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NHS
Isle of Wight
NHS Trust

End of Life Care Strategy

2023-2026

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Forward

The Isle of Wight NHS Trust is committed to providing the best possible end of life care that meets both the needs and wishes of the population. The Trust is an integrated Trust that covers acute, ambulance, community and mental health services which means that our patients require end of life care in varying clinical settings, while being cared for by various teams. This requires the Trust to have systems and process in place in all four parts of the organisation to ensure we can meet the needs of dying patients and their families at any time.

In order to achieve this, the Trust has undertaken an extensive piece of work to engage with our community to understand what matters most to them at the end of their life. The responses covered a wide range of topics which have been combined into five key themes to focus our refreshed end of life care strategy and our ongoing improvement plan in this area of care. In addition to this we have included your other suggestions (please see Appendix 3) which will be taken forward as part of this strategy as the opportunities arise.

Within this Strategy we are proud to present to you our findings from the community conversation and would like to take this opportunity to thank each and every person who took the time to talk to us and express their views. It is only by doing this that we can truly ensure that we have listened to the voice of the island in preparing our services for the future.

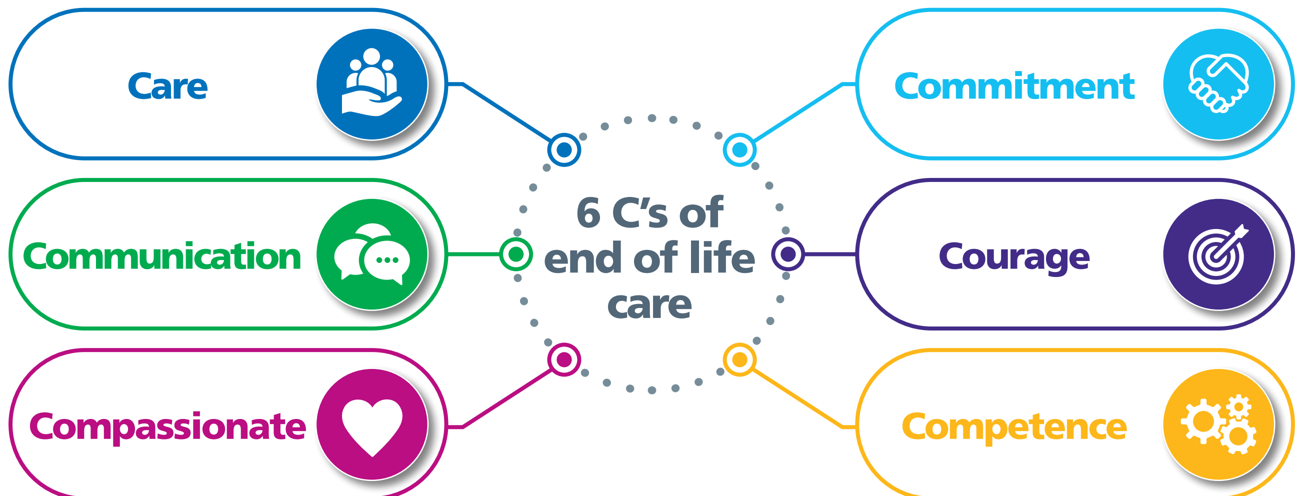
Juliet Pearce,
Director of Nursing,
Midwifery and AHPs

Shane Moody,
Clinical Director/Consultant Nurse
for End of Life and Palliative Care

Our Trust Vision for End-of-Life Care is:

To identify patients who are at risk of dying and ensure that future care planning occurs with them and other individuals that have been identified as important to the patient; to ensure they experience high quality End of Life Care. In order to do this we will create a prepared and able workforce that is ready to care for our patients and the individuals that are important to them. The principles underpinning this vision include our commitment to quality that is the heart of everything we do. Our staff are committed to maintaining and enhancing their knowledge and skills, as well as to their codes of professional and organisational conduct. All end-of-life care will have the underpinning 6 Cs at its core (DH 2013 Compassion in Practice). The care of the dying person must be personalised, reflect individual needs and preferences and have attention paid to assessing and addressing physical, emotional, psychological, social and spiritual needs of that individual, as well as that of his/her family and carers.

The 6 Cs of end of life care



1 Care

The care of the dying person must be personalised, reflect individual needs and preferences and have attention paid to assessing and addressing physical, emotional, psychological, social and spiritual needs of that individual, as well as that of his/her family and carers.

2 Communication

Regular, pro-active and responsive communication takes place between professionals, the person who is approaching the last days of their life, families and carers.

3 Compassionate

A compassionate approach supports the patient's wishes, respects the uniqueness of the individual, supporting the patient and family with kindness and empathy.

4 Commitment

A commitment to delivering high quality end-of-life care to patients and their families in a non-judgemental way. A commitment to service improvement via response to feedback from staff, patients and families.

5 Courage

Patient at the centre of care with staff taking the time to act as advocates to ensure that patients' needs and wishes are supported. Staff to consider new ways of working to deliver personalised care to patients and families.

6 Competence

All aspects of assessment, care and treatment must be carried out by staff who are competent to do so and who remain up to date in their knowledge and skills in End of Life Care.

Introduction

In 2016 the Care Quality Commission, our governing body, rated end of life care services here at the Isle of Wight NHS Trust as "inadequate". We have since commenced a programme of work that improved our rating to "good" at the 2019 inspection, and we are keen to provide an "outstanding" rated service going forwards. In order to achieve this, we needed to fully understand what is important to our community.

This was achieved in a number of ways:

- An online survey as part of the wider community conversation which yielded 276 responses to the end of life care question
- Feedback from bereaved families from the 2021 National Audit of Care at the End of Life (NACEL)
- Feedback from patients and families via the Trusts internal mechanism for gaining feedback
- Face to face meetings with the public at local support groups, church halls/meeting rooms, religious groups etc and a touring van where people could just turn up and talk over a cup of tea. (A full list of groups we have visited is available in Appendix One of this document). We have met with 35 different groups which involved talking to 450 people

The latter approach is a new way of working which has certainly helped us get to the bottom of what is important to people in a way that a survey never could. We were able to give time to listen which enabled us to gain a deeper understanding of what is important to our community. This, combined with the survey results, has led to the themes within this strategy that we will focus on to improve our services.

In order to achieve the needs of our local community when they need to access Trust services for end of life care we have also aligned the findings from the community conversations with the six national Ambitions for Palliative and End of Life Care. This document includes reference to how we will achieve these ambitions by meeting the needs of our community.

Full details of the ambitions can be seen as Appendix Two.

Themes

1 Communication

You told us:

- You want to have open and honest conversations and be spoken to in plain, simple language with no medical jargon.
- If a loved one is dying, we need to be honest and tell you. We shouldn't just say that they're really poorly.
- You want to fully understand what is meant by palliative and end of life care.
- You want staff to be sensitive to how you and your loved ones are feeling and bear this in mind when we talk to you.
- You want people to call you back when they say they will and have up to date information at hand.
- You want easily accessible information on writing wills, Power of Attorney, planning a funeral, etc.

How we will achieve this:

- We will provide education for our clinical staff to reiterate the need for plain language and how to be honest in a sensitive way so that people know when their loved ones are actively dying.
- We will provide communication training for our staff.
- We produce information leaflets that will be easily accessible on all wards that explain the difference between palliative and end of life care, and where to access information on wills, power of attorney, planning a funeral, etc.
- We will ensure that our clinical staff are aware of the importance of answering and returning phone calls in a timely manner.

How this satisfies the national Ambitions for End of Life Care:

This theme aligns specifically with Ambition One – Each person is seen as an individual.

We pledge that all of your personal needs and wishes will be explored through honest conversations about dying, death and bereavement at a time when you feel ready to have them; this will include you and the people that are important to you. These conversations will exclude medical jargon and we will be honest when death is near, and explain when you transition from palliative to end of life care.

Our staff will deliver care that is person centred and will ensure that choices about your care are recorded, supporting you to retain as much control as you wish to have. We will provide you and those important to you with information, advice and support to enable you to make timely decisions about your care, and will have this information available when we speak to you.

2 Choices

You told us:

- You want to be able to choose where you die and to choose who is with you in your final hours.
- You want us to make sure you're not in pain and that your death is peaceful and comfortable.
- You want to be respected and shown kindness and dignity.
- You want to be involved and engaged in ethical discussions around topics like assisted dying.
- You still want to look your best for your loved ones and be in comfortable surroundings, with your own things around you.
- You want your loved ones with you.
- Spiritual and religious needs are to be respected and supported.

How we will achieve this:

- We will encourage the use of Advanced Care Plans to ensure that your wishes are clearly known and recorded. In doing this we will ensure that we are respecting your wishes particularly on where you want to die and who is with you.
- We will ensure that your end of life care drugs are prescribed in a timely manner and that you have access to be given these when needed regardless of where you care location is.
- We will engage with our community with ethical debates around topics that are important to you.
- If you chose to die in hospital, whenever possible we will transfer you to Wellow Unit, our bespoke end of life care unit, that is equipped with single side rooms that have been made to look more like home than a hospital ward. This will ensure you have comfortable surroundings and can have the peace and tranquillity you desire whilst being surrounded with your own things and loved ones.

How this satisfies the national Ambitions for End of Life Care:

This theme aligns specifically with Ambition three – Maximising comfort and wellbeing.

We pledge that we will make sure that staff are aware of your personal choices in terms of comfort and pain control and adhere to these whenever possible. We will maintain your dignity at all times and use the compassion symbol (a blue ribbon) when appropriate to ensure you are in a calm environment when death is imminent.

We will regularly review your needs and if you change your mind about how you are cared for, we will adapt wherever possible. If you have any last requests, we will try our best to accommodate them.

3 Supported

You told us:

- You want to have people around you and not die alone.
- You want your family/loved ones supported during and after death, particularly with what to do next and what help is available to them.
- You want to have access to religious or spiritual support when you want it.
- You want your views and wishes respected and have to freedom of choice.
- You want to be able to wear your own clothes, listen to your preferred music, be kept clean/shaved.
- You want to be looked after by caring, kind staff.
- You want your care to be person-centred.

How we will achieve this:

- We will ensure that your loved ones are able to stay with you when you die.
- We will continue to provide support for your loved ones during and after death, and will refer on to local bereavement services in partner organisations for ongoing support as needed.
- We will continue to undertake follow up bereavement calls to families that are bereaved in the acute hospital.
- We will work with ward staff to ensure that your religious preferences are noted on admission to hospital so that we know who to call to support you as you die, should you or your loved ones request pastoral support from them.
- We will provide development opportunities and training to ensure that staff remain kind and caring, and continue to push the boundaries of allowing as much as possible to happen in terms of special requests to ensure you feel supported at the end of your life.
- We will ensure staff are supported to remain resilisant in providing compassionate end of life care via varies forms of clinical supervision, coaching and mentoring.

How this satisfies the national Ambitions for End of Life Care:

This theme aligns specifically with Ambition Two – Each person gets fair access to care and Ambition Six – Each community is prepared to help.

We pledge to ensure that you can expect the same level of care regardless of where you die within our Trust. We will ensure that your religious/spiritual needs are met and that we care for you and your loved ones regardless of who you are, where you live or the circumstances of your life.

We will ensure that our staff treat you and your loved ones with kindness, dignity and respect at all times.

4 Education

You told us:

- You want to be informed of your diagnosis as early as possible so that you can ask questions and understand what is going to happen to you.
- You want to understand what is meant by end of life and what will happen to you as you die; you want us to explain the process to you if you ask us to.
- You want to fully understand the implications of Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) and how to get an Advanced Care Plan completed.
- You want a fully integrated healthcare records system with all relevant staff in the hospital and community being able to access it.
- You want us to deliver end of life care education to professionals and carers, both in the hospital and community settings such as nursing homes; on what changes to look out for when a patient nears end of life, and how to manage them.
- You want guidelines developed for care homes on what to look out for and who to contact in and out of hours.
- Information needs to be accessible to all; we need to consider the audience and format that is being used.

How we will achieve this:

- We will ensure that we communicate effectively and in plain language, and give you the opportunity to ask questions.
- We will produce literature describing the difference between palliative care and end of life care and explain what you can expect from each.
- We will ensure you have access to a patient information leaflet on DNACPR and encourage staff to use this when having a DNACPR conversations.
- We are working with our IT team to roll out SystmOne across the organisation. This is the platform used by GP surgeries for patients' notes and once rolled out fully it will mean all relevant healthcare professionals will be able to access your record.
- Partner organisations are working with nursing home and care homes in supporting them with education and recognising when their residents begin to die.
- We will ensure we have a comprehensive programme of training and development opportunity that relate to end of life care in the Trust to ensure we have a workforce that is competent to care for you and your family at the end of your life.

How this satisfies the national Ambitions for End of Life Care:

This theme aligns specifically with Ambition Five – All staff are prepared to care; Ambition Six – Each community is prepared to help and also Ambition Four – Care is coordinated.

We pledge that we will work with our colleagues, both in and out of hospital, to ensure that we provide the relevant education to staff to enable them to deliver effective, high quality end of life care.

We will look at the information/literature that is available and ensure there are additional resources in place where required.

5 Diversity

You told us:

- You want us to take into account the changing needs of our population in terms of religious beliefs and educate staff according to their individual needs.
- You want us to ensure that staff don't judge our LGBTQ+ community and guarantee that their partners are treated fairly.
- You told us that staff need to fully understand same sex relationships in terms of power of attorney/welfare/finance.
- People with learning disabilities should be allowed to have someone with them of their choosing and be surrounded by their own things. They should be spoken to in plain English so that they understand what is happening and staff should follow their individualised care plans to ensure that pain thresholds are understood, and sensory needs are met.
- Homeless people and drug users are concerned about being judged and potentially being denied pain relief.
- Representatives of the travelling community have explained there is a lack of trust of people in uniform.

How we will achieve this:

- We will respect your cultural and spiritual needs and use appropriate language for the situation.
- We will ensure you have access to individual appropriate religious or spiritual representatives.
- We will ensure our staff are respectful of your wishes to be treated fairly and that your partners are equally recognised if you are a member of our LGBTQ+ community.
- Anyone, regardless of race, colour, creed, beliefs will be allowed to have someone with them when they die.
- Appropriate pain relief will be prescribed.
- We will work with our travelling community to instil trust in our clinical staff that we have their best interests at heart.
- Will ensure Trust staff have access to equality and diversity training.

Accountabilities and responsibilities

Delivery of the strategy will be overseen by the Director of Nursing and the Clinical Director of End of Life Care. The Operational End of Life Care group will report to the Patient Safety Sub-Committee on a quarterly basis which reports to Quality and Performance Committee. The End of Life Care Operational Group will take responsibility for implementation of the Strategy objectives, for setting out the methods of implementation and measuring progress. The clinical Divisions and Care Groups are responsible for embedding the strategy at local level and having a clear action plan on the delivery of End of Life Care in their respective areas – acute, mental health, community and ambulance. The Clinical Director of End of Life Care will ensure the Care Group action plans are aligned with the overarching improvement plan for End of Life Care within the Trust. The clinical divisions are also responsible for delivering the strategic goals at an operational level, with support from the End of Life Care Clinical Director and the Operational Group.

Measuring success and evaluation

Progress towards delivering the strategy objectives will be undertaken by the Trusts operational end of life care group and will report onwards to the Trusts patient experience sub-committee. Going forward future community conversations will be facilitated to gain feedback on the delivery of the commitments made in this strategy to our community.

Authors:

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List of all groups/places visited

- Age Friendly Island
- Age UK Isle of Wight
- Alzheimer café Cowes
- Alzheimer's Café, Sandown
- Applegate Breast cancer support group
- Aspire, Ryde
- Breathe Easy
- Brynhill Grove, Ventnor
- Camper van roadshow
- Community Spirited – community hub
- Front door for dying matters week
- Haylands Farm
- Independent Arts
- Isle of Wight Police
- Jame-e Mosque, Newport
- Knit and Natter, Newport and Freshwater libraries
- Large Community Conversation, Newport
- Living Room community café
- Men in Shed's, Cowes
- Newport Residential Home, Newport
- Open coffee morning, Newport
- Our Place, Freshwater community café
- Out on an Island
- People Matter Isle of Wight
- Ryde House
- Ryde Village supported living complex
- St Marys Church coffee morning, Cowes
- St Pauls Church, Shanklin
- The Moorings Care Home, Cowes
- Totland community café
- Two Saints Housing
- Veterans Event, Ryde
- Ward House Nursing home, Ventnor
- Way Forward
- Wellbeing Café Cowes
- WOW – Women on Wight refuge centre

The Six Ambitions for End of Life Care

1 Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

2 Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

3 Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

4 Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

5 All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

6 Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Your suggestions

- To have access to funeral plans and wills.
- Support rooms- so when someone has received unsettling news, they are taken somewhere for support and given a contact name and number.
- To have Anna Chaplaincy more widely available to the whole community.
- Information packs with will writing, funeral plans, Lasting Power of Attorney details, so people can be more prepared.
- To have access to funeral plans/costs and reassurance that your wishes would be abided by.
- To have more user-friendly information about End-of-Life care and what that means to a person with a learning disability.
- To turn off monitors, especially in ITU, these can be quite distracting- tended to watch the screens rather than concentrating on the person dying.
- Have open and honest conversations about what to expect when someone is End-of-Life and what that may look like- people would like to be prepared.
- To have more access and information about will writing and where to find it.
- To have access to signposting, some family members find that practical help is invaluable.
- To have more information on how/where to find information about wills/funeral plans.
- To have access to The Qur'ãn, either in book form or audio version.
- To know who can support Islamic Wills on The Isle of Wight.
- To let the homeless community have a voice.
- Colour coded stickers on patients end of bed notes to determine their resuscitation status (DNACPR).
- To have a training program made to support the staff around End-of-Life care and what they can expect and how to best support that service user.
- To have "link" nurses in place, so that it is an easy transition between home and hospital, and they could have more understanding individual conditions.

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