The route to success
in end of life care - achieving quality in acute hospitals

Contents

Introduction

The *End of Life Care Strategy* (DH 2008) was a blueprint for improving the care of all dying people over the next ten years regardless of diagnosis.

It emphasised that improved end of life care (EoLC) provision in acute hospitals is crucial given that more than half of all deaths take place 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 services so that more people can die at home if this is their preferred choice.

This guide aims to provide practical support for NHS managers and clinicians as they seek to deliver that agenda when pressure to make best use of resources is increasing. It can help trusts re-shape how their staff work with each other, their patients and community and social care partners to improve care quality and meet the agenda of Quality, Innovation, Productivity and Prevention (QIPP) by reacting to problems before they become a crisis perhaps requiring admission to hospital. In this case it means a smaller percentage of patients dying in hospital unless they have chosen to and fewer and shorter unplanned hospital admissions. Trusts implementing and embedding good practice will see well-trained and motivated staff improving the patient experience and fewer inappropriate costly interventions such as pathology, radiology and drugs. This will free up resources for improved community services – allowing people more control over their care and where they die.

Delivering end of life care quality and productivity

6 key levers
for rapid progress towards high quality end of life care

1 There should be co-ordinated care and discharge planning based on assessed need and by working with patients and families, as well as partners in the community and social care.

2 Senior clinicians should make treatment decisions close to the patient, intervening early and managing uncertain prognosis.

3 Use recognised tools already developed, such as advance care planning or the Liverpool Care Pathway for the Dying Patient (LCP), and train staff in their use.

4 There should be strong organisational governance including trust board oversight and senior management engagement.

5 There should be training and education as appropriate to each team member's role, with full use of e-learning and more traditional learning methods while addressing staff attitudes towards death and dying.

6 There should be access to a hospital specialist palliative care team seven days a week in line with Improving outcomes guidance (2004).

Delivering
improved outcomes

- Improve the patient experience and quality of care.
- Enable people to die in the place of their choice
- Allow the trust to manage its resources effectively, including by the reduction of inappropriate interventions
- Manage and reduce unplanned hospital admissions
- Develop a skilled workforce with improved staff morale and retention
- There will be fewer complaints and improved reputation for trust.

Care Quality Commission
EOLC 'Prompts' for registration standards and regulations

- Individuals are assessed (by specialists where appropriate) and involved in planning their care and can make choices, particularly around pain management
- Relevant information is provided
- Unnecessary disruption is minimised
- Individuals can have people present as they die
- Staff are respectful of their privacy, dignity and comfort
- The care plan records post-death wishes, including religious sensitivities (see resources page 24).

End of life care pathway for acute hospitals

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as the end of life approaches	**Assessment, care planning and review**	**Co-ordination of care**	**Delivery of high quality care in an acute hospital**	**Care in the last days of life**	**Care after death**

Step 1
- Open, honest communication
- Identifying triggers for discussion
- Advance care planning.

Step 2
- Conduct a holistic assessment
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers
- Advance care planning.

Step 3
- Strategic co-ordination working with primary and community health services, ambulance/transport services and social care
- Co-ordination of individual patient care
- Discharge planning
- Rapid discharge home to die
- Fast track continuing health care.

Step 4
- Dignified environment
- Access to specialist palliative care advice around the clock
- Specialist hospital palliative care team
- Access to spiritual care
- Access to tailored information.

Step 5
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation.

Step 6
- Recognition that end of life care does not stop at the point of death
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support.

High quality end of life care making best use of resources

Senior clinical decision-making close to the patient and an appropriately trained and supported workforce

Strong governance including board oversight and senior management engagement

End of Life Care Strategy DH
Improving Outcomes Guidance in Supportive and Palliative Care (IOG). NICE
Treatment and care towards the end of life: good practice in decision making. GMC

Who this guide is aimed at

- Board members: Board and senior management accountability should ideally include a thorough analysis of complaints/compliments and a commitment to support and review end of life care services. This guide, alongside the national quality markers (see resources page 24), will help board members to assess their services.This quality appraisal will help trusts as they go through the Care Quality Commission registration process
- Directorate managers: Managers should look to work with the board to ensure resources, education and training are available to deliver high quality palliative and end of life care
- Commissioners: The guide can help them assess the quality and range of EoLC services in acute trusts and how these can be co-ordinated with community services
- Specialist palliative care teams: The guide illustrates good practice within specialist palliative care and how such teams support generalist colleagues in the hospital and the community
- Generalist hospital clinicians: The guide outlines the questions they should be asking about services and emphasises how they should work in partnership with palliative care colleagues from an early stage in a patient's journey along the end of life care pathway
- Community service providers, including social care commissioners and providers and ambulance trusts: Hospitals can work closely with partners in the community to deliver co-ordinated services and ensure more people die at home if that is their wish.

Background

Health and social care providers and commissioners are also working within the context of the government's Quality, Innovation, Productivity and Prevention Challenge (QIPP). This has challenged end of life care services and several other key service areas to improve the quality of care while maximising the impact of resources (see www.evidence.nhs.uk).

In the case of EoLC this means addressing the variable standards of provision and unco-ordinated services highlighted in the National Audit Office report of 2008. This emphasised how better and co-ordinated working between health and social care - and between acute and community services - could improve care, allow more people to die in the place of their choosing and save money by reducing emergency hospital admissions and length of hospital stay.

In 2009 the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) review also highlighted the need for improved communication and co-ordination between and within clinical teams.

Part Two of the guide outlines the key factors that trust board members, senior managers and clinicians should consider along each step of the end of life care pathway.

The examples of good practice in Part 3 of this document are intended to be 'a living resource'. You can file your own examples for use on the NEoLCP website via a template by visiting http://www.endoflifecare.nhs.uk/eolc/studies.htm. Full case studies featured in Part 3 can be found on the website.

The journey towards improved services which better meet the needs of people approaching the end of their life while making best use of the resources available has started. This resource should help you continue it.

Step 1

Discussions as the end of life approaches

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.

Early confirmation that a patient is dying is a key element in quality end of life care – especially when it is accompanied by skilled communication with the individual and their family.

The specialist palliative care clinicians, the GP and a specialist in the relevant disease, eg a cardiologist, can work together to identify those nearing the end of life. They can then agree which clinician is best placed to initiate discussion with the individual and their family – often this will be the patient's GP.

This can lead to improved outcomes in terms of both patient care and best use of NHS resources. Early discussion gives the patient more control over their care and should result in the more frequent use of advance care planning. Such planning reduces the likelihood of professionals having to take decisions without being fully aware of a person's wishes and preferences if there is a sudden deterioration in the patient's condition.

Often this will mean a review of treatment in the patient's best interests, which might include stopping a particular treatment at an appropriate and agreed time. Such reviews and agreed care plans can also reduce unplanned hospital admissions.

TRUST BOARD MEMBERS AND SENIOR MANAGERS

Ask yourself
- Have your clinical staff got the skills and support to identify when an individual is approaching the end of their life and to respond by initiating discussions about their wishes and care preferences?
- Do they have access to adequate training, e-learning and support, including support from the specialist palliative care team?
- Are staff placing patients on an end of life care pathway where appropriate?
- What systems are in place to monitor the quality of EoLC and how are the results reported to the board?

Your role
- Ensure your trust has a recognised EoLC pathway and that all staff are trained in its use
- Establish with your community partners an EoLC supportive care register.
- Monitor use of the above tools and report to the board.

CLINICIANS

Ask yourself
- How do I identify those in my care approaching the end of their life?
- Have I seen triggers that indicate it is the appropriate time for discussion?
- Is the environment safe, comfortable and with a degree of privacy?

Your role
- Ask yourself the 'surprise question' and what you and colleagues are trying to achieve with a specific intervention
- Recognise change in symptoms or a deterioration in the patient's condition
- Take account of any recent change - such as the death of a spouse
- Select an appropriate time to initiate discussion, including conversations about placing the individual on an end of life supportive care register, usually held by the GP
- Openly discuss prognosis, disease trajectory and future care options
- Provide relevant information and be aware of other sources of help - including in areas such as benefits.

Top tips
- Train generalist and specialist staff to recognise a dying patient and in breaking bad news to relatives
- Seek to provide private spaces in which to break bad news or to initiate end of life care discussions
- Discuss with the patient and family/carers choice and planning and offer the opportunity to start advance care planning.

Relevant national quality markers
1. Have an action plan for the delivery of high quality end of life care which encompasses patients with all diagnoses and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life. This could include, for example, the use of the 'surprise question' when professionals ask themselves if they would be surprised if the patient died within the next six to 12 months.

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 unmet need. Too often an individual's needs and those of their family and carers are not adequately assessed.

Holistic assessment needs to cover physical, psychological, social, spiritual, cultural and financial needs. It provides the foundation for co-ordinated care by establishing an understanding of the individual's needs, preferences and priorities for care. It can open discussion around advance care planning (ACP) between patients and health care professionals.

Raising awareness about end of life care (EoLC) issues within social care and broadening understanding of social care's remit within the health care field could substantially improve EoLC – and not just for frail, older people. A single parent dying of cancer, an adult with learning disabilities or someone with dementia or mental health problems and their loved ones could all benefit.

The National End of Life Care Programme's social care framework, due to be published in July 2010, provides useful information (see resources page 24).

There is currently no single tool designed for holistic common assessment of supportive and palliative care needs for adults. Pilots of such tools are currently being evaluated.

Existing tools, such as the Pepsi-Cola aide memoire and distress thermometer, assess either a more limited range of end of life related needs or cover in depth a specific area of need - but they are still valuable resources.

The Sheffield Profile for Assessment and Referral to Palliative Care (SPARC) is also used in many organisations.

A holistic assessment, care planning and regular review can help prevent unwanted treatments, lengthy hospital stays and complaints. They can also prevent the patient being repeatedly asked the same questions – a process that can be exhausting and/or frustrating for the individual and wasteful of NHS and social care resources.

Assessment also helps individuals to make decisions in advance about their future care and treatment.

TRUST BOARD MEMBERS AND SENIOR MANAGERS

Ask yourself
- Is your organisation making the best use of existing assessment and care planning tools?
- What arrangements are in place for sharing the results of assessments conducted in your hospital with partners in primary care, social care, the voluntary sector and other community providers – and vice-versa?
- How do you ensure that suitably anonymised information obtained from assessments feeds into local registers or databases to facilitate service planning?

Your role
- Ensure there is appropriate training and education available for care professionals to conduct effective holistic needs assessments, incorporating advance care planning.

Relevant national quality markers

3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.

CLINICIANS

Ask yourself
- Who within your team or department is best placed to carry out holistic assessments and do they require additional training or support?
- Has the carer had an assessment where appropriate?

Your role
- Undertake or request holistic needs assessment when the end of life phase has been identified
- If you are conducting an assessment listen to the individual and understand what is important to them and record their views and wishes. Assessments should be 'concerns-led'
- Introduce advance care planning as a continuous process
- Ensure the assessment covers all aspects mentioned above and results are shared (with consent) with appropriate partner organisations, including the patient's GP, social care, ambulance/transport services and district nursing teams
- Ensure the assessment takes sufficient account of uncertain prognosis and how both crises and sudden deterioration can be managed if, for example, a patient presents to A&E.

Top tips

- Structured assessments should be undertaken at key points in the pathway
- Assessment is a skill in its own right – ensure your assessors are adequately trained in it
- Assessment is a process that often might need to be undertaken in stages to avoid tiring the patient
- Access e-ELCA's (End of Life Care for All) assessment modules at www.elca.org.uk

If a holistic assessment has been carried out and shared appropriately it should be possible to co-ordinate care for the patient, family and carers. This should cover primary, community and acute health providers, the local hospice, local transport services and social care.

The development of EoLC locality registers should enhance communication and transfer of information across sectors.

Such co-ordinated planning will increase the chances of an individual's wishes being met. It also helps informal carers to manage a crisis at home by calling on community-based services and so reducing inappropriate and expensive emergency hospital admissions.

In 2008, the National Audit Office suggested that reducing such admissions by 5% and the average length of stay in hospital by three days could release more than £100 million to support people to die in their preferred place of care. That figure refers to cancer patients in the last year of life, where total spending was estimated to be £1.8 billion. (See resources page 24).

Co-ordination in the planning, delivery and monitoring of end of life care services for individuals is rare. Research suggests that many people who die in hospital soon after being admitted from a care home would not have needed to be moved if the care home had had better support from the NHS.

In general, social workers and care managers in mainstream settings do not include end of life planning in their community care assessments and care plans. Acute hospitals and their community health partners, including hospices, must work more closely with their social care counterparts locally to counter this. Such co-operation would improve the chances of early intervention.

Strategic approaches such as this will only come about with the active involvement of members of the trust board and senior managers.

TRUST BOARD MEMBERS AND SENIOR MANAGERS

Ask yourself
- What arrangements are in place for shared representation at multi-disciplinary team meetings across acute, primary and community health services, out-of-hours services and social care?
- How do you assess if your trust can respond rapidly and appropriately to changes in an individual's circumstances through effective discharge planning, fast-tracking to continuing care and support at home?

Your role
- Establish a framework including governance arrangements with your counterparts in community health and social care services to ensure your teams can work in partnership
- Ensure your hospital has a specialist palliative care team that meets NICE guidance recommendations (see resources page 24) in line with Improving Outcomes Guidance (IOG) (see resources page 24)
- Ensure 9-5 seven day a week access to a specialist palliative care nurse in accordance with IOG
- Consider what systems and processes are in place to communicate with community services.

Relevant national quality marker

6. Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.

CLINICIANS

Ask yourself
- Is there a communication system in place to keep all members of the multi-disciplinary team across all sectors fully informed, including community health and social care services (including care homes)?
- Does your team know who to contact in each relevant organisation, including those in primary and community care and local transport services?
- Is there a structure in place for advance care planning, including preferred place of care, to be undertaken and communicated across all sectors?

Your role
- Identify individuals on an end of life supportive care register
- Ensure there is a key worker to act as the link between services
- Provide access to around the clock specialist palliative care advice, care and support
- Inform Out-of-Hours services, ambulance services and community services of anticipated care needs.

Top tips

- Develop shared information systems with community services and transport services
- Consider whether more community staff could work from the hospital as a base
- Ensure community representation (including social care) in palliative care multi-disciplinary team (MDT) meetings
- Appoint a designated EoLC discharge planning nurse
- Make appropriate use of an EoLC supportive care register.

Delivery of high quality care in an acute setting

Patients and families may need access to a complex combination of services. They should expect the same high quality of care regardless of the setting. The patient's care should be informed by senior clinical assessment and decision-making.

More than half the complaints about hospitals received by the former Healthcare Commission related to EoLC, highlighting the urgent need to improve care in this area.

The national strategy states that acute hospitals often fail to recognise that one of their core roles is to care for the dying (see resources page 24). This is frequently demonstrated by an absence of strong organisational governance – board oversight and senior management engagement. Staff should be trained to talk to the patient, family and carer about the changes they can expect as death approaches.

Staff should be trained to care for patients who are dying (the final days or hours), including how to discuss with the patient's loved ones the support care available.

Care bundles such as AMBER (Assessment, Management, Best Practice, Engagement of patients and carers, for patients whose Recovery is uncertain) can support hospital staff to identify people for whom recovery is uncertain. It helps to start conversations about possible outcomes, including death and dying and simplifies key interventions to support best practice.

TRUST BOARD MEMBERS AND SENIOR MANAGERS

Ask yourself
- Does your organisation have an operational policy for the management of EoLC?
- What systems are in place to monitor the quality of EoLC?
- Is there director-level representation on any EoLC group?
- How is EoLC represented in your governance structure?

Your role
- Monitor the use of EoLC tools in your organisation
- If a tool such as the Liverpool Care Pathway is used in your hospital, staff need to be trained in its use (including the need for regular review of the patient) with regular updates and a palliative care link nurse trained to provide extra support
- Monitor complaints relating to EoLC and ensure remedial plans are fully implemented to improve care
- Identify key quality markers relating to EoLC to report back at board level and have a robust process for collecting and sharing evidence of service improvements/complaints
- Ensure all staff are trained in EoLC core principles and values.

Top tips
- All ward staff should receive EoLC training and have access to free e-learning through e-ELCA (End of Life Care for All)
- Use palliative care link nurses and a permanent facilitator to embed an EoLC tool within the trust.

CLINICIANS

Ask yourself
- Does the environment offer privacy and respect for individuals and their families?
- How do you and your colleagues get feedback about complaints/compliments about EoLC?
- Do you feel you and your colleagues/teams are adequately trained and supported in EoLC?
- Can you access training and support where needed?
- Does your organisation have a recognised EoLC tool in place and do you feel adequately supported in its use?

Your role
- Promote or participate in relevant EoLC training, including communication skills, assessment and care planning, advance care planning, symptom management, comfort and wellbeing
- Recognise your limitations and know where to get help (eg drawing on other experts such as the chaplaincy or the trust's specialist palliative care team)
- Be aware of EoLC core competences and' principles (see resources page 24).

Relevant national quality markers

7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end of life care training opportunities and help relevant workers to access or attend appropriate programmes, dependent on their needs.

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 person is dying and deliver the appropriate care. How someone dies remains a lasting memory for the individual's relatives and carers as well as the staff involved.

In some wards or departments, staff at all levels lack the knowledge, skills and attitudes required to deliver high quality end of life care. There can also be a failure to recognise when continuation of treatment is not in the person's best interest. In other cases, inadequate planning or lack of discharge co-ordination means people are denied the chance to die at home, even if they have expressed the wish to do so.

For these patients "home" might mean a care home.

These problems can be remedied in many cases by senior clinical decision-making close to the patient. A decision that a patient is dying and their care is to be supported by the Liverpool Care Pathway (LCP) or equivalent tool should be taken by a senior clinician with appropriate training in end of life care and use of the pathway. This decision should be taken after discussions with the patient (where possible) and their loved ones and they should continue to be involved in decision-making.

Relatives and carers should be informed of likely changes as the patient approaches death. If the care planning and rapid discharge arrangements highlighted in earlier sections are in place then a patient can often be discharged to die at home with the support that will prevent unnecessary, distressing and expensive emergency re-admisssion.

TRUST BOARD MEMBERS AND SENIOR MANAGERS

Ask yourself
- Has your organisation implemented an appropriate EoLC tool such as the LCP?

Your role
- Provide training and education in EoLC, including correct use of, care of the dying, pathways
- Monitor the use of such pathways to ensure they are being used appropriately across your trust
- Ensure audit of the pathways informs education and training and service improvement
- Participate in the 'national care of the dying' audit for hospitals
- Ensure a 'rapid discharge home to die care pathway' is in place to enable more patients to die at home.

CLINICIANS

Ask yourself
- Do you and your colleagues fully understand the changes that can happen as someone dies and do your communication skills allow you to prepare the patient (where possible) and their loved ones?
- Are you confident about the use of an end of life care tool such as the LCP?
- Is a particular treatment or intervention still in the best interests of the patient?

Your role
- Inform families and loved ones that the patient is dying and involve them in discussions about the use of a tool such as the LCP to support care
- Inform relatives/carers of changes that may occur during the dying process
- Be aware of – and try to meet – any wishes that the dying person has expressed in advance. This includes the cessation or avoidance of treatments that are no longer in the patient's best interest while ensuring appropriate symptom relief and pain management, and addressing any cultural/spiritual needs
- Provide appropriate written information to the patient and family.

Relevant national quality marker

9. Adopt a standardised approach such as the LCP or equivalent to care for people in the last days of life.

Top tips

- Embed the use of a recognised tool, eg LCP, for the final days and hours
- Consider the need for privacy and dignity for the dying person and their loved ones.

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'.

Investment in these services, as well as helping people at one of the most vulnerable moments in their lives, can also benefit the local health economy by reducing demand for long-term counselling or psychological services.

The national *End of Life Care Strategy* noted that staff "dealing with carers and families of the deceased do not always have the confidence and skills to support them appropriately" (see resources page 24). It suggested the 'care after death' section of the Liverpool Care Pathway could be used across all settings, whether the death was sudden or anticipated.

The King's Fund's *Improving Environments for Care at the End of Life*, part of the organisation's *Improving the Healing Environment* series, reported significant changes in 2010 "with regard to the numbers of people who want to use mortuary viewing facilities" – often with large numbers visiting together and more than once (see resources page 24).

It emphasised the need for a bereavement suite and viewing facilities that provides a

sense of dignity and calm, and took account of the needs and sensitivities of different cultures and faiths. While these facilities should not be "hidden away", the document says, "the approach should be sensitively signed and decorated and be free from clutter".

TRUST BOARD MEMBERS AND SENIOR MANAGERS

Ask yourself
- Do all staff likely to be in contact with bereaved people, including bereavement counsellors, receive appropriate training – including advising the bereaved on accessing comprehensive spiritual, emotional, practical and financial support?
- Are carers' post-bereavement needs routinely recorded as part of the carer's assessment to which they are entitled while their loved one is still alive?
- Are all staff aware of the location of the bereavement suite and the need to respect its sensitivity?
- Has your trust done everything it can to reduce stress on the carer or family, eg centralising official documentation and the gathering of the deceased person's possessions in one place?

Your role
- Oversee arrangements with primary and community services, including the relevant social care authority, so that trust staff can guide bereaved people to the appropriate support according to assessed need
- Provide a bereavement suite and viewing facilities that are comfortable, private and dignified. It should also acknowledge the needs of different communities and faiths.

Relevant national quality marker

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

CLINICIANS

Ask yourself
- Do you have the communication skills to feel comfortable supporting people immediately after the death of their relative?
- Are you aware of the location of the bereavement suite and the services available there?

Your role
- You should support bereaved people and act in a sign-posting capacity towards comprehensive spiritual, emotional, practical and financial support
- If a carer had an assessment when the deceased person was alive you should be guided by any arrangements made or plans for post-bereavement. This could include putting them in touch with other agencies such as social care
- Provide appropriate written information to the family
- Provide a suitable container for the deceased person's possessions.

Top tips

- Send a sympathy card a few weeks after the death to the next-of-kin, including information on local bereavement and support services
- Train volunteers to support dying patients and their families and offer support to bereaved people
- Send relatives a bereavement questionnaire (eg VOICES) and provide frontline staff with feedback to support continuing improvement.

Step 1

Discussions as the end of life approaches

Early recognition of approaching death and the discussions that should result from that affect the extent to which the person's wishes and preferences for end of life care are met.

Few doctors and nurses have received pre-registration training in communicating with patients approaching the end of life. Research, such as that conducted by the National Confidential Enquiry into Patient Outcome and Death (NCEOPD) last year, also highlighted shortcomings in identifying approaching death.

One response to this challenge is the algorithm for opening discussion around death developed by **Healthcare for London**. At its core is the idea that health professionals should seek and track the markers of prognostic uncertainty and discuss early on who should initiate and lead discussion with the patient. This would include the GP, who might be the first to discuss death with the patient.

The algorithm includes indicators that might prompt staff to consider initiating discussion.

This is all in line with the four 'winning principles' outlined in 2008 by NHS Improvement's Transforming Inpatient Care Programme. Early identification and discussion empowers patients and families.

At the **Royal Marsden NHS Foundation Trust** a palliative care team member attends oncology multi-disciplinary team meetings, to introduce the option of transferring a patient from oncolog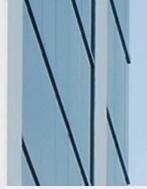y to palliative care. When such a decision is made the oncology and palliative consultants visit the patient together to effect a handover.

The palliative care team monitors third line chemotherapy and asks oncology colleagues about the patient's future quality of life. In many trusts palliative care link nurses on the wards help to identify patients nearing the end of their life and factors that can trigger discussion.

The NEoLCP has produced several pieces of work on advance care planning, including a factsheet, a support sheet for this series and a report on a joint initiative with registered social landlord Housing 21 on discussions of future end of life care options in extra care housing.

The support sheet emphasises that unlike general care planning, ACP takes place when deterioration in the individual's condition is anticipated.

The programme has also produced a chart setting out in plain language the differences between general care planning and decisions made in advance. The chart outlines the status and legal implications of several types of plans and decisions. That chart, together with the support sheet and factsheet, can be found on the Route to Success resources webpage (see websites page 25).

People who are dying, and their loved ones, will have a wide variety of needs. Assessments, which should shape care planning and be regularly reviewed, should address physical, psychological, social, spiritual and financial needs.
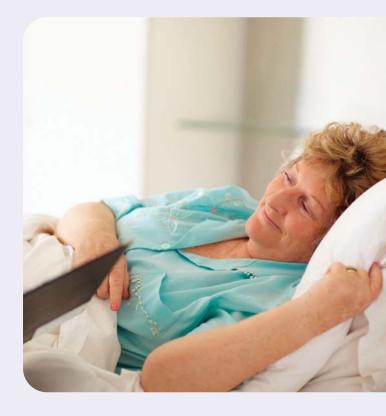
Assessment soon after diagnosis is vital and it needs to be regularly reviewed and shared with community services (with the patient's permission).

At **Basildon and Thurrock University Hospitals NHS Foundation Trust** local specialist palliative care providers liaise with the community Macmillan nurses and the local hospice. Any holistic assessments conducted in the hospital are shared with community services. The psychological elements of the assessment acts as a prompt for referral to the Macmillan counsellor.

Its holistic assessment has been benchmarked against guidance produced in 2007 by **King's College London** in partnership with the NHS National Cancer Action Team.

Other organisations use self-assessment tools, such as the patient distress thermometer, to measure how a patient is coping. The answers can act as triggers for a health professional to raise issues. In many trusts, holistic care plans emerge from the wide range of professionals attending multi-disciplinary meetings.

The AMBER care bundle (Assessment, Management, Best Practice, Engagement of patients and carers, for patients whose Recovery is uncertain) developed by the Modernisation Initiative End of Life Care Programme, includes systems to identify patients more reliably – increasing the chance that they will receive the best possible treatment and care at the appropriate time.

Being trialled at **Guy's and St Thomas' NHS Foundation Trust** and **King's College Hospital NHS Foundation Trust**, AMBER is for patients who are at risk of dying in the next one to two months who may still be receiving treatment.

It is an 'at-a-glance' reminder of the other key issues that the clinician dealing with the acute crisis should have in mind. This appears to allow for more timely communication, proactive prescribing and planning – helping to avoid last minute decision-making to meet patient preferences.

The first two steps on the end of life care pathway have involved communication. Such communication between professionals, patients and carers increases the opportunities for co-ordination of care and support.

Communication is crucial to delivering effective care co-ordination.

The Palliative Care Team at the **Royal Liverpool and Broadgreen University Hospital NHS Trust** has designed a 'rapid discharge home to die' pathway.

Using the integrated care pathway approach, this pathway helps clinicians to co-ordinate the rapid discharge of a patient in the last hours or days of life from hospital to home within a governance and risk framework. It is used when:
• An acute situation changes rapidly with a sudden and unexpected deterioration and change in condition
• The patient, relatives and carers are informed that death is imminent and there is an urgent request for the patient to die at home
• There is consensus this is in the best interest of the patient.

Some 31 patients were discharged in a year with no re-admissions – saving 257 bed days.

Meanwhile, a framework placing the district nursing team at the centre of care delivery in Leeds has resulted in more than 80% of patients achieving their wish to die at home.

The framework (see www.endoflifecareforadults.nhs.uk) improved the consistency and quality of palliative care in people's own homes. District nurses, supported in co-ordinating care by joint care management teams, oversee support workers, providing both health and social care.

As well as an increase in the home death rate, the framework has improved anticipatory medication and use of the **Leeds** Care of the Dying Pathway.

Lead clinical nurse specialist in palliative care at **Sandwell and West Birmingham Hospitals NHS Trust**, Kate Hall, explains how one local primary care trust (PCT) has helped to move more people back to their homes from hospital to die – if that is their wish.

"Sandwell PCT funds three discharge nurses who respond very quickly if we call and say that a patient wants to go home to die. One of them usually comes in within a day to assess the patient and arrange the discharge and community package."

The team has also established its own system for summary discharge letters to GPs, ensuring that they receive them within a day or two of discharge.

In **Hull**, the **City Healthcare Partnership** established a health and social care team to complement end of life care provided by community services. Some 76% of patients referred to the team in its first four months died at home. Previously that figure was below 20%. The service offers instant access to around the clock care by working together with other services.

Delivery of high quality care in an acute setting

Acute hospitals are seen as places where people go to be 'cured'. Yet ensuring people have 'a good death' is also a crucial part of their remit. In many trusts palliative care link nurses are the champions for quality EoLC, notably by implementing and embedding the Liverpool Care Pathway or similar tools.

Lead palliative care clinical nurse specialist at **Sandwell and West Birmingham Hospitals NHS Trust,** Kate Hall, says her trust retained the post of supportive care pathway (SCP) facilitator to embed the pathway.

"Rather than a scattergun approach the nurse spends a lot of time on one ward making sure the consultants and nurses are happy with the (SCP) algorithms and supporting them in understanding why they should make certain decisions. If we see that only three people out of ten deaths on a ward were cared for on the pathway the facilitator will look at the notes and discuss their care with the ward staff."

The trust is also investing in staff development in this area with EoLC competences for new staff nurses and the SCP facilitator and bereavement nurses teaching on the staff nurse development programme.

Similarly, at **Peterborough and Stamford Hospitals NHS Foundation Trust**, nurse education is key.

The lead cancer and palliative care nurse, Lyndsay Carter, says that preceptorship packs for grades 5-7 nurses include end of life care and all nurses must complete some of the 100-plus sessions available on the new e-learning resource, e-ELCA (End of Life Care for All). (see resources page 24).

Within **Stockport NHS Foundation Trust**, EoLC project facilitator Lyndsey McMurchy says the profile of EoLC has been increased by its presence on the corporate and quality dashboards. She monitors each pathway death to see if the patient was, or should have been, on the LCP. Those figures are reported to the board each month.

Deaths that occur in hospital within three days of admission from a care home are analysed to see if the admission was necessary.

Ms McMurchy says: "It might be right that the patient was brought to the hospital with new symptoms but we are looking to support homes and GPs so that residents can die at the care home if they wish."

There inevitably comes a time when clinicians will recognise that a person has entered his or her final days and that death could occur at any point in the near future.

In many ways the quality of death and a person's final hours and days are determined by the actions taken on steps 1 to 4 of the pathway.

If assessment, communication and planning have been proactive and of a high quality then a person is more likely to die in the place of their choice with the levels of treatment and interventions previously agreed.

However, a crucial element in this final phase of life is the team's decision, in consultation with the patient (where possible) and their carers, to use a recognised 'final days and hours' pathway, such as the Liverpool Care Pathway (LCP).

Audits have found wide variations in the extent to which a final phase of life tool has been 'rolled out' across a trust rather than limited to specific units or departments.

At **Leeds Teaching Hospitals NHS Trust** the LCP has been extended widely following the decision to deploy two fulltime facilitators. They deliver all necessary education and liaise with bereavement services, the specialist palliative care team and the trust's palliative care discharge facilitator.

The trust is developing its own LCP e-learning package to reinforce monthly educational LCP updates and sustainability sessions. A decision to place a patient on the pathway is not irreversible and regular reviews are vital.

Clearly, effective use of the pathway requires training and education of ward staff and access to - and support from - the hospital specialist palliative care team.

In some trusts figures around pathway and non-pathway deaths are included on corporate and quality dashboards.

Several trusts have placed the emphasis on a rapid discharge home to die.

At **Barking, Havering and Redbridge University Hospitals NHS Trust**, the palliative care team works closely with the Hospice at Home team to ensure hands-on care is available as the patient arrives home.

The **Midhurst Macmillan Specialist Palliative Care Service** has increased the percentage of patients able to fulfil their wish to die at home from 36% to 76% in three years. That change led to savings of around £600,000 per year. The service is made up of nearly 100 staff and volunteers providing palliative care in people's own homes.

Trusts are also striving to provide more single rooms for patients in the last hours or days of their life. This helps provide dignity for the patient and their family.

The hours and days after the death of a loved one can affect how relatives and friends cope with their loss in the long term.

Several acute hospitals have recently refurbished their bereavement suites, assisted by funding from the King's Fund's Enhancing the Healing Environment programme.

Central to such suites is the question: 'How will this make people feel?'

The King's Fund says that bereaved people asked for somewhere homely, comforting, safe and warm.

A new bereavement suite at **Southend University Hospital NHS Trust** acts as a 'one-stop shop' where administrative procedures – including death registration – can be completed in one visit.

The **Heart of England NHS Foundation Trust** also seeks to minimise legal and administrative pressures on the newly bereaved with a nurse-led centralised bereavement service across its three hospital sites.

The trust makes things easier for relatives by having information and documentation in one place. The trust educates its staff to be culturally sensitive to the way different faiths and races react to death and dying.

A registrar is based at one of the trust's hospitals so a death can be registered when medical certification is completed. The same hospital has been piloting a 'listening service', which maintains weekly phone calls for up to eight weeks. It will also refer people to formal bereavement counselling if necessary.

The anxiety and uncertainty of waiting for an inquest sometimes felt by staff and relatives led the trust to produce two DVDs – one for staff and one relatives – about coroner's courts (see www.endoflifecareforadults.nhs.uk).

Quality and co-ordinated information is clearly crucial for relatives at a time when they are at their most vulnerable. At **Barts and the London NHS Trust**, ward staff provide relatives with a booklet very soon after the patient's death. This contains practical information, which is backed up by a folder containing information on subjects such as probate and funeral arrangements.

The community bereavement counselling service is based within the trust and it is also planning support groups for bereaved people in the community to be delivered by its palliative care staff.

Documents

Algorithm to discuss end of life planning in hospital Healthcare for London (2009)
http://tiny.cc/g0wwz

AMBER (Assessment, Management, Best Practice, Engagement for patients whose Recovery is uncertain). Southwark and Lambeth Modernisation Initiative End of Life Care Programme. (2009)
http://tiny.cc/am3rs

Calman Hine Report. DH (1995) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/
PublicationsPolicyAndGuidance/DH_4071083.

Carers at the heart of the 21st Century families and communities: a caring system on your side, a life of your own DH (2008) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/
PublicationsPolicyAndGuidance/DH_085345

Common core competences and principles for health and social care workers working with adults at the end of life. NEoLCP, DH, Skills for Care and Skills for Health (2009) http://tinyurl.com/yc99rsa

Deaths in acute hospitals: caring to the end? NCEPOD (2009) http://tiny.cc/um1on

The differences between general care planning and decisions made in advance. National End of Life Care Programme (2010) http://tiny.cc/jl55s

End of Life Care Strategy. DH (2008) http://tiny.cc/5a712

End of Life Care National Audit Office (2008) http://tiny.cc/qszk5

End of life care - a framework of national occupational standards. Skills for Care and Skills for Health (2010)

End of Life Care Common core competences and principles for health and social care workers working with adults at the end of life. National End of Life Care Programme, DH, Skills for Care and Skills for Health (2009) http://tiny.cc/vk1oi

End of life care strategy: quality markers and measures for end of life care. DH (2009)
http://tinyurl.com/l2urn7

Guidance about Compliance: Essential standards of quality and safety Care Quality Commission (2010) http://www.cqc.org.uk/_db/_documents/Essential_standards_of_quality_and_safety_March_2010_FINAL.pdf

Improving Environments for Care at End of Life. Kings Fund (2009) http://tiny.cc/8sh1p

Improving supportive and palliative care for adults with cancer. NICE (2004)
http://www.nice.org.uk/nicemedia/pdf/csgspexecsummary.pdf

"Is it that time already?" Extra care housing at the end of life. NEoLCP and Housing 21 (2009)
http://tinyurl.com/389rgfm

Living well with dementia: A National Dementia Strategy. DH (2009)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097629.

Documents continued

Mental Capacity Act (2005) support sheet 12 NEoLCP (2010)
http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet12

The national framework for NHS continuing healthcare and NHS-funded nursing care (revised). DH (2009) http://tinyurl.com/kor2gc

Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care. Updates guidance on discharge practices for nurses and other practitioners. DH (2010) http://tinyurl.com/ykdlwry

Supporting people to live and die well: a framework for social care at the end of life. NEoLCP (2010) www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework

Websites and end of life care tools

The National End of Life Care Programme (NEoLCP) has developed a "useful resources" page on its website with support sheets developed especially for the Route to Success series and links to other useful information or documents.

The page can be found at www.endoflifecare.nhs.uk/routes_to_success

e-ELCA (End of Life Care for All) – more than 120 modules on e-learning for all levels
www.e-elca.org.uk

Gold Standards Framework
http://www.goldstandardsframework.nhs.uk/

Help the Hospices
www.helpthehospices.org.uk

Liverpool Care Pathway
http://www.mcpcil.org.uk/liverpool-care-pathway

Marie Curie Cancer Care
www.mariecurie.org.uk

National End of Life Care Intelligence Network
www.endoflifecare-intelligence.org.uk

National Council for Palliative Care
www.ncpc.org.uk

National End of Life Care Programme
www.endoflifecareforadults.nhs.uk

www.endoflifecareforadults.nhs.uk