

Transforming end of life
care in acute hospitals
The route to success 'how to' guide
(Revised December 2015)



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The route to success
Introduction

Foreword

Some years ago I nursed and cared for my daughter who had breast cancer. Wanting and needing to provide the best possible care for her I worked hard to ensure that this would happen. However due to fear and lack of knowledge, at the very end of her journey I had to call 999 which resulted in an emergency admission.

The ambulance took four hours to arrive and my daughter died in a busy accident and emergency department on a Friday evening. This had a profound and devastating effect on me, leaving me with a heavy burden of guilt even to this day.

Far more recently I was able to stay beside my mother-in-law in the hospital during her last days. The palliative care which she received was wonderful. I was able to assist with some of her care and she was treated with dignity and respect. I feel that I am able to look back without any guilt about her death knowing that it was almost as good as it could have been.

For the sake of the person dying and their carers, let us work towards a system of which we can all be proud, thus relieving families of unnecessary anxiety and guilt.



Roberta Lovick
User carer representative





Foreword

Our first national strategy for end of life care in England, published in 2008, has succeeded in reversing the trend of increasing the proportion of deaths taking place in hospital. Although that significant achievement must be appreciated, the reality is that many people will continue to die in hospitals, sometimes by their own choice, sometimes by necessity of the circumstances leading up to their death. As importantly, many people will need to spend a proportion of their last years, months and weeks of life in hospital because of care and treatment that they need, and wish, to receive. We owe it to them, and those important to them, to make that experience as good as we possibly can whilst they are there.

The route to success in end of life care – achieving quality in acute hospitals was published in 2010 as the first step in a national improvement programme. Then in 2012, the original *Transforming end of life care in acute hospitals: The route to success 'how to' guide* was published as a result of a collaboration between the National End of Life Care Programme and the NHS Institute for Innovation and Improvement. The first wave of 25 hospital trusts led the implementation in 2012, followed by a second wave of 51 hospital trusts, of the 'Transforming end of life care in acute hospitals' programme, commonly known as '*the Transform programme*'.

The publication of this version of the *Transforming end of life care in acute hospitals: The route to success 'how to' guide* marks another significant milestone in this journey. Commissioned by NHS England, the guide's revision has been led by NHS Improving Quality, with contributions from The National Council for Palliative Care, Macmillan Cancer Support and NHS Trust Development Authority, as an early component of our new partnership for improving end of life care in acute hospitals. This provides practical advice and support for front-line clinicians and leaders for the work required to transform end of life care in acute hospitals. I would strongly urge you all to use it to its fullest potential and encourage those who have not yet signed up to this commitment to read it too.

This is a good example of putting into action the recently published *'Ambitions for Palliative and End of Life Care: A national framework for local action: 2015-2020'*. There are six ambitions in the framework: each person is seen as an individual; each person has fair access to care; maximising comfort and wellbeing; care is coordinated; staff are prepared to care; communities are prepared to help. Like the NHS's Five Year Forward View, a fundamental principle of the Ambitions framework is that significant progress in end of life care can only be made and sustained through collaborative and cooperative efforts between people who are part of statutory bodies, voluntary organisations and community groups. It has to be 'everybody's business' and nowhere is this more true than in acute hospitals where every contact, between staff and those they care for, has the potential to make a lasting impact, good or bad. We all need to rise to the challenge of achieving personalised care, treatment and support for the individual within a fast-paced busy acute environment. We must make the experience of care in hospitals as good as it can possibly be for all those who need to be there, especially for those in the last years, months, weeks and days of their life, and those important to them, as well as the staff who work and provide care and support for people in these environments. This must happen in parallel with efforts to improve the conditions and care for people outside hospitals too, so that we do not create, or perpetuate, an artificial divide between hospital and out-of-hospital in terms of quality of care that people can expect to experience.



Professor Bee Wee

National Clinical Director for End of Life Care,
NHS England

Introduction

The Department of Health's *End of Life Care Strategy* (2008)¹ was an important turning point for improving end of life care provision in acute hospitals given that more than half of all deaths occur there.

As well as ensuring that those who die in hospital have a 'good death', the strategy called for improved discharge arrangements and better co-ordination with a range of community and social care services so that more people can die at home if that is their preferred choice.

The route to success in end of life care – achieving quality in acute hospitals (2010) highlighted best practice models developed by acute hospital trusts and supported by The National End of Life Care Programme (now part of NHS Improving Quality). It provided a comprehensive framework to enable acute hospitals to deliver high quality person centred care at the end of life.

This revised *Transforming end of life care in acute hospitals: The route to success 'how to' guide* builds on that overarching framework as well as:

- [NICE guideline on care of dying adults in the last days of life](#)
- [Actions for End of Life Care 2014/16](#) NHS England
- [One Chance to Get it Right](#) the Leadership Alliance for the Care of Dying People June 2014
- [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#)

It also draws on the valuable learning from The Productive Ward Releasing Time to Care programme² originally developed by the NHS Institute for Innovation and Improvement [NHS Improving Quality] helps wards focus on improving their processes and environments to help nurses and other staff spend more time giving direct care to patients.

¹ <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

² www.institute.nhs.uk/quality_and_value/productivity_series/productive_ward.html

Throughout this guide, you will be encouraged to use existing models and practical tools already identified as examples of good practice. They can help you achieve the improvements you wish to prioritise locally to improve the quality of end of life care for your patients and their families. The five key enablers outlined below will greatly assist you towards this aim.

- Advance Care Planning (ACP)
- Electronic Palliative Care Co-ordination Systems (EPaCCS) formerly known as end of life care locality registers
- AMBER care bundle
- Rapid Discharge Home
- Priorities of Care from 'One Chance to Get it Right'.

Ensuring quality of care and putting people's needs at the heart of the healthcare system requires a workforce that is equipped with the right knowledge, skills, competences, attitudes and behaviours.

Education, training and workforce development are essential elements that require embedding as core requirements in corporate governance frameworks to enable the achievement of the aims of the *Transforming end of life care in acute hospitals: The route to success 'how to' guide*.

The Productive Ward Releasing Time to Care³ is a proven approach to engage staff and also to build competence and confidence amongst staff so they can lead improvements in care for themselves. Utilising the principles of continuous improvement within The Productive Ward will help organisations and their staff reshape how they work with each other, with patients and their families and with other key partners for example social care. The Productive Ward six step approach illustrated in Figure 1 overleaf will help you achieve this.

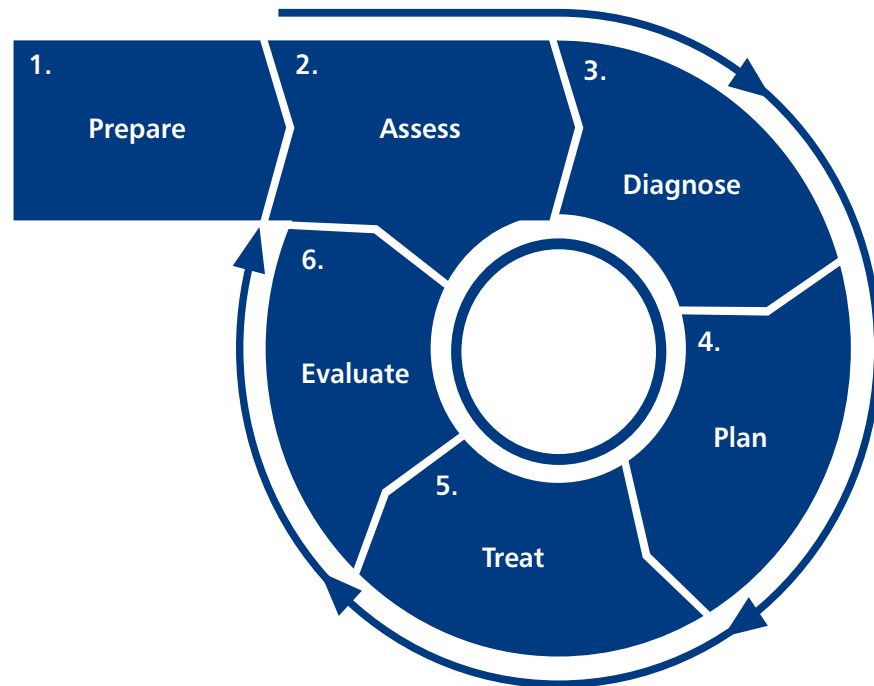
The recently published [Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020](#) will also help you build the momentum for working together locally.

³ www.institute.nhs.uk/images/documents/Quality_and_value/Productive_Ward/PW%20review%20full%20report.pdf



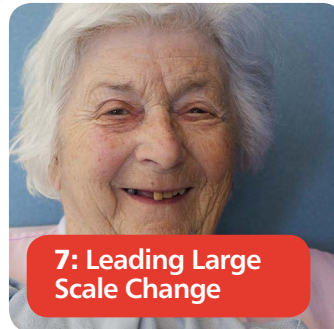
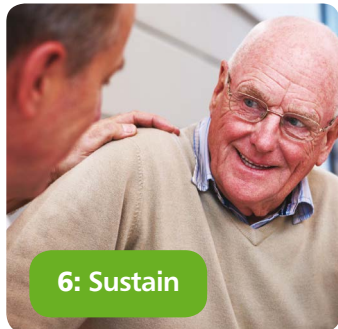
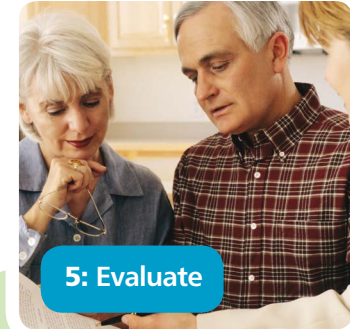
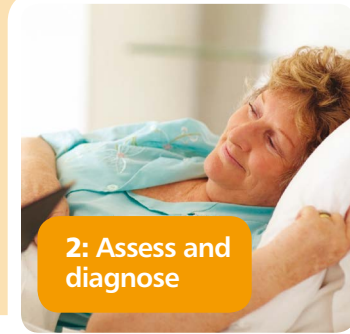
Figure 1:

Six step continuous improvement diagram from The Productive Ward: Releasing Time to Care™ (©NHS Improving Quality).




Introduction

This guide contains individual sections that can be worked on in the order of your choosing, dependent upon your individual hospital and its current end of life care provisions. These include:



The route to success 'how to' guide



A photograph of two women sitting and talking. The woman on the left is wearing a light green top and has long dark hair. The woman on the right is wearing a pink sweater, glasses, and has long dark hair. They appear to be in a professional or educational setting. A pink square graphic is in the top right corner.

Section 1 The route to success

Prepare

What does good look like?

Making good quality accessible end of life care a priority requires collaboration and cooperation to create the climate for change to bring about the improvements we all want to see. Professionals, local leaders within the health and care system and communities working together, collectively and differently is vital to designing new ways of working to achieve:

- Getting care as good as it can be wherever the person is - at all stages
- Care that matches the person's preferences as closely as possible and meets needs as far as possible
- Staff who have confidence to bring these skills into other parts of care
- Reducing the inequality gap
- Everybody feels responsible for playing a positive part in end of life care.

The framework for action developed by the National Palliative and End of Life Care Partnership [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#) is aimed at local health and social care and community leaders. It builds on the [Department of Health's 2008 Strategy for End of Life Care](#) and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

The six 'ambitions' within the framework are principles for how care for those nearing death should be delivered at local level (see the illustrations on the following three pages for further details).

- 1. Each person is seen as an individual**
- 2. Each person gets fair access to care**
- 3. Maximising comfort and wellbeing**
- 4. Care is coordinated**
- 5. All staff are prepared to care**
- 6. Each community is prepared to help.**

As well as meeting the needs of the individual being cared for, good end of life care would include giving care and support to families, friends, carers and all those who are important to the dying person. It should also include good bereavement and pre-bereavement care.

This section of the *Transforming end of life care in acute hospitals: The route to success 'how to' guide* introduces you to some models which may be helpful in the **Prepare** phase as you seek to engage your local stakeholders and formulate your plans to achieve improvement locally for the benefit of patients and their families.



The six ambitions for palliative and end of life care

01

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.

02

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.

03

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.

04

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.

05

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.

06

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.

The National Palliative and End of Life Care Partnership

<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

The foundations for the ambitions



The National Palliative and End of Life Care Partnership

<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>



The foundations for the ambitions

Personalised care planning

Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.

Education and training

It is vital that every locality and every profession has a framework for their education, training and continuing professional development to achieve and maintain competence and allow expertise and professionalism to flourish.

Shared records

To ensure the plan can guide a person centred approach it has to be available to the person and, with their consent, be shared with all those who may be involved in their care.

24/7 access

When we talk about end of life care we have to talk about access to 24/7 services as needed, as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'.

Evidence and information

Comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved. This, alongside strengthening the evidence-base, will help to drive service improvements.

Co-design

End of life care is best designed in collaboration with people who have personal and professional experience of care needs as people die.

Involving, supporting and caring for those important to the dying person

Families, friends, carers and those important to the dying person must be offered care and support. They may be an important part of the person's caring team, if they and the dying person wish them to be regarded in that way. They are also individuals who are facing loss and grief themselves.

Leadership

The leadership of Health and Wellbeing Boards, CCGs and Local Authorities are needed to create the circumstances necessary for action. Clinical leadership must be at the heart of individual service providers.

The National Palliative and End of Life Care Partnership

<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

End of Life Care - House of Care Model



As end of life approaches, individuals and those close to them need to be able to access high quality care that is compassionate, competent and respectful. For this to happen health and social care staff need to make sure they deliver the right person centred care 'the first time, every time.'

[The End of Life Care - House of Care framework](#) describes four key interdependent components that, if implemented together, offer the greatest opportunity for achieving person centred, coordinated care for people approaching the end of their life and those

important to them. Underpinning all four components is personalised care planning where people at or nearing end of life and those closest to them, and professionals work together using a collaborative process of shared decision-making to agree goals, identify support needs, develop and implement action plans, and monitor progress.

The framework is set in the broader context of the community and provides opportunities for organisations to improve the way they deliver care and ensure patients and those close to them have the best experience possible.



Preparation

The NHS Change Model

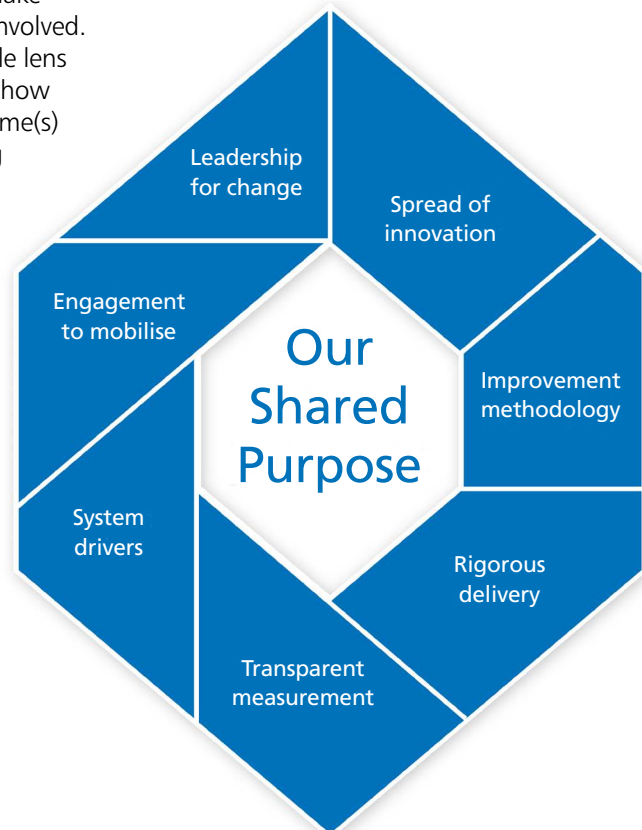
This model provides a useful organising framework for sustainable change and transformation that delivers real benefits for patients and the public. It has been created to support the NHS to adopt a shared approach to leading change and transformation and brings together what we know helps make change happen and who needs to be involved.

The Change Model provides a valuable lens that enables a better understanding of how to create an environment and programme(s) which can make change happen. Using all of the eight components together in equal measure will increase your chances of making change successful.

The eight components are:

- **Our shared purpose**
- **Leadership for change**
- **Spread of innovation**
- **Improvement methodology**
- **Rigorous delivery**
- **Transparent measurement**
- **System drivers**
- **Engagement to mobilise.**

See more at: www.nhs.uk/capacity-capability/nhs-change-model.aspx#sthash.0NY2BUQd.dpuf



Our shared purpose

A clear sense of shared purpose at every level, individuals and organisations, is essential to any successful change. Organisations whose communities are strong, passionate and committed to delivering improvement and outcomes, create shared purpose as a common thread. Shared purpose connects us with our commitment and contribution to our core values - the things that bring us into the NHS and care settings to deliver outcomes that matter to local communities, beyond just what we do as individuals, teams or organisations. We need to know not just what problems we are trying to solve and why it matters, but what our vision is for the future and why that future matters.

Investing in exploring the collective shared purpose at the start of your local improvement programme is central to creating the conditions that foster a climate for leading change, and requires commissioners, providers, voluntary and third sector organisations and people who use services to act together in the interests of patients where the quality of care is as important as the quality of treatment.

Acting together means something when it is connected to purpose, connecting people to the change in a very open way. Our values, which sometimes get eclipsed by structures and hierarchy, unite us to collectively work together to take action on what we hold in common to sustain the improvement programme, to deliver the vision, outcomes



and goals developed through the collective shared purpose. Shared purpose needs to be developed at different levels in the change process connecting back to the overall improvement we want to see. In reconnecting with our shared purpose the pull and push for delivering and adopting improvement is strengthened.



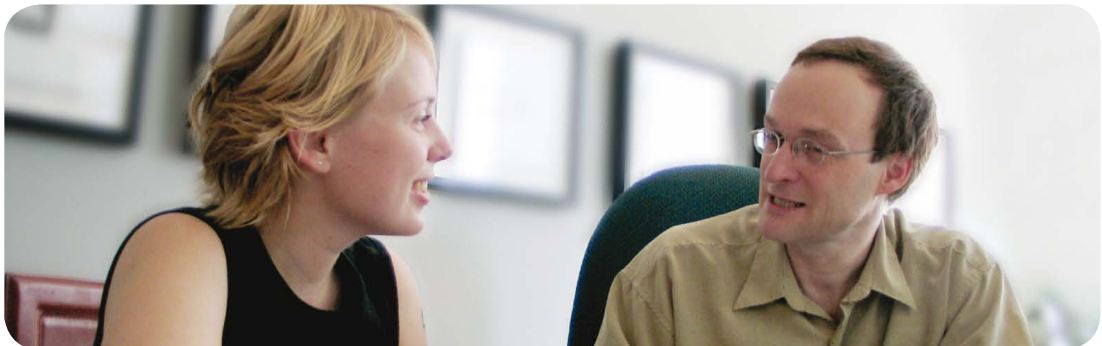
As part of your preparation for implementing *Transforming end of life care in acute hospitals: The route to success 'how to' guide* you will need to think about the following:

1. Why do it?

Currently almost half of all deaths (47%) take place in hospital ([National End of Life Care Intelligence Network, 2015](#)). Nearly 30% of all hospital beds are occupied by someone in their last year of life. ([Prevalent cohort study D. Clark et al 2014](#)) The majority of deaths occur following a period of chronic illness such as respiratory disease, heart disease or cancer. Almost 500,000 people die each year in England, two thirds of whom are 75 years or older. With an ageing population, the number of deaths is set to increase by 17% between 2012 and 2030 ([Local Preferences and Place of Death in Regions within England 2010](#) National End of Life Care Intelligence Network (2011).

Improved delivery outcomes should:

- Improve the experience and quality of care received
- Enable people to die in the place of their choice
- Reduce the number of inappropriate interventions
- Manage and reduce unplanned hospital admissions as well as length of stay
- Improve staff morale and staff retention
- Develop a skilled workforce
- Result in fewer complaints and improved reputation for the trust.
- Allow the trust to manage its resources effectively.





2. Who is it aimed at?

A wealth of reports focussed on quality at end of life have highlighted the variable standards of provision across wards and organisations as well as uncoordinated services for end of life ([More Care, Less Pathway A review of the Liverpool Care Pathway 2013](#); [Dying without Dignity: Investigations by the Parliamentary and Health Service Ombudsman](#) into complaints about end of life; [End of Life Care House of Commons Health Committee report 2015](#)).

In order to support implementation of *Transforming end of life care in acute hospitals: The route to success 'how to' guide* in practice and to accelerate tried and tested models, this guide is for the various combinations of multidisciplinary teams who are responsible for service development, commissioning and practice educators. It is also intended for front line staff who care for individuals at the end of life. While not exhaustive, this includes:

- Allied health professionals
- Bereavement staff
- Board directors
- Community and voluntary sector organisations and groups
- Directorate managers
- Education commissioners
- Generalist hospital clinicians
- Hospital chaplains
- Mortuary staff
- Nurses
- Primary, community and social care service providers
- Service commissioners
- Specialist palliative care teams
- Support staff
- Volunteers.



3. What is your starting point?

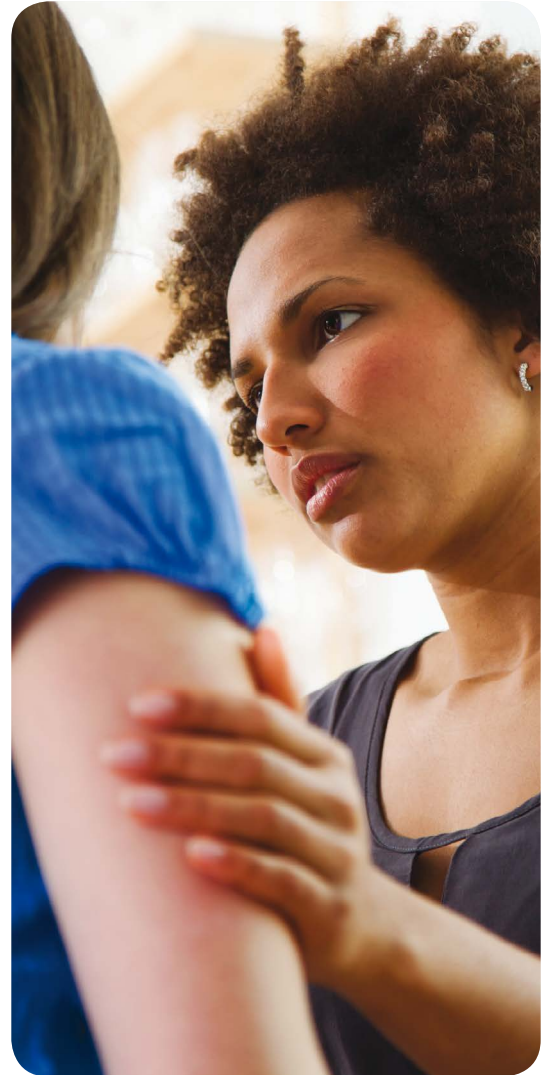
Knowing how your ward and organisation are doing will allow you to scope what is needed for improvement. Asking the following questions will help:


- Do you know how good you are?
- Do you know where you stand relative to your peers?
- Can you identify variations between you and your peers and possible reasons for it?
- Can you monitor your rate of improvement over time?

[Section 2](#) of this guide will show you how to assess and diagnose to help answer these questions.

TOP TIP

Build on what you've already got. Your hospital will be doing some things really well. Find out what they are and start from there. Comparing your performance locally and nationally will also help.



A photograph of two elderly women with short blonde hair looking intently at a tablet computer. The woman on the left is wearing a white top and a silver necklace, while the woman on the right is wearing a grey cardigan over a light-colored top and glasses. A yellow sticky note is overlaid on the image, containing text about organizational readiness.

TOP TIP

Use The Productive Ward six step approach to identify the level of organisational readiness for change including what you are already doing well and build on this as part of the 'prepare' phase.

Section 2 The route to success

Assess and diagnose



Assess and diagnose

As part of assess and diagnose, it is important to establish a baseline or starting point so you can demonstrate where you have made an improvement and sustain it over time.

There are numerous sources of information available to help you with your baseline and also where it would be helpful for you to benchmark your current position with other similar organisations, for example:

Jargon

PROMS – Patient Reported Outcome Measures
CQUINS – Commissioning for Quality and Innovation framework.

- Your trust's existing key performance indicators and strategic priorities
- National measures including any relevant CQUINS
- Use your multidisciplinary team to enable identification and overview of complaints related to end of life care
- Review of clinical coding
- Data from the National End of Life Care Intelligence Network's End of Life Care Profiles will inform how you are doing to enable you to prioritise and develop your trust's end of life care quality improvement dashboard¹
- A range of publications from National End of Life Care Intelligence Network including specific diseases, technical guidance, overview and partnership reports (2)²
- The NICE end of life care for adults quality standard³
- End of life care profiles are also available in the [Public Health England Profiles](#)
- [Place of death statistics](#) are reported quarterly, six months after the end of each quarter. These report the proportion and numbers of deaths in usual place of residence, hospital, hospice, care home other. Data is reported by clinical commissioning group, local authority, strategic clinical network and for England.

¹ www.endoflifecare-intelligence.org.uk/profiles.aspx

² www.endoflifecare-intelligence.org.uk/resources/publications/default.aspx

³ www.nice.org.uk/guidance/qs13



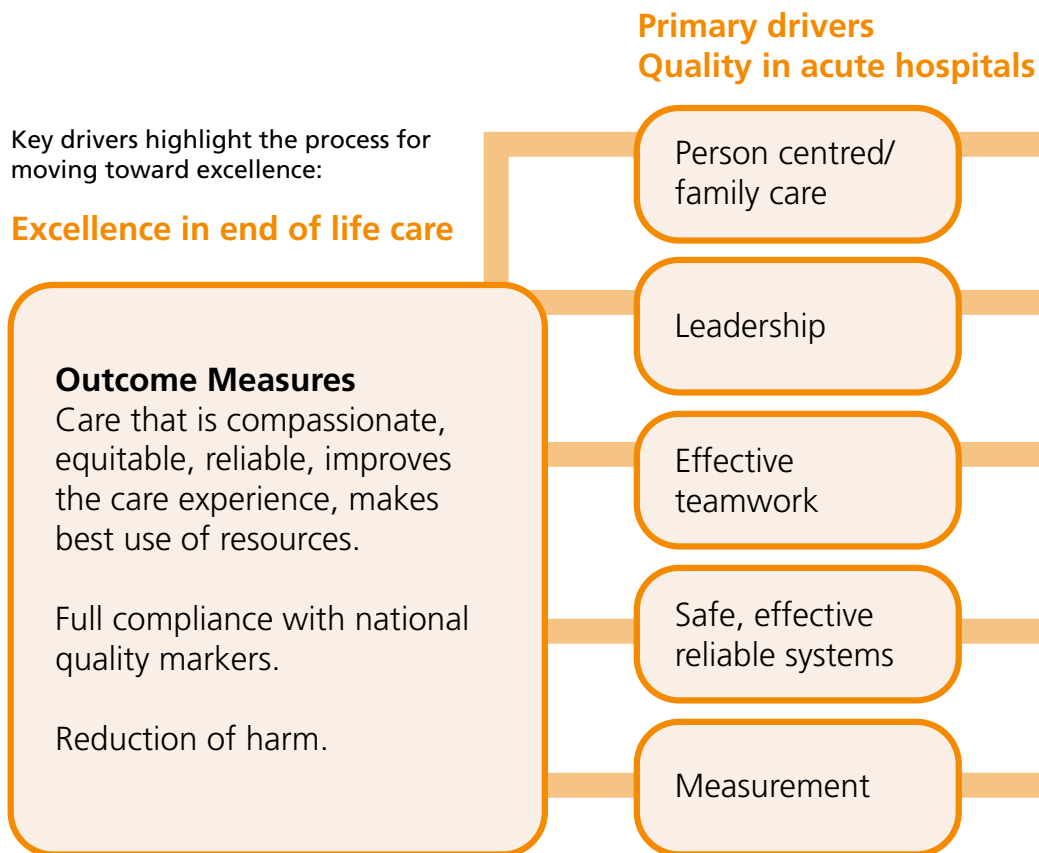
TOP TIP

You might find it useful to look at the measurement fact sheets and data sheets.

TOP TIP

Measurement for Improvement not judgement should be part of your plans from the outset. Measurement is a great way of engaging clinical colleagues in your organisation as well as your local analysts who can be a good source of support.


Figure 1: Key drivers for excellence in end of life care





Adapted from the Transform National Steering Group 2011, with input from the NHS Institute for Innovation and Improvement





Secondary drivers

- 
1. Engage individuals and families as active partners in care
 2. Open transparent communication that is respectful of preferred priorities for care and preferred place of death
 3. Involve families in the physical care of their relatives
 4. Involve families in improvement teams
 5. Facilitate user feedback within service improvement
 6. Care after death.

- 
1. Leadership explicit within the organisation's trust board agenda
 2. Senior management objectives
 3. Clinical champions for end of life care
 4. Competent trained staff – partnership between hospital palliative care/long term conditions teams
 5. Culture of compassionate care by staff caring for individuals approaching end of life.

- 
1. Agreed standards for effective communication with individual and family
 2. Effective identification and development of management plans
 3. Discharge liaison/community/GPs/ambulance/out-of-hours/social care
 4. Adopt common end of life care language – e.g. *Transforming end of life care in acute hospitals: The route to success 'how to' guide*.

- 
1. Implement end of life care good practice models – The Productive Series, advancing quality, clinical audit
 2. Use of agreed prognostic indicator guidance
 3. AMBER care bundle in use across trust
 4. Advance Care Planning, Do Not Attempt Cardio-Pulmonary Resuscitation, individual care plan
 5. Electronic Palliative Care Co-ordination System (EPaCCS)
 6. Rapid discharge home
 7. Symptom management
 8. Priorities for Care.

- 
1. Safe and effective care with regular review of serious untoward incidents, complaints etc
 2. Patient related outcome measures
 3. National bereavement survey (VOICES)
 4. *Transforming end of life care in acute hospitals: The route to success 'how to' guide* dashboard – each trust to develop their own utilising 'how to' guide metrics for wards and boards.

Section 3 The route to success

Plan



Getting started

As you and your organisation consider and put together a plan to implement this work, you will need to give some thought to the following:

1. Who to involve
2. What you need to do
3. Key enablers
4. Other tools to help
5. How to measure progress.

1. Who to involve

You need to communicate with as many people and in as many ways as possible about this initiative, its ethos and its outcomes.

Wherever possible a clinical champion or executive lead should be identified who can both support the work but also clearly articulate to the team what is expected from them, for example that they commit time and energy to the work and take ownership for the aspects of work in their area.

The clinical champion or executive lead can play an important role in keeping the trust board informed of progress and chairing a steering group, if one is established. As a clinical champion for the work, the executive lead can ensure that the multidisciplinary team work across boundaries. They can also help to overcome or unblock any issues which may arise.

A steering group should be established to engage key stakeholders to make valuable contributions to the work, as well as provide a key focus to drive progress and measure success.

The steering group can also be a useful way of involving commissioners of services from the local health and social care community who will be vital to the sustainability of transformational pathways going forward. The steering group will need to have clear terms of reference; membership and governance arrangements and will need to involve all partners in the implementation process.

Ward leaders are a key group to engage with from the start of the process so that the work is theirs to own and to avoid feelings of isolation from the process and being imposed upon. Through this *Transforming end of life care in acute hospitals: The route to success 'how to' guide*, you are giving them a set of good practice models and supporting tools to help them facilitate the transformational change required.

Individuals and their carers should be actively involved where appropriate in line with local patient and public involvement engagement strategies.

TOP TIP

The Transform start up pack houses a wealth of resources and tools to help you get started. For more information visit: www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care.aspx



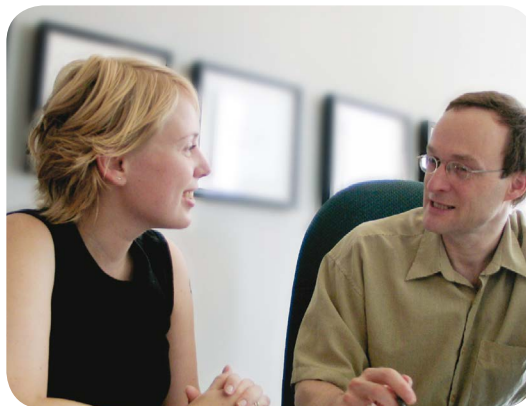
TOP TIP

The groups of people in the box below are also key to successful end of life care service improvement and should have representation on the steering group or task and finish groups as appropriate. Use the [Change Model](#) or [Ambitions](#) document to help you identify key stakeholders.

- Allied health professionals
- Ambulance services
- Clinical Commissioning Groups
- Clinical networks
- Clinical senates
- Community staff
- Hospices
- Hospital chaplains
- Primary care services
- Social care services
- Mental health services
- Public Health England
- Third sector organisations
- Patients, carers and their families.

2. What you need to do

- a. Firstly you need to assess your level of organisational readiness to lead the changes that are required to transform end of life care in your organisation. You can do this by working with your clinical champion or executive lead to identify the strategic priorities which align with end of life care, in order to avoid duplication and build on progress already being made.
- b. You also need to undertake a baseline assessment of your current end of life care provision. This also needs to include patient experience and insight data, assessing what progress has already been achieved and whether earlier work to raise standards of care is being sustained.
- c. With the support of your clinical champion or executive lead, you should agree what resources are available, where in the organisation you should start and governance arrangements, including steering group membership.
- d. You should also develop a project plan that seeks to build in spread and sustainability from the outset. Your project plan should have key milestones and where progress is checked, for example whether the first steering group meeting has happened or whether the baseline assessment has been completed. The project plan should outline how your organisation has:

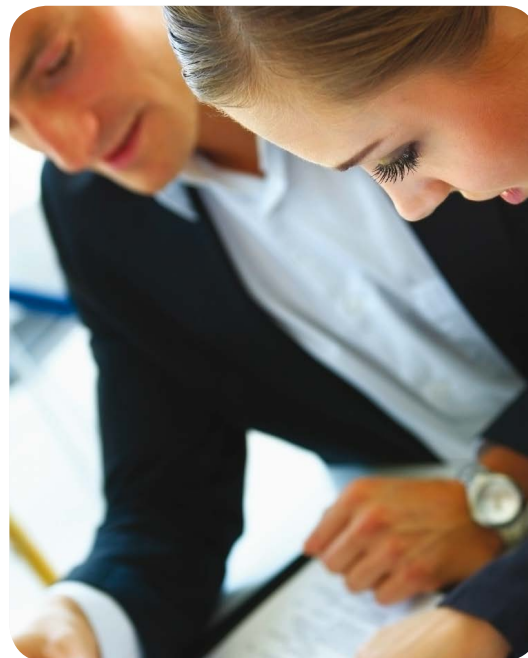


- Defined its strategic goals and how these align with your vision for transforming end of life care¹
- Aligned this work with current organisational and national strategy
- Geared up the whole organisation to support ambitions
- Signed off the project with trust board and steering group
- Established project governance
- Identified any existing national and local measures that can be integrated into the work programme
- Communicated the plan across the multidisciplinary teams and secured support from key stakeholders

¹The Productive Ward: Releasing Time to Care™ (NHS Institute for Innovation and Improvement)
www.institute.nhs.uk/quality_and_value/productivity_series/productive_ward.html



- Started to develop an agreed set of local measures to track progress based on the 'how to' guide metrics for wards and trust boards
 - Considered the starting point for the work, e.g. a 'showcase ward'
 - Have clear roll out and review plans for spread and sustainability over time.
- e. The plan should be built on a 'bottom up' approach, however its overall success will depend on clear and visible links to your organisation's strategy, as well as clear and visible leadership and support from the trust board
- f. You will need a communications plan and a realistic time frame to ensure you achieve good engagement across the organisation and stakeholders.



TOP TIP

Use the NHS GC's to help support the development of a culture for compassionate care.

These principles are:

- Courage
- Commitment
- Care
- Compassion
- Competence
- Communication



TOP TIPS

- Do you have the support and leadership at executive level?
- Are the changes you want to make aligned with the strategic priorities of your organisation and wider community?
- Are governance arrangements for the improvement work either planned or in place?
- Have you communication plans in place to ensure everyone is aware of the improvements you plan to undertake?



- Measurement for improvement not judgement is important
- Have you planned to undertake a baseline before you introduce change so you can demonstrate the improvements that you have made?
- Have you thought about building sustainability in from the outset in the prepare phase?
- Have you got the right people in place and are you enabling them to have local ownership for the change you have planned?



3. Key enablers

The focus is to ensure everyone is treated as an individual, identifying the key enablers that will help you and your organisation achieve high quality care for everyone will be key to your success. Enablers such as Electronic Palliative Care Co-ordination Systems (EPaCCS), Amber care bundle, Advance Care Planning will help you provide high quality care that is well planned, co-ordinated, monitored and responsive to the individual's needs and wishes.

This Transforming end of life care in acute hospitals: The route to success 'how to' guide will help you adopt and adapt tried and tested approaches to implementing end of life care - so you can accelerate your progress towards improving the quality and experience of end of life care in your local services.

Key approaches and enablers would include:

- Advance Care Planning (ACP)
- Electronic Palliative Care Co-ordination Systems (EPaCCS)
- Rapid discharge home
- AMBER care bundle
- Priorities for Care
- Large scale change.





Advance Care Planning (ACP)

Advance Care Planning is a voluntary process of discussion and review to help an individual who has the capacity to anticipate how their condition may affect them in the future.

If the person wishes to they can set on record choices about their care and treatment² (known as Advanced Statement) and/or an advance decision to refuse a treatment³ in specific circumstances.

These choices can then be referred to by those responsible for care and treatment (whether professional staff or family carers) in the event that the person loses capacity to decide once their illness progresses.

Advance Care Planning will involve a series of conversations and reviews in which a person's wishes are explored, identified and then recorded. There should be locally agreed policies about where care planning documentation is kept, including any formalised outcomes of Advance Care Planning.

There should also be systems in place to enable sharing between the health and social care professionals involved in the care and treatment, including out-of-hours providers and ambulance services.

Useful ACP support tools are:

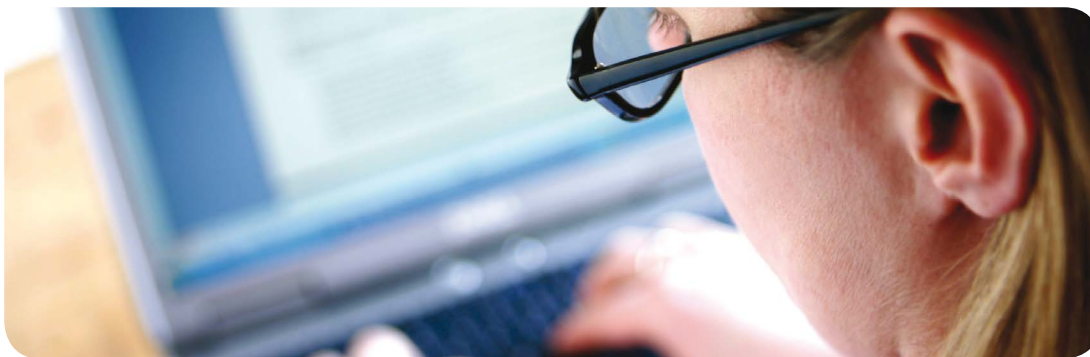
- [Preferred priorities for care documentation \(NEoLCP\)](#) (National PPC Review Team, 2007)
- [Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff](#) (NEoLCP, 2011)
- [The differences between general care planning and decisions made in advance](#) (NEoLCP, 2010)
- [Planning for your future care](#) (revised NHS Improving Quality 2014)
- [Holistic common assessment of supportive and palliative care needs for adults requiring end of life care](#) (NEoLCP, 2010)
- [e-ELCA End of Life Care for All e-learning, which includes modules on ACP](#)
- [Concise Guidance to Good Practice: Advance Care Planning](#) (NEoLCP, 2009)

For health and social care professionals:

- [Advance Care Planning e-learning toolkit](#)
This toolkit contains key information on Advance Care Planning for health and social care professionals – access to the toolkit is free
- [Advance Care Planning animation](#)
This five minute animation gives an overview of Advance Care Planning. Health and social care professionals may find this a useful tool to help explain Advance Care Planning to other professionals and people affected by cancer

² www.nhs.uk/media/2455504/supportsheet18_preferred_priorities_of_care_ajr_updated_28_oct.pdf

³ www.nhs.uk/resource-search/publications/eolc-adrt.aspx



Electronic Palliative Care Co-ordination Systems (EPaCCS)

EPaCCS enable professionals to share key information about end of life wishes, care preferences and key care details for those identified as likely being near the end of their life.

Within governance, the information can be accessed by a range of service providers. The ultimate aim is to improve patient choice and care co-ordination so that patients and families can benefit from active management at the point of care. This facilitates more people to be cared for in the place of their choosing.

EPaCCS have developed from an identified need to improve care co-ordination across multiple agencies recognised as providing end of life care. There is a growing body of

documentation about EPaCCS. A good starting point is NHS Improving Quality's '[Making the Case for Change](#)'.

The national information standard - [Palliative Care Co-ordination: core content \(SCC11580\)](#) - specifies the key data to be held in EPaCCS. It provides full details of the requirement including structure and definitions of the data items. The National End of Life Care Intelligence Network provide a [range of resources](#) to support implementation and application of the information standard.

[EPaCCS Recommended IT Requirements](#) have been defined through working in partnership with numerous professional bodies. This guidance is offered to help localities meet the national digital agenda for interoperability within their local EPaCCS.



Rapid Discharge Home

Many people who may be in the last twelve months of life would choose a rapid discharge home (or care home). It is important to begin these conversations as early as possible, preferably, with the GP and the patient so that the patient's wishes and preferences are recorded as soon as possible.

For patients in the last days of their lives then the process of rapid discharge home starts with **excellent clear communication:**

- Firstly between patient, family and clinical staff to ensure full recognition and understanding of dying, the possibility and choice of rapid discharge home and the risk of dying en route
- Secondly between hospital teams, pharmacy staff, ambulance services, GPs, out-of-hours medical services, district nursing services, social carers, hospice at home services, equipment loans, accompanied transfer staff (who can give a face to face handover) and others, dependent upon local service configuration.

It also requires each service to recognise this as important and urgent, to make it happen quickly and seamlessly for each patient and family, setting standards for delivering their own element within a specified time, measured in a very small number of hours.

Examples might be agreements for a high dependency (non paramedic) ambulance arriving within two hours, prescription dispensed within two hours, equipment delivered within four hours.

Cross boundary communication and documentation is vital so that **individual plans for care** (which may include an anticipatory management plan for a predictable clinical event e.g. major haemorrhage), involving patient and family, developed in one setting, can be continued in another, and medicines prescribed in hospital can be administered from a completed appropriate **community or care home drug administration order**.

TOP TIP

Remember to ensure written communication with primary care services, for example communicating discharge summaries with an individual's GP.

Appropriate plans for all predictable events need to be in place:

- **Cross boundary resuscitation plan** - if cardiopulmonary resuscitation is not to be attempted then a cross boundary order recognised by the ambulance service and community services needs to be in place
- **Death in transit plan** - if the patient should die en route - do the family wish them to continue home into their own bed or be brought back to A&E?
- **Death certification plan** - outlining which doctor is in a position to certify the death if the patient should die before being seen by their own GP.

Ward staff should telephone the GP and district nurse as the patient leaves the ward so that they are ready to receive them at home and make that initial assessment visit quickly to provide care and support for patient and family, and out-of-hours services should be faxed with information or **Electronic Palliative Care Co-ordination Systems** used to ensure good co-ordination of care 24/7.

Once a local process is established, and frontline staff become confident in offering a Rapid Discharge Home (or care home) to patients, then the number of patients and families who take up the offer is likely to increase. In one district general hospital for example, 1 in 4 of all patients who are dying in hospital are offered Rapid Discharge Home (or care home); 2 in 5 take up the offer, resulting in 1 in 10 of all those dying in hospital being successfully transferred.

Approximately 1 in 100 transfer attempts fail due to rapid deterioration in condition or delays in the process. Those who are transferred and die, have a median lifespan of four days, whilst 5% improve, require a change of care plan and live several months. For most of these people we have only one chance to get it right first time, there is no rehearsal!



Managing patients whose recovery is uncertain: the AMBER care bundle and treatment escalation plans

The AMBER care bundle is a simple approach used in hospitals for patients who are acutely unwell when clinicians are uncertain whether a patient will recover in part due to underlying chronic conditions or frailty. It supports the proactive management of these types of situations that may be dynamic and changing.

The approach encourages staff, patients and families to continue with treatment in the hope of a recovery, while talking openly about people's wishes and putting plans in place should the worst happen. It consists of four elements:

- Talking to the person and their family to let them know that the healthcare team has concerns about their condition, and to establish their preferences and wishes
- Deciding together how the person will be cared for should their condition get worse
- Documenting a medical plan
- Agreeing these plans with all of the clinical team looking after the person.

The AMBER acronym stands for:

- **A**ssessment
- **M**anagement
- **B**est practice
- **E**ngagement of individuals and carers
- **F**or people whose **R**ecovery is uncertain

Emerging evidence suggests:

- Improved decision making
- A positive impact on multi-professional team communication and working
- Increased nurses' confidence about when to approach medical colleagues to discuss treatment plans
- People being treated with greater dignity and respect
- Greater clarity around preferences and plans about how these can be met.

More information on the AMBER care bundle can be found at:

www.ambercarebundle.org

CASE STUDIES

Worcestershire Acute Hospitals NHS Trust

[Building on Board support, education and training and COQINs to sustain end of life care improvement.](#)

Derby Hospitals NHS Foundation Trust

[A measurable impact for patients whose recovery is uncertain.](#)

Section 3

The person's condition is then monitored closely and followed up on a daily basis to record and respond to any changes and address any concerns that they or their family may have.

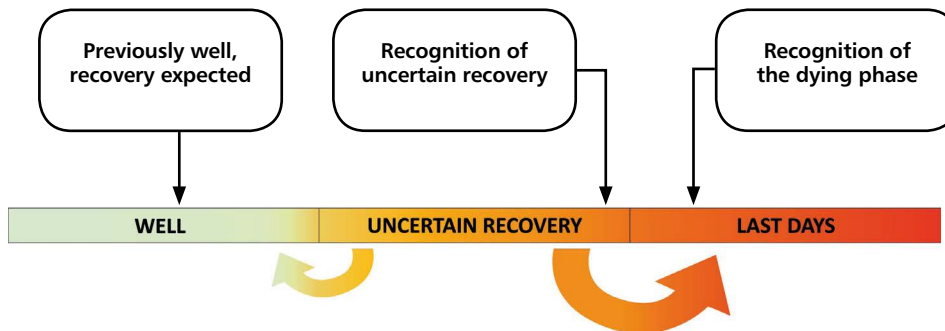
The AMBER care bundle contributes to people being treated with dignity and respect and enables them to receive consistent information from their healthcare team. It helps people and their carers to be fully involved in making decisions and knowing what is happening with their care.

It complements Treatment Escalation Plans (TEP) or similar approaches if these are in use within the hospital trust and in the wider health economy. These set out aspects of medical planning in the event of a patient deteriorating and their Do Not Attempt Cardio Pulmonary Resuscitation Status. Treatment Escalation Plans should also be developed in consultation with patients and those important to them.

If a patient's recovery becomes uncertain, any pre-existing TEP and advance care plans should be reviewed, considered, followed or adjusted as necessary with patients and those important to them.

Underpinning all these approaches is the principle of shared decision-making with patients, involving those important to them as appropriate and offering the necessary support.

Patients whose recovery is uncertain



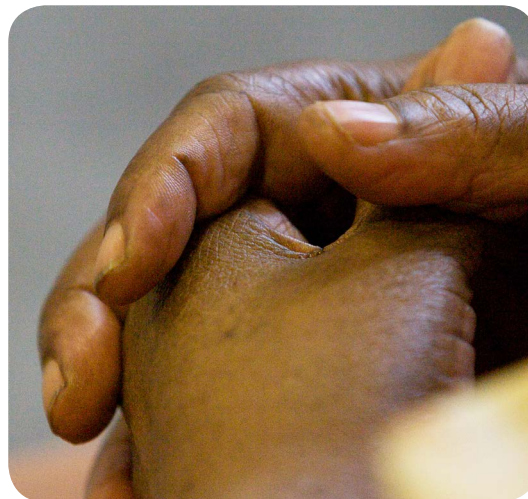


Priorities for Care of the Dying Person

Priorities for the care of the dying person:

- The possibility that a person may die within 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
- Sensitive communication takes place between staff and the dying person and those identified as important to them
- 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
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

The Leadership Alliance for the Care of Dying People has published a new approach to caring for dying 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.



One Chance to get it right - Published June 2014 by the Leadership Alliance for the Care of Dying People

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

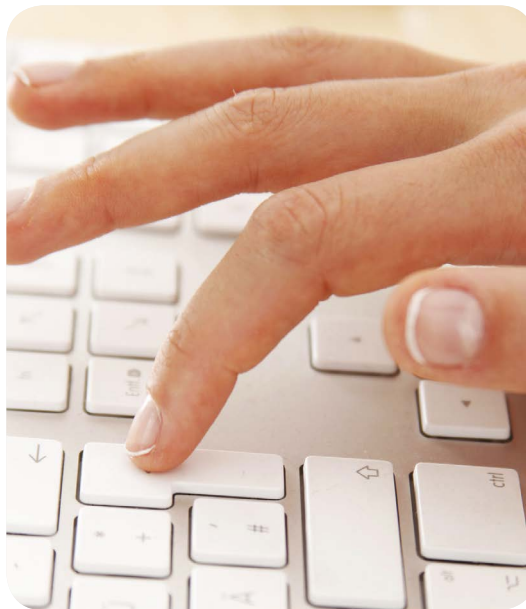
4. Other tools to help

You may have preferred approaches and tools within your organisation that you can use to establish your baseline or starting point. You can also use the tools provided in *The Productive Ward* – to help you do this.

There may also be national or local strategic measures already being reported, including [Five Year Forward View](#) priorities and [The Forward View into action: planning for 2015/16](#) that you can use as well. In addition, as part of your planning, you may also wish to reference the [Actions for End of Life Care: 2014–16](#) and the [Ambitions for Palliative and End of Life Care](#).

You can incorporate these into your baseline so that you can ensure that you are measuring what is important, avoiding duplication and establishing a robust baseline which will allow you to report progress with confidence.

Look at what you are already measuring and collecting, involve your executive board and information team to find out what data you collect so that you can build on this.



TOP TIPS

Measuring experience of care in end of life care:
www.nhs.uk/media/2642618/eolc_measuring_experience_of_care.pdf

An overview of Local Measurement: transforming end of life care in acute hospitals programme:
www.nhs.uk/media/2642623/factsheets3_eolc_measurement_analysis.pdf



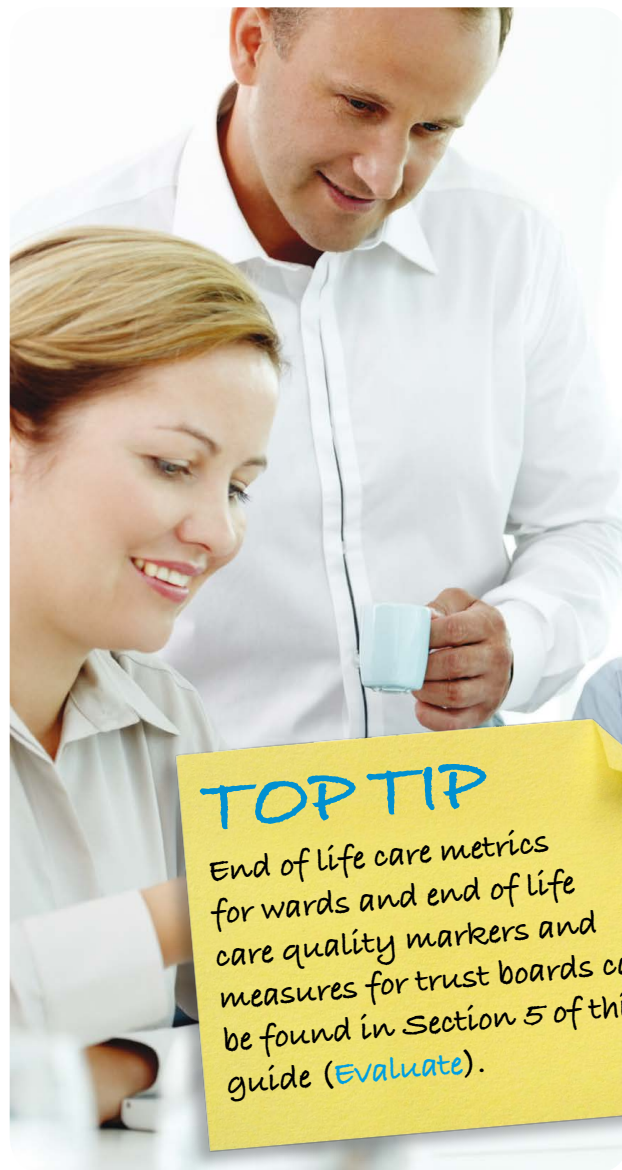
5. How to measure progress

Measures can be a great asset to you and your organisation in demonstrating whether or not the improvements you have made are working and whether you are making progress towards your strategic or team goals.

The emphasis is on measurement for improvement, not judgement. This is important because many staff get fed up with measures which are either poorly designed or inappropriately used after being set up as performance targets and not improvement goals.

Using measurement to track your progress will lead your team to develop, implement and frequently review a set of measures that are right for you. Measurement can help you move decisions away from opinion and towards facts. We need facts to track our performance over time, help us solve our own challenges and give us better control of our services.

Once you have identified what your organisation and team are currently measuring as part of establishing your baseline, you can make a decision about building these local or national measures into the set of measures you are designing to track the improvements you are planning to introduce.



TOP TIP

End of life care metrics for wards and end of life care quality markers and measures for trust boards can be found in Section 5 of this guide (*Evaluate*).

Section 3

When thinking about communicating and developing measures you may like to consider:

- Involving as many staff as possible from the outset as to what data and measures are currently being collected
- Getting opinions from staff, individuals and carers as to what they would like the measures to tell them so that you can establish what is important
- Making sure you communicate that measurement is not an end in itself but a way of raising standards of care
- Having a clear process for developing measures and collecting data along with how you will publicise and present the data. The *Productive Ward* uses a 'knowing how you are doing' board which you can link to or apply with this area of work
- Monitoring progress but most importantly evaluating and acting upon the information your data is showing
- Sharing data with your team, trust board, steering group and key partners.



TOP TIP

Keeping measurement simple, accessible and highly visible will be more motivating for staff than if you design a system with a few senior people in a room and then try to impose these on your team.



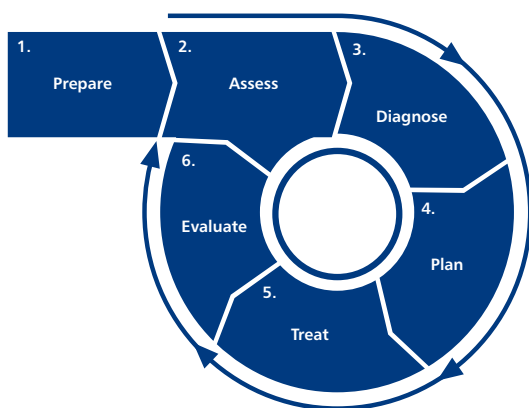
Section 4 The route to success

Treat

Section 4

Use the six step continuous improvement model to guide you step by step through implementing systems to facilitate recognition, good communication, advance care planning and care co-ordination, ultimately delivering high quality care.

- **Step 1** – discussions as the end of life approaches (Prepare)
- **Step 2** – assessment, care planning and review (Assess)
- **Step 3** – co-ordination of care (Diagnose)
- **Step 4** – delivery of high quality care in an acute setting (Plan)
- **Step 5** – care in the last days of life (Treat)
- **Step 6** – care after death (Evaluate)



Who to involve

- Multidisciplinary ward team
- Specialist palliative care team
- GPs, primary and community care staff
- Ambulance services
- Social care services
- Generalist and specialist staff
- Support staff
- Out-of-hours services
- Discharge liaison co-ordinators
- Hospices
- Pharmacies
- Equipment providers
- Service managers
- Commissioners and clinical commissioning groups
- Mortuary staff
- Bereavement services
- Volunteers.

Importantly, your service improvement activities will support you in developing good communication systems both within your hospital teams and with partners working in the community and social care services.



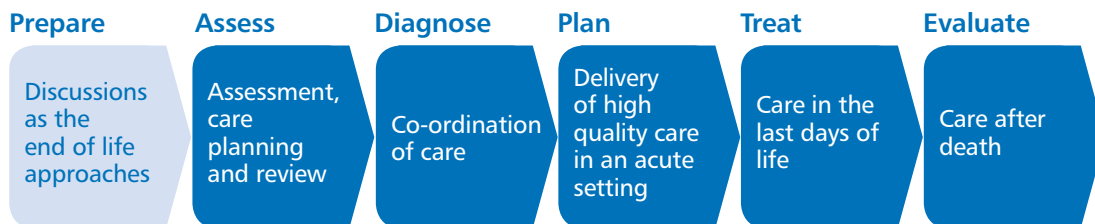
TOP TIPS

Section 8 of this guide contains links to disease and non-disease specific end of life care resource guides on:

- Advanced kidney disease
- Heart failure: A framework for implementation
- Learning disabilities

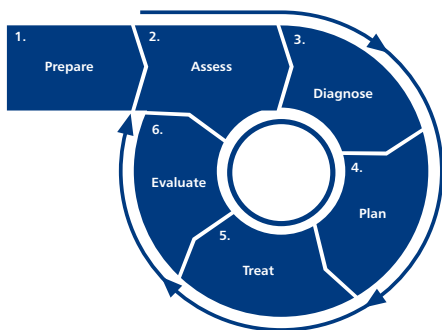


Step 1 – Discussions as the end of life approaches



Challenge: One of the key barriers to delivering good end of life care is a failure to discuss things openly. Agreement is needed on when discussions should occur, who should initiate them and the skills and competences staff need for this role.

Outcome: People receiving care and their families and carers will be given the opportunity for open and honest discussions with staff that form the basis for advance care planning and meets individual choices wherever possible.



What you need to do

1. Implement an identification model using recognised good practice to ensure generalist and specialist staff are trained to recognise a dying person, for example the Gold Standards Framework Prognostic Indicator Guidance (see step 1 resources)
2. Ensure generalist and specialist staff have capacity and are competent and confident in communications skills, including breaking bad news to individuals and their relatives
3. Check that your environment has safe, private and appropriate places for having these types of conversations with individuals and their relatives
4. With your primary care and community partners, work towards establishing an Electronic Palliative Care Co-ordination System (EPaCCS) and mechanisms for keeping it up to date
5. Find out if your trust has a recognised approach to delivering good end of life care and whether staff are trained appropriately.



Practice example

Bradford Teaching Hospitals NHS Foundation Trust

Getting more people approaching their last year of life home from hospital sooner, if that's their choice

Introduction

Bradford Teaching Hospitals NHS Foundation Trust has 855 inpatient beds, excluding maternity and children's wards. The Bradford Hospital Palliative Care Team (HPCT) undertook a pilot 'Last Year of Life' project on two acute medical wards and are now part of the national Transform programme.

Using a phased approach the team will implement the programme trust wide by April 2015. In December 2013, the programme which includes the implementation of the AMBER care bundle for care of people whose recovery may be uncertain, had implemented this on six wards. The HPCT's emphasis has been working with wards to achieve sustainable quality improvement in relation to end of life care. One of the aims of the programme was to streamline the Fast Track discharge process (prognosis of days to weeks) and if patients wish, to discharge them either home or to their existing care home within 48 hours. These changes are available to patients on all appropriate adult inpatient wards (27 in total).

Overview - making a measurable difference for patient End of Life Care choice

- The trust aim for 80% of patients identified as being in their last days to weeks of life who want to die in their own home or their existing care home, to be discharged within two days
- The HPCT had already carried out a baseline audit of 100 medical records of patients in their last year of life. This established that in the six month period patients had a total of 200 admissions over 1,592 bed days. The team then reviewed 100 patients who had documented decisions about their wishes around end of life care e.g. preferred place of death and then, been placed on the End of Life Register (Electronic Palliative Care Co-ordination System (EPaCCS)) and saw a reduction in the number of hospital admissions and a marked decrease in the number of occupied bed days
- Documentation of patients' preferred place of death increased from 4% to 88% in the second audit
- Of the 100 patients supported by EPaCCS who had died, 89% had their wishes for their preferred place of death documented and two thirds had their preference met
- In 2012, 45% of patients in the local district died in their usual place of residence (which includes their home or care home)
- The team are aware the data above are from a sample of 100 patients and future audits may not show the same outcomes for patients.

Benefits from being part of a national programme and regional network

Bradford Teaching Hospitals NHS Foundation The HPCT value being a part of the national Transform programme. Shared learning, and support from regional networks and from other acute trust colleagues is vital alongside access to the small dedicated national team, which includes the ability to benchmark their improvement data.

Impact

Individuals and loved ones

The HPCT undertook a baseline carers survey and have also implemented some changes to improve facilities for carers of patients who are actively dying with a prognosis of hours/days. The team are now working on a more comprehensive bereavement survey. They actively monitor patient compliments and complaints relating to end of life care, which are fed back to the trust board. End of life care was included in the trust "Experience Matters" open day for the public to give their views on services.

The Last Year of Life Project has won a number of awards – see resources below.

Staff

At the trust, end of life care teaching, leadership and audit is an integral part of the HPCT's role, alongside their regular clinical caseload.

When a member of the HPCT is on a ward, for example attending a consultant round, staff take the opportunity to ask for specialist information across all ward patients and not just those whose recovery may be uncertain. Staff feedback has been "It's helped us see patients more holistically." The HPCT has delivered communication skills training for senior medical and nursing staff working with and caring for patients who may be in their last year of life.

System

Where appropriate ward based staff aim to initiate discussions about Advance Care Planning with a patient or, with their consent, their family.

Information may include decisions on CPR, Preferred Place of Death or ceilings of care. In Bradford both Specialist Palliative Care Services and local GPs and district nurses use the same computer system; therefore with patient consent this information can be shared across settings. This can help prevent a patient being inappropriately re-admitted to hospital. If appropriate, discussions that began around end of life care in hospital can be continued when the patient has returned home.



Challenges

Identifying complaints specifically related to end of life care can be difficult, especially if there is no 'computer data code' for end of life care. However, highlighting these complaints can help target education needs around end of life care. The trust has now agreed a definition for complaints relating to end of life care, as all those relating to care within three months of a patient's death.

KEY LEARNING

- Change doesn't happen over night, it requires perseverance and visibility. This can be through presentations at trust wide events e.g. 'Grand Round' or being an active presence at speciality clinical governance meetings
- Keep senior management up to date on progress
- (Transform) "is not just implementing a tool it is about understanding and working with organisational culture"
- Do not underestimate the value of staff with in-depth understanding and experience of palliative and end of life care
- Be persistent and resilient
- Provide reliable, consistent data to demonstrate progress made, this supports the case for continual quality improvement and engagement.

Resources

1. **Electronic Palliative Care Co-ordination System** (see **Section 3: plan**)
2. **AMBER Care Bundle**
(see **Section 3: plan**)
3. **Gold Standards Framework (GSF)**



GSF is a systematic evidence based approach to optimising care for people in the last year of life with any condition in any setting. GSF focuses on enabling generalists in community and hospital settings to work more effectively with specialists, to care for patients from early identification, right through to discharge home or care in the final days. The programme leads to GSF Accreditation and the Quality Hallmark Award, recognised by CQC.

GSF Prognostic Indicator Guidance

Clinical prognostic indicators are an attempt to estimate when people have advanced disease or are in the last year or so of life. This indicates to those in primary and secondary care that people may be in need of palliative/supportive care:

www.goldstandardsframework.org.uk

4. **Quick guide to identifying patients for supportive and palliative care**

Developed by Macmillan Cancer Support, NHS Camden and NHS Islington to help identify those needing end of life care services:

<http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/quick-guide-to-identifying-patients-for-supportive-and-palliative-care.aspx>

5. **Dying Matters information resources**

Numerous resources available to raise awareness and promote conversations about death, dying and bereavement:

www.dyingmatters.org/overview/resources



A Party for Kath is an award-winning, five-minute film produced by the Dying Matters Coalition to demonstrate the benefits of greater openness around death and dying.

6. **e-ELCA e-learning**

Free to access for health and social care staff and includes modules on initiating conversations and communications skills:

www.e-lfh.org.uk/projects/e-elca/index.html



7. **Finding the Words**

A workbook was developed following discussions with people who have life limiting conditions or have experienced the death of a loved one. The aim is to help staff with end of life conversations:

www.nhsiq.nhs.uk/resource-search/publications/eolc-finding-the-words.aspx



This edit of *Finding the Words* focuses on the importance of initial conversations about end of life care and what it means to those who are dying and their families.

8. **Skills for Health Workforce Functional Analysis Tool**

Six workbooks which describe the workforce skills required to ensure people receive quality care in their last year of life:

http://endoflifecare-intelligence.org.uk/end_of_life_care_models/skills_for_health

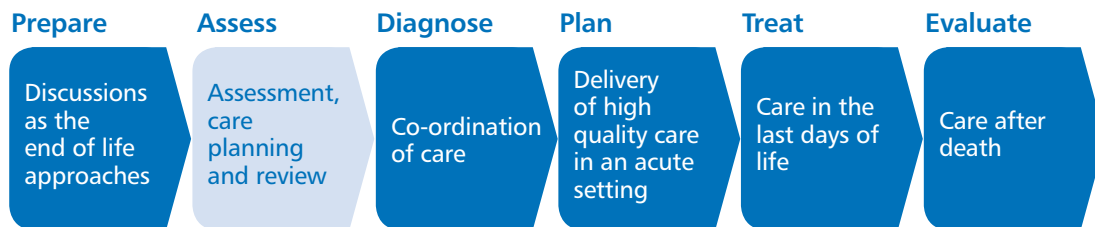
9. **Dying Matters** has produced a number of films that can be used where discussions about end of life planning are appropriate.



10. **NHS Improving Quality**

www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care/improvement-tools-and-resources-route-to-success-series.aspx

Step 2 – Assessment, care planning and review



Challenge: An early assessment of an individual's needs and an understanding of their wishes is vital to establish their preferences and choices and to identify any areas of urgent need. Too often an individual's needs and those of their family and carers are not adequately assessed.

Outcome: Each individual has a holistic assessment resulting in an agreed care plan with regular review of their needs and preferences. The needs of carers are assessed, acted on and reviewed regularly.

What you need to do

1. Utilising the AMBER care bundle will trigger a holistic needs assessment and should provide the opportunity for initiating Advance Care Planning conversations as part of an ongoing process
2. Establish a mechanism for checking whether an individual has an existing personal support plan or social care assessment and whether a joint assessment might be appropriate
3. Agree an appropriate holistic assessment tool or tools for your ward/trust
4. Establish a system whereby needs of carers are assessed, planned for and acted upon
5. Work with multidisciplinary teams and social care services to raise awareness and broaden understanding of the issues related to end of life care in order to ensure that both health and social care needs are met
6. Establish mechanisms for sharing results of assessments across teams and agencies that are meaningful but do not conflict with confidentiality, for example with GP out-of-hours and ambulance services
7. Ensure that appropriate training, which includes Advance Care Planning, takes place for all professionals undertaking assessments.



Key principles in Advance Care Planning

Advance Care Planning (ACP), when done well, can achieve a number of important outcomes. It can help:

- Improve people's wellbeing by improving their understanding of their illness
- Help people to be involved in decisions about their care
- Enable communication between individuals, families and clinical teams
- Ensure that the care and treatment people receive is informed by their own decisions and preferences when they become incapable of decision making
- Improve the healthcare decision making process by facilitating shared decision making between the individual, their family and clinical teams.

TOP TIPS

- Get the environment right
- Consider the person's emotional state and cultural background
- Create an opening
- Ask the person who they would like to include
- Arrange for appropriate support services
- Be prepared with information and the prognosis/options
- Don't avoid it until the need for a decision is urgent
- Allow time for reflection.

One useful way of thinking about Advance Care Planning is to consider it as a series of steps:

1. Assess the person's understanding of their illness
2. Determine how the person wants to make decisions
3. Determine what the person's expectations are about their illness and treatment
4. Determine if the person has any important care preferences or choices about their treatment and care, including end of life care, that they want to be taken into account once they can't make decisions for themselves.

Helping staff to start Advance Care Planning conversations is crucial but can be something that many find challenging. Advance Care Planning conversations must be sensitively introduced and not imposed on an unwilling person. However, all individuals should be provided with the opportunity to participate if they wish.



In addition, research-based suggestions include the following examples of better words to say:

Instead of:	Better words to say:
There is nothing more we can do	We want to find out how to help you
Would you like us to do everything possible?	How were you hoping we could help?
Withdrawal of treatment	Withdrawal of ventilation (or other specific treatments) and making sure you are comfortable

Davison S et al. (2010) Advance care planning in patients with end-stage renal disease. In: Chambers EJ, Germain MK, Brown EA (eds) Supportive Care in the Renal Patient. Oxford: Oxford University Press (2nd Edition)

Pantilat, S (2009) Communicating With Seriously Ill Patients - Better Words to Say. JAMA, 301(12): 1279-181



Practice example

The Leeds Teaching Hospitals NHS Foundation Trust

A systematic approach to delivering person-centred end of life care improvement across a large trust

Introduction

Leeds Teaching Hospitals NHS Trust has almost 2000 adult inpatient beds and includes Leeds General Infirmary and St James University Hospital. The Transform programme is seen as an umbrella for many specific end of life care projects, including AMBER care bundle for patients whose recovery is uncertain. The programme is reaching the appropriate 66 of the trust's 92 wards and into its wider local health and care settings. The end of life care team benefitted from stability and long established working relationships during widescale trust re-organisation in 2013.

Transform programme planning overview

- Energy initially focused on three areas: oncology, respiratory and medicine for the elderly
- Benefited from senior manager input in early planning stages
- Six months initial dedicated service improvement input provided a systematic approach, project management skills to identify success measures and setting up of workstreams as well as bringing the right people to the table
- An early combination of senior clinician, nurse, manager and improvement input has worked well. Driver diagrams helped identify really specific quality improvement aims
- There is recognition the data you collect can be driven by what you want to achieve
- There was access to early informatics experience for baseline and ongoing measurement
- Ward heatmaps were used in planning implementation
- There are four different workstreams: education and training; patient and public information needs, measurement; and interface with the community. These helped to improve overall team focus on goals and aims as well as to develop more end of life care leaders and system capability
- There has been a move from training to education, with a rolling education programme in addition to Transform programme.



Planning and implementation approach

Once the team identify wards, they meet with senior sisters, attend medical departmental meetings and offer one to one clinical consultant time before any education starts. This allows wards to plan for the release of staff time in advance. Two hour sessions for qualified nurses, cover all five Transform enablers, with communication skills training for clinical support workers. To connect with junior doctors and registrars they attend existing education or audit meetings. For a month, during initial change implementation, a team member is present at any daily board/ward round, or multidisciplinary team round. There's been excellent feedback from this visible presence. It also supports staff whose style is learning by doing. Real time feedback from case note audits provides opportunities to recognise good practice.

Impact

Individuals carers and loved ones

From a recent audit, there was evidence of advance end of life care communication with a very high percentage of relatives. While there is always more to improve, 90% of the public surveyed agree 'nurses always treat patients that are dying with respect and dignity.' There is more system evidence clinicians are acknowledging when someone is entering their last days of life, with an awareness of preferences and alternatives to care in hospital. Leeds has a dedicated palliative care ambulance

service covering seven days a week. There are a small number of wards within the trust with a dedicated discharge facilitator to support fast track discharges. There is an easily and quickly accessible rapid discharge flowchart and guidance for rapid discharge on the trust's intranet. The Leeds wide health needs assessment, funded by commissioners, with care focus group input may lead to different ways of managing discharge.

Staff

At the trust, all wards have an end of life care link nurse, with an annual link nurse conference that includes patient and carer representation. The link nurse role has also provided a staff development opportunity, with some staff moving into hospice or palliative care. The team recognise and value the daily contribution made by ward nurses to an individual's end of life care. The team also connect with allied health professionals, who can often identify patients they have regular contact with may have an uncertain recovery, and who may benefit from considering thinking about their wishes for where they would like to be cared for in future.

System

Looking ahead, the team have already piloted three palliative nursing care plans on three wards, for last year of life, uncertain recovery and care of the dying. These will be reviewed in light of future Leadership Alliance guidance. While there is a benefit from a standard end of life care improvement approach across the trust when staff move wards, different specialties may want to focus on different areas such as identification, escalation or advance care planning elements, depending on current practice. Identifying this early, supports implementation and outcomes.

Challenges and solutions

As there is no single trust wide electronic patient record as yet, it's more of a challenge to capture and analyse data consistently. There is an end of life care tab within oncology patient pathway manager (PPM) which captures patients' preferences and there are plans to add this to the PPM portal for roll out across the trust. 69 GP practices (75% of the Leeds population) now have an electronic system to co-ordinate palliative care in place. Leeds Care Record development to integrate all the different IT systems across the city and give a single view of a patient's future care preferences is ongoing.

Given the challenge between wider quality improvement roll out and the clinical team's 'day jobs', the approach is to build capacity and capability engaging wider leadership and ownership across the trust, building from link nurses and the trust wide end of life care group.

KEY LEARNING

- Driver diagrams help to identify specific quality improvement aims
- Focussed paper case note audits take time but give excellent evidence of actual clinical practice and communication
- Engage trust departments as partners. Ask "What is it we can help you with?"
- Customise, as well as standardise
- It helps for trust consultants to understand how their clinical recording and sharing impacts community out-of-hours and GP services. Feed back real stories to them of the difference it makes
- You need to work with individuals and their learning and development styles
- Having the ward manager on board helps sustain improvement during organisational change.



Practice example

The Conversation Project

Empowering Royal United Hospitals Bath NHS Foundation Trust staff to feel more comfortable having conversations about the wishes of patients approaching the end of their life

Introduction

The Conversation Project shows the importance of earlier identification of approaching end of life, need for greater involvement in conversations with patients and families around decision-making, ensuring appropriate understanding and how this helps to make informed decisions about the future.

The project team, which included the specialist palliative care team, recognised when health care professionals accept that a patient is dying, they may feel comfortable with the care that they need to give, and more confident in their actions since the plan of care feels more certain.

However, the period of time prior to identifying a patient is in the last few days of life, is often one of great uncertainty and anxiety, for the patient, family and also for staff. The team felt this area of care, for their staff, was in greatest need of exploration.

The Conversation Project was originally developed by the Royal United Hospital with the Kings Fund Patient and Family Centred Care Programme (PFCC), to support patients nearing

the end of life and their families/carers to have the opportunity to talk about their wishes, uncertainties and concerns as part of advance care planning, to then inform care planning. See www.kingsfund.org.uk/sites/files/kf/bath-poster-end-of-life-nov13.pdf

It has supported early identification of patients with end of life care needs in an acute setting, as well as communication and information sharing of discussions and decisions made across settings, to support care out of hospital.

Overview and approach

The approach taken was to collect evidence from clinical records, set up a working group, implement new ways of working and collect evidence to see if a positive change was taking place. Notes were reviewed on a regular basis and data collected. Selected data are shown in graphs 1–4 below. The palliative care team attended regular ward multidisciplinary team (MDT) meetings to ensure end of life care issues were included in the discussions and to act as a resource for staff.

The importance of having regular discussions with the patient and/or family, and recording the outcomes of discussions continues to be highlighted to the wards and is shared at the white board/MDT meetings.

- **Staff engagement** – small teaching sessions, one-to-one discussions with staff and staff questionnaires helped
- **Meeting the educational and training needs of staff** is an ongoing challenge and not easily achieved, but small pockets of training as at March 2015 have been carried out. The team continue to support all levels of staff in managing individual patient care
- **Sustaining change** – the team worked with staff who were most motivated, then supported and benefitted from them as change agents. The team used evidence to show where positive change has happened
- **Maintaining motivation** – patient stories have been a motivating force

Motivation has been maintained with a simple message. The team remain aware that change can take time.

Clinical record audit findings from April 2014 to March 2015

Apart from one month, all relevant records reviewed showed either a decision made by the MDT team that recovery for this patient is uncertain, or they may be approaching their end of life or likely to die in the next few days.

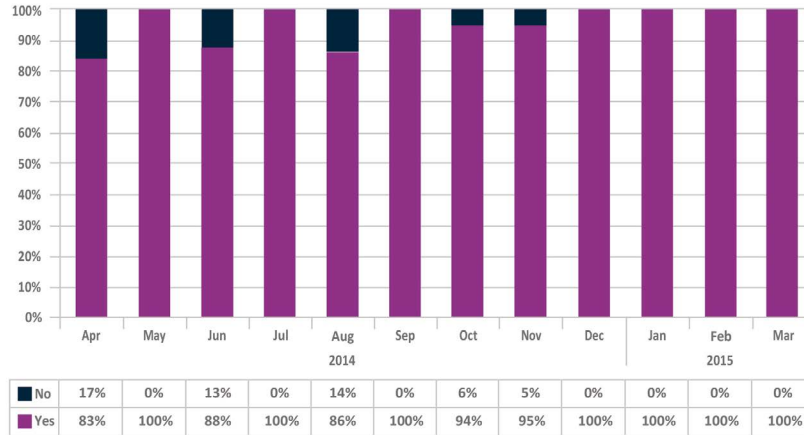
Audit evidence also showed when a patient did not have the capacity to take part in discussions about advance care planning or discussions at the end of life, the medical notes clearly evidenced this. At the time of writing there continues to be a higher percentage of

this being recorded on wards for the older person and the acute stroke unit.

Where discussions with the patient have been recorded as not appropriate, there was evidence of discussion being held with the family/carer for the patient. This again was predominantly on wards for the older person and the acute stroke unit. From April 2014 to March 2015 all reviewed records showed evidence of a discussion with a family member unless the person had none. The 2015/16 audit will include more detailed questions if there has been no discussion with a family member.

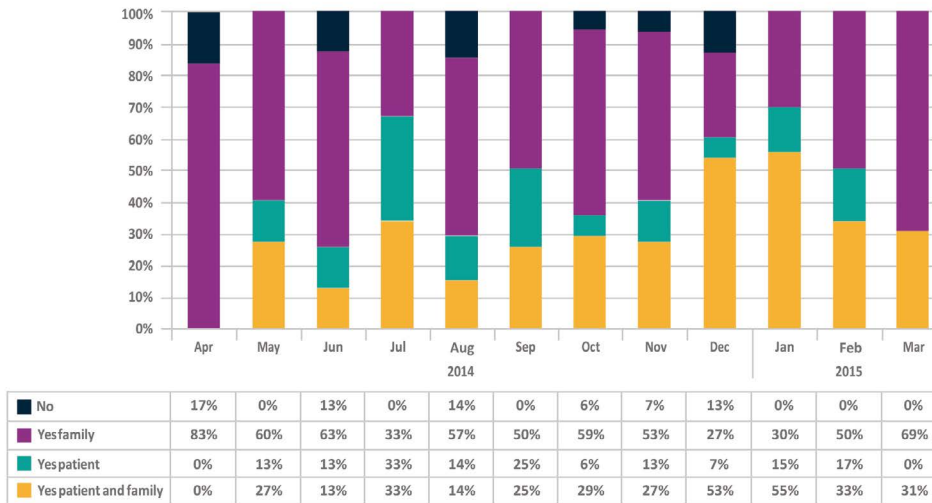
The following graphs show the change evident from clinical audits:

Graph 1: Percentage of records with a clear medical plan



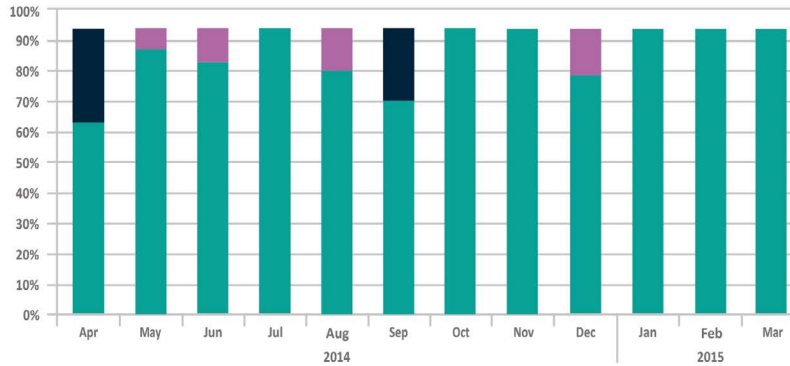
Note: data has been rounded to the nearest % so some columns may not add up to 100%.

Graph 2: Percentage of records with evidence of regular discussion with patient and/or family



Note: data has been rounded to the nearest % so some columns may not add up to 100%.

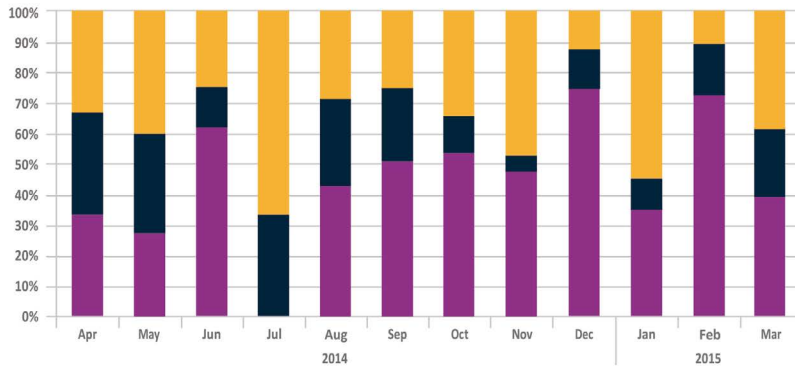
Graph 3: Percentage of records with a DNAR decision made or Ceiling of Treatment plan including DNAR



■ NA – decision already made	33%	0%	0%	0%	0%	25%	0%	0%	0%	0%	0%
■ No	0%	7%	13%	0%	14%	0%	0%	0%	17%	0%	0%
■ Yes	67%	93%	88%	100%	86%	75%	100%	100%	83%	100%	100%

Note: data has been rounded to the nearest % so some columns may not add up to 100%.

Graph 4: Percentage of records with evidence of advance care planning information passed onto the Primary Health Care Team on discharge



■ Yes	33%	40%	25%	67%	29%	25%	35%	47%	13%	55%	11%	38%
■ No	33%	33%	13%	33%	29%	25%	12%	5%	13%	10%	17%	23%
■ NA	33%	27%	63%	0%	43%	50%	53%	47%	75%	35%	72%	38%

Note: data has been rounded to the nearest % so some columns may not add up to 100%.

Where the audit identified 'not applicable', this was because the patient died in hospital. A number of records identified no evidence of information on advance care planning being passed on to the Primary Health Care Team on discharge, shown as 'No' in Graph 4. This is highlighted with the wards and information shared at white board/MDT meetings.

Spreading positive change

The Conversation Project was initially piloted on just one ward. Once this was felt to be working the project extended to a further five wards in 2013/14. In 2014/15 a further three wards had begun to implement the work. The plan is to adopt the themes of The Conversation Project as part of normal ward practice across all ward areas of the Royal United Hospitals Bath.

Patient experience

Measuring this can be a challenge. Identifying an opportunity to ask patients, when often they are very unwell can be particularly difficult. However, the team do know that if patients have had the opportunity to express their wishes, and been involved in decisions about their care, then it is more likely that their wishes will be met.

There are benefits to patients to ensure that there is appropriate decision-making and potential to reduce length of stay as the focus of care becomes more attuned to the patient's wishes.

Improving acute communication with primary care can enhance the coordination of care and help to ensure that appropriate care takes place.

Family experience

The project alerts staff to seek out families and be more proactive in their dialogue with them to ensure their questions are answered and concerns addressed.

From feedback from a small number of families about their experience of the conversations they had with health care professionals, all observed they valued the honesty and information they had been given.

Acute staff experience

Staffs' positive enthusiasm and engagement with this work has helped the project embed as staff understand the importance of what they are doing and why. It is greatly important to staff to make sure they meet the needs of patients and families at end of life care. This work has helped staff feel that this can be achieved, they recognise it is an area that can be continually improved and, equally their role and responsibility within it.

General Practice experience

GPs have welcomed information shared as part of discharge planning. Improving communication with primary care can enhance the co-ordination of care and help to ensure that appropriate care takes place.

Reflections and lessons learned

- Most advance care planning in the acute setting was consultant driven
- A greater multidisciplinary involvement in helping support patients and families as they approach the last phase of their life is beneficial
- Continual effort is needed to ensure advance care planning discussions are shared with relevant services
- A better collaborative approach between primary and secondary care and vice versa helps to improve patient care towards their end of life
- A focused project helps to identify areas of training and support that staff need
- Listening to the experience of patients and families can help to develop improved practice and services

Future development

The Conversation Project continues to grow and develop within the Trust, with the specialist palliative care team supporting a further five wards with implementation and nine wards with sustainability. In 2015/16 the Trust was also working with colleagues from the older person's unit and dementia coordinators to develop The Conversation Project as a model to support conversations and advance care planning for patients with frailty or dementia. It is hoped the model will be embedded across the whole Trust, so that it becomes part of normal practice to support and enable patients and families to have conversations about their wishes for future care.

Resources

1. *Holistic common assessment*

Guidance for holistic common assessment of the supportive and palliative care needs:

www.nhs.uk/resource-search/publications/eolc-hca-guide.aspx

2. *Capacity, care planning and Advance Care Planning in life limiting illness*

This guide covers the importance of assessing capacity to make particular decisions about care and treatment, and of acting in the best interests of those lacking capacity: www.nhs.uk/resource-search/publications/eolc-ccp-and-acp.aspx

3. *Thinking and planning ahead: learning from each other*

This training pack is designed to help people understand what advance care planning is, how to do it, and how to assist others: www.dyingmatters.org/sites/default/files/user/documents/Resources/ACP%20for%20volunteers/M3%20Booklet.pdf

4. *Preferred Priorities for Care tools*

Including documentation, an easy-read version, leaflet, poster and support sheet:

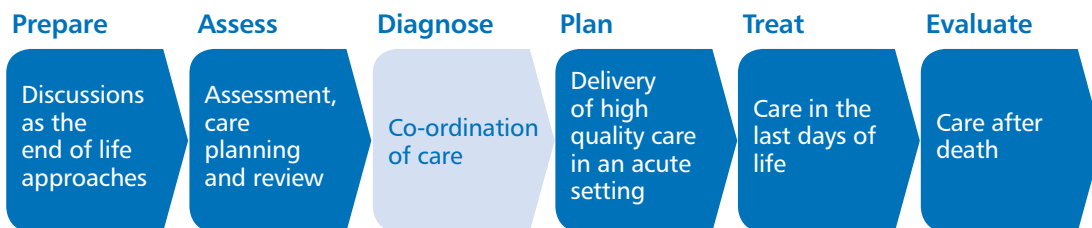
www.nhs.uk/resource-search/publications/eolc-ppc.aspx

5. *NHS Improving Quality support sheets*

- Support sheet 3 – Advance care planning: www.nhs.uk/media/2455429/supportsheet3_ajr_updated_28_oct.pdf
- Support sheet 4 – Advance decisions to refuse treatment: www.nhs.uk/media/2455434/supportsheet4_ajr_updated_28_oct.pdf
- Support sheet 6 – Dignity in end of life care: www.nhs.uk/media/2455444/supportsheet6_ajr_updated_28_oct.pdf
- Support sheet 12 – Mental Capacity Act (2005): www.nhs.uk/media/2455474/supportsheet12_ajr_updated_28_oct.pdf
- Support sheet 13 – Decisions made in a person's 'Best Interests': www.nhs.uk/media/2455479/supportsheet13_ajr_updated_28_oct.pdf
- Support sheet 16 – Holistic assessment: www.nhs.uk/media/2455494/supportsheet16_ajr_updated_28_oct.pdf
- Support sheet 17 – Independent Mental Capacity Advocates (IMCAs): www.nhs.uk/media/2455499/supportsheet17.pdf



Step 3 – Co-ordination of care



Challenge: If a holistic assessment has been carried out and shared appropriately it should be possible to co-ordinate care for the individual, their family and carers. This should cover out-of-hours, primary, community and acute health providers, the local hospice, transport services and social care. Electronic Palliative Care Co-ordination Systems (EPaCCS) provide the good practice model.

Outcome: Systems developed across local primary, community, secondary and social care as well as ambulance services will ensure co-ordinated care that is responsive to individuals and their carers' needs and choices.

What you need to do

1. Ensure there is a mechanism to identify a cross agency key worker for all people receiving end of life care
2. Examine the systems and processes in place for communicating across agencies and resolving blockages
3. Establish a framework for key agencies to ensure joint working, including governance arrangements
4. Establish a system to ensure rapid discharge home planning and access to continuing care
5. Establish a mechanism for review of rapid discharge home processes
6. Establish a system to ensure access to specialist palliative care services 24 hours a day
7. Ensure the day to day co-ordination of care for the individual whilst they are in hospital.

TOP TIPS

Remember to consider the needs of carers. Provide key worker contact details and signpost them to information and support services, such as:

- healthtalk.org: www.healthtalk.org
- Macmillan Support Services: www.macmillan.org.uk
- NHS Choices end of life care guide: www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx



Practice example

University Hospital Southampton NHS Foundation Trust

A whole system approach to improving acute end of life care

Introduction

University Hospital Southampton NHS Foundation Trust, one of England's largest trusts, includes an inpatient NHS hospice, community specialist palliative care team, day care and day case services, acute hospital palliative care team, bereavement service and education. Palliative care and end of life care sit in the same division as surgery, critical care and cancer care.

The Transform programme enabled the trust to bring together a continual programme of quality improvement, building on the 2008 End of Life Care Strategy.

As part of continual improvement in the provision of end of life care, working closely with commissioning partners and its wider community, the trust

- Asked members of an older people's forum to help rewrite their Advance Care Planning information
- Introduced a substantive end of life care facilitator post
- Provides a significant amount of education and training within the trust and its wider community, including care homes
- Provided training to General Practices to support them with understanding early identification of end of life care needs to support Advance Care Planning
- Has worked in partnership with the CCGs and primary care to facilitate the introduction of a Southampton wide Electronic Palliative Care Co-ordination System (EPaCCS)
- Values and encourages close working between clinical teams and the trust's well developed spiritual care and bereavement services
- Spiritual care service link regularly with the Southampton Council of Faiths
- Worked closely with community services for people who are homeless and use substances
- Supports and offers training to groups of staff who may not be immediately obvious such as cardiac technologists
- Introduced the options of organ and tissue donation as a normal part of end of life care
- Acted on direct feedback and introduced a free pass to waive car park charges when a death certificate is being collected
- Introduced nicer bags for families to collect loved ones' personal possessions
- Improved mortuary waiting and viewing facilities
- Notify GP practices more quickly by secure NHS email after a death as standard practice, in addition to individual clinical notifications.

Impact

Individuals and carers

From (West) patch pilot data 80% of people with their details and wishes recorded on EPaCCS were supported to die in the place they chose.

Over a recent six month period, 15 people who would have been at risk of dying on the streets or as an emergency acute admission, were supported in their hostels, with individualised Advance Care Planning addressing questions such as “who will look after my dog” and the option to connect with estranged families. Spiritual care support for a person who is not religious but “wants someone to listen and appreciate what is happening to me” can make a positive difference for that person, their relationships and sense of resolution during their final months.

Staff

Most nurses who join the trust now know about the Transform programme and its key enablers. Having an end of life care facilitator provided an opportunity to connect with the cardiac technologists who often work with patients with defibrillators for many years. The trust now offers the technologists advanced communication skills training and is looking at options for bereavement care and counselling.

The community hostel programme has given not just a more positive experience for people at the end of their life, but also for hostel workers supporting people at the end of life to know they have made a difference.

System

From Six Steps education and training for Southampton nursing homes, the number of people who can continue to be cared for and die in their nursing and care homes has increased, as staff there now have the relevant skills and capabilities.

Close links with the University of Southampton encourage translation of research into practice.

Challenges and solutions

As with many acute hospitals, due to ward changes and staff movement, there is a need to continually develop more staff as champions.



KEY LEARNING

- It is a major advantage to have commissioners who understand the different elements of end of life and palliative care
- Being part of a national initiative can add extra positive visibility to your service
- Do not let lack of resources stop you
- Make the case for change to senior managers "this is what we've achieved, this is where we want to get"
- As a clinical lead, seek appropriate opportunities to influence corporate understanding of your service
- Remember that ward clerks can be key end of life care champions
- Consider communication skills training and support for all staff with contact with patients at the end of their life
- Include spiritual care within end of life care documentation to make sure it's offered.

Additional links and resources

www.uhs.nhs.uk/PatientsAndVisitors/Visitorsandfamilies/Bereavementcareandsupport/Bereavementcareandsupport.aspx

Countess Mountbatten House

www.cmhcharity.org.uk

Dignity in death. Could the Six Steps of the national End of Life Care Pathway be applied to support people who are homeless and use substances?

Druglink, November/December 2013, Chrissie Dawson, Commissioning Manager, NHS Southampton City CCG

www.southamptoncityccg.nhs.uk/documents

End of Life Care Achieving Quality in hostels and for homeless people

www.nhs.uk/media/2387406/route-to-success-homeless-dec-2014.pdf

European Journal of Palliative Care Case Study Master Classes

30: And baby came too. Lucy's story

43: Fulfilling a patient's wish to go home from intensive care

www.haywardpublishing.co.uk/case-study-masterclass.aspx

Resources

1. ***NICE guideline on care of dying adults in the last days of life***

This revised guideline responds to a need for an evidence based guideline for the clinical care of a dying adult, with a specific focus on the last two to three days of life to ensure individualised high quality care at end of life: www.nice.org.uk/guidance/ng31/chapter/context

2. ***National Information Standard - Palliative Care Co-ordination: core content***

This national information standard sets out the minimum core content to be recorded in Electronic Palliative Care Co-ordination Systems: www.endoflifecare-intelligence.org.uk/national_information_standard/

3. ***Economic evaluation of EPaCCS early implementers***

This is the final report from an independent economic evaluation of EPaCCS early implementer sites published in 2013. www.england.nhs.uk/wp-content/uploads/2013/05/economic-eval-epaccs.pdf

4. ***NHS continuing healthcare***

More information about continuing healthcare is available on the NHS Choices website, including frequently asked questions: www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/continuing-care-faq.aspx

5. ***The six steps to success programme for care homes***

This North West workshop style training programme enables care homes to implement the structured organisational change required to deliver the best end of life care, with a view to reducing inappropriate admissions to hospital: www.cmcsenate.nhs.uk/files/7614/3333/8860/Six_Steps_Care_Homes_Programme_2015.pdf

6. ***Blackpool rapid discharge pathway***

Blackpool Teaching Hospitals' rapid discharge pathway for people at end of life aims to facilitate a safe, smooth and seamless transition of care from hospital to community: <http://webarchive.nationalarchives.gov.uk/20130718121128/http://endoflifecare.nhs.uk/search-resources/resources-search/case-studies/blackpool-rapid-discharge-pathway.aspx>



7. ***Lincolnshire discharge liaison nurse***

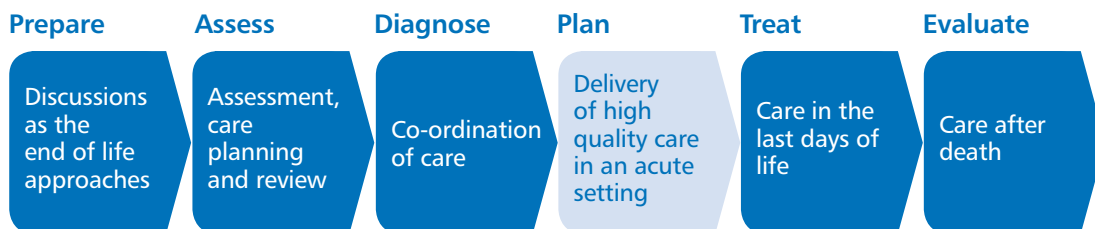
The Marie Curie Cancer Care delivering choice programme in Lincolnshire developed the role of the discharge liaison nurse and an independent evaluation found that 61% of patients referred to the service were transferred to their preferred place of care. Download the Lincolnshire evaluation reports:

<https://www.mariecurie.org.uk/professionals/commissioning-our-services/partnerships-innovations/past/delivering-choice-programme/lincolnshire>

8. ***Safeguarding adults practitioners guide***

Developed by Birmingham Safeguarding Adults Board, this guide promotes every adult's right to live in safety, be free from abuse and live an independent lifestyle free from discrimination: www.birmingham.gov.uk/safeguardingadults

Step 4 – Delivery of high quality care in an acute setting



Challenge:

Individuals and their families and carers may need access to a complex combination of services. They should expect the same high quality of care regardless of the setting. Their care should be informed by senior clinical assessment and decision making.

Outcome: Each individual will have access to tailored information, specialist palliative care advice 24/7 and access to spiritual care within a dignified environment, wherever that may be.

What you need to do

1. Ensure a fully complemented specialist hospital palliative care team is present, in line with NICE guidance
2. Gather information on how you are doing from complaints, compliments, suggestions and significant events
3. When things go wrong identify what happened and set up mechanisms for remedial action
4. Work through blockages across organisational boundaries and systems
5. Identify what has worked well and set up mechanisms to replicate for service improvement
6. Ensure all staff are trained and are confident and competent in end of life care
7. Ensure appropriate staff have communication skills, assessment and care planning, symptom management, and comfort and wellbeing training
8. Examine your ward environment to ensure it is supportive of dignity and respect for individuals and carers. Ensure feedback, comments and complaints are acted upon to improve your ward environment.

TOP TIP

Consider the individual's physical, cultural and spiritual needs, for example those with learning disabilities or dementia.



Practice example

Marie Curie Hospice, Cardiff and the Vale

Increasing the number of people from a Black, Asian and Minority Ethnic (BAME) background accessing palliative care services

Background

An increase in the number of patients from Black, Asian and Minority Ethnic communities, who represent 15% of Cardiff's population, accessing palliative care services has been achieved through a project focussed on building links and networks with those communities, consultation and implementing changes suggested by them. Building on knowledge and relationships developed, it's had a significantly positive impact on people and their families living with a terminal illness beyond the hospice, wider community organisations and employers.

In September 2012, Marie Curie employed a keyworker at its Cardiff and the Vale hospice to work with people in local Black, Asian and Minority Ethnic communities to improve awareness of palliative care and to increase access.

The three year project, which is Big Lottery funded, highlights the importance of working with people in communities to improve awareness of palliative care, and ensure equal access to services and the wide impact of a focused approach.

- The aim of the keyworker role is to build relationships with individuals in local Black, Asian and Minority Ethnic communities, to understand and address barriers that may prevent individuals accessing palliative care services
- 130 community members were consulted
- The keyworker identified barriers experienced by individuals in these communities in accessing palliative care, need for community engagement to increase awareness and highlighted steps needed to improve access to services
- As part of the project evaluation, the Marie Curie Palliative Care Research Centre, based at Cardiff University, interviewed community members and hospice staff at the start and end of the project to understand the difference made. The keyworker was interviewed at regular intervals.
- Initial Research Centre findings included:
 - “Despite the fact some participants had worked in Cardiff for many years (including in healthcare), most had never been to the hospice and most had never heard of the hospice or knew that it cares for patients with other terminal illnesses, and not just cancer”
 - “GPs are held in high regard and play a very important role in providing information. There is a need to ensure that GPs understand Marie Curie's services and refer patients from Black, Asian and Minority Ethnic backgrounds”

- “People from BAME backgrounds volunteer all the time in their day-to-day lives but do not see it, or name it, as volunteering. People are keen to help fundraise and volunteer and not just be seen as service users”
- Positive stories of patient experiences when accessing services were widely published through a variety of communication channels including the [BBC](#) and [local press](#).

Some changes from listening to the community and their impact.

Sample changes include:

- An improved quiet room and washing facilities for prayer or quiet contemplation, furnished with religious items for different faiths for use by staff, patients and families
- Consideration of patients who may feel isolated when in the inpatient unit. To reduce isolation, the purchase of iPads and CD players for patients to use, for example to listen to prayers, books and make contact with relatives
- Review of policies and processes, for example large number of visitors, information for staff around diet, religion, the cultural calendar and defining common words in bedside information for patients
- As part of the project evaluation, the Marie Curie case scenarios highlighting issues from the perspective of patients and families when accessing services and a professional’s perspective were created, based in part on real stories to help learning for professionals

- The hospice saw a significant increase in the number of patients who had been under represented accessing the service since September 2012. 120 people from Black, Asian and Minority Ethnic communities were supported in both the inpatient unit and/or community services in the first two and a half years (September 2012 to March 2015). In the last quarter (April – June 2015) an additional 25 people have been supported.

Partnership working with stakeholders includes:

- Input into the Older People’s Commissioner’s Residential Care Review
- Advisory input into the planned series of Velindre’s books for children whose family member had been diagnosed with cancer, which will be representative of the wide range of families and people across the community - [find out more](#)
- Member of the 2015 Cardiff Health Fair Planning Committee
- Cardiff University – training for interpreters
- Work nationally with EDF Energy’s Black Asian and Minority Ethnic staff networks to increase awareness - [find out more](#)
- Link person to disseminate information to community contacts.



Due to the knowledge and relationships that have been built up, signposting support has benefited people in the community and stakeholders outside the hospice. Examples of signposting to organisations include:

- Support for a patient who needed immigration advice for their family to come to the UK
- Support for another patient to receive counselling in another language
- Support for a young patient experiencing isolation and for whom English was a second language
- Support for a student from abroad who was diagnosed with cancer and needed social and financial support.

Sustainability and spread

- A resource pack for staff with a directory of community based services that support people from Black, Asian and Minority Ethnic communities was developed. It is based on some staff questions when supporting patients from these communities. These include:
 - Writing an Islamic Will
 - Whole family support for a patient's family
 - Support to access a paid carer who meets patients' religious and cultural needs
 - Registering a death out-of-hours
- Volunteer community champions will continue to share/promote the message of Marie Curie within Black, Asian and Minority Ethnic communities

- A DVD was created to showcase the hospice and its services in six community languages with English subtitles to help share information about Marie Curie in local communities
- Written literature is now available in community languages
- A report published around barriers to access has been widely disseminated
- Increasing Black, Asian and Minority Ethnic care needs on key stakeholders' agendas (for example on Cardiff and Vale's University Health Board's Local end of life delivery plan)
- Dissemination of lessons learnt and sharing good practice at national conferences and events including the Marie Curie Palliative Care Conference in March 2015.

Weblinks and resources

[Marie Curie Palliative Care Research Centre, Cardiff](#)

[Improving access to palliative care services for people from Black, Asian and Minority Ethnic backgrounds in South East Cardiff](#)

[Support for ethnic minorities](#)

[Breaking down barriers: evaluating a Marie Curie Hospice project aimed at improving access to palliative care by ethnic minority groups – article](#)

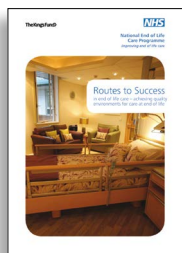
[Marie Curie and Cardiff and Vale College work together to break barriers – web story](#)

Resources

1. **Route to success in end of life care: achieving quality environments for care at end of life**

This guide identifies a number of key environmental principles to help improve privacy and dignity for individuals and their families at the end of life:

www.nhs.uk/resource-search/publications/eolc-rts-environments.aspx



2. **Nottingham information prescriptions**

NHS Nottingham City piloted a scheme of information prescriptions aimed at giving people approaching the end of their life more control over the management of their care: www.dyingmatters.org/gp_page/end-life-care-adults-learning-disability

3. **NHS Choices End of Life Care Guide**

This online guide is for people approaching the end of life and their carers. It explains what to expect from end of life care and provides information on rights and choices:

www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx

4. **Royal College of Nursing's dignity resource**

This resource aims to support everyone working in the nursing team in the delivery of dignified care:

www.rcn2.org.uk/development/practice/dignity

5. **Social Care Institute for Excellence (SCIE) – stand-up for dignity**

This online resource features a wealth of information about dignity in health and social care: www.scie.org.uk/publications/guides/guide15/index.asp

6. **The Dignity in Care network**

Hosted by SCIE, the network consists of dignity champions across the country, as well as the National Dignity Council:

www.dignityincare.org.uk/

7. **The route to success in end of life care – achieving quality for people with learning disabilities**

This practical guide supports anyone caring for people with learning disabilities to achieve high quality end of life care:

www.nhs.uk/resource-search/publications/eolc-rts-learning-disabilities.aspx

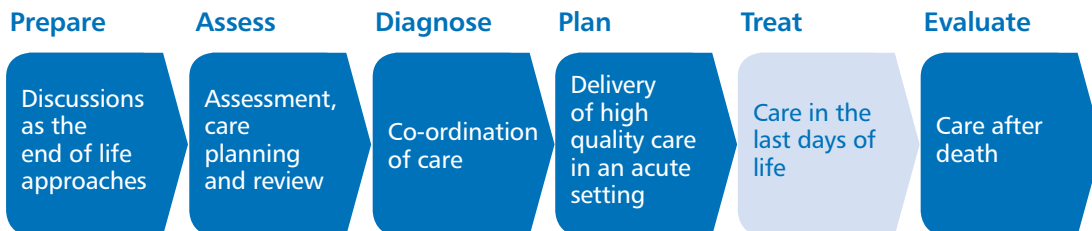


8. *National End of Life Care Programme support sheets*

- Support sheet 1 – Directory of key contacts: http://www.nhs.uk/media/2455419/supportsheet1_ajr_updated_28_oct.pdf
- Support sheet 6 – Dignity in end of life care: http://www.nhs.uk/media/2455444/supportsheet6_ajr_updated_28_oct.pdf



Step 5 – Care in the last days of life



Challenge: The point comes when a person enters the dying phase (the last hours or days). It is vital that those caring for them recognise that the person is dying and deliver the appropriate care. How someone dies remains a lasting memory for families and carers as well as staff.

Outcome: The person dying can be confident that their wishes, preferences and choices will be reviewed and acted upon and that their families and carers will be supported throughout.

What you need to do

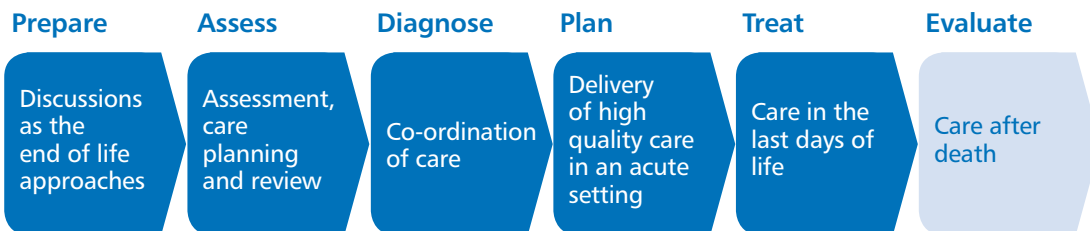
1. Ensure generalist and specialist staff are trained to recognise a dying person
2. Develop trust guidelines for implementing Priorities of Care and developing and delivering individual care plans
3. Identify relevant staff and ensure they are trained and skilled in communicating the implications to individuals and their carers as appropriate
4. Establish a mechanism to initiate review of advance care planning documentation at regular intervals so that a person's choices can be taken into account and acted upon wherever possible, for example Preferred Priorities for Care
5. Establish a system for rapid discharge identified through Advance Care Planning or through discussion with the individual and their carers to enable the person to die in a place of their choice
6. Re-examine your ward environment to ensure it is supportive of dignity and respect for individuals and carers throughout every stage of the end of life care pathway.



1. ***National End of Life Care Programme support sheets***

- Support sheet 8 – The dying process:
[www.nhs.uk/media/2455454/
supportsheet8_ajr_updated_6_nov.pdf](http://www.nhs.uk/media/2455454/supportsheet8_ajr_updated_6_nov.pdf)
- Support sheet 14 – NHS continuing care fast track pathway tool:
[www.nhs.uk/media/2455484/
supportsheet14_ajr_updated_28_oct.
pdf](http://www.nhs.uk/media/2455484/supportsheet14_ajr_updated_28_oct.pdf)

Step 6 – Care after death



Challenge: Good end of life care does not stop at the point of death. When someone dies all staff need to be familiar with good practice for the care and viewing of the body as well as being responsive to family wishes. The support and care provided to carers and relatives will help them cope with their loss and are essential to a 'good death'.

Outcome: A system is in place that ensures the emotional and practical needs of families and carers are supported after death. Verification and certification of death is timely, including notification to the coroner where necessary as well as appropriate and continuous carer support throughout bereavement.

What you need to do

1. Develop guidelines for your trust's viewing arrangements and facilities to ensure they are sensitive to different needs, cultures and faiths for relatives/friends of people who have died in hospital
2. Ensure communications skills training is in place and undertaken for all staff likely to be in contact with carers immediately post death
3. Establish a system whereby carers' post bereavement needs are assessed and recorded as part of the carers assessment whilst their loved one is still alive
4. Ensure all staff likely to be in contact with bereaved people have appropriate training to at least signpost to spiritual, emotional, practical and financial support
5. Identify and communicate the place and the process for collection of official documentation and the deceased person's possessions
6. Establish a system to send relatives a bereavement questionnaire, such as the National Bereavement Survey (VOICES), and to provide frontline staff with feedback in order to support continuing improvement.



Practice example

Health Education Yorkshire and the Humber

Funded training significantly increases practice based Advanced Care Planning in settings across the district.

More people supported to have their preference for end of life care discussed and recorded.

Background

By providing a whole system approach to Advance Care Planning, with a dedicated programme and trainers, the number of patients supported to think about and have their choices recorded through Advance Care Planning has increased across the district.

Wakefield is an industrial city within West Yorkshire, a largely white British ex-mining community with a population of approximately 306,500. There are three hospitals with all the district community services within the NHS trust, and 40 GP practices.

Health Education Yorkshire and the Humber funded a project, responding to an identified key area of need, to:

- Increase the percentage of patients who die in their preferred place of care/death (PPC/PPD)
- Improve anticipatory prescribing for symptom control
- Enhance staff skills, knowledge, confidence and competence

- Increase the number of patients with an Advanced Care Plan
- Reduce inappropriate investigations and treatments
- Reduce inappropriate hospital admissions.

The project runs concurrently with the EPaCCS (electronic systems to help co-ordinate end of life care for people), project launched on 1 April 2014.

Approach

Two End of Life Care Education Facilitators (1.60 whole time equivalent) were employed for 18 months from March 2014. A Macmillan Consultant in Palliative Medicine and a GP End of Life Care Lead were provided to support them.

The remit was to provide practice based training in Advance Care Planning for clinical teams within Mid Yorkshire Hospitals, Wakefield District Community and Wakefield GP practices.

As at June 2015, over 900 doctors, nurses and allied healthcare professionals have connected with the programme, with additional training planned to the current project end in September 2015.

The approach taken includes:

- Networking across the region to share resources and experiences
- Devising training packages that could be delivered in any setting, i.e. on the wards, GP practices, lecture theatres and offering flexibility on timing



- Building relations with key clinical and other influencers to gain opportunities to train different staff groups (for example, working with and through local contacts the team connected with local hospital ward sisters). This significantly helped in better understanding hospital structures during times of change
- Devising training packages that could be delivered in any setting, i.e. on the wards, GP practices, lecture theatres and offering flexibility on timing
- Taking every opportunity to deliver at local and regional events
- Using Clinical Commissioning Group and trust newsletters/bulletins to advertise the training available
- Pre-learning individual surveys to establish a baseline
- Employing learning approaches to engage staff such as a Pub Quiz and Circle of Life board game: <http://tinyurl.com/ncz43hs>
- Including a "Train the Trainer" option
- Drawing on up-to-date national reports and initiatives e.g. Dying Matters Week
- Ongoing evaluation of training and methods, with a report completed and shared with Wakefield CCG, Health Education Yorkshire and the Humber, the Chief Executive Officer and the Board of Trustees at Wakefield Hospice, Chief Nurse/Deputy CEO of The Mid Yorkshire Hospitals NHS Trust and the Regional End of Life Education Facilitators Forum.

Overcoming potential acute staff release challenges

The team recognised winter pressures can sometimes prevent trust staff being released from clinical areas; they also understood how important it was to consider trust staff levels.

During the winter the team took a flexible approach and concentrated on training specialist teams and GP practices, helping to avoid having to cancel ward based training.

Reflections on the project and what worked well

Working independently from the Specialist Palliative Care (SPC) team had advantages. It allowed the opportunity to network freely, explore different ways of training and offer flexibility in venues and audience requirements. The opportunity to deliver broader palliative care training would also be an advantage. Having no patient care responsibilities allowed the team to commit to the project 100%.

The team continually evaluated the training and used post training questionnaires. As a result of the feedback gained the initial amount of planned training time for each session was increased.

Following the training a clinical nurse specialist team now incorporate Advance Care Planning in their assessment process in the outpatient department. Furthermore, a community pharmacist has been able to facilitate this for patients in the community with positive outcomes.

The team observed that when they concentrated training on hospital teams the community figures for patients who have an Advanced Care Plan were decreasing but have now increased again.

Sample learner feedback included:

“I found this a valuable session. I now feel much more comfortable speaking to patients and family/carers.”

“Very informative course delivered in a relaxed manner that allows for explanations and discussion.”

It is important to remember each figure represents an individual person, their experience and that of those who matter to them.

These figures show an increasing number of patients have had the chance to think about and have their wishes for future care formally documented. This may mean that patients, with those who are important to them, have been able to be more involved in discussions around end of life care, and may be more likely to have their preferences for care met as a result.

One person said that her parent had an Advanced Care Plan and because of this it had “made it really easy for me.”

Another said that their teenage grandchild was able to be involved in the funeral as they knew it was what their grandparent had wanted from the Advanced Care Planning.

Sustaining improvement

The figures above suggest the training has led to a positive change in practice which benefits patients and those who are important to them.

While this project and its funding are time limited, there is good evidence to support a further future and sustainable programme of training.

The team’s substantial report (see www.wakefieldhospice.org/Our-Services/Who-We-Are/Information-for-Professionals/Education-Resources) includes several future recommendations.

Since this case study was developed, the programme is now due to be delivered in the Care Home Sector within Wakefield District on a part-time basis from September 2015 over 18 months with the agreement of all partner organisations.



Resources

1. ***Guidance for staff responsible for care after death***

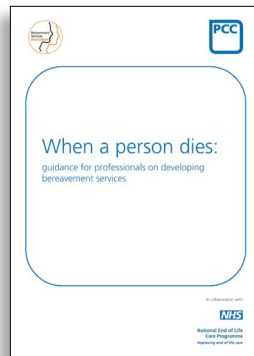
This publication emphasises that the care extends well beyond physically preparing the body for transfer. It also covers privacy and dignity, spiritual and cultural wishes, organ and tissue donation, health and safety and death certification procedures:

www.nhs.uk/nhsiq/media/2426968/care_after_death_guidance.pdf

2. ***When a person dies: guidance for professionals on developing bereavement services***

This covers the principles of bereavement services and guidance on workforce education and the commissioning and quality outcomes of bereavement care:

www.nhs.uk/nhsiq/resource-search/publications/eolc-when-person-dies.aspx



3. ***National Bereavement Survey (VOICES)***

The National Bereavement Survey aims to capture the Views of Informal Carers and an Evaluation of Services (VOICES). It is a postal questionnaire to measure satisfaction with services received in the year before death:

www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2014/stb-voices-2014.html

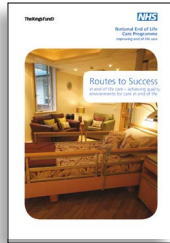
4. ***Improving Environments for Care at the End of Life***

A pilot programme was launched by The King's Fund across eight sites to improve environments for care at end of life:

www.kingsfund.org.uk/publications/improving-environments-care-end-life

5. **Route to success in end of life care: achieving quality environments for care at end of life**

This guide identifies a number of key environmental principles to help improve privacy and dignity for individuals and their families at the end of life:



www.nhs.uk/resource-search/publications/eolc-rts-environments.aspx

6. **National End of Life Care Programme support sheets**

- Support sheet 9 – What to do when someone dies:

www.nhs.uk/media/2455459/supportsheet9_what_to_do_when_someone_dies_v2_ajr_updated_28_oct.pdf

- Support sheet 15 – Enhancing the healing environment:

www.nhs.uk/media/2455489/supportsheet15_ajr_updated_28_oct.pdf



Practice example

An innovative nurse-led bereavement service transforming practice across three large acute hospital trusts in the north west of England.

The Royal's Alliance Bereavement Service is a nurse-led innovation, transforming practice across three large acute hospital trusts (Salford Royal Hospitals NHS Trust, Royal Bolton Hospital NHS Foundation Trust and Wigan, Wrightington and Leigh NHS Foundation Trust) with the purpose of providing excellent end of life care for all. Fiona Murphy, Assistant Director of Nursing Bereavement Support for the service, says "death and dying is very difficult to deal with, even for staff who work in hospitals, helping patients and families at their time of greatest need is hugely important us. To do this we must ensure they have easy access to and understand all of the services on offer supporting them in times of acute grief."

The Alliance has developed and driven an inclusive package of care irrespective of place of death and has transformed bereavement care and support. Some of the innovations include an easily recognisable 'dignity in death' symbol used throughout the organisations; 'memory bags' for deceased patients' property, replacing the traditional plastic bag; a 'Care after Death' policy; reduction in times from patient death to arrival in the mortuary and an improved organ and tissue donation referral rate.

This pioneering work has brought together multidisciplinary team members, including integration with external agencies such as Greater Manchester Police to achieve excellence whilst helping to change the culture in the acute hospital setting. View a short film on [YouTube](#). The model is now seen as 'best practice' with regular invites to deliver presentations about these ambitious and innovative developments.

The way end of life care is delivered is continually under review involving staff from across the hospital and community sector. This approach maximises inclusivity and demonstrates the importance of the part everyone can play. The overwhelming feedback according to Fiona Murphy is "It's the little things that count." The Alliance ensures that those little things become the big things for the 4,500 patients that die each year across our jurisdiction. "With five minutes quality our families will never forget us – with five minutes poor quality our families will never forgive us."



Section 5 The route to success

Evaluate

Core metrics

These core metrics have been developed to inform the progress of implementation of *The route to success in end of life care – achieving quality in acute hospitals* and to support the model of service improvement. They have been developed following consultation with the original first wave hospital trusts involved in the programme.

We strongly recommend that organisations providing specialist palliative care, continue submitting data to the Minimum Data Set (MDS) collection carried out annually by The National Council for Palliative Care in order to keep this resource as comprehensive as possible. The MDS reports are published annually and available from [NEoLCIN website](#).

Other locally developed metrics may also be used to inform and will contribute to overall reporting. We suggest that reports are collected at the beginning, middle and end of the implementation period.

The core metrics are designed to inform at two levels within the organisation:

1. Reporting at ward level
2. Reporting at executive trust board level.

Reporting at ward level

The core metrics developed at ward level are those that link directly with the five key enablers identified in **Section 3** of this guide.

These are Advance Care Planning, Electronic Palliative Care Co-ordination Systems (EPaCCS), the Rapid Discharge Home, the AMBER care bundle and the Priorities of Care. These enablers can most inform The Productive Ward model of service improvement.

Using the metrics in the first instance to assess your baseline will enable wards to develop a plan for service improvement according to individual starting points, priorities and agreed time scales.

Reporting at executive trust board level

Metrics for the executive trust board level are based firstly on the ward core metrics and secondly are aligned with the hospital quality markers from the National End of Life Care Quality Assessment Tool.

How can the core metrics improve care?

As a national programme to improve end of life care in acute hospitals, these core metrics can support improvement in care. They can identify areas of best practice which can then be highlighted within the programme and disseminated to speed up shared learning and service improvement



Development of the core metrics

One of the outcomes of this initiative will be to inform the development of the most relevant metrics both at ward level, and at trust board level. This will further inform the roll out of *Transforming end of life care in acute hospitals: The route to success 'how to' guide*. Alongside the [NICE End of Life Care for Adults Quality Standard](#), it will also influence the updating of the national indicators for hospitals.

Core metrics: Trust Board

Organisational baseline data:	Number
1. Number of beds in your trust	
2. Number of adult wards in trust	
3. Number of eligible wards (e.g. more than five deaths per year) for <i>The route to success improvement programme</i>	
4. Number of deaths per year in the trust	
5. Number of people who die in the trust's catchment area per year	
6. Number of people who die in their usual place of residence in trust catchment area (national key performance indicators – KPIs)	
7. Number of people in the trust discharged on the Rapid Discharge Home in the last three months	
Please record or attach any end of life care KPIs currently in use in your trust	
Please record or attach any 'best practice' models of end of life care education and training initiatives in your trust	

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care/improvement-tools-and-resources.aspx



Section 5

Core metrics: Trust Board (continued)

Please complete below the number of eligible wards (e.g. more than five deaths per year) that have implemented the five key enablers or equivalent and the number planning to implement during the next 12 months.

Enablers:	Baseline No. of wards implemented	Midpoint Planned no. of wards implemented	Endpoint Planned no. of wards implemented
Advance Care Planning model (ACP)			
Integration within an Electronic Palliative Care Co-ordination Systems (EPaCCS)			
AMBER care bundle			
Rapid Discharge Home (e.g. anticipated prognosis – hours/days)			
Priorities of Care			

1. The trust has an action plan for the delivery of high quality end of life care, which encompasses people with all diagnoses, and is reviewed for impact and progress

Numerical indicator: The trust has an end of life care action plan which feeds into a locality wide strategic plan for end of life care	Plan not developed	Plan partially developed	Plan in place and post implementation of the strategic plan for impact and progress
	RED	AMBER	GREEN
Baseline			
Comment on next steps			



Core metrics: Trust Board (continued)

2. Promote end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs

Numerical indicator: Identification of end of life care training needs of staff and training is in place to meet this	No curriculum evidenced	Curriculum being developed against trust Training Needs Analysis	Curriculum evidenced based on trust Training Needs Analysis
	RED	AMBER	GREEN
Baseline			
Comment on next steps			

3. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits

Numerical indicator: Identification of end of life care audit programme in trust	Minimal audit and review	Infrequent audit and review, actions not followed	Regular and comprehensive audit, including participation in National Care of the Dying Audit – Hospitals (NCDAH)
	RED	AMBER	GREEN
Baseline			
Comment on next steps			

Section 5

Core metrics: Ward

Baseline data:	Number of people
Number of admissions per year on the ward	
Number of deaths per year on the ward	

Red Level 0 **Amber Level 1** **Yellow Level 2** **Blue Level 4** **Green Level 5**

1. Advance Care Planning (ACP)					
Indicator: Ward implementation of ACP model	The ward has not implemented ACP model	The ward has plans in place to implement ACP model	The ward has an education and training programme for implementing ACP model	The ward is able to demonstrate implementation of ACP model	The ward has embedded and sustained the use of ACP model
	RED	AMBER	YELLOW	BLUE	GREEN
Baseline					
Midpoint					
Endpoint					



Core metrics: Ward (continued)

2. Electronic Palliative Care Co-ordination Systems (EPaCCS)

Indicator: Ward implementation of EPaCCS	The ward has not implemented EPaCCS	The ward has plans in place to implement EPaCCS	The ward has an education and training programme for implementing EPaCCS	The ward is able to demonstrate implementation of EPaCCS	The ward has embedded and sustained the use of EPaCCS
	RED	AMBER	YELLOW	BLUE	GREEN
Baseline					
Midpoint					
Endpoint					

3. AMBER care bundle

Indicator: Ward implementation of AMBER	The ward has not implemented AMBER	The ward has plans in place to implement AMBER	The ward has an education and training programme for implementing AMBER	The ward is able to demonstrate implementation of AMBER	The ward has embedded and sustained the use of AMBER
	RED	AMBER	YELLOW	BLUE	GREEN
Baseline					
Midpoint					
Endpoint					

Core metrics: Ward (continued)

4. Rapid Discharge Home (RDH)					
Indicator: Ward implementation of RDH	The ward has not implemented RDH	The ward has plans in place to implement RDH	The ward has an education and training programme for implementing RDH	The ward is able to demonstrate implementation of RDH	The ward has embedded and sustained the use of RDH
	RED	AMBER	YELLOW	BLUE	GREEN
Baseline					
Midpoint					
Endpoint					





Section 6 The route to success

Sustain

The most successful organisations are those that can provide the right organisational context in which frontline staff feel both empowered and enabled to lead, implement and sustain changes which will make a big difference by improving the quality and experience of care. This section along with section 7 about large scale change can help an organisation successfully achieve change that is sustained over time.

Sustainability can be described as ‘when new ways of working and improved outcomes become the norm’ (NHS Improving Quality).

Six critical success factors

A comprehensive review of the successful *The Productive Ward: Releasing Time to Care*¹ programme¹ identified that the organisations who had gained the most out of the programme have six critical success factors:



¹ www.institute.nhs.uk/quality_and_value/productivity_series/productive_ward.html

1. Leadership engagement

Having visible executive support for implementing this *Transforming end of life care in acute hospitals: The route to success ‘how to’ guide* will ensure there is good communication between the trust board and the wards. It will also ensure that resources can be clearly defined to support programme leadership and implementation activities.

The learning from *The Productive Ward* demonstrated that having executive directors on the steering group, along with frontline staff and other stakeholders including individuals and carers, provided a monthly forum through which a focus could be established for the work. This was key to driving improvements and harnessing the energy of the collective stakeholders.

2. Strategic alignment

Here the trust board have the opportunity to ensure that implementing *Transforming end of life care in acute hospitals: The route to success ‘how to’ guide* is amongst their top five priorities and is integrated and aligned with other priorities supporting choice, privacy and dignity by raising standards of care.

The trust board can lead the way in supporting staff to build on existing evidence and good practice, such as the AMBER care bundle and the Rapid Discharge Home.



3. Governance

Visible leadership is key to show how implementing *Transforming end of life care in acute hospitals: The route to success 'how to' guide* features in the organisational governance arrangements and should be communicated widely across the organisation. In addition the steering group can provide a mechanism for tracking progress, monitoring quality and ensuring local policies and ethical considerations are upheld.

Progress can and should be communicated and celebrated widely as part of an organisation wide communications strategy to show that this is not just another new initiative but a continuous way of working for the long term.

4. Measurement

What gets measured gets done. Therefore having a simple but comprehensive set of measures for everything we do is important.

Ideally these will consist of national, local and organisational measures which are priorities, along with the opportunity for frontline teams to identify measures that are important for them at ward level. Lessons learned from *The Productive Ward* show that staff who were empowered to identify and track some measures for themselves felt great ownership and involvement with their work.

5. Capability and learning

Involving frontline teams and empowering them to identify, lead and implement changes for themselves creates increased staff awareness and energy to both embed and sustain change.

Building capability within the organisation results in having a resource that can deliver and sustain change over the longer term. Staff who are enabled to lead the process of change for themselves will acquire both knowledge and skills that will be of benefit to the organisation and themselves. This will lead to continuous improvements in standards of care.

6. Resourcing (people)

Frontline staff who can see they have visible support from the executive team, along with the resources and headroom to implement a change programme, will feel more energised and committed to the work over the longer term.

If executives invest in their staff to acquire new skills and build on their existing knowledge, the result will be a more mutually beneficial collaboration that is more likely to deliver and sustain good results for those receiving care.

These six factors are important both for implementation success and sustainability over time.

So what does all this mean in practical terms?

One of the opportunities for sustainability is through active engagement and ownership of frontline leaders and their teams from the beginning of the work. Allowing teams to identify what needs to be done and how to develop their own solutions will greatly enhance the opportunity for sustainability.

TOP TIP

Having a designated frontline team member who can act as a project leader for the initial phase of this work will greatly enhance early implementation and ongoing sustainability.

Leaders at trust board level need to lead by example and visit the clinical areas who are making transformational changes to show their commitment and support. These visits will also send a powerful message that the work is important, a priority and therefore needs to be sustained.

TOP TIP

Having a visible means of displaying visits, by whom and when, will motivate and energise staff who can see that senior leaders are both interested and committed to their work.

Periodically, frontline staff could also be given the opportunity to update the trust board through both the steering group and through bi-annual board reports. An annual celebration through a learning and sharing event may also help to sustain the momentum over time.

Strategic alignment and robust governance will be important to track progress, but also to identify any duplication and detect if progress or standards are falling away early on. Staff will be able to see that there is visible leadership support that values their efforts and is looking all the time to smooth their improvement journey by increasing alignment and eliminating waste, including duplication of effort.



Who to involve

The trust board or steering group can help the frontline teams choose their starting point, which should result in increased opportunities for the work to be sustained.

Your starting point should be in areas where there is 'high energy' for making change and where there is a commitment to engage multidisciplinary team members and people receiving care to seek their views. This will ensure that sustainable opportunities are built in from the beginning.

There is an opportunity to involve patients, carers and families, data analysts and commissioners who may want to include your new service standards into their specifications. This can also further enhance sustainability going forward.

When thinking about sustainability this is also a good time to consider whether you have engaged all the strategic partners fully with the project plan or whether there are any gaps that you should address. [The NHS Change Model](#) can help you do this.

Ensuring you have broad multidisciplinary engagement across an organisation will enhance the success of your roll out plans and sustainability over the long term.

Tools to help

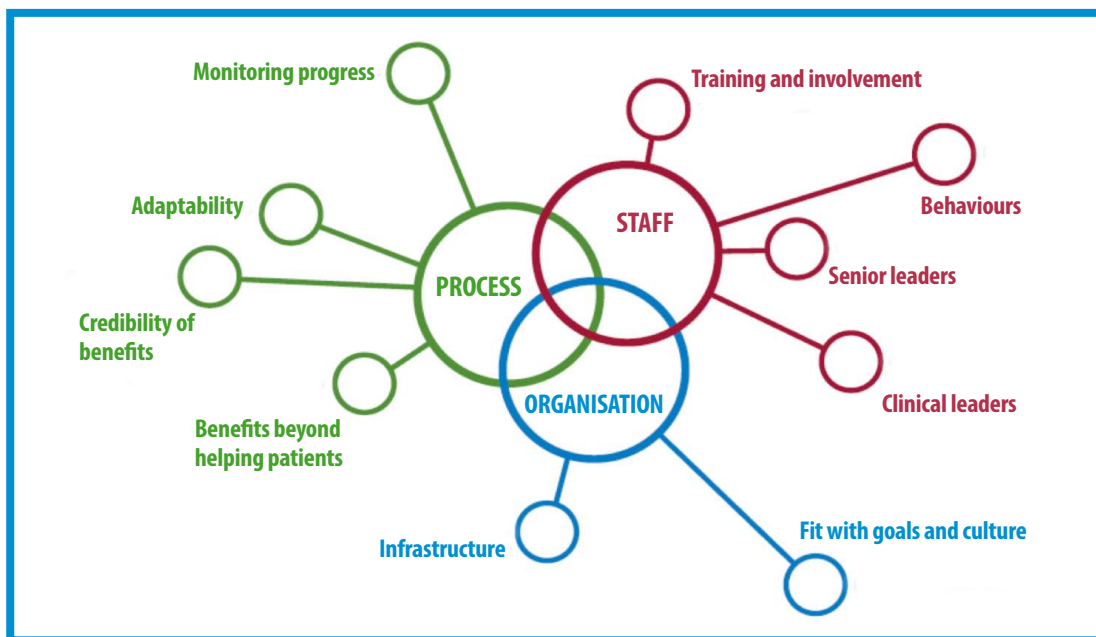
Organisations may have existing models for sustainability that they use. However there are tools within *The Productive Ward: Releasing Time to Care™* programme that maybe helpful.



In addition, the NHS Improving Quality 'quick checklist to determine how sustainable an improvement will be' is shown on the following pages.

Section 6

Below are 10 factors to consider throughout your improvement project that have been shown to improve the likelihood of sustaining your changes.



PROCESS

1.0 - In addition to helping patients, are there other benefits?

- Does the change reduce waste, duplication and added effort?
- Will it make things run more smoothly?
- Will staff notice a difference in their daily working lives?

2.0 - Credibility of the evidence

- Are benefits to patients, staff and the organisation visible?
- Do staff believe in the benefits?
- Can all staff describe the benefits clearly?
- Is there evidence that this type of change has been achieved elsewhere?



3.0 - Adaptability of improved process

- Can the process overcome internal pressures and continually improve?
- Does the change continue to meet ongoing needs effectively?
- Does the change rely on an individual or group of people, technology, finance etc. to keep it going?
- Can it keep going when these are removed?

4.0 - Effectiveness of the system to monitor progress

- Does the change require special monitoring systems to identify improvement?
- Is this data already collected and is it easily accessible?
- Is there a feedback system to reinforce benefits and progress and initiate action?
- Are the results of the change communicated to patients, staff, the organisation and the wider NHS?

STAFF

5.0 - Staff involvement and training to sustain the process

- Do staff play a part in innovation, design and implementation of change?
- Have they used their ideas to inform the change process from the very beginning?
- Is there a training and development infrastructure to identify gaps in skills and knowledge and are staff educated and trained to take change forward?

6.0 - Staff behaviours toward sustaining the change

- Are staff encouraged and able to express their ideas and is their input taken on board?
- Are staff able to run small-scale tests, e.g. Plan, Do, Study, Act, (PDSA cycles) based on their ideas, to see if additional improvements should be recommended?
- Do staff think that the change is a better way of doing things that they want to preserve for the future?

7.0 - Senior leadership engagement

- Are the senior leaders trustworthy, influential, respected and believable?
- Are they involved in the initiative, do they understand it and do they promote it?
- Are they respected by their peers and can they influence others to get on board?
- Are they taking personal responsibility and giving time to help ensure the change is sustained?

8.0 - Clinical leadership engagement

- Are the clinical leaders trustworthy, influential, respected and believable?
- Are they involved in the initiative, do they understand it and do they promote it?
- Are they respected by their peers and can they influence others to get on board?
- Are they taking personal responsibility and giving time to help ensure the change is sustained?

ORGANISATION

9.0 - Fit with the organisation's strategic aims and culture

- Has the organisation successfully sustained improvement in the past?
- Are the goals of the change clear and shared?
- Is the improvement aligned with the organisation's strategic aims and direction?
- Is it contributing to the overall organisational aims?
- Is change important to the organisation and its leadership?
- Does your organisation have a 'can do' culture?

10 - Infrastructure for sustainability

- Are there enough staff who are trained and able to work in the new way?
- Are there enough facilities and equipment to support the new process?
- Are new requirements built into job descriptions?
- Are there policies and procedures supporting the new way of working?
- Is there a communication system in place?



How to measure progress

Your initial assessment of organisational readiness and subsequent project plan may give you some valuable insights into whether previous change initiatives have been successful or not. If they have not been successful you may want to explore the reasons why and take this learning to the steering group so that action can be taken to address this as appropriate.

As part of your measures you may want to consider tracking the following which all impact on sustainability:

- The percentage and frequency of staff involvement and training to enhance knowledge and skills
- Evidence of staff behaviours toward sustaining the change
- The percentage and frequency of senior leadership engagement
- The percentage of awareness of clinical leadership and engagement
- Evidence of active engagement of key stakeholders locally and nationally such as local healthwatch and Patient Association
- Evidence of involvement locally of people receiving care, their families and carers.

Other things which can give insights on how to measure and track progress about sustainability going forward include:

- Decrease in complaints
- Increase in compliments
- Satisfaction surveys of people using services
- Audits of people using services possibly through NHS Friends and Family Test
- Staff satisfaction surveys
- Decrease in unplanned sick leave
- Retention and recruitment
- Improved relationships with key stakeholders
- Steering group governance reports
- Bi-annual reports to the trust board.





Section 7 The route to success

Leading Large Scale Change



80 leaders from across the NHS in England participated over 18 months in an Academy for Large Scale Change led by colleagues from NHS Improving Quality. Against this background the following learning is shared with you to support your local efforts to help you make changes at scale and pace that will benefit many many patients, carers and their families rather than the few.

Large scale change can be defined as 'the emergent process of mobilising a large collection of individuals, groups and organisations' towards a vision of a fundamentally new future state by means of:

- High leverage key themes
- A shift in power and a more distributed leadership
- Massive and active engagement of stakeholders
- Mutually reinforcing changes in multiple systems and processes.

Done properly this leads to such deep changes in attitudes, beliefs and behaviours that sustainability becomes inherent.

The following are five key messages from the NHS Academy for Large Scale Change

- **1. Match our mindset and methods for change to the level of ambition for change**
- **2. Manage our own energy and that of the people around us for the long haul**
- **3. Build leadership systems that are managerially loose but culturally tight**
- **4. Redefine leadership boundaries within the NHS system**
- **5. Act to accelerate large scale change to a revolutionary pace.**



SUMMARY

This is a summary of the five messages in Part 2 of Leading Large Scale Change:

MESSAGE ONE:

Match our mindset and methods for change to our level of ambition for change

Currently, many NHS provider organisations are facing unprecedented challenges to improve quality and reduce costs. The scale and pace of change they are seeking is large scale, in line with the definition used by the NHS Academy for Large Scale Change. We have to match these transformational ambitions for change with change methods and a mindset that is also transformational in nature. If we have transformational ambitions but we utilise our existing improvement methods, many of which are not designed to create transformational change, the outcome is likely to be underachievement of goals for large scale change. [Leading Large Scale Change: A Practical Guide](#) offers a set of transformational methods that match with transformational ambitions and increase the likelihood of achieving large scale change goals at pace.

MESSAGE TWO:

Manage our own energy and that of the people around us for the long haulchange to our level of ambition for change

Energy, not resources or time, is the fuel of high performance (Loehr and Schwartz). Building and maintaining energy for change is one of the most critical tasks for a leader of large scale change. We need to unleash sources of energy for change at all levels, across the entire system, not just rely on those at the top of the organisation to generate the energy. In the current NHS context, we particularly need to build emotional energy (the energy of connectivity, collaboration and relationships) and spiritual energy (the energy that is created by building a sense of a hopeful future, shared purpose and connecting with core values) to complement and enhance the intellectual energy and physical energy that is often prevalent in NHS organisations and systems.

MESSAGE THREE:

Build leadership systems that are managerially loose but culturally tight

As NHS leaders, if we want more control of change, paradoxically, we have to give up some control. Successful leaders of large scale change typically build strong cultures based on a common purpose and shared values, thus reducing the need for micromanagement. They are likely to have built their efforts on a platform of commitment (collective action towards a different future and shared purpose) rather than through compliance with new policies, payment systems or operating rules. They are also likely to be working through a distributed leadership system focussing less on the behaviours and actions of individual leaders and more on the relationships, interventions and leadership practice across the whole system including connectivity with other leaders.

www.nhs.uk/media/2589223/leading-large-scale-change-part-2.pdf

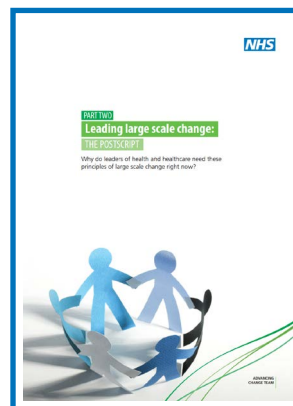


MESSAGE FOUR:

Redefine the boundaries of leadership within the 'NHS system'

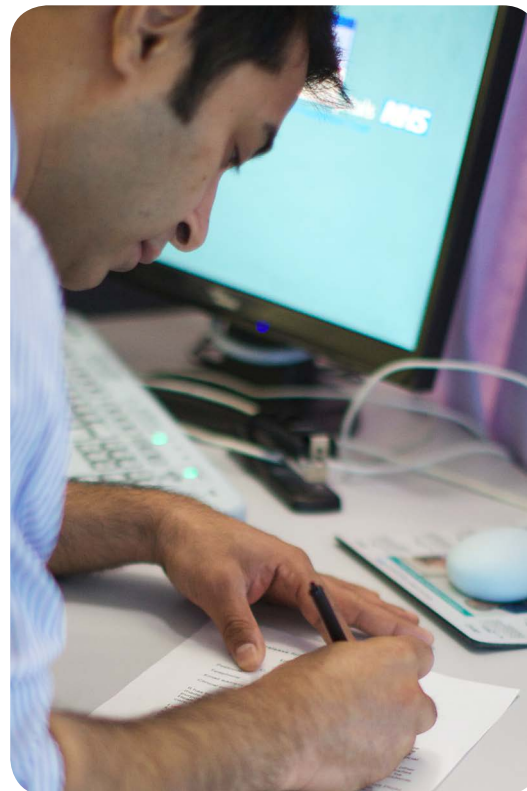
As the task of delivering health and healthcare becomes more complex and the scale and scope of change increases, we need to think widely and innovatively about how we define the leadership role in a future distributed system. Leaders of the future are likely to include clinical leaders, community leaders, service users and local government, voluntary and independent sector leaders. We can call these leaders to action if we can create a sense of 'us', a shared purpose around a common cause. There is potentially a huge pool of leadership talent if we build the capability to organise and develop these leaders.

www.nhs.uk/media/2589218/leading-large-scale-change-part-1.pdf



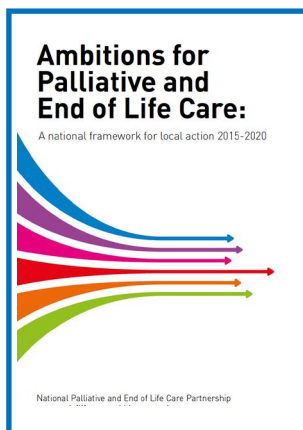
**MESSAGE FIVE:****Take actions that will accelerate large scale change to a revolutionary pace**

The NHS Academy for Large Scale Change identified a series of tools and strategies that leaders in the health and healthcare system can use to accelerate large scale change. We can connect NHS leadership tasks to a higher purpose and a deeper meaning, creating powerful narratives that frame the challenges that the NHS faces in ways that produce conviction, understanding and energy for action amongst key stakeholders. We should not over-rely on reorganising structures and processes as catalysts for change. Successful transformation depends as much upon changing the patterns of relationships, organisational power, conflict, decision-making and learning that underpin behaviour in organisational systems. We can organise for action using a complex adaptive systems perspective as well as a traditional programme planning and management lens. We need to consider how we create mutually reinforcing changes across multiple areas if we want to achieve pervasive change at scale.



Tools to help

The following can provide you with a rich source of evidence supporting large scale change along with tools or approaches that can help you and your organisation in a practical way.



<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>





Section 8 The route to success

Further resources



Public Health
England

The National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) is part of Public Health England, an executive agency of the Department of Health.

NEoLCIN aims to improve the collection and analysis of national data about end of life care for adults in England, providing knowledge and intelligence to drive improvements in the quality of end of life care services, supporting efficient use of resources and responding to the evidence collected on the wishes of dying people and their families.

A range of resources are available from the [NEoLCIN website](#) including:

End of life care profiles

Data and statistics on end of life for each Clinical Commissioning Group (CCG) and local authority in England broken down by age, gender, place of death and cause of death. New reports will also present data for government office regions, strategic clinical networks and upper and lower tier local authorities.

Proportion of deaths

National statistics on 'number and proportion of deaths by place of occurrence (home, hospital, hospice, care home, usual place of residence). Data is reported quarterly by CCGs, local authority, strategic clinical networks and the Public Health England centre. Data is published six months after the end of each quarter.

Resources

Data and analytical tools, reports, information on research, publications, e-alerts and links to other useful sources of information. What We Know Now - a collation of new information and evidence published annually.

Data sources

A guide to key health, social care and related data sources in the field.

Advice and information

Signposting to advice and information for individuals, their relatives and carers.

Information standards

Information on the two national information standards for end of life care:

- [Palliative Care Co-ordination: core content](#) (SCCI 1580)
- [Palliative Care Clinical Data Set](#) (SCCI2036) (in development)

Other

[News](#) and [Events](#) – information about new publications and upcoming events. [Sign up for e-alerts](#) to keep up to date with news and progress.

www.endoflifecare-intelligence.org.uk



AMBER care bundle for patients whose recovery is uncertain

www.ambercarebundle.org/homepage.aspx

Caring for Carers

www.nhs.uk/media/2519527/caring_for_carers_staff_booklet.pdf

Caring to the end

www.nhs.uk/media/2519532/caring_to_the_end_carers_booklet.pdf

Capacity, care planning and advance care planning in life limiting illness

www.nhs.uk/media/2519342/capacity_care_planning_guide.pdf

Electronic Palliative Care Coordination Systems (EPaCCS)

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/coordination-of-care.aspx

End of Life Care in Advanced Kidney Disease: A Framework for Implementation

www.nhs.uk/11739.aspx

Guidance for staff responsible for care after death (last offices)

www.nhs.uk/media/2426968/care_after_death_guidance.pdf

Improvement Leaders' Guides

www.nhs.uk/capacity-capability/advancing-change/publications.aspx

Intelligence Handbook

www.nhs.uk/capacity-capability/knowledge-and-intelligence/iq-handbooks/intelligence-handbook.aspx

Learning Handbook

www.nhs.uk/capacity-capability/knowledge-and-intelligence/iq-handbooks/learning-handbook.aspx

Long Term Conditions House of Care Framework

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/long-term-conditions-improvement-programme/house-of-care-toolkit.aspx

Route to success series

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care/improvement-tools-and-resources/route-to-success-series.aspx

The Edge

<http://theedge.nhs.uk/>

Advance decisions to refuse treatment

www.nhs.uk/resource-search/publications/eolc-ardt.aspx

Heart failure: A framework for implementation

www.nhs.uk/media/2574509/end-of-life-care-in-heart-failure-framework-for-implementation.pdf

Learning disabilities

www.nhs.uk/resource-search/publications/eolc-rts-learning-disabilities.aspx

Every Moment Counts: A narrative for person centred coordinated care for people near the end of life

www.nationalvoices.org.uk/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations

Royal College of General Practitioners Palliative and End of Life care Toolkit

The toolkit may be used by any general practice in the UK. The resources it provides can be used by healthcare professionals, informal carers, patients, and those close to someone nearing the end of life.

www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx

General Medical Council

Treatment and care towards the end of life: good practice in decision making

This guidance provides a framework for good practice when providing treatment and care for patients who are reaching the end of their lives. There are links to a range of resources that provide help and advice about different

aspects of end of life care for doctors, patients, relatives and carers.

www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

NHS North East Clinical Networks

Deciding right initiative – making advance decisions about care and treatment

www.nescn.nhs.uk/common-themes/deciding-right/

Deciding right app to support doctors decision making with patients nearing the end of life

<https://itunes.apple.com/gb/app/deciding-right/id918441387?mt=8>

Together for short lives

www.togetherforshortlives.org.uk

Resources for professionals

www.togetherforshortlives.org.uk/professionals/resources

Resources for families

www.togetherforshortlives.org.uk/families/information_for_families

Difficult Conversations for Young Adults

A free resource designed to help families and professionals approach conversations with young adults about their end of life plans.

www.togetherforshortlives.org.uk/professionals/resources/7837_difficult_conversations_for_young_adults



Child Bereavement UK

Supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement. They provide training to professionals, helping them to better understand and meet the needs of grieving families.

www.childbereavementuk.org

NHS England – Transforming participation in health and Care (2013)

Provides practical guidance on how to improve individual and public participation in all stages of commissioning.

www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf

Smart Guides to Engagement series

Written by experts to provide straightforward advice on all aspects of patient and public engagement in an easily digested format.

www.networks.nhs.uk/nhs-networks/smart-guides

The National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. It believes that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. It works with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters coalition.

www.ncpc.org.uk

Free downloads –

www.ncpc.org.uk/freedownloads

About Dying Matters

Dying Matters is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

- www.dyingmatters.org
- www.dyingmatters.org/page/dying-matters-leaflets
- www.dyingmatters.org/overview/resources
- www.dyingmatters.org/page/dying-matters-films

Find Me Help

Find Me Help is the UK's largest directory of services for people in the last years of life, their families, carers and friends. There are currently listings for organisations providing services. Find Me Help is the product of a partnership between a large number of organisations and individuals led by Dying Matters.

www.findmehelp.org.uk

A Guide to involving patients, carers and the public in palliative care and end of life care services (NHS National Centre for Involvement and NCPC)

www.ncpc.org.uk/sites/default/files/InvolvingPatientsCarersAndThePublicInPalliativeCareAndEndOfLifeCareServices.pdf

How would I know? What can I do? How to help someone with dementia who is in pain or distress

This leaflet aims to help anyone looking after someone with dementia to understand and help alleviate any pain or distress they might be suffering. It gives tips on things to look out for, including patterns or changes in behaviour that may indicate when someone is experiencing discomfort. It includes advice for relieving pain and distress, including ways to spot problems before they become serious.

<http://ncpc.org.uk/publication/how-would-i-know>

Rising to the Prime Minister's Challenge on Dementia – A spotlight on end of life care

The Prime Minister's Dementia Challenge, launched in March 2012, offers a major opportunity to improve end of life care for people with dementia. This short briefing highlights key points for attention.

http://www.ncpc.org.uk/sites/default/files/DementiaChallenge_Pages%20in%20Order.pdf

Difficult Conversations

NCPC's Difficult Conversations series looks at a range of conditions, and aims to help anyone, paid or unpaid, caring for someone with those conditions to open up conversations about end of life wishes and preferences, in order to enhance quality of life.

http://ncpc.org.uk/difficult_conversations

Advance Care Planning e-learning toolkit
www.learnzone.org.uk/advancecareplanning

What's Important To Me: A Review of Choice in End of Life Care

http://ncpc.org.uk/sites/default/files/CHOICE%20REVIEW_FINAL%20for%20web.pdf

Skills for Care – Working together to improve end of life care

www.skillsforcare.org.uk/Skills/End-of-life-care/Working-together-to-improve-end-of-life-care.aspx

Implantable cardioverter defibrillators in patients who are reaching the end of life

<http://www.ncpc.org.uk/publication/implantable-cardioverter-defibrillators-patients-who-are-reaching-end-life>

Macmillan

<http://be.macmillan.org.uk/be/default.aspx>

Your Life and Your Choices: Plan Ahead (England and Wales) MAC 13616

This booklet is for the public, it explains how a person can plan ahead for their future care. Copies can be ordered free from Macmillan by calling 0808 808 0000 or by going to <http://be.macmillan.org.uk/be/p-20337-your-life-and-your-choices-plan-ahead-england-and-wales.aspx>

End of life: a guide MAC 14313

This booklet is for the public, it explains what happens at the end of life and how to plan for it. Copies can be ordered free from Macmillan by calling 0808 808 0000 or by going to <http://be.macmillan.org.uk/be/p-20885-end-of-life-a-guide.aspx>

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- Palliative Care and End of Life Care Network leads
- Public Health England, National End of Life Care Intelligence Network
- Social care colleagues
- Teams from trusts participating in the Transform programme.

These contributions have been invaluable in making this *Transforming end of life care in acute hospitals: The route to success 'how to' guide* a tool that can be used by a wide range of staff involved directly or indirectly in end of life care, ranging from frontline staff to educators and service commissioners.

www.nhs.uk/endoflifecare

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