

End of life care strategy

2025 - 2030





Foreword



Gail Byrne, chief nursing officer

We are proud to launch this strategy for end of life care at University Hospital Southampton. Supporting and caring for our patients at the end of their lives is very important to all our staff at UHS. We are committed to providing excellent care for patients and those important to them. We recognise that the time during the last months, weeks and days of life is precious and that we have one opportunity to get it right.

We will support our patients to live as comfortably and as well as is possible during this time. We will provide opportunities to talk openly with them about their illness, listen to what is important to them, and provide treatment and care in accordance with their wishes wherever possible.

We firmly believe that all our staff have a vital role in providing excellent end of life care. We will educate, support and equip our staff to be confident in delivering end of life care that is effective, compassionate, sensitive and individualised.

In accordance with our Trust values, this strategy sets out our commitments to our patients and those important to them. Our values are patients first, working together and always improving. Aligned with this, we want every patient and family experience to be as good as is possible at the end of life. Our clinical teams will work together and collaborate with other health and social care partners to promote the delivery of excellent patient care. We will continue to improve, to promote the delivery of consistent and compassionate high-quality end of life care in every clinical area of the Trust.

This document sets out some background information about UHS as an organisation and defines end of life care. We describe our provision for end of life care, including the specialist support services available. We then detail our pledges to our patients and their families as to how we will fulfil the objectives set out in this strategy. We will meet these objectives by ensuring staff readiness to provide excellent end of life care and through continual improvement informed by our patient outcomes data including feedback from patients and their families, ensuring their voice is heard in our care.



PATIENTS FIRST



WORKING TOGETHER



ALWAYS IMPROVING



Our hospital

University Hospital Southampton is a leading teaching hospital, providing care to the local population and tertiary services to a catchment of four million people. Through our long-standing values of patients first, working together and always improving, we are proud of the care we provide and the outcomes we achieve.

Care of patients in their last year of life, known as end of life care, is a core priority for UHS. We recognise that there is one chance to get this right for patients and their loved ones. We aspire to deliver excellent compassionate end of life care that enhances patient quality of life and involves those important to the patient.

End of life care at UHS was last assessed by the Care Quality Commission (CQC) in 2017 and rated as GOOD. UHS participates in the National Audit of Care at the End of Life (NACEL). In 2022 the Trust exceeded the national benchmarking scores in a number of aspects, including involving patients in decisions about their care, individualised plan of care, governance and workforce, and specialist palliative care.

We will continue to make high-quality end of life care core business for all staff at the Trust. Every staff member has a responsibility to support patients and those important to them as they approach their last months, weeks and days of life.

This strategy document sets out how the Trust will ensure the provision of high-quality end of life care between 2025 and 2030. The Trust end of life care programme board, led by the chief nursing officer, will ensure implementation and monitoring of this strategy through the establishment of a work programme to be implemented by the end of life care operational group.





Our hospital

End of life care

End of life care includes the care of patients of any age whose death is expected within a few hours or days (imminent) and patients who are thought to be in their last year of life.



This includes patients who are diagnosed with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions which may lead to death 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
- persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to death
- extreme prematurity at birth where the prospects for survival are known to be very poor





End of life care

End of life care at UHS

The delivery of good end of life care relies on the recognition that a patient is approaching the end of life. Clinical teams at UHS are encouraged to do this by asking themselves the 'surprise question': "Would you be surprised if the patient died within the next twelve months?"

This recognition prompts communication to ensure that the patient and those important to them have the information and understanding they require to create with their clinical team a plan of care that:

- respects individual choices and priorities regarding treatment and care
- offers appropriate treatments that may be beneficial to the patient
- offers the opportunity to plan ahead for predictable changes in the patient's condition due to progression or complications from their underlying life-limiting illness

For patients who are recognised to be in their last days or hours of life, staff work with patients and families to create an individualised plan of care. This is based on a holistic assessment of the patient's needs including physical care and symptoms, food and drink, and family, social, cultural and spiritual aspects. This plan of care is regularly reviewed to ensure that any change in needs is recognised and acted-upon.





End of life care

The Trust has a supportive and palliative care team who provide advice, support and expertise in the management of adult patients with more complex symptom control, psychological and social needs.

In-person patient reviews are provided seven days a week, with consultant specialist advice available 24 hours a day, 7 days a week, by telephone. The team have close links with other community and hospital-based palliative care services within the area. The team's input is not restricted to patients in the last year of life, recognising that patients with potentially life-limiting conditions, or those undergoing certain active treatments with potential to cure, may face a significant symptom burden that we can help to address and alleviate.



Supportive and palliative care team



Specialist paediatric palliative care team

The Trust has a specialist paediatric palliative care team who provide inpatient palliative care support in an advisory capacity across the working week. The team collaborate closely with hospitals, community teams, and hospices across the region. Similar to the adult team, their input is not limited to end of life care, but from the point of diagnosis and recognition of a life-limiting or life-threatening condition.

The Trust provides specialist supportive and palliative care support for teenagers and young adults who have cancer, through dedicated nursing and medical staff and a specialist ward.



End of life care

Spiritual care team

The Trust's spiritual care service is available every day to support patients and families. You do not have to have a religious belief to use the service.



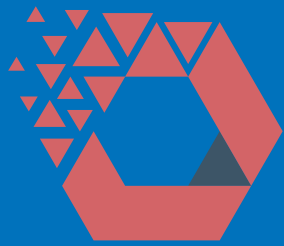
Bereavement and family support team

The Trust has a bereavement and family support team who can provide bespoke advice and support to patients and those important to them following an end of life diagnosis.

The team can provide:

- practical and emotional support from the point of diagnosis all the way through to the patient's final days
- a safe space to talk
- additional support by signposting to services in the local community

The team are based in Trust Headquarters (Old Nurses' Home), opposite the North Wing of Southampton General Hospital and are available Monday to Friday, 8am to 4pm (excluding bank holidays).



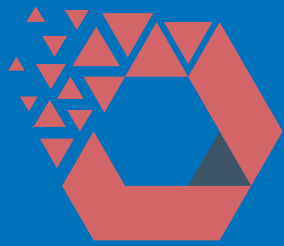
Patients first

At the end of life, we want every patient and family experience to be as good as possible.



We will do this by:

- ensuring each patient knows which consultant and nurse are responsible for their care and treatment.
- actively creating opportunities to regularly communicate with patients and families in a sensitive way, recognising they may choose the level of information that is right for them at that time.
- having staff skilled in communication, including taking cues from patients and families to promote conversations about what matters to them.
- having staff confident in the skills required for the delivery of compassionate end of life care, through experience, training and education.
- committing to shared decision-making, to support better conversations with patients, enabling them to make decisions on their treatment and care, based on their values and preferences.



Patients first

- offering patients advance care planning discussions, which are an opportunity to plan ahead for predictable changes in their condition.
- agreeing treatment escalation plans with patients to support appropriate care in accordance with their wishes.
- supporting the care of patients who are actively dying with an individualised plan of care.
- involving family members and those important to the patient in planning their care.
- supporting those people who are important to the dying person through assessment of needs, practical advice and emotional, spiritual, cultural and bereavement support.
- maintaining 24/7 access to specialist palliative care advice for adult patients to support clinical teams in ensuring patients have good symptom control and psychosocial support.
- supporting the specialist paediatric palliative care team to continue to develop service provision, with the ambition to provide a seven day a week service.
- developing digital solutions to support care planning and delivery for patients in the last year of life.
- working with patients and families to help make the process of discharge (leaving hospital) easier.
- learning from patient outcomes, and patient, carer and staff feedback.
- prioritising the creation of better environments for care.





Working together

Our clinical teams will work together and collaborate with other health and social care partners to promote the delivery of excellent patient care.



We will do this by:

- harnessing the ideas, energy and focus of all our staff, people at every level and in every job, to continue to provide compassionate end of life care at a consistently high standard.
- nurturing the UHS palliative and end of life care link nurse community of practice through our education and support programme.
- working with our community partners to develop seamless services, allowing care to be delivered to best meet the patients' needs, irrespective of organisations or boundaries and whenever possible in the location of our patients' choosing.
- engaging with local and regional end of life care strategy meetings to actively plan the future provision of services and to forge integrated working with our commissioning partners, other acute trusts, community, and social care providers as well as the voluntary sector for the benefit of our patients.



Working together

- continuing to work with the Hampshire and Isle of Wight Integrated Care Board (ICB) to improve services and infrastructure for end of life care and to ensure the strategic priorities of the ICB relevant to acute hospital care are reflected in our action plan.
- recognising the increasing need for support for young patients who require ongoing specialist medical and nursing care beyond 18 years of age. (In the hospital setting, we are developing improved models of collaborative working to ensure the complex needs in this group of patients are met. More widely, we are pivotal in the development of the Wessex Children and Young Adult's Palliative Care Network and engaged in the South East Palliative and End of Life Care Network.)
- supporting the delivery of end of life care education for our higher education partner organisations, including University of Southampton, Solent University and Bournemouth University.
- actively seeking opportunities to work with local, national and international research partners to further the knowledge and understanding of care at the end of life.
- participating in national awareness campaigns such as Dying Matters Week to support our community to start talking about future wishes and planning ahead.





Always improving

We will continually improve, to promote the delivery of consistent and compassionate high quality end of life care in every clinical area of our trust.



We will do this by:

- investing in staff development through role-specific education and training delivered by education teams, clinical teams and specialist services and through the electronic virtual learning environment.
- focussing on communication skills development to ensure conversations with patients and families are centred on what is important to them, to help them to make choices about their care, treatment and future.
- ensuring staff are trained in, and comply with, the legal requirements of the Mental Capacity Act 2005. (Decisions made for patients lacking mental capacity must take into account any advance care planning, advance decisions to refuse treatment, or lasting power of attorney for health and welfare.)
- supporting career opportunities for staff wishing to develop their expertise or pursue roles in end of life and palliative care, including link nurse roles, staff shadowing, and secondment opportunities.



Always improving

- utilising the latest available evidence, research and national end of life care frameworks to inform our strategic priorities and our day-to-day delivery of care.
- working with our digital team to develop our outcome measures to ensure that those aspects of care that matter most to patients are assessed. (We will use this information to inform service development and to bring clinical innovations to improve end of life care.)
- working with our digital team to improve documentation and accessibility of patient information relevant to the last year of life, to enhance care and communication with primary and onward care providers.
- developing our research activities and working with research partners including the University of Southampton, and collaborating with other organisations in multi-centre projects with the aim of increasing the number of trials accessible to patients in the last year of life.





Meeting our strategic objectives

Outcomes for patients

We will evaluate the end of life care provided by the Trust, to ensure it meets the needs of patients and those important to them. In response, plans of action will be developed and acted upon, to ensure care is of high quality and addresses aspects such as information needs, patient and family involvement, personalised care, patient comfort, and cultural and spiritual needs.

Our patient outcomes data comes from:

- Care Quality Commission (CQC) inspections and reports
- National Audit of Care at the End of Life (NACEL)
- surveys of bereaved relatives, through the UHS bereavement survey or NACEL
- supportive and palliative care team carer experience survey
- thematic analysis of all feedback from patients and families, whether from compliments, suggestions or complaints and clinical incidents
- learning from patient deaths including those of people with learning disabilities and autism



Staff readiness

The Trust recognises that all staff have a responsibility to care for patients and those important to them as they approach their last months, weeks and days of life. The Trust will support the delivery of staff education and training to enable the provision of the best possible end of life care.

As part of the end of life care education, the Trust will deliver essential education to all relevant identified staff groups including:

- training in clear, sensitive and compassionate communication
- support for families and those important to the patient
- shared-decision-making and advance care planning
- treatment escalation plans (TEP)
- recognition of patients who may be approaching the end of their life
- individualised end of life care and management of common symptoms





Meeting our strategic objectives

There is a range of services at the Trust to support staff wellbeing, including:

- the staff well-being service, local well-being practitioners and safe-space practitioners
- the chaplaincy team
- local team debriefing
- TRIM (support after traumatic and significantly distressing situations)
- Staffline (psychological support from trained psychologists, available daily)
- employee assistance programme, including independent psychology advice
- palliative and end of life care link nurses
- occupational health department





National context

National frameworks and reports

Improving end of life care is a national priority. The NHS End of Life Care Strategy (2008) sets out the need to improve end of life care in acute hospitals. The UHS end of life care strategy is built upon important national policy initiatives including the national strategy, NICE guidance and recommendations from the Neuberger Report:

- *One chance to get it right (2014)* is an approach to caring for people in the last few days and hours of life, that focuses on the needs and wishes of the dying person and those closest to them, in both the planning and delivery of care wherever that may be. It sets out the five priorities for care of the dying person. These are the key points of care for those in the last days and hours of life.
- *The Ambitions for Palliative and End of Life Care (2015)* was developed by a partnership of national organisations across the statutory and voluntary sectors. It provides a framework to develop a culture of good end of life planning for all at a local level, based on quality of care and on the wishes of the individual, regardless of their age. This was reviewed and refreshed in the 2021 Ambitions for Palliative and End of Life Care: National Framework for Local Action (2021-2026).
- *The Neuberger Report, More Care Less Pathway (2013)* was commissioned by the government amid concerns about the care of dying people in hospitals. This made key recommendations including embedding individualised end of life care plans.
- *The Together for Short Lives Standards framework for children's palliative care (2015)* sets out the key standards covering neonatal care for babies with palliative care needs, children with life-limiting and life-threatening conditions, transition to adult services, and care in the terminal phase.
- *The Health and Care Act (2022) clause 16 (palliative care)* directly led to the palliative and end of life care statutory guidance for integrated care boards (ICBs) (2022) which sets out that ICBs have a legal responsibility to commission health services that meet their population needs including palliative care.



NICE guidelines

National Institute for Clinical Excellence (NICE Guidance)

- 'NICE Quality Standard 13 (2021) - End of life care for adults' outlines the need to consistently identify patients who are likely to be approaching the end of their life, and the provision of opportunities to discuss advance care planning, the co-ordination of care within and across services, 24/7 access to patient support, and support for carers.
- 'NICE Guidance 142 (2019) - End of life care for adults: service delivery' covers organising and delivering care services which provide support in the final weeks and months of life (or for some conditions, years). It includes how we recognise this patient group, holistic needs assessment, advance care planning, treatment decisions, information provision, and patient information sharing between organisations.
- 'NICE Guidance 61 (2019) - End of life care for infants, children and young people with life-limiting conditions: planning and management' covers the planning and management of end of life and palliative care for infants, children and young people (aged 0 to 17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care and improve the support that is available to them throughout their lives.
- 'NICE Quality Standard 160 (2017) - End of life care for infants, children and young people' specifies six quality measures to improve the care of children and young people who may be at risk of dying or approaching death, and their parents and families. These measures include advance care planning, coordination of care, and provision and access to specialist services in hospital and at home as well as emotional and psychological support for patients and families.
- 'NICE Quality Standard 144 (2017) - Care of dying adults in the last days of life' sets out quality measures in areas for improvement: assessing signs and symptoms when a person may be dying, patient and family involvement in individualised care planning, appropriate anticipatory end of life care prescribing and daily assessment of hydration status, and a discussion about the risks and benefits of hydration options.
- 'NICE Guidance 31 (2015) - Care of dying adults in the last days of life' aims to improve end of life care for adults in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms in the last days of life.

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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