 PRN doses consider SC infusion via syringe pump | Haloperidol, Levomepromazine, Midazolam, Hyoscine Butylbromide (combination of 3 drugs)                    |
|  | Oxycodone (2 <sup>nd</sup> ) (if renal failure stage 4 or 5 / eGFR <30ml/min)                                  | 2.5mg to 5mg hourly PRN (Older adult 1.25mg to 2.5mg) PRN  | No maximum however review if reach 120mg/ 24 hours (not including patch) | If requiring more than 3 PRN doses consider SC infusion via syringe pump | Haloperidol Levomepromazine, Midazolam, Hyoscine Butylbromide (combination of 3 drugs)                     |
| Nausea and Vomiting / Agitation  | Haloperidol (1 <sup>st</sup> )<br><i>Do not give in Lewy body dementia or Parkinson's Disease</i>              | 0.5mg to 1.5mg every 2 hours PRN (nausea & vomiting)<br>1mg to 5mg every 2 hours PRN (agitation)             | 5mg for Nausea and vomiting<br>5mg for agitation*                        | If requiring more than 3 PRN doses consider SC infusion via syringe pump | Morphine Sulphate, Hyoscine Butylbromide, Midazolam, Oxycodone (combination of 3 drugs)                    |
|  | Levomepromazine (2 <sup>nd</sup> ) (1 <sup>st</sup> line in <u>Lewy body dementia or Parkinson's Disease</u> ) | 6.25mg to 25mg twice a day (12 hourly) PRN for nausea and vomiting<br>6.25mg every 2 hours PRN for agitation | 50mg for nausea and vomiting<br><br>50mg for agitation**                 | If requiring more than 3 PRN doses consider SC infusion via syringe pump | Morphine Sulphate, Levomepromazine, Midazolam, Hyoscine Butylbromide, Oxycodone (combination of 3 drugs)   |
| Agitation  | Midazolam 10mg/2ml   | 2.5 to 5mg hourly PRN (1.25mg-2.5mg) hourly PRN in older adults  | 15mg (10mg for eGFR <30ml/min)***  | If requiring more than 3 PRN doses consider SC infusion via syringe pump | Haloperidol, Levomepromazine, Morphine Sulphate, Oxycodone, Hyoscine Butylbromide (combination of 3 drugs) |
| Chest secretions   | Hyoscine Butylbromide 20mg   | 20mg hourly PRN  | 240mg  | If requiring more than 3 PRN doses consider SC infusion via syringe pump | Haloperidol, Levomepromazine, Midazolam, Morphine Sulphate, Oxycodone (combination of 3 drugs)             |

\*Haloperidol max dose for agitation can go up to 20mg in patients who are not antipsychotic naïve (10mg in older adults)

\*\*Levomepromazine max dose for agitation can go up to 100mg who are not antipsychotic naïve

\*\*\*Midazolam max dose can go up 60mg in patients with agitation who have a psychiatric history but to monitor for respiratory depression

## **Appendix 6**

### **Bereavement Support Services Bereavement Advice Line**

There are many practical issues to manage when someone dies. Bereavement Advice Centre supports and advises people on what they need to do after a death.

National Helpline: 0800 634 9494

Website: [www.bereavementadvice.org](http://www.bereavementadvice.org)

### **Cruse Bereavement Care**

Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable anyone bereaved by death to understand their grief and cope with their loss. Services are free to bereaved people. The charity provides support and offers information, advice, education and training services.

Cruse has a special website for young people, [www.rdf4u.org.uk](http://www.rdf4u.org.uk). A special feature of this site is a message board where young people can share their experiences and receive replies from trained young supporters.

Tel: 0114 249 3328

Website: [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

Young People's Helpline: 0808 808 1677

Website: [www.r4u.org.uk](http://www.r4u.org.uk)

### **Samaritans**

Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair.

Tel: 0845 790 90 90

Website: [www.samaritans.org](http://www.samaritans.org)

### **St Luke's Hospice Bereavement Service**

A team of trained volunteers and professional staff provide a bereavement service.

[Full details for St Luke's Hospice Bereavement Service](#)

### **SHSC Chaplaincy Service.**

Any member of staff can contact the Chaplaincy team:

Tel: 0114 271 8022

[chaplains@shsc.nhs.uk](mailto:chaplains@shsc.nhs.uk),

during office hours Sunday to Friday.



## Appendix 7

### Referral to Specialist Palliative Care Services

St Luke's Hospice: Information for healthcare professionals

GPs, District Nurses and other healthcare professionals can access urgent telephone advice and support 7 days a week, 9am - 5pm, by contacting the clinician in charge via Reception on 0114 236 9911.

Professionals should consider referral to specialist palliative care services for any person with serious progressive illness, whose level of need is considered beyond the scope of the current caring team.

Referral should be considered for people with the following:

- Symptoms that are difficult to control
- Psychological concerns (e.g. anxiety, depression)
- Social concerns (e.g. family/carer's needs)
- Spiritual concerns (e.g. requiring help in adjusting to diagnosis or prognosis)

Intervention may take the form of direct contact with the person or may consist of advice and support to the referring team.

In order to access St Luke's services a person will need to have been diagnosed with a serious and progressive illness for which there is no known cure.

Referrals for admissions to St Lukes In-Patient Centre are discussed at a daily referral meeting. A bed may not be available immediately, but urgent referrals will be admitted as soon as possible.

#### **Contacting the Referral Process:**

**Telephone number:** 0114 236 9911

**Fax number:** 0114 235 1321

The below link provides further information relating to the referral process.

<https://www.sheffieldccg.nhs.uk/Your-Health/end-of-life-care/referral-process.htm>

## Appendix 8

### Care in the Last Days of Life

#### ***‘One chance to get it right’***

1. The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly by doctors and nurses.

Out of Hours this would be on-call SHO or GP, depending on the environment in which care is being provided.

If the persons condition is deemed reversible all efforts will be taken to attempt this provided it is in keeping with the person's wishes or best interests if capacity is lacking.

2. Sensitive communication takes place between staff the person who is dying and those important to them.

High quality care will be informed by open and honest communication between the multi-disciplinary team, the dying person and those important to them.

Staff must seek to engage in regular and pro-active communication with the dying person and those important to them to listen as well as provide information.

Communication must be respectful and maintain privacy and sensitivity.

Staff must check the other person's understanding of the information they communicate providing clarity where necessary.

3. The dying person, and those identified as important to them, are involved in decisions about treatment and care.

The NHS Constitution pledges the right for all individuals to be involved in discussions and decisions about their health and care which includes end of life care. "Where appropriate this right includes your family and carers." Sensitive and honest communication with the dying person and those important to them must be undertaken to assess to what extent they wish to be involved in the decisions about the treatment and the way it is delivered.

In order to alleviate confusion, it is important to make clear to dying people and those important to them whether they are being informed about, consulted about, involved in or taking particular decisions about treatment and care.

4. The people important to the dying person are listened to and their needs are respected.

Families and those identified as important to the dying person are likely to have needs during such a time of distress and therefore these must not be overlooked. It is not always possible to meet the needs of all family members however staff must ensure

opportunities are available for sensitive and open conversation in quiet surroundings to provide updates on care provided and to offer support.

If a lack of capacity is assessed in the dying person, the decision-making process should be explained to those people who are supporting the person and they should be involved as much as possible.

5. Care is tailored to the individual and delivered with compassion. This is accomplished through development of a collaborative, holistic, person centred care plan. Involving the individual and those important to them, LPA's, Court Appointed Deputy and/or Advocate where appropriate.

## **Appendix 9**

### **What to expect when someone is in the last days of life**

Some of these signs might look distressing, but most of the time the person is not in any pain or distress and the outward signs are just a normal part of dying.

#### **Loss of appetite**

When someone is at the end of life they will typically have less appetite, as their need for food and drink reduces. If they stop drinking and their mouth looks dry, this does not necessarily mean they are dehydrated.

It might be too much effort to eat and drink. If this is the case you can offer sips or small bites, provided they are conscious and can still swallow. You can also help someone with a dry mouth by:

- offering a drink through a straw (or from a teaspoon)
- moistening the mouth with a damp sponge - special kinds of sponge are available for this purpose (the person may bite on this at first, but keep holding it, as they will let go)
- placing ice chips in their mouth
- applying lip balm

#### **Changes to breathing**

As a person becomes less active towards the end of their life, they need less oxygen. Breathing may become shallower and there may be long pauses between breaths. They might yawn frequently, as this is a natural response to draw more oxygen into the body.

Their breathing can make a noise because they are not able to properly re-absorb fluids in their chest or throat, which can cause a rattling sound. This may be upsetting to hear, but it doesn't mean they are in distress or need oxygen. It can be a bit like snoring – it affects those who hear it more than the person who is making the sound.

If their breathing is very loud, it may be helpful to change their position, so they are on their side, as long as this doesn't disturb them.

The doctor or nurse may also suggest medication to reduce the fluids in their chest or throat. This is not always needed, and it does not always make a difference.

Anxiety can cause their breath rate to increase a little.

Breathlessness can be frightening but simply sitting with them, talking and providing comfort, so they know you are there can help to reduce anxiety at this time.

#### **Needing more sleep**

They are likely to spend more time sleeping and will often be drowsy even when they are awake. They may also drift in and out of consciousness.

Some people become completely unconscious for periods of time before they die - this could be for a short period or as long as several days.

They may seem less interested in what is going on around them, and have less energy to take part, but this does not mean they can't hear you.

You can carry on speaking quietly to them.

You could also try letting them know you are there in other ways, for instance by holding their hand, reading to them, or playing their favourite music.

## **Restlessness**

Some people can become restless in the last few days of life this is called terminal agitation. They will usually become calm again before they die.

They may appear confused and not recognise familiar faces, and even see or hear people or things that are not actually there - for instance, they may see pets or people who have died. While this can be upsetting for those who are no longer recognised it is not a sign that they feel differently about people who are currently important to them who may need support through this time. This can be caused by medicines or changes in the chemical balance of the brain, or as a result of drifting in and out of sleep so they are unable to clearly distinguish between what is real and what is not.

If they are agitated, often just sitting with the person can help to calm them down. You can also help by:

- speaking clearly and audibly
- reminding them who you are (and being prepared to do so repeatedly)
- keeping their surroundings calm with few changes in noise level
- trying not to correct them if they say something wrong, or insist on them getting things right,
- Agitation could also be a sign of constipation or difficulty passing urine. Ask the medical team if you have any concerns so they can rule out any underlying causes and, if necessary, prescribe medicine.

## **Changes to skin**

Changes to the metabolism of the dying person can cause their breath, skin and body fluids to have a distinctive smell similar to that of nail polish remover.

The person's hands, feet, ears and nose may feel cold.

Their skin may also become mottled and blue, or patchy and uneven in colour.

Occasionally, a person's hands or other body parts may swell a little.

This happens due to reduced circulation and is normal. As the body's functions slow down, blood may coagulate or pool, particularly at the base of the spine, which can cause patches that look like dark purple bruising.

This is not usually painful or uncomfortable. Gentle massage can help.

## **Losing control of bladder or bowels**

When someone is in the last few days of life the muscles in their bladder and bowels relax, which can cause them to lose control of their movements. This may be distressing for those important to them to see, and they might feel embarrassed, if they remain aware.

Ensuring the person is kept clean and comfortable is essential during these times.

It is also common to have fewer bowel movements if they are eating less, and urine may get darker as they drink less.

## **Further supportive information/references**

### **Recent National Policy and Clinical Guidance for Professionals Working in Palliative and End of Life Care.**

Care Quality Commission (2019) [State of Care 2018/19](#)  
Department of Health and Social Care (2008) [End of life care strategy: promoting high quality care for adults at the end of their life](#)  
Department of Health and Social Care (2015) [Improvements to care in the last days and hours of life](#)  
Department of Health and Social Care (2015) [One Chance to Get it Right: One Year On Report](#)  
Department of Health and Social Care (2018) [NHS continuing healthcare fast-track pathway tool](#)  
General Medical Council (2010) [Treatment and care towards the end of life: good practice in decision making](#)  
Independent review of the Liverpool Care Pathway (2013) [More care less pathway](#)  
National Institute for Health and Care Excellence (2011) [End of life care for adults](#) [QS13]  
National Institute for Health and Care Excellence (2015) [Care of dying adults in the last days of life](#) [NG31]  
National Institute for Health and Care Excellence (2017) [Care of dying adults in the last days of life](#) [QS144]  
National Institute for Health and Care Excellence (2018) [End of life care for adults in the last year of life: service delivery](#)  
National Palliative and End of Life Care Partnership (2015) [Ambitions for palliative and end of life: A national framework for local action 2015-2020](#)  
National Palliative and End of Life Care Partnership (2018) [Ambitions for palliative and end of life](#)  
NHS (2019) [NHS Long term plan](#)  
NHS England (2015) [Transforming end of life care in hospitals](#)  
NHS England [End of life care](#)  
The Leadership Alliance for the Care of Dying People (2014) [One chance to get it right - Improving people's experience of care in the last few days and hours of life](#) (Liverpool Care Pathway Review)

## Appendix A

### Equality Impact Assessment Process and Record for Written Policies

**Stage 1 – Relevance** - Is the policy potentially relevant to equality i.e. will this policy potentially impact on staff, patients or the public? This should be considered as part of the Case of Need for new policies.

**NO** – No further action is required – please sign and date the following statement.  
**I confirm that this policy does not impact on staff, patients or the public.**

***I confirm that this policy does not impact on staff, patients or the public.***

Name/Date: Mo MacKenzie 26/06/2023

**YES, Go to Stage 2**

**Stage 2 Policy Screening and Drafting Policy** - Public authorities are legally required to have 'due regard' to eliminating discrimination, advancing equal opportunity and fostering good relations in relation to people who share certain 'protected characteristics' and those that do not. The following table should be used to consider this and inform changes to the policy (indicate yes/no/ don't know and note reasons). Please see the SHSC Guidance and Flow Chart.

**Stage 3 – Policy Revision** - Make amendments to the policy or identify any remedial action required and record any action planned in the policy implementation plan section

| SCREENING RECORD        | Does any aspect of this policy or potentially discriminate against this group? | Can equality of opportunity for this group be improved through this policy or changes to this policy? | Can this policy be amended so that it works to enhance relations between people in this group and people not in this group? |
|-------------------------|--|---|---|
| Age                     | NO   |   |   |
| Disability              | NO   |   |   |
| Gender Reassignment     | NO   |   |   |
| Pregnancy and Maternity | NO   |   |   |

|                                      |           |  |  |
|--------------------------------------|-----------|--|--|
| <b>Race</b>                          | <b>NO</b> |  |  |
| <b>Religion or Belief</b>            | <b>NO</b> |  |  |
| <b>Sex</b>                           | <b>NO</b> |  |  |
| <b>Sexual Orientation</b>            | <b>NO</b> |  |  |
| <b>Marriage or Civil Partnership</b> | <b>NO</b> |  |  |

Please delete as appropriate: - Policy Amended / Action Identified (see Implementation Plan) / no changes made.

Impact Assessment Completed by:  
Name /Date Mo MacKenzie, June 2023



## Appendix B

### Review/New Policy Checklist

This checklist to be used as part of the development or review of a policy and presented to the Policy Governance Group (PGG) with the revised policy.

|     |   | Tick to confirm |
|-----|---|-----------------|
|     | <b>Engagement</b>   |                 |
| 1.  | Is the Executive Lead sighted on the development/review of the policy?  | ✓               |
| 2.  | Is the local Policy Champion member sighted on the development/review of the policy?  | ✓               |
|     | <b>Development and Consultation</b>   |                 |
| 3.  | If the policy is a new policy, has the development of the policy been approved through the Case for Need approval process?      | ✓               |
| 4.  | Is there evidence of consultation with all relevant services, partners and other relevant bodies?                               | ✓               |
| 5.  | Has the policy been discussed and agreed by the local governance groups?  | ✓               |
| 6.  | Have any relevant recommendations from Internal Audit or other relevant bodies been taken into account in preparing the policy? | ✓               |
|     | <b>Template Compliance</b>  |                 |
| 7.  | Has the version control/storage section been updated?   | ✓               |
| 8.  | Is the policy title clear and unambiguous?  | ✓               |
| 9.  | Is the policy in Arial font 12?   | ✓               |
| 10. | Have page numbers been inserted?  | ✓               |
| 11. | Has the policy been quality checked for spelling errors, links, accuracy?   | ✓               |
|     | <b>Policy Content</b>   |                 |
| 12. | Is the purpose of the policy clear?   | ✓               |
| 13. | Does the policy comply with requirements of the CQC or other relevant bodies? (where appropriate)                               | ✓               |
| 14. | Does the policy reflect changes as a result of lessons identified from incidents, complaints, near misses, etc.?                | ✓               |
| 15. | Where appropriate, does the policy contain a list of definitions of terms used?   | ✓               |
| 16. | Does the policy include any references to other associated policies and key documents?  | ✓               |
| 17. | Has the EIA Form been completed (Appendix 1)?   | ✓               |
|     | <b>Dissemination, Implementation, Review and Audit Compliance</b>   |                 |
| 18. | Does the dissemination plan identify how the policy will be implemented?  | ✓               |
| 19. | Does the dissemination plan include the necessary training/support to ensure compliance?  | ✓               |
| 20. | Is there a plan to<br>i. review<br>ii. audit compliance with the document?  | ✓               |
| 21. | Is the review date identified, and is it appropriate and justifiable?   | ✓               |