NHS
Barts Health
NHS Trust

End of Life Care

Study guide

End Of Life Care

There are approximately half a million deaths in England each year, mostly in people aged over 75. For the majority - these deaths can be anticipated. 30% of hospital patients in acute trusts die within 12 months, with many deaths following a prolonged period of ill health from long-term conditions such as heart disease, cancer or dementia (End of Life Care Intelligence, 2015).

Nationally, patients are considered to be '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 mean that 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

(General Medical Council, 2010)

Our commitment to our patients and their loved ones at Barts Health

'End of life care focuses on the last years or months of an individual's life. We are committed to working with you and your family to ensure you get the sensitive care and support you need at this important time in your life.

We will ensure your needs and wishes are met, attending to any physical, social, emotional, spiritual or religious needs that you may have. Supporting the people we care for to die with dignity, in a place of their choice, is a priority for us; this involves us planning your care together.

We recognise the importance of your support network; therefore we offer our staff training to enable them to look after you and your family. This also involves working with our community partners to ensure you and your family receive compassionate and coordinated care.'

Barts Health End of Life Care Strategy 2017—2020

Our End of Life Care Strategy is based on the National Ambitions for Palliative Care Framework.

Our focus is on six priorities:

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and well being
- Care is co-ordinated
- Building a capable and compassionate workforce
- Working within our local communities

Our commitment to our patients and their families at the end of life are based on these priorities.

Our full strategy is located on WeShare via this link

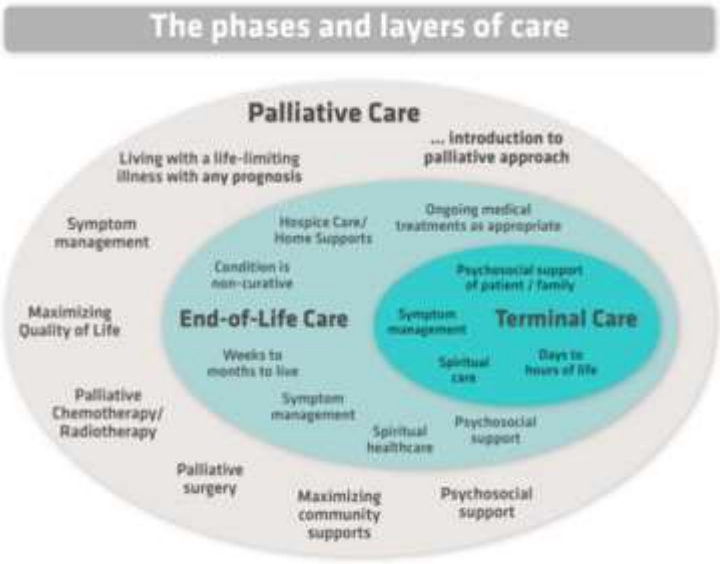
Specialist Palliative Care Team

Palliative Care refers to the treatment, care and support for people with a life-limiting illness and their family and loved ones.

At Barts Health, we have a Specialist Palliative Care Team at each site for adult patients, who can give face-to-face support during working hours (9-5) Monday to Saturday and an on-call Consultant available via switchboard outside of these hours.

Our paediatric teams can access advice and support from the Great Ormond Street (GOSH) Palliative Care Team.

Patients receiving palliative care input may not be at the end of their life. The following image may help your understanding of some of the differences between Palliative Care and End of Life Care.



Principles of Palliative Care

Affirms life and regards dying as a normal process

Neither hastens nor postpones death

Provides relief from pain and other distressing symptoms

Integrates the psychological and spiritual aspects of care

Offers a support system to help patients live as actively as possible until death

Offers a support system to help patients' families cope during the patient's illness and into their own bereavement.

Advance Care Planning

Advance care planning (commonly known as ACP) is the term used to describe conversations held between a person, their families, carers and those looking after them about their future wishes and priorities for care. ACP is everybody's responsibility, and many health care professionals can be involved. General care planning is not the same process as ACP.

ACP is really important for people to ensure their wishes are known as they approach the end of their life – especially if the time comes when they can no longer tell us.

A simple 5-step guide to advanced care planning can be seen by following the attached link:

https://www.youtube.com/watch?v=i2k6U6inIjQ

ACP may lead to making:

- An advance statement
- An Advance Decision to Refuse Treatment
- A Do Not Attempt Cardiopulmonary Resuscitation decision (DNACPR)
- Other types of decisions such as appointing a Lasting Power of Attorney (LPA)

Co-ordinate My Care (CMC)

The Trust advocates the use of Co-ordinate My Care (CMC); an innovative NHS service that builds care around the wishes of each patient and can be shared electronically with all healthcare professionals involved in the care of the patient.

Symptom Control at End of Life

There are many symptoms that may be associated with a person coming to the end of their life, some of which are quite complex and you may wish to contact your Palliative Care Team for support.

The most common symptoms associated with the dying phase are:

- Pain
- Breathlessness
- Agitation
- Respiratory secretions
- Nausea and vomiting

If the patient and their loved ones agree, our policy highlights that 'anticipatory medications' should be prescribed PRN via the subcutaneous route for all of the above symptoms.

The term 'anticipatory medication' refers to medications prescribed in anticipation of symptoms, designed to enable rapid relief at whatever time the patient develops distressing symptoms (NICE, 2017).

Our Barts Health guide will provide you with algorithms for our first-line management plans for each symptom described. This is located on the intranet under Palliative and End of Life Care – or you can follow the link below.

https://weshare.bartshealth.nhs.uk/download.cfm?doc=docm93jijm4n2109.pdf&ver=2734

However, it is also important to consider the use of non-pharmacological treatments such as repositioning, reassurance or fan therapy. The patient should be involved in these decisions.

If a patient requires multiple doses of medication to control a symptom, a 24-hour syringe driver (CSCI) may need to be commenced to optimise their care. The patient and their loved ones must be involved in this decision and any side effects explained.

Recognising the dying phase (Last days of life)

An MDT approach must be adopted when considering the possibility that a patient may be dying. This includes an appropriate senior physician, who can assess for any reversible causes.

The last days or hours of a person's life are often called the terminal phase or dying phase. It might be referred to as when someone is 'actively dying'. It may last for hours or for several days.

Everyone's experience of dying is different, and some people will die suddenly or unexpectedly. However in most cases, you may recognise signs a person is entering the terminal phase. These include:

- Getting worse day by day or hour by hour
- Reduced mobility, or becoming bed-bound
- Extreme tiredness and weakness
- Needing assistance with all personal care
- Little interest in getting out of bed
- Little interest in food or drink
- Difficulty swallowing oral medication
- Being less able to communicate
- Sleepiness or drowsiness
- Reduced urine output
- Increased restlessness, confusion and agitation
- Changes in their normal breathing pattern
- Noisy chest secretions
- Mottled skin and feeling cold to the touch
- The patient may tell you that they feel as if they are dying.

Honest communication with the patient and their loved ones at this point is of the highest importance and should be documented carefully. Multiple conversations may be needed at this time whilst the patient talks through what is important to them.

Priorities for Care of the Dying Person

The Priorities for Care is a national approach for caring for people in the last days and hours of life, which involves assessing and responding to the holistic and changing needs of the individual dying and their loved ones. The following five priorities are outlined.

Recognise

The possibility that the person may die is recognised and communicated clearly. Decisions made and actions taken are in accordance with the person needs and wishes, and are reviewed and revised regularly.

Reversible causes are considered e.g. infection, dehydration, hypercalcaemia etc.

Communicate

Sensitive communication takes place between staff and the dying person and their loved ones

Involve

The dying person, and their loved ones, are involved in decisions about treatment and care

Support

The needs of families and loved ones are explored, respected and met as far as possible

Plan & Do

An individual plan of care is agreed and delivered with compassion.

At Barts Health, we have developed a care plan for the dying person based on these priorities – The Compassionate Care Plan.

The Compassionate Care Plan

The Compassionate Care Plan (often referred to as the CCP) provides a framework to enable clinical staff to deliver the best practice care to patients in the last days and hours of life.

It does not apply to the care of children and young people (0-18 years) although the priorities of care are equally applicable. Where care is provided to children in the last days and hours of life the team involved should refer to the specialist palliative care team at Great Ormond Street Hospital as required

The Compassionate Care Plan prompts the delivery of an individualised plan of care, which includes food and drink, symptom control and psychological, spiritual and family support. It is located on the intranet under Palliative and End of Life Care – or you can follow the link below.

https://weshare.bartshealth.nhs.uk/download.cfm?doc=docm93jijm4n2109.pdf&ver=2734

It must be completed by a consultant or senior trainee, in conjunction with the wider MDT, patient and those important to the patient.

If the patient and family agree, patients at Barts Health who are thought to be dying, with the CCP in place, should have the 'Compassionate Sign' on their door (as shown)

The aim of this sign is to ensure all members of staff – including those who are non-clinical (e.g. domestic staff and porters) are aware that the patient is dying.

Hydration and Nutrition for the Dying Patient

The dying patient must be supported to eat and drink for as long as they are able to do so. The patient may experiences difficulty in swallowing but may wish to continue to eat and drink. It may be appropriate to 'risk-feed', and the patient must be involved in this decision. The dying patient should not usually be made 'nil my mouth'.

There may come a time when the patient no longer wants to eat and drink, nor may this be needed. This can be quite distressing for any family and loved ones, and sensitive explanations are important at this time.

If the patient is no longer able to swallow, they must be reviewed on an individual basis as to whether it would be appropriate to have artificial hydration or nutrition.

Providing artificial nutrition and hydration (e.g. by tube or drip) may provide symptom relief, or improve the quality of the patient's life, but it is not without risks and burdens.

Artificial hydration and nutrition is regarded in law as a medical treatment, and should be treated in the same way as other medical interventions.

However it is important that the views of the patient and their loved ones are listened to and considered (including cultural and religious views) and all benefits, risks and burdens thoroughly explained.

A plan must be put in place for the hydration and nutrition needs of the dying patient, which includes mouth-care. This will be reviewed regularly and when a patient's condition changes.

Spirituality

Spiritual care refers to care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness.

Many patients become spiritual towards the end of their life, especially when aware of a poor prognosis.

It can be difficult for health care professionals to ask about spirituality when they do not feel like the 'experts'.

Our multi-faith chaplaincy team are available to talk to any patient; they do not have to be religious.

Some useful questions to help you, particularly if your patient is dying and you wish to deliver a holistic plan of care can include:

Do you have a way of making sense of the things that happen to you?

Would you like to see someone who can help you talk or think through the impact of this illness/life event?

RCN (2011)

It is also important to recognise that different faiths will have different funeral arrangements that may need to be planned for in advance – particularly before a weekend - for those whose last wishes are to be buried within a certain time frame. You may wish to involve our chaplaincy team to support this – particularly if we cannot ensure these wishes are met (e.g if a post-mortem is needed).

Psychological Support

At the end of life, alongside the physical and spiritual aspects of care, it is important to be able to offer help with managing emotional and psychological distress. Patients may want to talk about:

- Issues concerning the diagnosis or prognosis of their disease
- The impact of the illness
- The impact of the treatment
- Relationship issues, unresolved matters, the impact on family members
- Preparing for death

Patients often seek to express their feelings about dying in their own. Some people:

- May have regrets to express to someone who will not judge them
- Want to share unresolved issues from the past that trouble them
- Want to help to express themselves to people close to them
- Need to be able to say their goodbyes to life

There is no formula or prescription for what people want to talk about at the end of their life. It is important to have someone listen to their memories, joys, fears, anxieties and grief, to have time to talk about life, death, suffering, their loved ones, finances and what will happen after they die.

Bereavement Support

'How people die remains in the memory of those who live on'

Dame Cicely Saunders, founder of the Modern Hospice Movement.

Caring for the bereaved sensitively and carefully when a patient has died is crucial and will have a lasting impact on how carers and families grieve – we may never witness the impact of our actions and reactions.

Supporting staff

Caring for a dying patient, their carer and family is often stressful, by having information close to hand will reassure junior staff, and staff who infrequently care for a dying patient, while ensuring hospital policy is followed.

At Barts Health we have a number of resources to help support you while caring for bereaved carers and families. Located on the intranet under *Patient Care/Bereavement Support and Mortuary Services* – or you can follow the link below.

https://weshare.bartshealth.nhs.uk/bereavement-and-mortuary

Here you will find the following information:

- Barts Health Bereavement Policy 2017— which includes Care of the Deceased Patient (formally known as Last Offices)
- Coronial referral forms (site specific)
- Policy linked documents and information on: Death of an adult/Death of a child/ Pregnancy loss/ Death of a colleague
- Printable resources include: content pages for the Trust bereavement boxes, bereavement folder and Compassionate Care sign (previously mentioned)

Supporting bereaved carers and families

The bereavement service work alongside families whose loved ones have recently died, ensuring the legal paperwork is completed in a timely manner, they also provide practical information and advice.
Following a ward death the following actions are required by staff:

1. Give the next of kin the hospital booklet '***What to do when someone dies***' (stock is available from the bereavement office), refer to page 3 on what they should do next.
   NB: it is recommended that all staff read the booklet.
2. Inform the bereavement office you have had a patient die, giving the patient details (a message can be left overnight).

Bereaved carers and families receive a condolence card four to six weeks after a death from the bereavement team, offering support if they have unanswered questions or require sign posting to further help. The bereaved are also invited to the Annual Service of Remembrance at St Paul's Cathedral.

Understanding the experience of the bereaved - around the lead up to death, at the time of death and the processes after, is important to Barts Health; the bereaved carers survey is sent with the condolence card and our learning from the feedback can be found here: https://weshare.bartshealth.nhs.uk/bereavement-and-mortuary under the title *Report on the Annual Bereavement Survey Barts Health NHS Trust 2017.*

Recognising children are bereaved and offering support to families in the form of leaflets from the charity Child Bereavement UK before they leave the hospital is crucial. The booklets provide ways of explaining death to children of different ages, normalises how they might feel, what a funeral is and recognises the importance of creating memories (supplies are available from the hospital bereavement offices and paediatric wards).

Short films -
Explaining the dying phase to families – Kathryn Mannix
https://www.bbc.com/ideas/videos/dying-is-not-as-bad-as-you-think/p062m0xt?playlist=imho

How to speak to someone who has been bereaved
http://www.sad.scot.nhs.uk/bereavement/communication-around-the-end-of-life-with-the-bereaved/

Talking to children who are bereaved
http://www.sad.scot.nhs.uk/bereavement/children-who-are-bereaved/

Self-care

Self-care is critical to professional quality of life.

Staff providing end of life care are at high risk for compassion fatigue and professional grief. Professional self-care requires a variety of positive self-care strategies at both the personal and organizational levels.

For information of how you can access support whilst working at Barts Health, please access the '*Support at work*' page on the intranet, or follow this link:

https://weshare.bartshealth.nhs.uk/support-at-work

Please also consider attending our monthly **Schwartz Rounds** at each site; multi-disciplinary discussions that focus on the human side of caring for patients, allowing us to reflect on the impact work has on us without judgment, problem solving or giving advice.

Further training and information

At Barts Health, we offer a number of training days to help you feel more confident to deliver outstanding end of life care.

You can contact our End of Life Care Education Team (endoflifecare.bartshealth@nhs.net) to find out more.
We also recommend the free e-learning resources End of Life Care for All (e-ELCA) – developed and regularly updated by HEE and the Association for Palliative Medicine.

www.elfh.org.uk/programmes/end-of-life-care/

The following is suggested for further information:

NICE Guideline (2015) '**Caring for adults dying in the last days of life'** https://www.nice.org.uk/guidance/ng31

Leadership Alliance (2014) '**One chance to get it right: Improving people's experience of care in the last days and hours of life'** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Gold Standards Framework (2016) **Proactive Identification Guidance (PIG)** - guidance for clinicians to support early identification of patients nearing the end of life https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf

Ambitions for Palliative and End of Life Care - endoflifecareambitions.org.uk

General Medical Council (2010) **Treatment and care towards the end of life** - https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

References

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Spirituality in Nursing care (2011), Available at: https://www.rcn.org.uk/professional-development/publications/pub-003887

General Medical Council (2010) Treatment and care towards the end of life: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

International Association for Hospice and Palliative care , Principles of Palliative Care, Available at: https://hospicecare.com/.../publications/getting-started/6-principles-of-palliative-care

Gold Standards Framework, Advance Care Planning. Available at: http://www.goldstandardsframework.org.uk/advance-care-planning

NICE (2015) Care in the last days of life Available at: https://www.nice.org.uk/guidance/ng31/chapter/Recommendations