



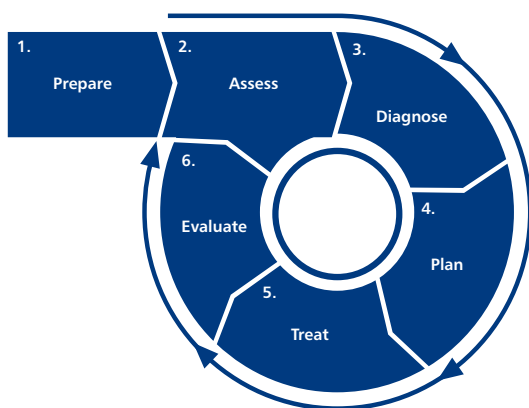
Section 4 The route to success

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.

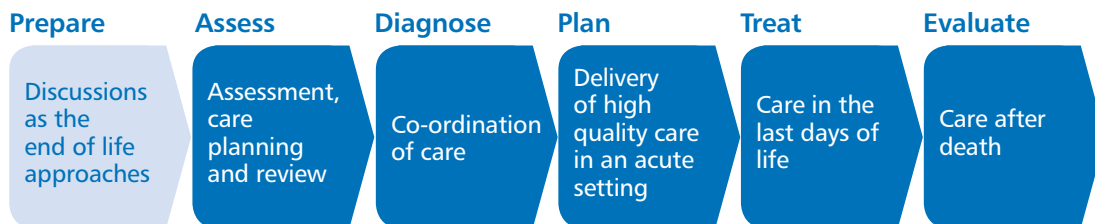


TOP TIPS

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

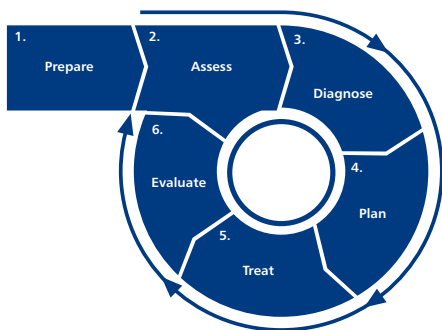
- Advanced kidney disease
- Heart failure: A framework for implementation
- Learning disabilities

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

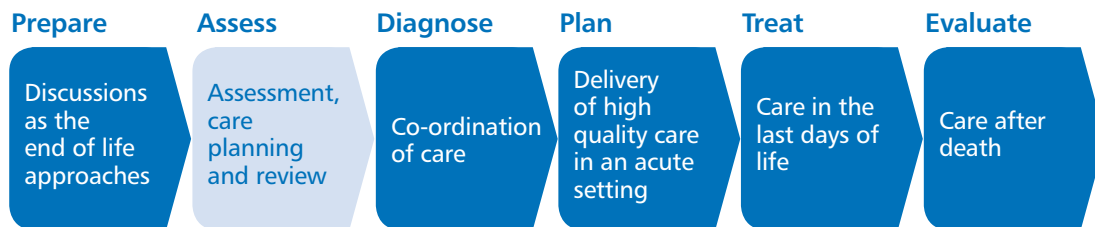
9. **Dying Matters** has produced a number of films that can be used where discussions about end of life planning are appropriate.



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.

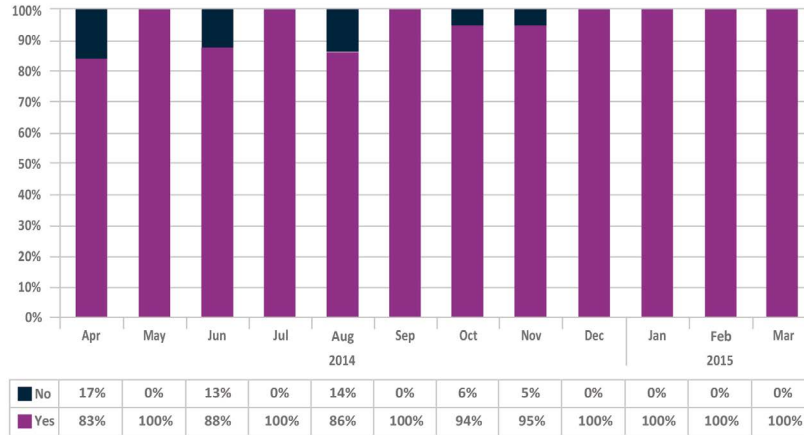
Audit evidence also showed when a patient did not have the capacity to take part in discussions about advance care planning or discussions at the end of life, the medical notes clearly evidenced this. At the time of writing there continues to be a higher percentage of

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.

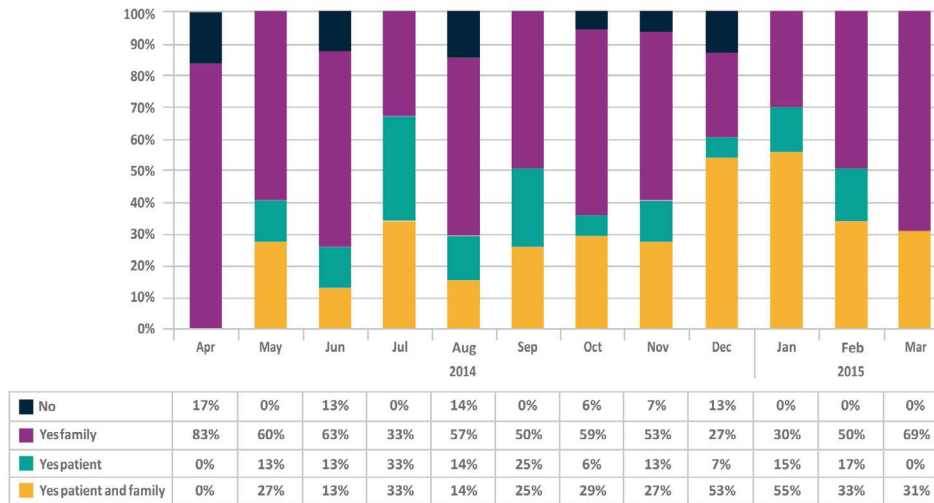
The following graphs show the change evident from clinical audits:

Graph 1: Percentage of records with a clear medical plan



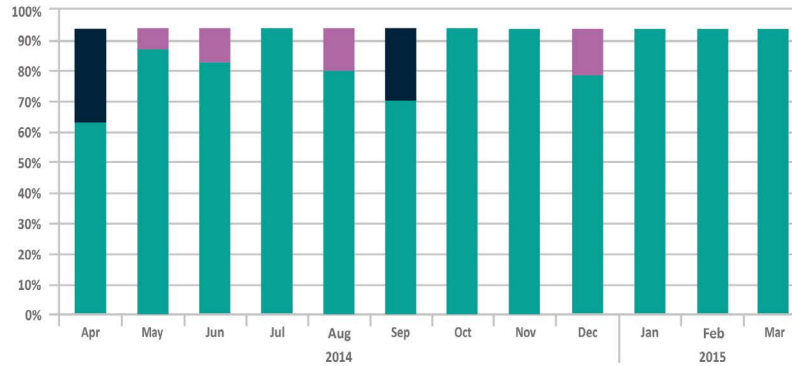
Note: data has been rounded to the nearest % so some columns may not add up to 100%.

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%.

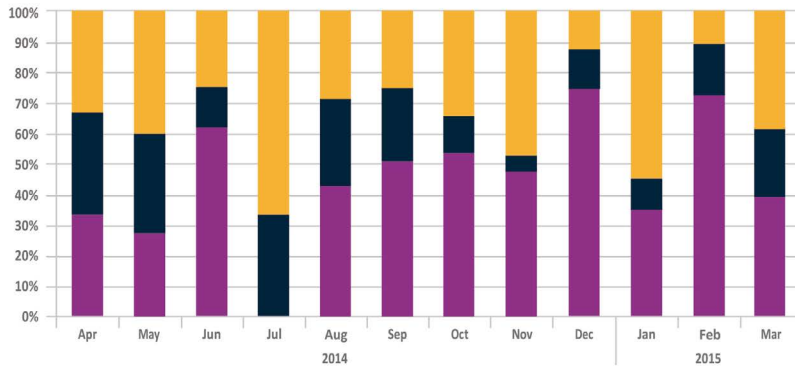
Graph 3: Percentage of records with a DNAR decision made or Ceiling of Treatment plan including DNAR



■ 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:

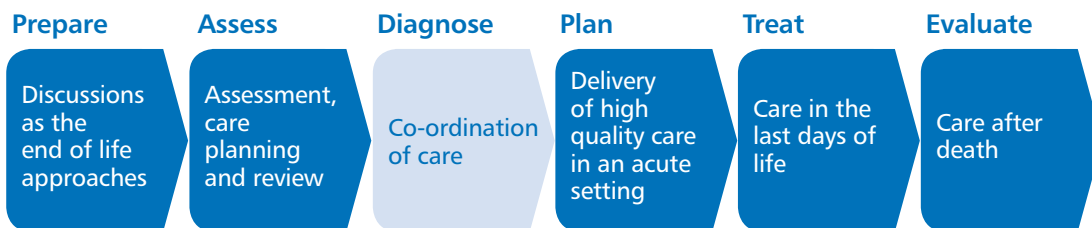
www.nhs.uk/resource-search/publications/eolc-ppc.aspx

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 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***

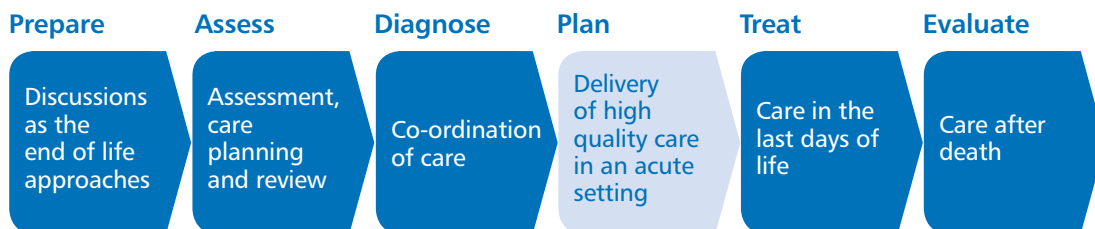
The Marie Curie Cancer Care delivering choice programme in Lincolnshire developed the role of the discharge liaison nurse and an independent evaluation found that 61% of patients referred to the service were transferred to their preferred place of care. Download the Lincolnshire evaluation reports:

<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](#)

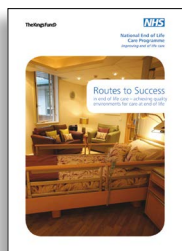
[Marie Curie and Cardiff and Vale College work together to break barriers – web story](#)

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:

www2.rcn.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

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

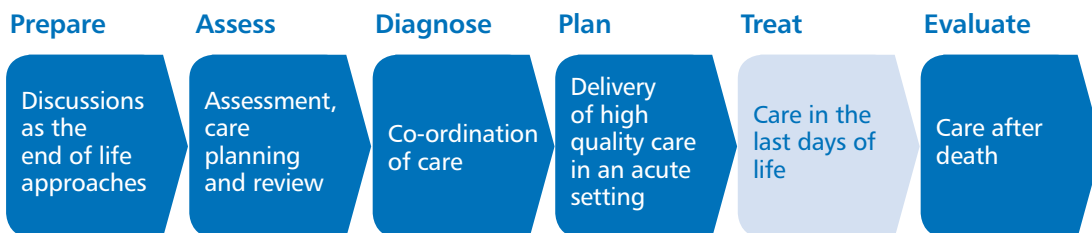


8. *National End of Life Care Programme support sheets*

- 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

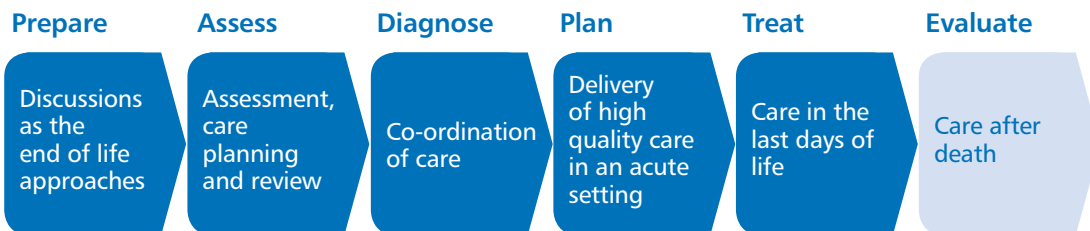
1. Ensure generalist and specialist staff are trained to recognise a dying person
2. Develop trust guidelines for implementing Priorities of Care and developing and delivering individual care plans
3. Identify relevant staff and ensure they are trained and skilled in communicating the implications to 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**

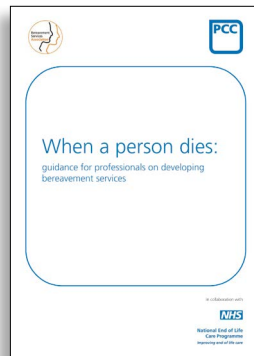
This publication emphasises that the care extends well beyond physically preparing the body for transfer. It also covers privacy and dignity, spiritual and cultural wishes, organ and tissue donation, health and safety and death certification procedures:

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

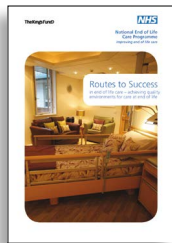
4. **Improving Environments for Care at the End of Life**

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."

