East Sussex Healthcare
NHS Trust

FOI REF: 25/739

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Kings Drive
Eastbourne
East Sussex
BN21 2UD

Tel: 0300 131 4500
Website: www.esht.nhs.uk

7th November 2025

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

1. **What are the names of each hospital where there is an emergency department (ED)(A&E)in your trust?**

   Eastbourne District General Hospital
   Conquest Hospital, Hastings.

2. **For each ED (A&E) in your trust could you answer the following:**

   a. **Is there a Medical End of life (EOL)/Palliative Care Lead in the ED?**

      The medical palliative care lead for the Trust is Dr David Matthews.

   b. **Is there a Nursing End of life (EOL)/Palliative Care Lead in the ED?**

      The nursing palliative care lead for the Trust is Jayne Winter.

   c. **Does the ED have access to palliative care advice/guidance/input? If so, what hours is this for? What type of service is this; is it an in person, phone advice, is it nursing or medical lead?**

      Yes, there is a face-to-face service, 8am – 4pm 7 days a week, this could be nursing or medical lead depending on the needs of the patient and availability on the day. Outside of the hospital teams working hours there is telephone support available from St Wilfrid’s Hospice in Eastbourne and St Michaels Hospice in Hastings.

   d. **Does your ED have specific resources for patients who are dying/ EOL in the ED? - What are these resources?**

      We do not have any specific resources for ED, but there are lots of resources available to staff, for end-of-life care, via the Trust’s extranet.

e. **Is there a specific space in your ED for patients who are dying to be looked after by the ED team?**

No, the Trust will try to allocate them to a side room when available and will try to prioritise an admission under the medical time to bring them into a calmer ward area rather than remain in the ED.

f. **Is there a fast track option to a side room in the hospital for patients who are recognised as dying in the ED?**

This is explored when a patient is identified as dying, but not always available.

g. **Are you able to fast track dying patients' home from the ED?**

Yes, within working hours of the palliative care team.

h. **Does your ED prescribe anticipatory meds for the patient to go home with? If not, who does this?**

Yes.

i. **Does your department use RESPECT forms? If not, what do you use for your DNACPR options?**

Yes, we use ReSPECT forms within East Sussex Healthcare NHS Trust. We do accept and recognise other Trust's DNACPR forms in case the patient is outside of our area but will try and assimilate these into a ReSPECT form.

j. **Is your department able to access religious support 24 hours a day?**

Yes.

3. **What are your first line medications recommended for each of the following Agitation, Analgesia (Pain), Respiratory Secretions and Nausea and Vomiting**

Currently midazolam for agitation, morphine sulfate or oxycodone for pain, hyoscine butylbromide for respiratory secretions and haloperidol for nausea and vomiting.

4. **Do you have a specific ED prescription with electronic or paper for these medications?**

Not a specific ED prescription, but there is a Trust wide prescription for anticipatory prescribing.

5. **Are you able to share any of your specific ED documentation or guidelines that you use for EOL care and the dying patient both nursing and medical?**

Please see the attached documents - 'End of Life Care Policy (Adults)', 'Policy for Palliative and End of Life Care for Babies, Children and Young People and 'Last Days of Life Personalised Care Plan'.

We also follow guidance from Sussex Health & Care. Please contact NHS Sussex for this information via the following email address:

sxicb.foi@nhs.net

Please note that it is East Sussex Healthcare NHS Trust's FOI policy to only provided the names of staff that are grade 8a or above. Therefore, names below this criterion have been redacted from the attached policies.

We have also redacted the telephone numbers and names of the Trust's IT Systems and in doing so we are applying Sections 44 and Section 31(1)(a) respectively.

We are unable to provide the contact details of staff as we consider this information to be exempt from release in accordance with section 44 of the Freedom of Information Act (Prohibition on disclosure) and would refer to the Privacy and Electronic Communications EC Directive Regulations 2003 which provide specific rules on electronic communication services, including marketing (by phone, fax, email or text) and keeping communications services secure. We will not provide any information that could result in the transmission of unsolicited communications which may place an unacceptable risk to our email network and could also have a detrimental impact on patient care and treatment.

The contact number for the Trust is accessible on the Trust website http://www.esht.nhs.uk.

This is an absolute exemption and there is, therefore, no requirement to consider the public interest.

Under Section 31(1)(a) of the Freedom of Information Act (FOIA), the Trust can confirm that it holds information relevant to your request, however, we are unable to disclose it for the reasons explained below.

Historically, we would disclose information relevant to the Trust's IT systems, infrastructure and software as part of our transparency agenda under the terms of the Freedom of Information Act (FOIA). However, in light of the recent cyber-attacks on NHS hospitals and the serious impact these have had on patient services and the loss of patient data, we are having to reconsider this approach. Please see several links to news articles about these recent cyber incidents provided below for your information.

- *NHS England — London » Synnovis Ransomware Cyber-Attack*
- *NHS England confirm patient data stolen in cyber attack - BBC News*

- *Merseyside: Three more hospitals hit by cyber attack - BBC News*

As a result of these attacks, thousands of hospital and GP appointments were disrupted, operations were cancelled, and confidential patient data was stolen which included patient names, dates of birth, NHS numbers and descriptions of blood tests.

When we respond to a Freedom of Information request, we are unable to establish the intent behind the request. Disclosure under the FOIA involves the release of information to the world at large, free from any duty of confidence. Providing information about our systems or security measures to one person is the same as publishing it for everyone. While most people are honest and have no intention of misusing information to cause damage, there are criminals who look for opportunities to exploit system weaknesses for financial gain or to cause disruption.

In the context of the FOIA, the term ‘’public interest’’ does not refer to the private or commercial interests of a requestor; its meaning is for the “public good”. The Trust receives a significant number of requests each year regarding our IT systems, infrastructure and cyber security measures. Most of these requests are commercially driven and serve no direct public interest. Information relevant to our IT portfolio is often requested by consultancy companies who then pass on this information to their client base. Many of these requests are submitted through the FOI portal whatdotheyknow.com who publish our responses, making this information available to an even wider audience.

As a large NHS Trust we hold extensive personal data relevant to our patients and staff, much of which is considered very sensitive. A lot of this information is held electronically on various administration and clinical systems. We have a duty under the Data Protection Act 2018 and the UK GDPR to protect this personal information and take all necessary steps to ensure this data is kept safe. This means not disclosing information that could allow criminals to gain unlawful access to our systems and infrastructure. The Trust can be heavily fined should it be found to have acted in a negligent way which results in a personal data breach. We need to demonstrate that we comply with our legal obligations under data protection and freedom of information legislation, but we must be careful that too much transparency does not result in harm to our patients or staff, or cause disruption to our services.

Moreover, under the Network and Information Systems (NIS) Regulations Act 2018, operators of essential services such as NHS organisations like ours have a legal obligation to protect the security of our networks and information systems in order to safeguard our essential services. By releasing information that could increase the likelihood or severity of a cyber-attack, the Trust would fail to meet its security duties as stated in section 10 of the Network and Information Systems Regulations 2018. Should we not comply with these requirements regulatory action can be taken against the Trust. Further information about the Network and Information Systems (NIS) Regulations Act 2018 can be found here – The Network and Information Systems Regulations 2018: guide for the health sector in England - GOV.UK

Your request asks for specific guidelines which details the names of our IT Systems which, for the reasons explained above, would be inappropriate to release into the public domain. If disclosed, it is possible that patient data as well as other confidential information would be put at risk. Such disclosure could also impact on the security of our systems and result in serious disruption to the health services we deliver to the local community. Section 31(1)(a) of FOIA provides that information is exempt if its disclosure would, or would be likely to, prejudice (a) the prevention or detection of crime. In this case, disclosure would be likely to prejudice the prevention of crime by enabling or encouraging malicious acts which could compromise the Trust's IT systems and infrastructure. The Trust's capacity to defend itself from such acts relates to the purposes of crime prevention and therefore section 31(a) exemption is applicable in these circumstances. For these reasons, the Trust considers disclosure of the names of the Trust's IT Systems to be exempt under section 31(1)(a) [*law enforcement*] of the FOIA and this information is therefore being withheld. The full wording of section 31 can be found here: Freedom of Information Act 2000

Section 31 is a *qualified* exemption and therefore we must consider the prejudice or harm that may be caused by disclosure of the information you have requested, as well as apply a public interest test that weighs up the factors in maintaining the exemption against those in favour of disclosure.

In considering the prejudice or harm that disclosure may cause, as explained should the Trust release information into the public domain which draws attention to any weaknesses relevant to the security of our systems or those of a supplier, this information could be exploited by individuals with criminal intent. Increasing the likelihood of criminal activity in this way would be irresponsible and could encourage malicious acts which could compromise our IT systems or infrastructure, result in the loss of personal data and/or impact on the delivery of our patient services. We consider these concerns particularly relevant and valid considering the increasing number of cyber incidents affecting NHS systems in recent years and the view by government, the ICO and NHS leaders that the threat of cyber incidents to the public sector is real and increasing.

- Organisations must do more to combat the growing threat of cyber attacks | ICO

In the Government's Cyber Security Strategy 2022-2030, the Chancellor of the Duchy of Lancaster and Minister for the Cabinet Office states on page 7:

> *"Government organisations - and the functions and services they deliver - are the cornerstone of our society. It is their significance, however, that makes them an attractive target for an ever-expanding army of adversaries, often with the kind of powerful cyber capabilities which, not so long ago, would have been the sole preserve of nation states. Whether in the pursuit of government data for strategic advantage or in seeking the disruption of public services for financial or political gain, the threat faced by government is very real and present.*
>
> *Government organisations are routinely and relentlessly targeted: of the 777 incidents managed by the National Cyber Security Centre between September 2020 and August 2021, around 40% were aimed at the public sector. This upward trend shows no signs of abating."*

With this in mind, we then considered the public interest test for and against disclosure. It should be noted that the public interest in this context refers to the public good, not what is ‘of interest’ to the public or the private or commercial interests of the requester. In this case we consider the public interest factors in favour of disclosure are:

- Evidences the Trust’s transparency and accountability
- Provides information relevant to the IT systems and applications the Trust uses
- Reassures the public and partners that the Trust procures these systems in line with Procurement legislation
- Reassures the public and partners that the Trust’s IT infrastructure and systems are secure

Factors in favour of withholding this information are:

- Public interest in crime prevention
- Public interest in avoiding disruption to our health services
- Public interest in maintaining the integrity and security of the Trust’s systems
- Public interest in the Trust avoiding the costs associated with any malicious acts (e.g. recovery, revenue, regulatory fines)
- Public interest in complying with our legal obligations to safeguard the sensitive confidential information we hold

In considering all of these factors, we have concluded that the balance of public interest lies in upholding the exemption and not releasing the information requested. Although disclosure would provide transparency about our software systems and IT infrastructure, this is outweighed by the harm that could be caused by people who wish to use this information to assess any vulnerabilities in our security measures and consequently use this information for unlawful purposes. Cybercrime can not only lead to major service disruption but can also result in significant financial losses. As a publicly funded organisation, we have a duty for ensuring our public funding is protected and spent responsibly. Moreover, as a public body the Trust must demonstrate that it keeps its confidential data and IT infrastructure safe and complies with relevant legislation, but at the same time we must be vigilant that transparency does not provide an opportunity for individuals to act against the Trust. In considering the impact that recent cyber-attacks have had on NHS services, including the cancellation of thousands of patient appointments and procedures as well as the loss of confidential patient data, we consider the overriding public interest lies in withholding this information. The private or commercial interests of a requester should not outweigh the public interest in protecting the integrity of our systems and continuity of our essential patient services. Although we appreciate there may be legitimate intentions behind requesting this information, we must take a cautious approach to requests of this nature and appreciate your understanding in this matter.

It is important to note that the Trust and its commissioning partners are required to follow very specific rules when procuring equipment or services. Information about procurement and tendering can be found on our website –
Governing documents, incorporating: Standing Orders, Standing Financial Instructions, Scheme of Delegation.

To contact the Procurement Service, please email - esht.procurement@nhs.net.

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Freedom of Information Department
esh-tr.foi@nhs.net

NHS
East Sussex Healthcare
NHS Trust

End of Life Care Policy (Adults)

Document ID Number	407
Legacy ID Number	1463
Version:	V6
Ratified by:	Integrated Governance Meeting (IGM)
Date ratified:	01st May 2025
Name of author and title:	Mark Collins, ESHT Macmillan Lead Cancer Nurse [redacted], End of Life Care Facilitator
Date originally written:	July 2017
Date current version was completed:	February 2025
Name of responsible committee/individual:	End of Life Care Steering Group
Date issued:	20TH May 2025
Review date:	February 2028
Target audience:	All Staff
CQC Fundamental Standard:	Regulation 9: Person-centred care Regulation 10: Dignity and respect Regulation 11: Need for Consent Regulation 12: Safe Care & Treatment Regulation 13: Safeguarding service users from abuse and improper treatment Regulation 14: Meeting Nutritional and Hydration Needs Regulation 17: Good Governance
Compliance with any other external requirements (e.g. Information Governance):	NICE Quality Standard 13 for End of Life Care for Adults NICE caring for adults in last days of life NG31 NICE guidance NG 61 December 2016
Associated Documents:	Policy for palliative and end of life care for babies, children and young people Organ and Tissue Donation Policy Policy for Advance Decisions Guidance for Staff Responsible for Care After Death in adults (formerly Last Offices) PEACE Plan Policy (PErsonalised Advisory CarE – PEACE Plan) Guidance for staff on the implementation of the Mental Capacity Act (MCA) Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) incorporating decisions about cardiopulmonary resuscitation (CPR) Verification of Expected Death by Registered Nurses Policy (Adult Services Only) Adult Discharge Policy A Procedure for the use of subcutaneous infusion devices: BD Bodyguard T™ Ambulatory Syringe Pump Policy for the Care of People with a Learning Disability in the Acute Hospital Trust Nutrition and hydration policy for adults

Version Control Table

Version number and issue number	Date	Author	Reason for Change	Description of Changes Made
V5	March 2022	Jayne Winter	Scheduled review	Amendments to all sections to bring the policy in line with national guidance
V6	February 2025	Jayne Winter	Scheduled review	Addition of Medical Examiner and Medical Examiner Officer Role

Consultation Table

This document has been developed in consultation with the groups and/or individuals in this table:

Name of Individual or group	Title	Date
End of Life Care Steering Group		February 2022
Assistant Directors of Nursing and Heads of Nursing, AHP's and Midwives		February 2022
Medicine Division Clinical Governance meeting		March 2022
Joy Jones, Graham Atfield, Paul Smith, Deborah James		December 2024
End of Life Care Steering Group		February 2025

This information may be made available in alternative languages and formats, such as large print, upon request. Please contact the document author to discuss.

Table of Contents

1. Introduction

1.1 There are currently 15 million people in England with long-term conditions (LTC). Over the next ten years this figure is expected to increase, especially among those living with multiple conditions. These individuals will require palliative/end of life care and it is therefore essential that staff within ESHT have an awareness of their responsibilities in supporting the needs of these patients.

1.2 The purpose of this policy is to assist clinicians in enabling the identification of individuals nearing the end of their life, outlining best practice principles and a comprehensive framework for providing appropriate support and whole-person care to patients and those most important to them.

1.3 Good end of life care enables those with advanced, progressive, incurable illness to have a quality of life that is as personalised and dignified as possible throughout the last phase of their life. This care should be holistic and include symptom management, psychological, social and spiritual support.

1.4 ESHT provides care to a wide range of service users with varying needs. In the CQC (2016) report ‘A Different Ending’ it was highlighted that the end-of-life care needs of some groups of people is not always considered and understood in a way that meets the requirements of the Equality Act (2010). It is essential that staff have an awareness of the needs of different services users, and their experiences and preferences at the end of life, ensuring that end of life care for individuals within ESHT is delivered to the highest standard. This includes recognising and responding sensitively to the potential that some groups may have particular fears or concerns - for example regarding discrimination and how they are perceived, the use of preferred pronouns, or acceptance and involvement of partners or loved ones. Staff are encouraged to review additional guidance such as that referenced in specific needs assessments e.g. East Sussex Lesbian Gay Bisexual Trans Queer + (LGBTQ+) Comprehensive Needs Assessment 2021

1.5 This document outlines the expected standards of care for our adult patients and those most important to them as they approach the end of their lives, while actively dying, and care after death.

2. Purpose

2.1 Rationale

We know there is only one chance to get care of the dying right and it is essential that all staff members are equipped to support the dying patient, their family and loved ones. The main purpose of this policy is to provide staff with a framework, clear direction and standards to deliver planned, compassionate and competent person-centred care at end of life.

2.2 Principles

East Sussex Healthcare NHS Trust is committed to the delivery of high quality, sensitive end of life care for individual patients and when appropriate, to their families and others identified as important to them.

This should be done in accordance with national guidance, including Ambitions Framework (National Palliative and End of Life Care Partnership 2021):

And to ensure that all staff work within the 5 Priorities of Care for the Dying person (Leadership Alliance for the Care of Dying People 2014):

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

Communicate
Sensitive communication takes place between staff and the dying person and those identified as important to them.

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

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

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

2.3 Scope

This policy incorporates all aspects of end of life and the dying phase for adults. It does not cover:

- Perinatal, neonatal and paediatric deaths and bereavement (please refer to the relevant policies for Maternity and Children and Young Adults).
- All Mortuary or post-mortem examination procedures

3 Definitions

3.1 Definitions of terms used within this policy are listed below. Further definitions can be obtained within the National End of Life Strategy 2008:

- **End of Life Care (EoLC)** – Patients are 'approaching the end of life' when they are likely to die within the next 12 months.
  This includes patients whose death is imminent (expected within a few hours or days) and those with: advanced, progressive, incurable conditions; general frailty and co-existing conditions that mean they are expected to die within 12

months; existing conditions if they are at risk of dying from a sudden acute crisis in their condition; life-threatening acute conditions caused by sudden catastrophic events." (GMC 2010)
There are several tools that can help identify patients, whose health is deteriorating, including SPICT (2019) https://www.spict.org.uk/

- **Palliative Care:** An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual (World Health Organisation (WHO) 2002).

- **Expected Death** – a death which is anticipated in a patient where active treatment has been withdrawn, and the patient is usually not for resuscitation.

- **Unexpected or Sudden Death** – a death which was not anticipated and where the patient did not have a terminal diagnosis or life limiting illness and did not have a DNACPR in place.

4 Accountabilities and Responsibilities

4.1 Chief Executive

The Chief Executive has overall final responsibility for the management of patient experience and ensuring that end of life care in the organisation has the appropriate resources available for employees and others who may be affected.

4.2 Medical Director and Chief Nurse

Both have joint responsibilities for ensuring processes are in place to provide patients with appropriate end of life care. They will provide clinical and cultural leadership which recognises that the care of a dying person is a priority and a responsibility of all healthcare staff. The Chief Nurse is the lead Director within the Trust responsible for ensuring the implementation of the end-of-life care policies within the Trust through the management structure.

4.3 End of Life Care Improvement Group

The End-of-Life Care Improvement Group is responsible for the review of this policy. It has a leadership role for end-of-life care, providing good integrated working within and across the health community, supporting clinical divisions and teams to promote excellent end of life care across the organisation.

4.4 Senior Responsible Clinician

The senior responsible clinician is usually the patient's consultant in hospital and GP in the community; they will have supportive discussions with patients (and those closest to them) that are identified as being in the last year of life, so that the patient's wishes can be taken in account. Discussions will be recorded in the clinical record and on the treatment escalation plan.

They are responsible for identifying patients within the last few days of life and planning, reviewing, coordinating, communicating and delivering an individualised plan of care in conjunction with the wider multi-disciplinary team.

4.5 Health Care Professionals

Any professional with direct responsibility for a patient or for an aspect of their care and treatment must respect the five priorities of care as outlined in section 2.2. They must ensure that they maintain the skills and competencies appropriate to their role to manage the assessment, communication and symptom management of patients at End of Life. They must raise any need for additional training with their line manager and review their experience and competencies within their PDR. All staff must operate within the legal framework provided by the Mental Capacity Act 2005 and their relevant code of practice.

4.6 Community Nurses

The Community Nurse is the ‘key worker’ and holds the clinical responsibility for an individual’s nursing needs in the community; where needed the community nurse liaises with other health care professionals providing care at home, including the local hospices and GPs, seeking support about symptom management, making and supporting decisions about the patients future care plan and acting accordingly.

4.7 All Staff

End of life care is ‘everybody’s business’. All staff will actively contribute to meeting the standards of care for the dying person and their family as outlined in this document.

4.8 Supportive and Palliative Care Team

The Supportive and Palliative Care Team are responsible for the support and education of Trust staff in regard to end of life care. They review all patients identified as being on the Last days of Life Personalised Care Plan (LDOLPCP) and support clinical areas to provide excellent end of life care, ensuring this policy is followed.

4.9 Chaplaincy & Pastoral Support Team

The Chaplaincy & Pastoral Support Team provide spiritual, religious and pastoral care for all patients, relatives and staff regardless of whether they have any faith or belief. The Team is available 24/7 (via Switchboard or on [redacted]) to assist with any dying patient and their family members.

4.10 Porters

Porters are responsible for transferring the deceased from the ward to the mortuary. They should be suitably trained and ensure the deceased is always treated with dignity.

4.11 Anatomical Pathology Technologists (APTs)

APTs are specifically trained to continue care of the deceased following admission to the mortuary. Ensure the End-of-Life Care Policy (Adults) is followed and participate in any mortuary pre-admission discussions as necessary.

4.12 Bereavement Services

The Bereavement Service support and advise the family following the death of their relative. They co-ordinate documentation, share information and need to be fully aware of any wishes or requests the patient may have made prior to death and follow the End-of-Life Care Policy (Adults).

5 Advance Care Planning

A key barrier to delivering good end of life care is a failure to have open discussions with the patient and those closest to them. Agreement is needed on when discussions should occur and who should initiate them. Clinicians involved with patients requiring end of life care should plan with the team as to who is the most appropriate person to have an end-of-life discussion with the patient, at what point and in which environment.

When the patient does not have the mental capacity to participate in these discussions, families should be involved. For patients without relatives and friends the Independent Mental Capacity Advocate (IMCA) service should be used.
Discussions about advance care planning must be:

- Recorded in the patient notes
- Include a ReSPECT discussion and form completion
- Be communicated to the GP
- Included in the discharge summary on leaving hospital, with requests made to the GP to update the information on Summary Care Record if required.

More formal Advance Care Planning can include Advance Statements, Preferred Priorities for Care, Advanced Decision to Refuse Treatment and Lasting Power of Attorney.

5.1 Preferred Priorities for Care and the **Planning Ahead** documents are available for patients use to record their wishes and preferences for their end-of-life care. Communication and assessment skills support the recognition of the right time and the right person to enter into discussion about these matters, which must be handled sensitively. The Trust is committed to provide education/training to support this.

5.2 An advance statement is an indication by a patient of the treatment they would wish to receive in the event that they lose mental capacity to make a decision about those particular aspects of their clinical care. It is important to ask the patient (if able) and the family if an advance care plan has been undertaken. If the patient has been identified as being in the last six to twelve months of life their preferences and wishes may be recorded on the GP Summary Care Record that can be shared if the patient has consented to this.

5.3 An Advance Decision to Refuse Treatment (ADRT) is a statement made by a mentally competent person aged over 18 years, which defines in advance their refusal of medical treatment should they become mentally or physically incapable of making their wishes known. To be legally binding the ADRT should be appropriately signed and witnessed, should be applicable to the condition being considered and should include a statement indicating that the patient understands that their life may be at risk if treatment is refused. The ADRT only comes into force if the individual that made it loses mental capacity. Advance decisions to refuse treatment are legislated for in the Mental Capacity Act (2005). A properly documented ADRT is legally binding upon healthcare professionals in the same way that a contemporaneous refusal to consent is.

Staff must be aware of the Trust Policy for Advance Decisions to refuse treatment and ascertain if the patient has made such a decision.

5.4 Lasting Powers of Attorney (LPAs) allows people to make appropriate arrangements for family members or trusted friends to be authorised to make decisions on their behalf, often when they no longer have capacity to make decisions for themselves.
There are two types of LPA:

- Property and financial affairs
- Health and welfare (include medical care) – this only comes into effect if the person has lost capacity.

Each LPA is a separate document, and staff must see the correct documents from the Office of the Public Guardian to confirm the presence of a LPA.

5.5 ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) The ReSPECT process creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices. Such emergencies may include death or cardiac arrest but are not limited to those events. The process is intended to respect both patient preferences and clinical judgement. The agreed realistic clinical recommendations that are recorded include a recommendation on whether CPR should be attempted if the person's heart and breathing stop.

The plan is created through conversations between a person and one or more of the health professionals who are involved with their care. The plan should stay with the person and be available immediately to health and care professionals faced with making immediate decisions in an emergency in which the person themselves has lost capacity to participate in making those decisions (https://www.resus.org.uk/respect/respect-healthcare-professionals).

5.6 Organ, Tissue and Body Donation

Consideration of Organ and tissue donation should form a usual part of end-of-life care planning.

It is important to ensure that the explicit wishes of an individual in relation to organ and/or tissue donation after their death are identified, acknowledged and respected and where appropriate referred to external specialist teams to be carried out in a respectful, sensitive and dignified manner.

Ideally donation discussions should be an integral component of all end of life care planning, ensuring that all bereaved families are offered the opportunity to consider organ/tissue donation in a timely and sensitive manner by trained staff that have access to specialist advice. Full guidance is available within ESHT Organ and Tissue Donation Policy.

5.7 Requests to make a Last Will & Testament

A dying patient may wish to make a will. Staff must be aware of the potential vulnerability of such patients to pressure from those who might have an interest and should refer to the Safeguarding Team if concerned. It is not permitted for staff to witness a will.

6. Care of the Dying Patient

All staff are expected to apply a set of principles when caring for the dying and their family. Staff must always listen to the patient's wishes regarding the remainder of their life, answer questions and concerns that the patient and/or the family may have and provide information that is needed.

The patient shall be treated as an individual, with respect, their voice being heard and their opinion regarding treatment respected. At the heart of caring for the dying patient is the forging of valued partnerships between the patient, their family, those identified as important to them (if appropriate) and health and social care professionals in order to achieve best outcomes.

Staff must endeavour to promote and preserve the patient's independence, dignity and sense of personal control throughout this phase of their illness. Staff must ensure the remaining time (whether hours or days) is as comfortable as possible for the patient with support from all involved in the patient's care.

6.1 Recognition and Communication of Dying

The recognition and timing of dying is always complex. Patients will often have several conditions, and some may be reversible. It is important to start conversations about uncertainty and likely outcomes of treatments early, allowing patients to make informed choices about treatments available. This communication should be delivered in a sensitive manner, avoiding the use of euphemisms; phrases such as 'sick enough to die' might be helpful to make patients and their families aware of how unwell the person is, while still being actively treated.

Doctors and nurses must acknowledge, accept and communicate the uncertainty that exists about prognosis. An approach should be adopted that focuses on changes in the condition of someone who is likely to be dying, rather than diagnosing dying only. Staff may seek a second opinion and consider referral to the Supportive and Palliative Care Team.

Any decision that a person under the care of ESHT is likely to die in the next few days should ideally be taken by the multidisciplinary team, led by the Consultant / GP, not by any one individual health care professional. Good comprehensive, honest and open communication should take place with the patient (if able) and with those important to the dying person, including carers. Training to enhance these skills is available via Learning and Development.

Information needs to be of high quality to inform, support and reassure patients and family and delivered in an appropriate form to ensure it is understood. This should take into account the needs of those whose preferred language is not English and should be tailored to the needs of those with disabilities and communication difficulties. If an interpreter is needed, on-demand video and telephone interpreters in a wide range of languages can be accessed using LanguageLine (foreign language) or SignLive (British Sign language). In addition, for more complex and sensitive conversations it may be possible, subject to availability at short notice, to source face to face interpreters if necessary.

The Accessible Information Standard (AIS) requires an assessment of the patient's preferred communication method must be undertaken and staff should check if the person has documentation that highlights how they communicate i.e., Disability Distress Assessment Tool, '(DisDAT) This is me' care passport or if an Alert is included on the patient information system, and any reasonable adjustments that may be required e.g., large print written information. In order to maximise engagement with a patient with learning disabilities understanding of individual communication styles is essential and any reasonable adjustments to meet their needs must be made.

Any advance care planning undertaken by the patient must be considered and reviewed during the dying phase. Staff should seek information regarding any advance statement of wishes which may indicate their preferences regarding treatments as well as their preferred place of care/preferred place of death.

It is essential that next of kin details are accurate and are checked, discussions should be held with the next of kin regarding when they would like to be contacted, particularly overnight. If the next of kin details are not documented, firstly contact the patient's GP. If there are no GP contact details recorded, it may be necessary to contact the police to gain next of kin information.

6.2 Individualised Care Planning for Dying Patients

If the possibility that a person is likely to die within a few days or hours is recognised, and it is felt that there are no reversible factors, a senior clinician in consultation with the multidisciplinary team should document this decision and care should be planned using the priorities outlined in ‘One Chance to Get it Right’, published by the Leadership Alliance for the Care of Dying People (2014). An individualised care plan should be started as soon as the senior clinician has identified that the patient has entered the dying phase. In the acute and community hospital settings the ‘Last Days of Life Personalised Care Plan’ (LDOLPCP) should be started and the patient and those closest to them should be involved in its creation to ensure the information recorded is personalised to the needs of the patient. For patients dying at home, the same principle is followed but is recorded in the end-of-life care plan section of [redacted].

The senior clinician must document in the patient record or LDOLPCP details of the conversations in which the end-of-life care plan was first discussed with the patient and those closest to them.

All discussions should take place with the patient if they have capacity (unless they do not wish to discuss) and with family members, only with the patient’s permission. If the patient lacks capacity, then discussion must take place with any person holding Lasting Power of Attorney for Personal Health and Welfare purposes, and further decisions made in the patients’ best interests.

Discussions should include the following:

- The clinician’s explanation that the person is likely to be dying, the basis for this judgement, and that the patient and those closest to them have had the opportunity to ask questions.
- ReSPECT discussion and documentation (if not already completed)
- Ceiling of treatment – to include continuation or not of active treatment e.g., antibiotics for sepsis
- Managing nutrition and hydration (see 6.3)
- Any other relevant discussion specific to individual case.

At this point it is important to review the treatment and care being provided for the patient, reviewing any interventions that are no longer needed, or giving a clear review date for those that may be felt to be contributing to the comfort of the dying person e.g., oxygen or antibiotics. Medications should be reviewed and if not already prescribed, anticipatory end of life care drugs should be prescribed (see section 6.4).

Further discussions should be undertaken with the patient and those closest to them around sensitive subjects such as spiritual needs, hydration and nutrition and what personal care would be wanted. By having these conversations and clearly documenting them within the personalised care plan we can individualise the care provided to the patient. Regarding an assessment of spiritual need the Chaplaincy & Pastoral Support Team can be contacted to provide specialist advice and support and will review patients unless requested not to.

If the person is dying in hospital, it may be possible to consider transfer either home, to a nursing home or a hospice if they have indicated their preferences; ideally these discussions will have occurred before the patient enters the dying phase to allow time to facilitate discharge (see section 6.5).

The decision that a person is dying should be reviewed regularly (daily if possible) to ensure no change in condition possibly indicating improvement, however unexpected, may be missed.

6.3 Nutrition and Hydration in the Last Days of Life (NICE QS144, NG31)

The dying person should be supported to eat and drink if they wish to and are able to. Check for any difficulties with swallowing and for risk of aspiration using the Trust Swallowing Risk Assessment. Discuss the risks and benefits of continuing to eat and drink with the dying person and those most important to them.

Offer frequent mouth and lip care to the dying person and include the management of dry mouth within the individualised care plan. This should include help with cleaning teeth or dentures and frequent sips of water (Appendix A). Encourage those most important to the dying person to help with mouth and lip care and giving food and drinks. Provide any necessary aids and give advice on giving food and fluids safely.

A review of hydration status should occur daily by a nurse or doctor. This includes checks for dehydration (e.g., dry mouth, thirst, confusion and agitation) or over hydration (e.g., swelling or fluid overload). This should include objective and subjective measures (e.g., hydration of oral mucosa, skin turgor, evidence of peripheral oedema or pulmonary congestion). Although blood tests should not routinely form part of the assessment, if results are present, then they may form part of the assessment. Following assessment of hydration status, if dehydration is felt to be present, clinically assisted hydration (CAH) should be considered, respecting the person’s wishes and preferences; any concerns raised by the dying person or those closest to them should be addressed before starting CAH.

If CAH is indicated, the risks and benefits should be discussed with the dying person and those most important to them. This should include:

- CAH may relieve distressing symptoms related to dehydration but may cause other problems such as over hydration, fluid retention and retained secretions
- It is uncertain if giving CAH will prolong life or extend the dying process
- It is uncertain if not giving CAH will hasten death

When considering CAH use an individualised approach, taking into account:

- Whether they have expressed a preference for or against CAH, or have any cultural, spiritual or religious beliefs that might affect this, documented in an advance statement or an advance decision to refuse treatment
- Their level of consciousness
- Any swallowing difficulties
- Their level of thirst
- The risk of pulmonary oedema
- Whether even temporary recovery is possible

Consider a therapeutic trial of CAH if the person has distressing symptoms or signs of dehydration, such as thirst or delirium, and oral hydration is inadequate
If CAH is started this must be monitored every 12 hours for changes in the symptoms or signs of dehydration and for any evidence of benefit or harm. Continue with CAH if there are signs of clinical benefit and reduce or stop if there are signs of possible harm such as fluid overload, or they no longer want it.

For those already dependent on CAH before the last days of life:

- Review the risks and benefits of continuing CAH with the person and those important to them
- Consider whether to continue, reduce or stop CAH as the person nears death.

6.4 Anticipatory Prescribing for Dying Patients

It is important that as soon as the patient is identified as dying that anticipatory or ‘just in case’ drugs are prescribed in anticipation of any symptoms that may be experienced. These medications will be used for the symptoms most commonly experienced at end of life namely pain, breathlessness, nausea and vomiting, agitation and distress and retained respiratory secretions. Each prescription should be individualised to the patient, particularly regarding the type of medications used and the doses prescribed. Each prescription should have a clear indication for use documented e.g., morphine sulphate can be used for both pain and breathlessness.

General prescribing advice can be found on the Trust intranet pages and can also be found on the back of the drug dispensing chart available from pharmacy.
For patients in an inpatient setting the four drugs commonly used at end of life should be prescribed within the PRN section of the drug chart on ePMA.
For patients in their own homes and in nursing homes they must be prescribed on the ‘medication instruction chart’

6.5 Transfer to Preferred Place of Care and/or Death from a hospital setting

Some patients will want to choose the place they die and need to be supported to get there. Some families will want to care for their dying relative at home or another appropriate place e.g., a hospice. Where this request is possible, it should be acted upon.

It is important to discuss this as soon as it has been recognised that the patient is dying so that they may be transferred with the necessary support services in place.
Refer to the Rapid Discharge pathways within discharge/transfer policy to enable this to occur if the patient is in the acute/community hospitals within the Trust. Any patient requiring consideration for hospice admission should be referred to the SPCT for assessment of suitability.

6.6 Discharging patients from the acute setting with anticipatory medications

It is important to ensure that all patients discharged from the acute setting for end-of-life care are discharged with anticipatory medications. Both the ‘medication instruction chart’ and the ‘drug dispensing charts’ must be completed and sent to pharmacy quickly. Unless a patient is already on a syringe pump on discharge, only drugs for prn ‘just in case’ injections will be prescribed, and it will be the responsibility of community teams to have a syringe pump prescribed when the patient requires one. Trying to anticipate the medication needs of patients in a syringe pump poses several risks unless we understand how many prn doses are needed.

6.7 Care of patients receiving last days care in emergency departments and other gateway units

Patients do occasionally present at our gateway areas when in their last days of life. It is recognised that this is not a preferred place of care and as such every effort will be made to find the most appropriate area for care to be delivered.

It is the responsibility of staff in these areas to seek training and learning in End-of-Life Care and the ability of staff in these areas will be comparable with that of staff across the Trust.

At times of operational pressure when patients are not being discharged at a rate that allows new patients to be admitted our commitment to support patients in their last days includes:

- Swift and effective communication with the site management team and the Supportive and Palliative Care Team to ensure that we are working collaboratively to ensure that any move for the patient is appropriate and will not reduce the standard of end-of-life care that they receive.
- Where patients have a preferred place of care this will be communicated to senior nurse and all efforts will be made to satisfy these preferences.
- In times of extreme pressure that might affect business continuity, for example a major incident, end of life care remains a constant and a priority.

These measures will be in place at times of operational pressure on the patient pathway when admissions outnumber discharges. This is exclusively when the Trust is operating at its highest declared state of pressure on the patient pathway.

7. Resuscitation and ReSPECT (link to section 5.5)

Staff must be conversant with policy and procedures in relation to 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions.

Family members may attend the resuscitation attempt if:

- There is a nurse dedicated to escorting them,
- They understand that they must not interfere in the process of resuscitation including the decision to discontinue resuscitation

In the event of an unsuccessful resuscitation, it is important for patient's relatives or carers to be informed of their death quickly and sensitively by an experienced member of staff.

8. Religious Observances & Cultural Requirements

The Chaplaincy & Pastoral Support Team are committed to providing pastoral and spiritual care in the widest sense to any hospital patient or their family. Chaplains and the Chaplaincy volunteers are an independent listening ear and a supportive and compassionate presence during difficult times and their role extends far beyond providing religious support. It is important that this is emphasised when the service is offered. The Chaplaincy & Pastoral Support Team are available for anyone regardless of whether they have any faith or belief.

The Chaplaincy & Pastoral Support Team can also be contacted for specialist advice 24hrs a day and there is a comprehensive multi-faith guidance document on the Chaplaincy & Pastoral Support Team page on the Intranet called 'A Guide to Religious, Belief & Lifestyle Traditions'.
http://nww.esht.nhs.uk/wp-content/uploads/2011/06/A-guide-to-religious-belief-and-lifestyle-traditions.pdf
If in any doubt, contact the duty chaplain (via switchboard) for advice and to co-ordinate the provision of appropriate spiritual care. The CPST has a list of available community faith leaders which can be used when this contact is requested by the patient.

Special religious or cultural requirements e.g., anointing the sick or specific dietary requirements should be noted; see special record at recognition of dying if this has not already taken place. Staff should not make assumptions about practices purely on the basis of a recorded faith on the patient record without clarifying with the patient and/or family.

8.1 Support for the Patient

The Chaplaincy & Pastoral Support Team offer support and care for dying patients and their family members together with support for dying patients who have no family and are dying alone. This support and care is available to all regardless of whether the patient or family have any kind of faith or belief. Such support would include sitting with the patient and family members providing a compassionate and understanding presence, reading to the patient, playing quiet music, holding hands, any appropriate practical support and generally offering a reassuring presence. This all applies even if the patient is unresponsive. This support can be accessed by calling [redacted] or calling Switchboard.

It is important that a multi-disciplinary team approach that includes the Supportive and Palliative Care Team, the Chaplaincy & Pastoral Support Team, community carers, counsellors, as appropriate, should be coordinated by the key worker. This may be the ward Matron or named District Nurse in order to maximise the effectiveness of the process and avoid conflicting advice being given.

Spirituality: "A quality that goes beyond religious affiliation; that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in any God. The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite and comes into focus when the person faces emotional stress, physical illness and death"
Talking About Spirituality in Healthcare Practice, Gillian White (Jessica Kingsley Publications: 2006)

"Spirituality enables us to not only connect and relate to other people but also experience some 'higher' or 'other' state relating to humanity and the rest of the world. It is what gives our life, as an individual, meaning and purpose. It involves needs of reassurance, comfort, peace, happiness, dealing with guilt and forgiveness, listening and being listened to, feeling valued and having self-esteem."
Religion and Belief Matter, NHS Scotland Information Resource for Healthcare Staff
Religion and Belief.indd

Practising spiritual care:

- The practice of spiritual care is about meeting people at the point of deepest need.
- It is about not just 'doing to' but 'being with' them.
- It is about our attitudes, behaviours and our personal qualities i.e. how we are with people.
- It is about treating spiritual needs with the same level of attention as physical needs.

Royal College of Nursing (2011)

9. Care of Relatives, Partners and Carers (those most important to the dying person)

In whatever care setting, give family (relatives) and/ or carer/s time with the patient prior to death with unrestricted visiting times. Privacy for a dying person and their relatives/carers should be prioritised.

All relatives / carers will have needs of their own during this time, it is important that these are assessed and documented clearly within the personalised care plan. In the hospital setting, efforts must be made to ensure that there is comfortable seating available at the bedside and efforts should be made to provide a means of sleeping, if possible, i.e., a ‘put you up’ bed or reclining chair. Drinks and meals should be offered if available, or directions given to the staff canteen or coffee shops.

There is some accommodation available to be used by families if needed on both acute hospital sites; updated information is available on the Trust Website.

Regular communication with those most important to the dying person is important, to address questions or concerns about any aspect of care. This opportunity must be presented regularly to follow up on any queries arising from the initial discussion about dying. Families need to continue to be updated if the time remaining becomes clearer, so that they have time to begin preparing themselves and communicate with other family members further away who may wish to travel to visit.

At the time of the death of the patient those most important to the dying person will be given a bereavement booklet which guides them through the next steps in registering the death and other key activities that need to be carried out after a person dies.

10. Care of Staff

It is important to make good-quality care services available to the staff involved in caring for dying and bereaved people. From time to time a patient who is dying may be well known to the staff that has cared for them on a ward or in the community. Staff debriefing is available in consultation with the Supportive and Palliative Care Team, the Chaplaincy & Pastoral Support Team or Staff Wellbeing Team. The Chaplaincy & Pastoral Support Team is available 24/7 to assist with staff debriefing. Contact can be made through Switchboard.

In such circumstances they should have access to:

- A private area away from patients and relatives
- A debriefing session
- The opportunity to receive clinical supervision

11. Handling of and Care for the Deceased Patient

Please refer to the ‘Guidance for Staff Responsible for Care After Death’ Policy.
It is recognised that patient care does not finish when a patient dies. The events that follow death will be carried out with the same dignity and respect as would be afforded the patient when they were alive, together with their family and appropriate to their faith and culture.

11.1 Transfer from the Ward

The senior nurse on duty will request that the porters attend to remove the deceased patient from the ward after verification of death. This will only happen after the relatives have left and all personal care after death has been completed. This must be dealt with in a timely manner with any delays reported immediately to the Site Team and the Duty Portering Team Leader. The ward or department must make sure that the bed space is accessible for the Portering staff and clear of obstacles. Once the deceased patient is ready for collection, all ward/department staff must pull together all bed curtains around beds and close any side room doors as a mark of dignity and respect.

Once a deceased patient has left the ward any visits from the family will be arranged via the Bereavement Service.

11.2 The Mortuary

All deceased patients who are admitted to the mortuary will be registered and cared for by the APTs. The mortuary is a designated safe, secure, clean environment where the deceased patient is kept and monitored until transfer from the hospital to another place, such as the nominated funeral directors.

The mortuary is licensed by the Human Tissue Authority. Mortuary SOPs, audits and inspections are in place to ensure appropriate patient care is continued.

The APTs are available to answer queries about the facility and processes should a family request this.

The mortuary team endeavour to provide a service which ensures both staff and visitors feel confident and at ease when discussing processes or visiting the area for a specific reason.

11.3 Unexpected or Sudden Death

Any non-essential equipment should be removed to allow the deceased patient to be as visibly normal as possible. If the Coroner's Officer is likely to be involved the endo tracheal tube and all lines and catheters must remain in situ until specific permission is given by the Coroner's Officer or the death has been deemed not to be a Coroner's case, or until a Post Mortem examination has been performed.

11.4 Role of the Medical Examiner and Medical Examiner Officer

The role of the Medical Examiner Officer (MEO) is to support the medical Examiner (ME) in their role in scrutinising the circumstances and causes of death and to be a point of contact for coroner and registration services. The MEO will also be a source of advice for relatives of deceased patients, healthcare professionals and the bereavement service.
The ME scrutiny looks into the cause of death of the deceased, if the Coroner needs to be notified and was the care before death appropriate. This is done by providing independent scrutiny with a proportionate review of relevant medical records, interaction with the doctor completing the Medical Certificate of cause of Death and interaction with the next of kin, providing an opportunity to ask questions and raise concerns.
ME's conclusions can inform learning to improve care for future patients and in a minority of cases are referred to established clinical governance processes for further review.

11.5 The Release of the Deceased Patient

The family will inform the Bereavement Team of their nominated funeral director. Once all relevant paperwork is complete in the Bereavement Office, the Bereavement Team will confirm with the funeral director that their required paperwork has been completed by the family.

The Bereavement Officer will then send a release document to the named funeral directors and copy the APT's in, so they are aware of who to expect for collection of the deceased.

At the time of release there are a number of identification checks which will be conducted, and the deceased patient will be transferred.

On occasion the family may wish to carry out their own bespoke funeral. This is arranged with the APTs to ensure their mortuary experience is as smooth and personal as possible.

12. On-going Education and Training

End of Life Care educational resources are available to all staff. These are available in many formats including e-Learning packages and informal and formally delivered education sessions. Please see [redacted] for more information.

12.1 Mandatory End of Life Training

The level of training required is dependent on the role of the staff member.
There are 3 levels of training:

<u>Level 1</u> – all non-clinical staff or staff who have no contact with patients at end of life, will be given the Skills for Health leaflet ‘Working together: Improving end of life care through better integration’
<u>Level 2</u> – all patient facing staff who have regular contact with patients at end of life will attend a 3-hour face to face taught session 3 yearly. Depending on job role staff will attend either an acute, community or general session.
<u>Level 3</u> – simulation training will be developed for those whose primary role is to deliver end of life care to patients e.g., supportive and palliative care team members, 3 yearly.

13. Equality and Human Rights Statement

This document has been analysed for its impact on promoting the health and wellbeing of all of our patients, and in particular to ensure that Trust policy is compliant with the Trusts Human Rights and Public Sector Equality Duties (PSED). In providing end of life care the needs, preferences, beliefs, wishes and any spiritual requests of patients and carers are respected.

14. Monitoring Compliance with the Document

Monitoring Table

Element to be Monitored	**Lead**	**Tool for Monitoring**	**Frequency**	**Responsible Individual/Group/ Committee for review of results/report**	**Responsible individual/ group/ committee for acting on recommendations/action plan**	**Responsible individual/group/ committee for ensuring action plan/lessons learnt are Implemented**
NICE Standard. Statement 13	Director of Nursing	Excellence in Care	Monthly	Divisional Integrated Performance Reviews	Divisional Governance Groups	Ward Matrons/Community Team Leaders

15. References

Care Quality Commission (2016) *A different ending. Addressing inequalities in end of life care.* CQC, London.

Department of Health (2008) *National end of life strategy: promoting high quality care for all adults at the end of life.* Department of Health.

East Sussex County Council (2021) East Sussex Lesbian Gay Bisexual Trans Queer + (LGBTQ+) Comprehensive needs assessment http://www.eastsussexjsna.org.uk/JsnaSiteAspx/media/jsna-media/documents/comprehensiveneedsassessment/East-Sussex-Lesbian-Gay-Bisexual-Trans-Queer-Plus-Needs-Assessment-Dec-2021.pdf

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Appendix A: Mouthcare for End of Life Care patients

Mouthcare for End of Life Care patients

General information: The oral health of end of life and palliative care patients is crucial but is an area that has often been overlooked.

- End of life patients are susceptible to a range of problems with their mouths including dysphagia, dry mouth, thick mucus secretions, nutritional and taste problems, mucositis, and denture related problems.
- Poor oral health can have a big impact on the function and quality of life for these patients.
- Maintaining a comfortable mouth is not only reassuring for the patient but also their family.

Mouth care:

Mouth care for palliative care patients should ***seek to make the patient as comfortable as possible in the least invasive way***:

Tooth brushing:

Twice daily brushing of teeth and gums using a fluoridated but non foaming toothpaste with a small headed toothbrush.

Dry mouth and lip care :

For patients with dry lips and mouths use dry mouth gels or hydrate the mouth with a soft toothbrush / mouth eze dipped in water.

Moisture gel: (from stock)

Massage the gel in, like a hand cream, onto the lips and soft tissues (cheeks tongue palate). Do not just leave to gel to sit on the surface. Once massaged in, allow the gel to work. Repeat this process as required to prevent a dry mouth .The gel helps to support lubrication and hydration of the soft tissues.

Don’t forget to look up at the palate.

If secretions are present, once the gel has been massaged in, carefully remove these using a soft toothbrush / suctioning toothbrush or mouth eze . If necessary repeat this process. ***Non-prescription gels*** can be applied as often as a patient requires.

Denture(s): Clean denture(s) at least once daily, twice if feasible

- **AM**: remove from denture pot, clean, rinse and replace in the mouth once mouth has also been cleaned and if necessary moisturised.
- **PM**: remove denture(s), clean the oral cavity, clean the denture(s) then store the clean ,dry denture(s) overnight in a labelled dry denture pot with lid. In the morning, as above.

Comfort:

Dipping a toothbrush in the patient’s favourite drink and then placing in the mouth can be really comforting.

Pain:

Prescription of topical pain relief can support discomfort.

Difflam (benzydamine hydrochloride) spray or mouth wash. Supported by the Palliative team

Patients with increased oral health risk factors

- Regular removal of oral/dried secretions using moisture gel applied by a mouth eze, gentle suctioning or a toothbrush. Repeat as required.
- Families can be shown how to give dry mouth care as some will want to be involved in their care
- Check the mouth regularly for sign of thrush/ oral infection.

Appendix B: Equality and Health Inequalities Impact Assessment (EHIA)

Undertaking EHIA helps us to make sure that our services and polices do not inadvertently benefit some groups more than others, ensuring that we meet everyone’s needs, and our legal and professional duties.

This is important because:

- Assessing the potential for services and policies to impact differently on some groups compared with others is a legal requirement.
- People who find it harder to access healthcare services are more likely to present later when their disease may be more progressed, have poorer outcomes from treatment, and need more services than other groups who have better access.

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It is against the law to discriminate against anyone because of:

- age
- gender reassignment
- being married or in a civil partnership
- being pregnant or on maternity leave
- disability
- race including colour, nationality, ethnic or national origin
- religion or belief
- sex
- sexual orientation.

These are called ‘protected characteristics’. The Act requires that public sector organisations meet specific equality duties in respect of these protected characteristics. This is known as the public sector equality duty.

Public Sector Equality Duty

Public bodies have to consider all individuals when carrying out their day-to-day work – in shaping policy, in delivering services and in relation to their own employees.

Public bodies must have due regard to the need to:

- eliminate discrimination
- advance equality of opportunity
- foster good relations.

Armed Forces Covenant Duty

The new Covenant Duty raises awareness of how Service life can impact on the Armed Forces community, and how disadvantages can arise due to Service when members of that community seek to access key local services. The Duty requires organisations to pay due regard to the Covenant principles when exercising functions in healthcare. “Due regard” means that we need to consciously consider the unique obligations and sacrifices made by the Armed Forces; that it is desirable to remove disadvantages faced by the Armed Forces community; and that special provision may be justified in some circumstances.

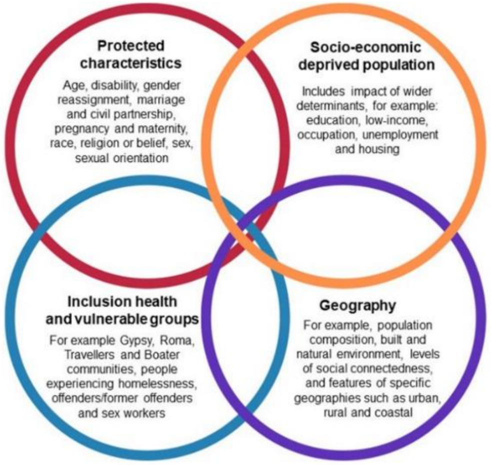
Health Inequalities Duties- Equity for all

In addition to our legal duties in relation to Protected Characteristics, the Health and Social Care Act and other legislation, NHS Planning Guidance and sector specific recommendations require the NHS to have regard to the need to address health inequalities (or differences in access to or outcomes from healthcare) and take specific action to address them.

Figure 1 shows the different population groups, factors associated with where we live, or our individual circumstances, which separately, or when combined, influence access to and outcomes from health care.

Getting equal outcomes may require different inputs (or services). In completing an EHIA its important to think about whether a one size fits all approach will generate the same good outcomes for everyone, or whether we might need to make some tweaks or adjustments to enable everyone to benefit equally. The health tree diagram shows that unless we think about the needs of different people, equal services might generate unequal outcomes.

Factors associated with poorer health outcomes (PHE 2021)[1]



The Health Tree[1]

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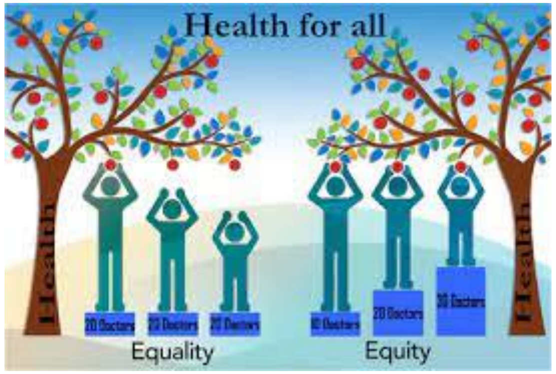
[1] https://www.researchgate.net/figure/Equality-and-equity-of-medical-resources-distribution_fig2_323266914



The following principles, drawn from case law, explain what we must do to fulfil our duties under the Equality Act:

- **Knowledge:** everyone working for the Trust must be aware of our equality duties and apply them appropriately in their work.
- **Timeliness:** the duty applies at the time of considering policy options and/or <u>before</u> a final decision is taken – not afterwards.
- **Real Consideration:** the duty must be an integral and rigorous part of your decision-making and influence the process.
- **Sufficient Information:** you must assess what information you have and what is needed to give proper consideration.
- **No delegation:** the Trust is responsible for ensuring that any contracted services which provide services on our behalf can comply with the duty, are required in contracts to comply with it, and do comply in practice. It is a duty that cannot be delegated.
- **Review:** the equality duty is a continuing duty. It applies when a policy/process is developed/agreed, and when it is implemented/reviewed.
- **Proper Record Keeping:** to show that we have fulfilled our duties we must keep records of the process and the impacts identified.

NB: Filling out this EHIA in itself does not meet the requirements of the equality and health inequalities duties. All the requirements above must be fulfilled or the EHIA (and any decision based on it) may be open to challenge. Properly used, an EHIA can be a <u>tool</u> to help us comply with our equality and health inequalities duty and as a <u>record</u> that to demonstrate that we have done so. It is advised that you complete the short EHIA training session on [redacted] before completing this EHIA.

SECTION A ADMINISTRATIVE INFORMATION

This form is a central part of how the Trust makes sure and can demonstrate to others that we are meeting our legal duties; and how we can assure ourselves that all patients will get the best outcome for them from our services.

A completed copy of this form must be provided to the decision-makers in relation to your proposal. The decision-makers must consider the results of this assessment when they make their decision about your proposal. Function/policy/service name and number:	End of Life Care Policy (Adults)
Main aims and intended outcomes of the function/policy/service and summary of the changes you are making (if existing policy/service):	To raise awareness and understanding of end of life care across ESHT, ensuring all staff recognise that they have a role to play in delivering good end of life care to everyone and that all of us will be impacted by people close to us dying. We have ensured that this document has been shared widely for comment with a view to ensuring that we are covering the needs

	of as many people as possible, recognising that different groups who share a protected characteristics may have different needs and preferences to those who share other protected characteristics. Changes made: • section 11.4 – removal of role of the bereavement office and addition of the role of the medical examiner and medical examiner officer. • Update of current interpreter services in section 6.1 • Checking of hyperlinks and telephone numbers		
How will the function/policy/service change be put into practice?			
Who will be affected/benefit from the policy?	All ESHT staff working within the Trust who have contact with adults in the last year of their lives. Patients at the end of life, and those people closest to them and all staff groups supporting them		
State type of policy/service	Policy x☐	Service ☐	
	Business Case ☐	Function ☐	Existing
Is an EHIA required? NB :Most policies/functions will require an EA with few exceptions such as routine procedures	Yes x		
	No ☐ (If no state reasons)		
Accountable Director: (Job Title)	End of Life Care Lead		
Assessment Carried out by:	Jayne Winter		
Contact Details:	[redacted]		
Date Completed:	27/2/25		

SECTION B ANALYSIS AND EVIDENCE

Analysis of the potential impact – Equality and Health Inequalities Duties

For this section you will need to think about all the different groups of people who are more likely to experience poorer access or have poorer outcomes from health and care services. For each group please describe in the first column the potential impact you have identified, in the second column explain how you have arrived at this conclusion and what information you used to identify the potential impact, and in the third column say what you are going to do to prevent it from happening, or which elements of a service or policy specifically address the potential impact. Key things to remember.

- Everyone has protected characteristics but some groups who share one or more protected characteristics may be more likely to have poorer outcomes or access compared with others – and it is this potential that the EHIA process seeks to identify and address.
- The information included here should be proportionate to the type and size of the policy/service/change.
- An update to a policy should demonstrate that you have considered the potential for the policy to impact differently on different groups and taken steps to address that.
- A minor policy update is likely to need to be much less comprehensive than an EHIA for a major service change.
- You will need to know information about who uses or could use your service/policy will apply to (the population). You can use information about current patients or staff, and about the general population the Trust serves.

3. PROTECTED CHARACTERISTICS - Main potential positive or negative impact of the proposal for protected characteristic groups summarised

Please write in the box below a brief summary of the main potential impact (positive or negative) Please state **N/A if your proposal will not impact adversely or positively on the protected characteristic groups listed below, but make sure you include information on how you know there will be no impact.**

Protected characteristic groups	**Summary explanation of the *potential* positive or adverse impact of your proposal**	**How do you know this? (include here a brief explanation of what information you have used to identify potential adverse impact e.g. NICE guidance, local data, evidence reviews, stakeholder or patient feedback**	**Action that will be taken to address the potential for negative impact.**
Age: older people; middle years; early years; children and young people.	This policy is specifically aimed at management of adult patients at end of life. Care of children is covered in the associated policy 'Policy for palliative and end of life care for babies, children and young people'	Specific needs may need to be referred toother providers such as paediatrics who offer more specialized care.	No negative impact anticipated
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions.	This policy recognises the impact disability might have on making end of life choices for both the patient and those closest to them.	This guidance supports those patients with both physical and mental health needs to access effective safe end of life care	No negative impact anticipated
Gender Reassignment and/or people who identify as Transgender	The policy makes reference to additional guidance in respect of the needs of some groups who share a protected characteristic	East Sussex Lesbian Gay Bisexual Trans Queer + (LGBTQ+) Comprehensive Needs Assessment 2021	No negative impact anticipated
Marriage & Civil Partnership: people married or in a civil partnership.	The policy makes reference to respecting patients relationships, this includes marriage and civil partnership	End of life is provided in ESHT to all patients regardless of marital or civil partnership status.	No negative impact anticipated
Pregnancy and Maternity: before and after childbirth and who are breastfeeding.	This policy does not have a negative impact on patients who are pregnant/parent	End of life care is provided in ESHT to all patients regardless of whether they are a parent or pregnant	No negative impact anticipated
Race:	This policy has a positive impact for all patients regardless of their race or ethnicity	End of life care is provided in ESHT to all patients regardless of their race or ethnicity	No negative impact anticipated

Protected characteristic groups	**Summary explanation of the *potential* positive or adverse impact of your proposal**	**How do you know this? (include here a brief explanation of what information you have used to identify potential adverse impact e.g. NICE guidance, local data, evidence reviews, stakeholder or patient feedback**	**Action that will be taken to address the potential for negative impact.**
Religion and belief: people with different religions/faiths or beliefs, or none.	This policy has a positive impact for all patients regardless of their religion or belief	End of life care is provided in ESHT to all patients regardless of their religion or belief	No negative impact anticipated
Sex:	This policy has a positive impact for all patients regardless of their sex	End of life care is provided in ESHT to all patients regardless of their sex	No negative impact anticipated
Sexual orientation	This policy has a positive impact for all patients no matter what their sexual orientation is	End of life care is provided in ESHT to all patients regardless of their sexual orientation	No negative impact anticipated
Veterans/Armed Forces Communities	This policy ensures 'due regard' is considered for veterans ad the armed forces community	End of life care is provided in ESHT to all patients	No negative impact anticipated

4. HEALTH INEQUALITIES -Potential positive or adverse impact for people who experience health inequalities summarised

Please briefly summarise the main potential impact (positive or negative) on people at particular risk of health inequalities (as listed below). **If the policy/procedure is unrelated to patients, this sections does not require completion.**

Please state none if you have assessed that there is not an impact, but please make sure you complete the 'how do you know this' column to demonstrate that you have considered the potential for impact**. If you identify the potential for impact for one or more of these groups please complete the full assessment in Appendix**

Groups who face health inequalities[2]	**Summary explanation of the potential positive or adverse impact of your proposal**	**How do you know this? (include here a brief explanation of what information you have used to identify potential adverse impact e.g. NICE guidance, local data, evidence reviews, stakeholder or patient feedback**	**Action that will be taken to address the potential for negative impact.**
This includes all groups of people who may have poorer access to or outcomes from healthcare services. It includes: People who have experienced the care system; carers; homeless people; people involved in the criminal justice system; people who experience substance misuse or addiction; people who experience income or other deprivation; people with poor health literacy; people living in rural areas with limited access to services; refugees or asylum seekers; people in or who have been in the armed force; other groups who you identify as potentially having poorer access and outcomes.	None	End of life care is provided to all adult patients in the last year of their life	No negative impact anticipated

SECTION C ENGAGEMENT

5. Engagement and consultation

---

a. Talking to patients, families and local communities can be a rich source of information to inform health care services. If you are making substantial changes it's likely that you'll have to undertake specific engagement with patients. For smaller changes and policies your may have undertaken some engagement with patient groups, gained insight from routine sources e.g. patient surveys, PALS or Complaints information or information from Healthwatch, you may also have looked at relevant engagement that others have undertaken in the Trust, or locally
Have any engagement or consultative activities been undertaken that considered how to address equalities issues or reduce health inequalities? Please place an x in the appropriate box below.

Yes	**No x**

b. If yes, please ensure all stakeholders are listed in the consultation table at the beginning of the policy.

SECTION D SUMMARY OF FINDINGS

Reflecting on all of the information included in your review-

6. EQUALITY DUTIES: Is your assessment that your proposal will support compliance with the Public Sector Equality Duty?
Please **add an x** to the relevant box below.

	Tackling discrimination	Advancing equality of opportunity	Fostering good relations
The proposal will support?	x	x	x
The proposal may support?			
Uncertain whether the proposal will support?			

7. HEALTH INEQUALITIES: Is your assessment that your proposal will support reducing health inequalities faced by patients?
Please add an x to the relevant box below.

	Reducing inequalities in access to health care	Reducing inequalities in health outcomes
The proposal will support?		x
The proposal may support?		
Uncertain if the proposal will support?		

8. Outstanding key issues/questions that may require further consultation, research or additional evidence. Please list your top 3 in order of priority or state N/A

Key issue or question to be answered		Type of consultation, research or other evidence that would address the issue and/or answer the question
1	N/A	
2		
3		

9. EHIA sign-off: (this section must be signed)

Person completing the EHIA:	**Jayne Winter – Lead Nurse Supportive and Palliative Care**	**Date:**
Line Manager of person completing:	**Paul Smith**	**Date:**

Appendix A

Breakdown of Groups who are more likely to experience health inequalities:

Groups who face health inequalities[3]	Summary explanation of the potential positive or adverse impact of your proposal	How do you know this? (include here a brief explanation of what information you have used to identify potential adverse impact e.g. NICE guidance, local data, evidence reviews, stakeholder or patient feedback	Action that will be taken to address the potential for negative impact.
Looked after children and young people			
Carers of patients			

Groups who face health inequalities[3]	**Summary explanation of the potential positive or adverse impact of your proposal**	**How do you know this? (include here a brief explanation of what information you have used to identify potential adverse impact e.g. NICE guidance, local data, evidence reviews, stakeholder or patient feedback**	**Action that will be taken to address the potential for negative impact.**
Homeless people. People on the street; staying temporarily with friends /family; in hostels or B&Bs.			
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.			
People with addictions and/or substance misuse issues			
People or families on a low income			
People with poor literacy or health Literacy: (e.g. poor understanding of health services poor language skills).			
People living in deprived areas			
People living in remote, rural and island locations			
Refugees, asylum seekers or those experiencing modern slavery			

Groups who face health inequalities[3]	Summary explanation of the potential positive or adverse impact of your proposal	How do you know this? (include here a brief explanation of what information you have used to identify potential adverse impact e.g. NICE guidance, local data, evidence reviews, stakeholder or patient feedback	Action that will be taken to address the potential for negative impact.
People who have served in the Armed Forces			
Other groups experiencing health inequalities (please describe)			

EHIA Resources
Sources of Information on the East Sussex population and sources of community or patient insight.

Population Data
State of the County 2021 Focus on East Sussex

East Sussex JSNA

Community Insight

Further Reading on Equality and Health Inequalities

Training

NHS

East Sussex Healthcare
NHS Trust

Consultant Name	
Date & Time Started	
Ward	

Stick PAS label here

Last Days of Life Personalised Care Plan

This Care Plan is only for use in adults over the age of 18 years

Last Days of Life Personalised Care Plan SHOULD ONLY BE COMMENCED AFTER:

The Multi-professional team, led by the responsible consultant (or a senior clinician to whom the responsibility has been delegated) agree that:

- The possibility that the person may die within the next few days or hours is recognised
- All reversible causes have been considered and managed appropriately

AND

- Sensitive discussion about the prognosis with the person (wherever possible) and/or those identified as important to them has taken place

Personalised Plan for: ______________________ (insert name)

Family Contact Details

1st Contact:

Name:………………………………………………..

Relationship……………………………………...

Tel No:……………………………………………….

Mobile No:…………………………………………..

At any time: ☐ Not at night time: ☐

2nd Contact:

Name:………………………………………………..

Relationship……………………………………...

Tel No:……………………………………………….

Mobile No:…………………………………………..

At any time: ☐ Not at night time: ☐

Those responsible for the plan of care to sign below:

Doctor Name…………………………………………………………. ……………………………… .

Signature………………………………………………………….. Date & Time………………………….

Responsible Consultant Name……………………………………………………………………….

Signature ………………………………………………………….. Date & Time………………………….

Nurse Name……………………………………………………………………………………………….

Signature ………………………………………………………….. Date & Time………………………….

All decisions must include the responsible Consultant as soon as possible

Patient Name:.................................
NHS Number: ....

All practitioners completing this document are required to fill this section in prior to making an entry. This only needs to be completed once.

Date	Print Name	Designation/Bleep No.	Signature

Recognition that the person is likely to be in their last days of life

Patient Name:................................

NHS Number: ....

Document who is involved in making the decision:

....

....

Document diagnoses and relevant clinical features that suggest the person is likely to die:

....

....

....

....

....

Have all reversible causes for deterioration been considered?

Document details of relevant considerations:

....

....

....

....

....

Initial Communication with person and those identified as important to them

Initial discussion should include:

- Recognition that there is a high probability that the person is dying and reason for this
- Uncertainty and difficulty making an accurate prognosis
- The person's preferred degree of involvement
- Identification of key decision makers to consult
- ReSPECT / DNACPR decision if not already in place
- Preferred place of care (complete box on page 4)

If the person was not involved in the initial discussion please document reason why.

....

Document who was present and key conversation points:..

....

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....

Involve person and those identified as important to them

Patient Name:................................

NHS Number: ....

Does the person have capacity to express preferences for their care in their last days?

Yes ☐ No ☐ If the person does not have mental capacity, please refer to capacity assessment.

If the person does not have capacity:

Has the person made any advance care planning (ACP) decisions before admission? Yes ☐ No ☐
(This could include: advance care plans, PEACE, advance decisions to refuse treatment, LPA for health and welfare or ReSPECT)

Has the contents of the ACP been taken into account when making decisions / planning care? Yes ☐ No ☐

If no state the main reason why the ACP was not followed:

....

....

....

Please ensure a copy of any ACP is placed in the medical records

Preferred Place of Care (PPC)

What is the person's preferred place of care? Tick appropriate box:

Usual place of residence e.g. home / care home – **start rapid discharge process** ☐

New place of residence e.g. nursing home / relatives home – **start rapid discharge process** ☐

Hospital ☐ Hospice (discuss with SPCT) ☐ Too unwell to leave hospital ☐

What is the plan to address PPC

....

....

....

....

Check ReSPECT or DNACPR has been discussed and completed as appropriate ☐

Reviewing Current Interventions

Stop routine observations and commence Symptom Observation Chart for the Last Days of Life ☐

Use Abbey Pain Scale for persons who cannot communicate ☐

Discontinue investigations, blood tests and treatments that do not promote comfort, dignity and peace ☐

Review uneccessary medications ☐

What is being continued and reason (this might include oxygen, antibiotics, essential medications, CBG's):

....

....

....

....

....

Pastoral, Spiritual and Religious Needs

Patient Name:……………………………

NHS Number: ……………………………

Every person's life has a spiritual dimension. For some this may be a religious belief whereas for others it may not. Spiritual need relates to what gives life meaning and purpose and involves needs of reassurance, comfort, peace, happiness, dealing with guilt and the need for forgiveness, being given dignity, listening and being listened to, feeling valued and having self-esteem.

Explore these needs by asking questions e.g.

- How are you feeling in yourself?
- Do you have a religious faith of any kind?
- What is most important to you in life

Further examples of questions can be found in the leaflet 'A Guide to Spiritual Care'.

The Chaplaincy and Pastoral Support Team can advise and support at all stages as needed.

Religion / Belief: ……………………………………………………………………………………………

Document pastoral, spiritual and religious needs identified:

………
………
………
………
………
………
………
………

Spiritual adviser / Chaplaincy and Pastoral Support contact (if appropriate): ……………………………………

All persons on this care plan will be visited by the Chapaincy and Pastoral Support Team unless there is a documented reason why they should not visit.

The Chaplaincy and Pastoral Support Team can offer out of hours visits in cases of urgency.

Support and care for family / those identified as important to the person

Everyone will have a need of some kind at this difficult time this may include time alone with the person.

Assessed needs of the family / those identified as important (this should include emotional, spiritual, cultural, social and practical needs):

………
………
………
………
………

Document plan to meet assessed needs identified above (if needs cannot be met please document reason):

………
………
………
………

Has the following been offered (tick when offered):

Parking permits ☐ 'Coping with Dying' or appropriate leaflet ☐ Comfort box ☐

Has the following been explained:

Open visiting ☐ Accomodation ☐ Food facilities ☐ Other ……………………………………………

Personalised Assessment and Plan of Care

Patient Name:................................

NHS Number: ....

Personalised Assessment	Care Plan	JIC px	Signature / date
1.Communication Any communication needs?			
2.Emotional /psychological What is most important to you at this time? (Can be asked of family in relation to the person). Any worries, concerns etc.			
3.Symptoms		**JIC px**	
Pain			
Nausea & vomiting			
Shortness of breath			
Agitation & delerium			
Retained secretions			
Has the possibility of side effects of medications, such as drowsiness, been discussed with the person and those identified as important to the person? Yes ☐ No ☐ If no document reason …………………………………………………………………………………………………			
4.Hydration & nutrition Able to eat/drink, risk feeding. Artificial hydration / nutrition (plans to stop if continuing) Signs of dehydration – dry mouth, thirst, confusion, agitation Signs of overhydration – swelling, fluid overload Persons preference if unable to maintain hydration			
5.Personal care / skin integrity / mouth care			
6.Elimination			
7.Other			

Evaluation & Communication

Date & Time	Details	Sign & Print Name

Last Days of Life Personalised Care Plan

Patient Name:................................

NHS Number: ....

Daily Review & Communication

- Are any issues highlighted from the previous day outstanding?
- MDT review and evaluation of person's condition and needs and wishes
- **Is the Last Days of Life Care Plan still appropriate?**

Date & Time	**Details**	**Sign & Print Name**

Last Days of Life Personalised Care Plan

Patient Name:................................
NHS Number: ....

Evaluation & Communication

Date & Time	Details	Sign & Print Name

Last Days of Life Personalised Care Plan

Patient Name:................................

NHS Number: ....

Daily Review & Communication

- Are any issues highlighted from the previous day outstanding?
- MDT review and evaluation of person's condition and needs and wishes
- **Is the Last Days of Life Care Plan still appropriate?**

Date & Time	**Details**	**Sign & Print Name**

Last Days of Life Personalised Care Plan

Patient Name:................................

NHS Number: ....

Evaluation & Communication

Date & Time	Details	Sign & Print Name

Discontinuation of Last Days of Life Personalised Care Plan

Reasons for discontinuation:	Date:
Patient/family involved in discussion:	
Consultant name:	Signature:
Other staff:	Signature:

Care immediately prior to and after death

Who was present at time of death? (those important to the patient / HCP's):

What care was given to the patient immediately prior to and after death? (This may include religious / cultural / Spiritual care)

What care and support was provided to the family / those important to the patient at the time of and immediately after death?

The Chaplaincy and Pastoral Support Team can be called to support the family when the patient has died.

Was the family / those important to the patient given opportunity to ask questions immediately after death:

Yes ☐ No ☐

Details:

Document the process followed regarding property / valuables:

Any other comments:

NHS
East Sussex Healthcare
NHS Trust

Policy for Palliative and End of Life Care for Babies, Children and Young People

Document ID Number:	1464
Version:	V2
Ratified by:	Clinical Documentation and Policy Ratification Group
Date ratified:	October 2023
Name of author and title:	[redacted], East Sussex Well Child Nurse [redacted], Clinical Services Manager, Paediatrics. Review team Dr Stephanie Gill, Consultant Paediatrician, Fran Edmunds Head of Nursing,
Date Originally Written:	August 2014
Date of current version was completed	October 2023
Name of responsible committee/individual:	Chair of the Guideline Implementation Group for Women and Children's Division
Date issued:	03 November 2023
Review date:	October 2026
Target audience:	All Clinical Staff in paediatric and neonatal services
Compliance with CQC Fundamental Standard	Person Centred Care Dignity and Respect Need for Consent Safe Care and Treatment
Compliance with any other external requirements (e.g. Information Governance):	NICE Quality Standard - End of Life Care for infants and Young People (ng61 2016)
Associated Documents	West Midlands Palliative Care Toolkit Guidance for Staff Responsible for Care After Death (Last Offices) Organ and Tissue Donation Policy Safeguarding of Children Policy Guidance for staff on the implementation of the Mental Capacity Act Policy for the Management of Resuscitation A Framework for the development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions, ACT, 2011 Policy and Procedure for Standard/Universal Precautions for the Prevention of Infections Policy for the Spillage of Bodily Fluids Policy for the Control of Tuberculosis in Hospitals & Community Prevention and Management of Occupational Exposure to Meningococcal Disease Including Meningitis in Health Care Settings The Management of Scabies Policy

Version Control Table

Version number and issue number	Date	Author	Reason for Change	Description of Changes Made
V1.0 2014174	August 2014	[redacted]	New document	
V1.1 2018335	March 2018	Stephanie Gill [redacted]	Revision in line with NICE guidance	Revision in line with NICE guidance
V2	October 2023	Mark Standen	Manager Review	Minor administration changes

Consultation Table

This document has been developed in consultation with the groups and/or individuals in this table:

Name of Individual or group	Title	Date
Children's Community Nursing Team		6/8/14
Paediatric and Neonatal Matrons		6/8/14
Paediatric Consultants		6/8/14
Joy Jones	Bereavement Officer	6/8/14
Steve Rochester	Resuscitation Officer	6/8/14
Demelza House and Chestnut Tree House Hospices		
Women and Children’s Guideline Implementation Group		April 2018
Women and Children’s Governance and Accountability meeting		May 2018
Policy and documentation Group		May June 2018
Women and Children’s Guideline Implementation Group		January 2022
Women and Children’s Governance and Accountability Attendees. Virtual		November 2023
Policy and documentation Group		

This information may be made available in alternative languages and formats, such as large print, upon request. Please contact the document author to discuss.

Did you print this yourself?
Please be advised the Trust discourages retention of hard copies of the procedural document and can only guarantee that the procedural document on the Trust website is the most up to date version.

Table of Contents

1. Introduction

This document outlines the planning and management of end of life (EOLC) and palliative care for infants, children and young people (0-17 years) with life-limiting conditions who are receiving care through ESHT. Decisions about this care should be made with the children, young people and their families. Guidance is based on NICE guidance 61: End of Life Care for infants, children and young people with life-limiting conditions: planning and management (https://www.nice.org.uk/guidance/ng61/chapter/Implementation-getting-started)

Some children will be born with life-threatening or life-limiting conditions; some may develop or acquire them. Some children may live with their conditions for a number of years and may transition through into adult services. Some children will experience a slow decline in health and wellbeing; others may experience short, aggressive illnesses with rapid deterioration, requiring prompt escalation in supportive care.

Palliative care for children is a complete approach to care from the point of diagnosis, throughout the child's life, death and beyond and encompasses all aspects of a child's life with the emphasis on quality of life for the child and support for the whole family. The time at which palliative care is introduced to the family is very individual, with some children requiring palliative care from birth and others only as their condition deteriorates (West Midlands Children and Young Peoples Palliative Care Tool Kit, 2018). All situations where a child is requiring palliative and end of life care (EOLC) requires careful and specifically tailored care delivered to the highest standard to ensure that families concerned receive the best, research based, highest standard of care through this most difficult of times (ref West Midlands Children and Young Peoples Palliative Care Tool Kit, 2018)

2. Rationale

East Sussex Healthcare NHS Trust is committed to the delivery of high quality, sensitive care for families whose children have life-limiting or life-threatening conditions or who are at the end of their lives. Sensitive communication should take place between staff and the child's family/parents/carer and where age appropriate, the child or young person themselves. Care continues after the patient's death, to include appropriate transfer of the patient's body to the mortuary, hospice or funeral home, and supportive care offered to the bereaved family.

2.1 Principles

The Trust is committed to ensuring that cultural preferences and religious observances will be born in mind at all times.

The Trust will ensure that staff understand the relevant statutory and legal frameworks and all best practice guidance.

Education and training needed for the delivery of good end of life care is provided for all staff.

3. Scope

This document covers the care of children and young people under 18 years, including neonates and infants, with life-limiting conditions.
It does not cover unexpected child deaths (including children and young people with life-limiting conditions who die unexpectedly, for example, accidental deaths). In this instance please refer to the Sussex Child Protection and Safeguarding Procedures via the Extranet.

For the purposes of this policy, "Tertiary Centres" refers to our local children's hospices and NHS Hospitals providing specialist support.

This policy does not seek to set out legal obligations for procedures in the mortuary or during a post-mortem.

4. Definitions

All definitions are referenced to the Together for Short Lives website, 2021

CCN – Children's community nurse

Children's Palliative Care

"An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social, and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement".

End of Life Care

"End of life care is care that helps all those with advanced, progressive, incurable illness, to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support and support for the family into bereavement".

Life-threatening Condition

"Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included".

Life-limiting Condition

"Life-limiting /life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers".

5. Accountabilities and Responsibilities

5.1. Chief Executive

The Chief Executive has overall final responsibility for the management of patient experience and ensuring that Palliative and End of Life Care for children and young people in the organisation has the appropriate resources available for employees and others who may be affected.

5.2. Chief Nurse

The Chief Nurse is the lead Director within the Trust and is responsible for ensuring the implementation of the palliative and end of life care policies for children and young people, within the Trust, through the management structure.

5.3. Senior Managers and Heads of Nursing

Ensure that managers are aware of the policy and are supported in implementing the policy with staff.

5.4. Ward Matrons/Line Managers

Ensure that the policy for Palliative and End of Life Care for Children is adhered to. Levels of responsibility should be monitored and improvement actions taken where appropriate.

Maintain safe staffing levels and adequate cover in ward/department at all times

5.5. Service Managers

Service Managers are expected to promote and ensure that the Palliative and End of Life Care for Children Policy is implemented within their areas of responsibility.

5.6. All staff working within ESHT service

Have a responsibility to ensure that they comply with this policy arrangement at all times.

6. Procedures and Actions to Follow

6.1. Identification of a child in need of Palliative care

Children are determined as being in need of Palliative care when their condition meets the definitions of Life-Threatening or Life-limiting Conditions (see section 3).

6.2. Identification of a Child who is considered to be End of Life

Children are determined to be End of Life when their condition meets the definition of End of Life (see Section 3). This is likely to be a joint decision between the family and the Multi-disciplinary Team and may also be a decision taken by our tertiary partners in conjunction with the family.

6.3. Having Essential and Difficult Conversations

Children and young people with life-limiting conditions and their parents/carers have a central role in decision-making and care planning with the multi-disciplinary team. Discussion and regular review with the child and family in how they wish to be involved in making decisions about their care will take place. This may vary between individuals, at different times, and depending on which decisions are being made. The child/family may also wish other friends or family to inform these discussions.

Discussions should begin at the earliest appropriate opportunity, to give children and their families enough time to discuss difficult decisions with the multi-disciplinary team. Discussions will be required when the life-limiting condition is first recognised, when the Advanced Care Plan is developed and reviewed, if their condition worsens and when they are approaching end of life. Where needed, the transition from children to adult services should be managed in line with NICE Transition guidance.

Information needs to be of high quality to inform and support children and families and delivered in an appropriate format to ensure it is understood. This should take into account the needs of those whose first language is not English and should be tailored to the needs of those with disabilities and communication difficulties. If a translator is required, the appropriate approved service should be contacted.

Every child or young person with a life-limiting condition should have a named medical specialist who leads and co-ordinates their care. Continuity of care is important to children and families, and where possible frequent changes to the team caring for them should be avoided. Children and families should consent to the relevant sharing of information about their care. All sharing of information must be documented in the patient's records clearly showing date, times and details.

These conversations may not take place within ESHT but may be undertaken by our tertiary or non-government organisations colleagues (NGO). Feedback should be received, and appropriate documentation be sent back to the local team.

6.4. Advanced Care Plans

When it is determined that a child has a life-limiting condition, families should be approached to consider their wishes for the care of their child during deteriorating health and at end of life. Discussing this early in the child's life allows time for difficult decisions to be made and should take into account possible unpredictability in the course of the condition.

An Advanced Care Plan can be completed by the family, supported by the medical team best known to them. The plans should be reviewed and revised as circumstances and wishes change and circulated to all those potentially involved in the child's care. The Advanced Care Plan should be accompanied by the ReSPECT form, which is a summary of the plans for care (including resuscitation efforts) at the end of life.

If an Advanced Care Plan / ReSPECT form have been completed by another organisation or tertiary centre, it will be recognised by ESHT on the original documentation (not copies). Details will be checked with the family by the Consultant on call or the most senior member of medical staff available at the time.

Original documentation remains the property of the child and must travel with the child between hospital, home, tertiary centre/hospice ***Policy & Procedures for the Management of Resuscitation*** 01242_P.pdf (esht.nhs.uk)

6.5. Organ and Tissue Donation

Further guidance on this topic can be found in the NICE guidance on organ donation for transplantation (including donor identification and consent, when and how to discuss the topic).

When it is certain that a patient will die, staff will wish to consider, where appropriate, issues relating to the donation of organs or tissue for use in transplantation, therapy, education or research. Patients and/or families will need access to a range of information before making a decision and close liaison across a number of disciplines may be necessary, e.g. with organ transplant coordinators (24 hour telephone [redacted]).

Formal, informed consent is needed for the donation of organs or tissue. Where donation is for transplantation, formal consent could come either from the potential donor (e.g. from a living will or through being on the Organ Donor Register) or from a person in a 'qualifying relationship' as stated in Section 27 of the Human Tissue Act 2004.

If organ or tissue donation is not possible, explain why.

6.6. Emotional and Psychological support

Be aware that children with life-limiting conditions and their families may have emotional and psychological distress and crises. Conversations about psychological well-being should be held at the earliest appropriate opportunity, and regularly throughout their care. Information should be provided to the child and family about the emotional and psychological support available and how to access it.

Discussions about psychological well-being should be held regularly, particularly at times of change such as:

- When life-limiting condition is diagnosed
- If their clinical condition deteriorates (when they might need access to emergency interventions and urgent access to psychological services)
- If their personal circumstances change
- If there are changes to their nursery/school/college arrangements
- If there are changes in their clinical care (for example, if care changes focus from treatment of the condition to end of life care)

It is important that a multi-disciplinary team approach involving the Specialist Palliative Care Team (including hospital – tertiary and local, community and hospice services), the Pastoral Care and Chaplaincy Team, Community carers, charities, counsellors, as appropriate, should be maintained by the key worker.

When having discussions about psychological well-being, consider the following:-

- It is vital that the dying child and families wishes are respected at all times, where possible, together with those of the family /carers.
- There should be a nominated lead, who can liaise between staff, patient, parents/carers and family. This may be a health professional from one of our tertiary partners.
- A multi- disciplinary team approach including child, family and carers should be followed
- Aim for a co-ordinated and consistent approach, where all carers are working with shared goals
- The timing of these conversations, and when they are revisited is important
- The chaplaincy multi faith service or another facilitator may be helpful in these discussions
- Where children and their families have formal counselling requirements, additional support should be provided by qualified counsellors / psychotherapists.

6.7. Religious, spiritual and cultural support

It is essential that all religious and cultural beliefs be identified as early as possible.

It is important at all times to respond to the cultural and religious needs of dying children and their families. In the hospital setting staff should refer to the ‘Faiths & Practice’ book held in the Bereavement Offices. However, the information given is generalised and basic, and must not replace discussion with individual patients and/or families, as to their personal requirements.

Remember that the religious/ spiritual beliefs and cultural values may differ between the child and parents, and individuals may differ in how they think these should influence the care of the child.

Patients should have access to staff who are sensitive to the family's spiritual needs. Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual care givers who can act as a resource for patients and staff.

The Chaplaincy team can be contacted for specialist advice 24hrs a day and there is a comprehensive multi-faith guidance document on the chaplaincy website called At Hastings and Rother NHS Trust we are committed to respecting the culture and religion of all those in our care. (esht.nhs.uk)

If in any doubt, contact the duty chaplain (via switchboard) for advice and to co-ordinate the provision of authorised, appropriate spiritual care. Chaplaincy has a list of community faith leaders which can be used when requested by the family.

Recognise the need for an interpreter or advocate at the earliest opportunity, to reduce any possible delays in obtaining help.

The child's faith e.g. Christian, Muslim, Hindu, Sikh, Jewish, should have been entered in their medical/nursing record on initial assessment including humanism or atheism which are belief systems in their own right.

Special religious or cultural requirements e.g., anointing the sick or specific dietary requirements should be noted if this has not already taken place. It is important that staff should not make assumptions about appropriate practices purely on the basis of a recorded faith on the patient record without clarifying with the family.

The family may require a visit from their own faith leader. If it is not known how to contact that person, the Duty Chaplain may be able to contact a local representative of that faith community. Patients, relatives or partner should always be asked if they wish to see a Chaplain or representative from their own faith community.

The Chaplains will support any request or referral regardless of what faith has been entered on the patient's records.

East Sussex Healthcare Trust will work with different religious and cultural groups to ensure that, wherever possible, appropriate religious or cultural care procedures are carried out following the death of patient.

6.8. Social and Practical Support

The needs of the child and family may change during the course of the condition, but consideration should be given to:

- Material support (for example housing modifications, provision of equipment)
- Practical support (for example, access to respite care)
- Technical support (for example, training to administer medications at home)
- Education support
- Financial support

6.9. Care of the family of a child who is dying

Dealing sensitively with bereavement relies on people carrying out their duties and responsibilities in a professional and sensitive manner. This includes being able to explore what families in distress need.

If possible, services should ensure that children and young people can be cared for at their preferred place of care and die at their preferred place of death. The place of death may change for clinical reasons, due to problems with service provision, or because the child/family change their mind. If a death is expected soon, and the child is not in the preferred place of death, consider whether a rapid transfer is possible and in their best interest. Discuss this with them and their family.

In whatever care setting, give family (relatives) and / or carer time with the patient prior to death.

Ensure that communication by all staff to relatives is honest. Do not give false or misplaced hope. If death is expected, tell the family as soon as possible and use the words “death” and “dying”. Euphemisms can lead to confusion.

All communication with relatives **must be documented** to ensure effective inter-professional / family communication is fully understood. All entries must be as contemporaneous as possible, and show details of the communication, the date, the time and the initials and printed signature of the member of staff making the entry. If the next of kin are not present every effort must be made to contact them as soon as practicable following the death. Staff must be aware of any specific requests from the family.

Parents/ Carers

- Know that the dying child is comfortable and that they are as pain free as possible.
- Be kept informed of their child’s condition
- Know of the impending death
- Be able to experience and express emotions
- Be comforted and supported
- Be relieved of as much anxiety as possible
- Plan for actions which might support them such as important rituals, recording or preserving memories.

Sometimes a family member may choose not to be with their dying child. Likewise the child may have expressed the wish to be alone when the end comes. These choices must be respected and supported.

The involvement of siblings and the extended family is at the discretion parents/carers and their decisions will be supported and accommodated by staff.

Special Considerations

- Relatives should not be excluded, as far as is practicable, from the emergency treatment of a child who is close to death, but they should be supported throughout the process.
- Update of information about the child's condition should be given regularly.
- Respect must be given to the wishes of the relatives to stop emergency treatment as appropriate, unless it is in direct opposition to the known wishes of the patient.
- The privacy of a relative's waiting room should be offered.
- Support from the Chaplaincy Team should be offered as early as possible.

On-going Support: Immediate family members should be made aware that on-going support is available to them through the Chaplaincy Department following death in the hospital. Please note that this is not in the form of professional counselling. In the community, bereavement support is offered by our local Children's hospices and Cruse organisation; support for siblings may be available via Dragonflies. Financial Support may also be available following the Death of a child for assistance with the funeral costs and headstone costs.

6.10. Care of Staff

It is important to make good-quality care services available to the staff who are involved in caring for the dying and bereaved families. From time to time a patient who is dying may be well known to the staff who have cared for them on a ward or in the community.

It is suggested that in such circumstances they should have access to:

- A private area away from patients and relatives
- A debriefing session
- The opportunity to receive counselling or to speak with someone not associated with the ward if they wish.
- Clinical supervision

Support can be accessed by referral to the Occupational Health Department.

Advice can be sought from the Lead of the Trust's Cancer Counselling Service

6.11. Referral to Children's Hospice Services

ESHT can access two different Children's Hospices for our children and families: Demelza (Sittingbourne) and Chestnut Tree (Arundel). Each has its own referral criteria and catchment area; each has a residential hospice and a community service. Each may offer Respite services, End of Life and Bereavement Care to children and their families. Each has access to facilities to enable a family to stay with their child through death, up until the time of the funeral.

6.12. Palliative Care in the Home

As children's care needs increase their families may find it increasingly difficult to care for them in the home. Support is available to them via a number of routes in order to facilitate caring for the child at home:

I. Referral to Demelza Community Team for Assessment for Respite
II. Referral to Chestnut Tree House for Community Support.
III. Referral to the appropriate CCN Team.
IV. Request for a Continuing Healthcare Assessment to be made via the Lead Nurse for Disabled Children for the CCG.
V. Refer to the Children with Disabilities Team (Social Services).
VI. Follow the CITES Hospital Discharge Pathway for children requiring complex discharges, NB 4-6 weeks' notice is required for planned discharges.
VII. Consider referral to Paediatric Continence Team, Paediatric Epilepsy Nurse, Dietician, Family Keyworker, Health Visitor, School Nurse as indicated.

6.13. End of Life Care in the Home

Children's Hospice Teams with the support of the local Children's Community Nurses will take the lead / keyworker role in children who are receiving End of Life Care. Each team will work to its own Hospice Policies and Protocols and actively involve the GP/tertiary centre.

6.14. Out of hours prescribing support for End-of-Life Care

Frequently children are in receipt of 24hour care in the home from the Hospice teams as their condition deteriorates. Out of hours prescribing support to increase medication, as indicated by the child's condition, in the home will be provided by Consultant Paediatrician on call (this may be a tertiary centre Consultant) with the support of the on-call medical team on Kipling, and the GP, if needed. Some of the tertiary centres will offer telephone support out of hours, but not all. In the absence of an alternative out-of-hours plan: -

I. The Keyworker will liaise with the named ESHT Consultant or Consultant of the week in the absence of a named Consultant, at the planning stage to advise them of the expected death of a child in advance of the episode of increased care, particularly if there is likely to be a need for prescribing support out-of-hours.
II. The Keyworker will liaise with the named Consultant at ESHT or Consultant of the week as the situation changes and the need for increased nursing support at home is identified.
III. Child's details to be maintained and updated on the Kipling handover sheet in order that information is shared, and the team can provide prescribing support to the on-call Hospice care teams as needed.
IV. It is the responsibility of the Keyworker to liaise with the Consultant daily to update them, it is the responsibility of the Consultant to ensure that the handover sheet is kept up-to date and 24hr team are aware of the child and their needs.

6.15. End of Life Care in Hospital

The expected death of a child in hospital is a very rare event. Ward staff need to be supported to provide high quality care and support which the family and child needs.

- Provide a cubicle for the family, preferable one with its own bathroom and bed for both parents, if possible.
- Unrestricted visiting for the family.
- Ensure Advanced Care Plan and ReSPECT documentation is completed and retained in the notes.
- Ensure clear plans are discussed, updated, agreed with the family and documented in the notes.
- Ensure team are aware of the plans.

- Obtain support from the Tertiary Palliative Care Team involved with the family to obtain guidance and assistance with the appropriate prescribing if one is involved with the child.
- Obtain support from the community children's nursing team.
- Consider and accommodate, within reason, religious, spiritual and cultural needs. Obtain the support of the Hospital Chaplaincy or the families own religious leader as requested.
- Early involvement of the Pharmacist to ensure good supplies of the necessary drugs are available and for them to support the prescribing process.
- Ensure nursing staff have the appropriate training to prepare the complex infusions required to maintain good analgesia for these children.
- Limit the numbers of staff caring for the family to maintain continuity.
- Consider the appropriateness of any monitoring equipment and withdraw it if it is felt to be unnecessary. Clearly document this decision and rationale.
- Provide care as planned; escalate analgesia as necessary, as prescribed. Request early and prompt review of analgesia, should prescribed levels be insufficient.
- Maintain contemporaneous, accurate records.
- Be aware that "Louis" Memory boxes are available on Kipling Ward, if deemed to be appropriate.
- Consider involving the Adult Palliative Care Team within ESHT if age appropriate, e.g 16 and 17 year olds.
- Liaise with the relevant Hospice Team for support during this time and to refer the family for Bereavement Support.
- Early referral to the ESHT Bereavement Service at Conquest on ext 8398.
- Be ready for the parents to change their mind and want to take their child home to die. Should the situation arise, immediately liaise with the Hospice teams and CCN teams and liaise with SECAMB for a 'Mercy' transfer to home (NB Original Advance Care Plans and ReSPECT documentation must travel with the child)
- Should parents wish, they are able to meet with the team who will be caring for their child after death (contact the mortuary manager to arrange). This is not often requested but may reassure some families about the care of their child after death.
- Discuss the option of transferring their child to either Demelza (Sittingbourne) or Chestnut Tree House (Arundel) after death in order for them to be with their child prior to the funeral. Liaise with the appropriate Hospice to ascertain availability at the earliest opportunity.
- Verification of death.

6.16. The Expected Death of a Child in Hospital

Once the death of a patient has occurred the medical staff must be informed, and verification of death must be made. This should occur within one hour of death and must be undertaken by a member of the medical staff. The verification of death must be clearly recorded in the patient's medical notes and the verification of death form completed.

The family should be allowed sufficient time with their deceased child/baby and may wish for other relatives to attend to pay their respects.

All child/neonatal deaths under 18 years of age must be reported to the coroner. This includes expected and unexpected deaths and is a legal requirement.
It will be necessary for the senior doctor present around the time of death to discuss with the coroner's officer whether the death was expected, and that the manner of death is in keeping with this.

The coroner will then issue a Part A certificate which is sent via encrypted email from the coroner's office to the registrar of deaths. Without this notification the family will not be able to register the death of a child. The bereavement office will notify the family when this notice has been sent. Following discussion with the coroner, the paediatrician will be able to issue the Medical Cause of Death certificate, and if required, Doctors' Papers 4 and 5 (needed if cremation is planned).

6.17. Procedure for Personal Care After Death

Staff are advised to adopt universal infection control precautions at all times. Please ensure you refer to Infection control considerations.

> Cannulae, surgical drains, central lines, urinary catheters etc are to be left in situ, ensuring tubes are capped (tied off) to prevent leakage until removal is authorised following discussion with the coroner. Drainage sites or open wounds should be covered with a clear occlusive dressing to prevent leakage of body fluid. Body fluids should be absorbed using incontinence pads. Orifices must not be packed.

The parents may wish to wash their child/baby and dress them in the clothes specified by the family. If this is the case offer them the equipment required. If the parents decline this then staff can undertake this task once the family have left unless requested not to do so for religious or cultural reasons.

All jewellery should be removed from the child/baby, unless requested by the family to leave in situ but this must be documented in the patients notes and on the mortuary risk assessment form in the section provided. If there are no personal effects accompanying the child/baby to the mortuary this must be clearly recorded as **'NONE'** on the risk assessment form. **This section must not be left blank.**

The child/baby must have two name bands correctly completed and attached, one to a wrist the other to an ankle.

The mortuary risk assessment form must be accurately and fully completed as follows and handed to the porters at the time of transfer to the mortuary:

Write legibly using CAPITAL letters. It is acceptable to use a patient identification label from the notes.
Do NOT leave any section blank.

The mortuary risk assessment is handed to the porter when the child/baby is transferred to the mortuary.

The family should be given a copy of the bereavement leaflet which should be available in all areas where children/babies are treated. Parents/carers should be advised to contact the bereavement office the next working day after 10.00am.

Once the family have left the unit the child/baby can be prepared for transporting to the mortuary. They should be wrapped in a sheet with their face and feet covered. They should be covered before the porter arrives to facilitate the transfer. Transportation will be in the most appropriate mode for that child/baby.

6.18. **Process for Transferring a Deceased Child from the ward to Home/Hospice**

Refer the family to Demelza, Sittingbourne, or Chestnut Tree House, Arundel, to ascertain availability of a Bereavement Suite. Obtain guidance from them as to the safe transport of a child to them after death and confirm the formalities that need to be observed. All documentation must be complete prior to the child/baby leaving the Trust premises, including permission from the Coroner.

The transfer of a deceased child into or out of the hospital or home environment is usually facilitated by a nominated funeral director; families should be advised that there may be a charge for transferring their child. The Hospice's will be able to provide assistance with identifying appropriate Funeral Directors

All legal documentation will need to be in place prior to transfer. If the deceased child is to be transferred from a hospital into the hospice the funeral director must be informed of:

- The child's name
- The child's date of birth
- The hospital address and precise location of the child within the hospital
- Infection control issues associated with the child's diagnosis (refer to infection control policy)
- A named contact / contact number within the hospital
- The time at which the child may be collected and the route that will be used (this will be different according to the age/size of the child)
- A named contact within Demelza / Chestnut Tree House
- The hospice address / telephone number

If the deceased child is to be transferred to their home environment the transfer should be arranged in liaison with the funeral director to ensure the newly bereaved family are appropriately supported and equipped to accommodate the child. This must not be undertaken without the support of our local Children's Hospice Teams.

Deceased babies, children and young people that are under palliative or end of life care can leave the hospital without being admitted to the mortuary. Clear traceable documentation is a necessity. This includes the patients details, which coroners officer has confirmed there will be no coronial involvement, where the child is being taken to (this can be different from the parents usual address), who is giving permission for their child to leave – a name and signature of the family member (usually mum), which staff member is organising and facilitating the transfer (name and signature) this is usually a site manager or senior member of staff who can be assured all legal aspects have been completed, which documents are complete, and the date and time of collection.

The mortuary services are available to help facilitate correct documentation is completed and that correct procedures are being adhered to when arranging transport for collection of the child.

It is also essential to ensure the parents understand what to do if they change their mind and want their child collected from home once they have arrived. The Trust is unable to re-admit anyone who has been collected.

6.19. Infection Control Considerations

Under the Health and Safety at Work Act it is a statutory duty to make staff aware if a body presents a positive or possible infection hazard. It is expected that a member of the treating clinical team will advise relatives of the risks of infection associated with physical contact with the deceased, where a clear potential risk has been identified e.g. Tuberculosis, Hepatitis, and HIV. This needs to be clearly documented in the patient’s notes and mortuary identification card.
Deceased children may need to be placed in a body bag because of a positive or possible infection hazard.

Children/babies dying from the following common infections, whether proven or suspected, must be placed in a body bag with the nature of the infection clearly marked on the mortuary card.

A body bag should be used for the following:

- Acute gastro-enteritis/dysentery
- Meningitis
- Hepatitis (any)
- Prion disease -e.g. CJD
- Group A Streptococcal infections - e.g. necrotising fasciitis, scarlet fever
- Septicaemia
- HIV
- Scabies (untreated)
- Tuberculosis
- Any patient specifically identified by the infection control team
- Any patient in whom there is continued bleeding or production of excessive fluid.

If a body bag is being used, the body should be dressed only and not wrapped in a sheet before placing inside the bag. If excessive leakage is present, the body bag may be lined with absorbent pads.

A **verification/notification of death** form must be completed and attached to the front of the medical notes. Ensure that the name of the Doctor confirming death has been recorded in the space provided.

Medical notes must be fully completed. All notes should accompany the child/baby to the mortuary.

Contact the porters to transfer the child to the mortuary informing them of the age of the child so that they can bring the most appropriate trolley. All children and babies must be transported to the mortuary this way and under no circumstances should they be carried or transferred in a pram or moses basket.

The child/baby should be transferred to the mortuary within a reasonable time, pathology suggests this is between 4 and 6 hours after death.

6.20. Property of the Deceased Child and their Family following a death in Hospital

Staff must be aware of the Trust Policy and Procedures for the management of patient cash and valuables.

If the family take home all property pertaining to the child/baby this must be documented in the child/babies' notes. Any property not removed must be placed in a bag clearly labelled and a check list completed and taken to the bereavement office the next working day. Again, this must be documented clearly in the child/babies' notes.

6.21. Role of the Bereavement Officer

It is the role of the Bereavement Officers to deal with the practical aspects of the death of a child.

There is a quiet room where the Bereavement Officer may talk privately and confidentially about the next steps.

The officer will:

- Ensure the medical certificate is completed
- Explain the forms and process that release the deceased child for cremation
- Make arrangements with the mortuary, & also the Coroner where necessary, for viewing the deceased child
- Give information about local undertakers
- Advise about registering the death
- Organise the proper return of deceased patients' property in accordance with the Trust's Standing Financial Instructions
- Give all relatives Social Security Booklet D49 *'What to do after a death in England and Wales'*
- With the exception of weekends and Bank Holidays seek to make the Cremation Certificate available to the funeral director the next working day.

7. Evidence Base/References

Together for Short Lives is a very active organisation whose work encompasses Palliative and End of Life care for Children and their families, a variety of resources can be found at http://www.togetherforshortlives.org.uk/professionals/resources

Hospice Services:-	Demelza House, Rook Lane, Sittingbourne, Kent ME9 8DZ	01795 845200 Demelza Community Team 01323 446461 **http://www.demelza.org.uk/**
	Chestnut Tree House Children's hospice Dover Lane Arundel West Sussex BN18 9PX	**01903 871800**
	Chestnut Tree House Community Team	01903 871802 http://www.chestnut-tree-house.org.uk/
	Conquest Hospital CCN Team	esht.childrenscommunitynursing-conq@nhs.net

	Eastbourne District General Hospital CCN Team	esht.childrenscommunitynursing-edgh@nhs.net
Charity Support:-	Below is a selection of charities, both national and local which may be able to offer assistance. This list is not exhaustive.	
Dragonflies FSN Robsack Centre Bodiam Drive, St. Leonards on Sea, TN38 9TW Tel: 01424 855222 ext. 211 email: **lbrown@fsncharity.co.uk**	Child Bereavement Trust http://www.childbereavement.org.uk/	Children with Cancer Fund (local charity) http://www.childrenwithcancerfund.co.uk/
Winston's Wish	For Book, Memory Boxes etc	http://www.winstonswish.org.uk/

8. Competencies and Training

- Staff to be aware of this policy.
- Staff caring for these families will have had Infusion Device Training.
- Staff caring for these families will have undertaken IV Drug

9. Monitoring Compliance with the Document

Monitoring Table

Element to be Monitored	Lead	Tool for Monitoring	Frequency	Responsible Individual/Group/ Committee for review of results/report	Responsible individual/ group/ committee for acting on recommendations/action plan	Responsible individual/group/ committee for ensuring action plan/lessons learnt are Implemented
Compliance with legal obligations around the notification of the death to the coroner or was an unexpected death	Matron	Audit	Annual	Hon/Named Nurse for Safeguarding Children (Acute] Women's and Children's Management Team	Hon/Named Nurse for Safeguarding Children (Acute] Women's and Children's Management Team	Hon/Named Nurse for Safeguarding Children (Acute) Women's and Children's Management Team
Clinical Incidents	Matrons	[redacted] incidents reported	Bi monthly at unit risk meetings	Hon/Named Nurse for Safeguarding Children (Acute] Women's and Children's Management Team	Hon/Named Nurse for Safeguarding Children (Acute] Women's and Children's Management Team	Hon/Named Nurse for Safeguarding Children (Acute] Women's and Children's Management Team

Appendix A: **PLEASE HAND THIS FORM TO THE PORTERS**
Risk Assessment Information for Mortuary Staff
COMPLETE ALL SECTIONS

NHS
East Sussex Healthcare
NHS Trust

Please affix PAS label

WARD

Consultant:

Date and time of death:

*Is there an **implanted medical device** e.g.; a pacemaker? **Yes [ ]** or No [**]**

*Is the patient **suspected** or **known** to have any risk of infection? **Yes [ ]** or **No [ ]**

If yes, the Mortuary Staff will call and ask for more information.

*If there is a suspected or known risk of infection please write **Yes** next to all routes of transmission:

Airborne/Inhalation		Faecal/Oral	
Needle Stick/ Blood borne		Contact	

*A body bag is to be used if YES is indicated for any potential infection risk.

*A body bag is to be used if the patient is likely to leak or has some form of infestation.

*Please list all personal belongings including clothing that are **accompanying the patient** to the

Mortuary **or** state that there are **none**.

Printed Name: **Date and time:**

Registered Nurse Signature:

Appendix B, Equality Impact assessment Form

1. Cover Sheet

Strategy, policy or service name	**Policy for Palliative and End of Life Care for Babies, Children and Young People**
Date of completion	October 2023
Name of the person(s) completing this form	[redacted], East Sussex Well Child Nurse [redacted], Clinical Services Manager, Paediatrics. Review team Dr Stephanie Gill, Consultant Paediatrician, [redacted] Head of Nursing,
Brief description of the aims of the Strategy/ Policy/ Service	This document outlines the planning and management of end of life (EOLC) and palliative care for infants, children and young people (0-17 years) with life-limiting conditions who are receiving care through ESHT. Decisions about this care should be made with the children, young people and their families. Guidance is based on NICE guidance 61: End of Life Care for infants, children and young people with life-limiting conditions: planning and management
Which Department owns the strategy/ policy/ function	Women and Children's
Version number	V2
Pre Equality analysis considerations	
Who will be affected by this work? **E.g. staff, patients, service users, partner organisations etc.**	**Patients and families, staff**
Review date	November 2025
If negative impacts have been identified that you need support mitigating please escalate to the appropriate leader in your directorate and contact the EDHR team for further discussion.	To whom has this been escalated? Name: Date:
Have you sent the final copy to the EDHR Team?	

2. EIA Analysis

<table>
<tr><td></td><td>☺ 😐 ☹</td><td>Evidence:</td></tr>
<tr><td>Will the proposal impact the safety of patients’, carers’ visitors and/or staff?

<i>Safe:</i> <i>Protected from abuse and avoidable harm.</i></td><td>Choose:
Positive
[✓ Neutral]
Negative</td><td></td></tr>
<tr><td><i>Equality Consideration</i>
<i>Highlight the protected characteristic impact or social economic impact (e.g. homelessness, poverty, income or education)</i></td><td>N/A</td><td>
<table>
<tr><td>Race</td><td>Gender</td><td>Sexual orientation</td><td>Age</td><td>Disability & carers</td></tr>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
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<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
</table>
</td></tr>
<tr><td>Is the proposal of change effective?

Effective: Peoples care, treatment and support achieves good outcomes, That staff are enabled to work in an inclusive environment. That the changes are made on the best available evidence for all involved with due regards across all 9 protected Characteristics</td><td>Choose:
[✓ Positive]
Neutral
Negative</td><td>For the EOL policy the authors have positively considered religious and cultural beliefs for the end-of-life care process.</td></tr>
</table>

<table>
<tr><td><i>Equality Consideration</i>
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<tr><td>What impact will this have on people receiving a positive experience of care?</td><td>Choose:
Positive
Neutral
Negativel</td><td></td></tr>
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<tr><td>Does the proposal impact on the responsiveness to people's needs?</td><td>Choose:
Positive
Neutral
Negative</td><td>The policy takes into consideration the needs of the patient and their family during the end of life process.</td></tr>
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<tr><td>What considerations have been put in place to consider the organisations approach on improving equality and diversity in the workforce and leadership?</td><td>Choose:
Positive
Neutral
Negative</td><td></td></tr>
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</tr>
<tr>
<td colspan="3">Access
Could the proposal impact positively or negatively on any of the following:</td>
</tr>
<tr>
<td>• Patient Choice</td>
<td>Choose:
Positive
[✓ Neutral]
Negative</td>
<td>N/A</td>
</tr>
<tr>
<td>• Access</td>
<td>Choose:
Positive
[✓ Neutral]
Negative</td>
<td>N/A</td>
</tr>
<tr>
<td>• Integration</td>
<td>Choose:
Positive
[✓ Neutral]
Negative</td>
<td>N/A</td>
</tr>
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</table>
</td>
</tr>
<tr>
<td>Engagement and Involvement
How have you made sure that the views of stakeholders, including people likely to face exclusion have been influential in the development of the strategy / policy / service:</td>
<td>Choose:
Positive
[✓ Neutral]
Negative</td>
<td>Approved via MDT process – no exclusion</td>
</tr>
</table>

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<tr><td>Duty of Equality
Use the space below to provide more detail where you have identified how your proposal of change will impact.</td><td>Choose:
Positive
Neutral
Negative</td><td>this Policy is for all patients that meet the criteria as outlined in the Introduction.</td></tr>
<tr><td>Characteristic</td><td>Rating
☺ ☹ 😐</td><td>Description</td></tr>
<tr><td>Race</td><td>Choose:
Positive
Neutral
Negative</td><td>This Policy is for all patients who meet the criteria as outlined in the Introduction</td></tr>
<tr><td>Age</td><td>Choose:
Positive
Neutral
Negative</td><td>This policy is regarding babies, children and young people under an end of life care pathway</td></tr>
<tr><td>Disability and Carers</td><td>Choose:
Positive
Neutral
Negative</td><td>This Policy is for all patients who meet the criteria as outlined in the Introduction</td></tr>
<tr><td>Religion or belief</td><td>Choose:
Positive
Neutral
Negative</td><td>For the EOL policy the authors have positively considered religious and cultural beliefs for the end of life care process.</td></tr>
<tr><td>Sex</td><td>Choose:
Positive
Neutral
Negative</td><td>This Policy is for all patients who meet the criteria as outlined in the Introduction</td></tr>
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Sexual orientation	Choose: Positive [✓ Neutral] Negative	This Policy is for all patients who meet the criteria as outlined in the Introduction
Gender re-assignment	Choose: Positive [✓ Neutral] Negative	This Policy is for all patients who meet the criteria as outlined in the Introduction
Pregnancy and maternity	Choose: Positive [✓ Neutral] Negative	This Policy is for all patients who meet the criteria as outlined in the Introduction
Marriage and civil partnership	Choose: Positive [✓ Neutral] Negative	N/A

Human Rights

Please look at the table below to consider if your proposal of change may potentially conflict with the Human Right Act 1998

A2	Right to life	**N**
A3	Prohibition of torture, inhuman or degrading treatment	**N**
A4	Prohibition of slavery and forced labour	**N**
A5	Right to liberty and security	**N**
A6 &7	Rights to a fair trial; and no punishment without law	**N**
A8	Right to respect for private and family life, home and correspondence	**N**
A9	Freedom of thought, conscience and religion	**N**
A10	Freedom of expression	**N**
A11	Freedom of assembly and association	**N**
A12	Right to marry and found a family	**N**
Protocols		
P1.A1	Protection of property	**N**
P1.A2	Right to education	**N**
P1.A3	Right to free elections	**N**