Document title: **End of Life Care Strategy**

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Staff involved in Development (job titles):	Dr Sarah Grove Consultant in Palliative Medicine
Document author/owner:	Consultant in Palliative Medicine
Directorate:	Nursing
Department:	Supportive & Palliative Care
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Key points of this document

- 'End of life care' is defined as care in the last year of someone's life, and possibly longer for some conditions.
- 'How we care for the dying is an indicator of how we care for all sick and vulnerable people.' National End of Life Care Strategy 2008
- The purpose of this strategy is to ensure that patients who are cared for by Royal Papworth NHS Foundation trust experience the best possible care in the last year(s) of their life and when they are imminently dying.

Background

'End of Life care' is defined by NHS England as 'care that is provided in the 'last year of life'; although for some conditions, end of life care may be provided for months or years'[1].

We know that death is a fact of life and that many people will die in hospital, either through choice or necessity. According to the Office of National Statistics there were 530,841 deaths registered in England and Wales in 2019, of which about half occurred in hospital [2]. Ischaemic heart disease, chronic respiratory disease, respiratory infection and cancers of the respiratory tract remain in the top 6 causes of all-age mortality in the UK[3].

Here at Royal Papworth Hospital we care for many people who are living with chronic, but life-limiting, cardio-respiratory conditions and who need to have supportive care alongside their disease-modifying treatment. We also care for people for whom there are no further active treatment options and who are dying. It is vital that the outstanding care we deliver here is continued into the last days of their life and beyond, in care after death and in bereavement support for their loved ones.

Living with a life-limiting illness is likely to have an impact on every part of someone's life – their physical condition, their emotional state, their financial position, their ability to care for themselves and their spirituality. Therefore, good end of life care needs to treat the whole person and should involve, when needed, excellent symptom control, psychological, social, financial and spiritual support and timely advance care planning. The purpose of this holistic care is to ensure that everyone has as good a quality of life as possible – that they can live well until they die.

'End of Life care' clearly also incorporates care in the last days of life, when people are imminently dying. We have relatively few expected ward deaths here at Royal Papworth Hospital. Most deaths happen on the Critical Care Area (CCA) when people deteriorate despite maximal intensive support. In 2020, 65% of deaths happened on CCA, 28% on the general wards and 7% elsewhere (e.g. theatre). In the 2020 audit of care in the last days of life, there were only 19 predicted deaths on 8 different wards in the audit period of 6 months. This low death rate is a testament to the high quality of care delivered here at RPH, but also reflects the fact that we are a tertiary referral centre and many patients are repatriated to their local hospital or discharged home when there is no further treatment available here.

It is vital that, here at Royal Papworth Hospital, all staff are willing and able to provide high quality care to those patients who are dying despite our best medical efforts.

Providing excellent end of life care is the responsibility of every staff member here at RPH. However, many patients will also need specialist input. Depending on their needs, they may need to be referred to some or all of:

- Supportive and Palliative care team,
- Psychological medicine services,
- Chaplaincy team,
- Social Work team.

Bereavement support is provided by the Patient Advice and Liaison Team (PALS).

Royal Papworth Hospital Supportive and Palliative Care Team (SPCT), is led by a Consultant in Palliative Medicine and also staffed by a Specialist Trainee in Palliative Medicine, two Band 7 Clinical Nurse Specialists, three Band 6 Clinical Nurse Specialists and an administrative assistant. The team provides 7-day face-to-face CNS support and 24-hour Consultant palliative care on call support. The team is here to provide supportive care alongside disease-modifying treatment to people living with chronic and life-limiting illness as well as to provide care to patients who are imminently dying. The SPCT also provides support to relatives and to staff here at RPH.

Psychological medicine services may also play an important role in end-of-life care when there is concern that a person's mental health is having a significant impact on their condition. This is particularly true for patients who already have an established therapeutic relationship with psychological medicine services e.g., people with Cystic fibrosis or those who have had an organ transplant.

Chaplaincy support is led by a Hospital Chaplain provided by Cambridge University Hospitals NHS Foundation Trust via a Service Level Agreement with support from volunteers. They provide spiritual, religious and pastoral care to anyone who wants this – people of any faiths or of no faith. The Chaplaincy service is also here to provide support to relatives and staff as well as patients.

The Social Work team may have a role to play in end-of life care by providing Safeguarding advice covering adults and children, as well as specialist social work advice and support to vulnerable patients and families.

Care after death is provided by the staff within the specific clinical area and bereavement administration support is provided by the Patient Advice and Liaison Team (PALS). The Trust recognises that bereavement is a very difficult time for families, not only emotionally and spiritually, but also in

knowing what practical steps to take following the death of their loved one. PALS offer help, support and guidance to families and hospital teams during this challenging time.
The PALS team also provide a bereavement follow up service where the next of kin is contacted 6-8 weeks following the death. This reach out is to provide an opportunity for families to reconnect with the Trust in a supportive and informal way if they have any outstanding questions or concerns regarding the death of their loved one.

In 2020 we have had the additional challenge of the SARS-CoV-2 pandemic which has had, and continues to have, a direct impact on morbidity and mortality as well as an indirect impact due to cancellations and delays on treatment for other conditions. It has also had, and continues to have, a significant impact on staff well-being across health and social care services.

Key Guidance

There are a number of national guidance documents which have informed this strategy.

1. National End of Life care strategy 2008[4] set out the following priorities:

- Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly;
- Coordination of care;
- Delivery of high quality services in all locations;
- Management of the last days of life;
- Care after death; and
- Support for carers, both during a person's illness and after their death.

2. The Leadership Alliance for the care of Dying People developed the 'One Chance to get it Right' document in 2014[5] which listed five main priorities for the care of the dying patient:

- Dying is recognised and communicated;
- There is sensitive communication between staff and patients and families;
- Patients and their families are involved in decision-making processes;
- Needs of family are recognised, supported and met as far as possible;
- Individual plan of care which should include assessment of nutrition and hydration needs and symptoms – physical, psychological, social and spiritual.

3. NICE guidance[6]

QS13 covers the care of adults who are approaching the end of their life. In this quality standard 'approaching end of life' is defined as those patients 'who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions.' QS144 covers care of adults in the last days of life and lists 4 quality statements:

- Assessing signs and symptoms;
- Individualised care;
- Anticipatory prescribing
- Hydration.

We have also assessed our care of young people who are dying using the NICE Baseline Assessment Tool (NG61) and were compliant with all relevant recommendations.

4. Royal Papworth Hospital Strategy 2020-25

1. Deliver clinical excellence
2. Grow pathways with partners
3. Offer positive staff experience
4. Share and educate
5. Research and innovate
6. Achieve sustainability

The Royal Papworth hospital End of Life Care Strategy 2020 – 2025 is based on this trust-wide strategy.

Deliver clinical excellence

Our annual audits of care of the dying patient and SPCT surveys of patient and carer satisfaction show that we are already providing an excellent standard of care, but there is always room for improvement. We need to ensure that all patients are given the opportunity to participate in advance care planning as appropriate. We also need to ensure that care of the dying patient is seen as a fundamental of care at RPH.
We will aim to improve standards by:

1. Embedding the use of the newly established 'Personalised Care Plan for the Last days of Life' into clinical practice.
2. Reviewing and updating documentation of care of the dying patient in Critical Care.
3. Embedding the use of the ReSPECT process into clinical practice, so that all staff members are empowered to carry out advance care planning discussions with patients as appropriate.
4. Maintaining the 7-day face-to-face Supportive and Palliative Care team service.
5. Improving communication with ward staff by creating a quarterly E-newsletter with updates on end-of-life care.
6. Continuing to regularly audit practice within the SPCT and across the trust.
7. Carrying out a survey of bereaved relatives to assess and improve standards.
8. Improving access to Chaplaincy support for all patients.
9. Improving and update the Bereavement Service intranet pages.

Grow pathways with partners

The primary treating teams and SPCT already liaise with many different community services across the country for the benefit of our patients. This includes GP practices, community palliative care services, community occupational therapy and physiotherapy and community nursing teams. The SPCT also provides regular telephone support to patients and their relatives who may live at quite a distance from Cambridge. The SPCT consultant and Specialty Trainee also work at Arthur Rank hospice in Cambridge which provides good continuity of care for many of our patients between hospital and community. Palliative care out of hours support for RPH is provided by consultants from Arthur Rank Hospice and Cambridge University Hospital. The Palliative Medicine consultant is in regular contact with peers in other transplant centres (Royal Brompton Hospital, University Hospital Birmingham and Newcastle Hospitals Trust) in order to share learning and expertise and the Palliative Medicine CNSs are planning to set up links with the Royal Brompton Hospital.
Our Chaplaincy service has close connections with the CUH service.

We will aim to further develop this by:

1. Improving access to Supportive and Palliative Care team for more patients at RPH, especially patients with advanced heart failure and transplant patients.
2. Improving measurement of Preferred Place of death and make any necessary changes to improve this outcome for patients.
3. Improving nursing contacts between different transplant centres to enable sharing of learning and expertise.
4. Obtaining access to other electronic patient records used in the community in order to improve continuity of care.

Offer positive staff experience

The SPCT has had a recent substantial increase in the team size which means they are now able to deliver a 7-day face-to-face service which is an exciting and long-overdue development. The SPCT is also committed to providing staff support and was a key part of this during the Covid-19 pandemic. Psychological support services, Chaplaincy service and SPCT are working together in order to maintain this support.
We will aim to:

1. Continue to develop and empower the SPCT staff members' skill set, particularly with regard to workforce planning for the future.
2. Continue to develop and improve all staff members' confidence with caring for end-of-life care patients through developing and educating our End of life care champions.
3. Continue collaborative working between SPCT, Psychological Medicine Services and Chaplaincy service to support staff at RPH.
4. Consider implementing regular formal reflective opportunities for staff at RPH (such as Schwartz or Balint groups).

Share and educate

The SPCT is committed to teaching and training and participates in teaching of medical and nursing students, healthcare support workers, newly qualified nurses and junior doctors. The team also carries out regular syringe pump training on the wards and provides informal teaching wherever possible. We recognise the importance of upskilling ward staff in order to better disseminate learning and we have a number of End-of-Life Care Champions. We have recently changed the name from 'link nurses' to reflect the fact that we now have representation from allied healthcare professionals as well as nursing staff.
We will aim to improve this by:

1. Providing 'essential to role' e-learning for all ward staff.
2. Continuing the current SPCT teaching programme.
3. Maintaining a regular programme of study days for End-of-Life Care Champions.
4. Improving staff confidence and expertise to explore spiritual needs and to refer to Chaplaincy service - through teaching and training.

Research and innovate

We are committed to the principles of research and innovation but have not had the resources to be able to participate in this actively as a team. We will aim to improve this by:

1. Consider pilot study into use of acupuncture in the hospital setting.

Achieve sustainability

The SPCT is keen to continue to work as efficiently as possible and to make the best use of resources. We need to ensure that end of life care is seen as everyone's responsibility here at RPH. In order to maintain a sustainable service, we need to continue with teaching and training and ensure that End of life care is seen as everyone's responsibility.

1. Increase the profile and active membership of the End-of-Life care steering group in order to ensure that providing outstanding care for those in their last years, months or days of life is seen as everyone's responsibility.

References

1. www.nice.org.uk/guidance/ng142.
2. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2019
3. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/datasets/leadingcausesofdeathuk
4. https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life
5. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf
6. https://www.nice.org.uk/guidance/ng142

What key element(s) need(s) monitoring as per local approved policy/ procedureor guidance?	Who will lead on this aspect of monitoring? Name the lead and what is the role of the multidisciplinary team or others.	What tool will be used to monitor/check/ observe/assess/ inspect/ authenticate that everything is working according to this key element from the approved policy/ procedure?	How often is the need to monitor each element? How often is the need complete a report? How often is the need to share the report?	Who or what committee will the completed report goes to. How will each report be interrogated to identify the required actions and how thoroughly should this be documented in e.g. meeting minutes.	Which committee, department or lead will undertake subsequent recommendations and action planning for any or all deficiencies and recommendations within reasonable timeframes?	How will system or practice changes be implemented the lessons learned and how will these be shared?
Element to be monitored	**Lead**	**Tool**	**Frequency**	**Reporting arrangements**	**Acting on recommendations and Lead(s)**	**Change in practice and lessons to be shared**
Continue to audit end of life care	***Dr Sarah Grove and Supportive and Palliative Care team***	***Local and national audit tool***	Annual	End of life care steering group – results to be presented and included in minutes for reporting to trust board.	Supportive and palliative care team	Via hospital supportive and palliative care team
Develop personalised care plan for last days of life		**Audit as above**	Annual audit	As above	As above	As above

Further document information

Approval – this is required for all documents. Approval should be by the relevant committee(s)*. State the name(s) of the committee(s) and the full date(s) of the relevant meeting(s): *In exceptional circumstances only, approval can be by Chair's Action or by appropriate ED or NED – state full date of approval	End of Life Care Steering Group 26.9.19
Approval date (*this version*) (Day, month, year):	Q&R 24.6.21
Approval by Board of Directors or Committee of the Board **(required for Strategies and Policies only):**	As Above
Date (Day, month, year):	
This document supports: *standards and legislation – include exact details of any CQC.*	Trust strategy
Key associated documents:	
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