

## Introduction

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This module has been designed to provide a firm grounding in the background to developments in end of life care, using practice in England and the UK. The reader will be given the opportunity to explore personal experiences and feelings, and consider the patient's perspective regarding end of life care and other concomitant issues.

At the outset of this module, consideration needs to be given to what we personally might be bringing to bear on this. You are encouraged to consider what your own experiences and feelings may be around end of life care. Reflect on the following questions.

- What have my own personal experiences been of the deaths of loved ones?
- How comfortable am I talking about death and dying among family, friends or colleagues? Have I talked about how I would like my own death to be, what choices I would like to be able to make in regard to my death?
- What do I even understand by the term 'end of life care'?
- In my role as a professional, working with cancer patients, how important is it to consider end of life care issues?

Take some time to note your thoughts and responses to these questions.

This module should take approximately 6 hours to complete, comprising the learning activities and time for reading, thinking and reflection.

## Learning objectives

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The activities and content of this module are built around the following learning objectives:

- Exploration of personal issues around death and dying
- Clarification of terminology used in this aspect of care.
- Appreciation of the history of developments in end of life care in the United Kingdom and England in particular
- Understanding of End of Life Care Tools and their application
- Development of ethical issues around nutrition, hydration and resuscitation issues in end of life care in the UK.

## 'End of life care' for cancer patients

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A major change, when the National End of Life Care Programme in the UK was set up at the end of 2004, was the intention to make good quality end of life care available to all adult patients, irrespective of diagnosis. It remains the case, however, that cancer accounts for around a quarter of all deaths in the United Kingdom (Office of National Statistics, 2008) and across Europe (European Communities document, 2006).

In 2007, there were more than 155,000 cancer deaths in the UK. Deaths from cancers of the lung, bowel, breast and prostate, together account for almost a half (47%) of all cancer deaths. Lung cancer is still, by far, the most common cause of death from cancer, accounting for just under a quarter of all male cancer deaths and a fifth of all female cancer deaths – a figure which is on the rise. (Cancer Research UK data; available at: [http://info.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@sta/documents/geralcontent/018070.pdf](http://info.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@sta/documents/geralcontent/018070.pdf))

Besides the possibility that some of your cancer patients may die from the presenting disease, there is the impact of outstanding bereavement and unresolved grief issues to consider, when working with any patient group.

The National Council for Palliative Care have calculated that over the course of the next Parliament, over 12 million people will suffer a family bereavement (NCPC, 2009). Depending on how positive or negative that experience will have been, this may affect your patient's capacity to participate in the care you would wish to deliver. Being aware of the consequences of such grief reactions and knowing how to access appropriate help for your patient may be an important step in improving the care of your patient.

Organisations such as Cruse produce supportive leaflets in such situations, an example of which may be found at: <http://www.cruse.org.uk/PDFs/CoreLeaflet.pdf>

## **What does 'end of life care' mean?**

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Quite a few terms are used, sometimes interchangeably, when discussing care delivered to a patient, who is approaching the last stages of their life. To avoid confusion it is worth considering and defining what we mean by these terms.

### **Palliative care**

The World Health Organisation has a long all-encompassing definition for palliative care (available at: <http://www.who.int/cancer/palliative/definition/en/>), but it has been defined more succinctly, in 2004, by the National Institute for Health and Clinical Excellence (NICE) in their *Improving Supportive and Palliative Care for Adults with Cancer* as: "the active holistic care of patients, with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments." This definition has been adopted by the National Council for Palliative Care (NCPC). ([http://www.ncpc.org.uk/palliative\\_care.html](http://www.ncpc.org.uk/palliative_care.html))

### **Specialist palliative care**

In 2004, NICE differentiated between generalist and specialist palliative care, where the specialist care was delivered by an expert team including consultants in palliative medicine, nurse specialists and allied health professionals, who are specialists within the field. When most health and social care professionals speak of 'palliative care', it is this specialist palliative care, to which they refer.

According to NCPC, specialist palliative care is "provided by specialist multidisciplinary palliative care teams" and includes:

- Assessment, advice and care for patients and families in all care settings, including hospitals and care homes.

- Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams.
- Intensive co-ordinated home support for patients with complex needs who wish to stay at home.
- Day care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies.
- Advice and support to all the people involved in a patient's care.
- Bereavement support services, which provide support for the people involved in a patient's care following the patient's death.
- Education and training in palliative care.

### **Supportive care**

This term is often used in conjunction with 'palliative care'. It is discussed in the NICE Guidance (2004), and is defined by the National Council for Palliative Care as: "Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment."

### **Terminal care**

This term is usually used for those with very advanced disease who are expected to die within days or weeks. While this may be generally accepted, with individual patients, it can be exceptionally difficult to pinpoint when the terminal phase begins. If the patient is being considered for the Liverpool Care Pathway (see page 12), however, this would be a clear signal that the patient is in the terminal phase.

### **End of life care**

Dr Keri Thomas proposes: "The term 'end of life care', includes the months or years before the death of patients living with advanced irreversible illness, rather than just the terminal stage towards the final few days. It includes the specialty of palliative care, but also care that is provided by all healthcare professionals for people nearing the end of their lives." (Thomas, 2006).

In their proposal to the Government, prior to publication of the National End of Life Care Strategy, the National Council for Palliative Care (NCPC) outlined their concerns around use of the term 'end of life care'. It can be very difficult to pinpoint the beginning of end of life care, particularly with patients with long-term conditions, given the variations due to condition, patient perspective and professional judgement. Equally, given the need to provide support for some carers and family after death, end of life care cannot necessarily be said to end at the time of the patient's death.

NCPC, therefore, proposed the following definition: "End of life care is simply acknowledged to be the provision of supportive and palliative care in response to the assessed needs of patient and family, during the last phase of life." (NCPC, 2006).

'End of life care' as defined by the National End of Life Care Team is: "All elements of support to people approaching the end of their lives. In addition to the highly-skilled and focused care and support that may be provided by those working as palliative care specialists, all of the other significant support that is given needs to take on a different focus and perspective to

accommodate this stage of life. It encompasses the management of all symptoms including pain, and provides psychological, social, spiritual and practical support.” (National End of Life Care Programme, 2009).

**Thinking Point:**

What does ‘end of life care’ mean to colleagues in your organisation? Is it perceived as something ‘others’ do or is it considered as part of your role, as a team, department or organisation?

## Activity 1 (allow 1 hours)

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**Task 1:** Think back to the last patient you encountered, who died. When did their ‘end of life care’ begin and who delivered it, initially? Was the patient aware that they might die? Were their preferences for end of life care achieved or even recorded?

**Allow 30 minutes**

**Task 2:** For the same patient, when did the end of life care end? If there were carers involved, were they offered any form of bereavement support? Is such support available in your organisation?

**Allow 30 minutes**

## Resources required to complete this activity

### Useful websites

National Council for Palliative Care

[www.ncpc.org.uk](http://www.ncpc.org.uk)

Cruse

[www.cruse.org.uk](http://www.cruse.org.uk)

World Health Organisation (definition for palliative care)

<http://www.who.int/cancer/palliative/definition/en/>

### Background reading

Cancer Research UK data; available at:

[http://info.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@sta/documents/generalcontent/018070.pdf](http://info.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@sta/documents/generalcontent/018070.pdf)

European Communities (2006) Causes of death in the EU. Statistics in Focus: Population and Social Conditions. European Communities. ISSN: 1024-4352.

Office for National Statistics (2008) Mortality Statistics: Deaths registered in 2007. Office for National Statistics, Newport. Available from:

[http://www.statistics.gov.uk/downloads/theme\\_health/DR2007/DR\\_07\\_2007.pdf](http://www.statistics.gov.uk/downloads/theme_health/DR2007/DR_07_2007.pdf) [Accessed 18th February 2010]

National Council for Palliative Care (2009) End of Life Care Manifesto 2010. National Council for Palliative Care, London.

National End of Life Care Programme (2009) 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, London. Available at: [http://www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC\\_Core\\_competences-Guide-Jul2009.pdf](http://www.endoflifecare.nhs.uk/eolc/files/NHS-EoLC_Core_competences-Guide-Jul2009.pdf) [Accessed 18th February 2010]

National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. National Institute for Clinical Excellence (N0474), London.

Thomas, K. (2006) Palliative Care. Geriatric Medicine, 36, Supplement GM2, 9 – 13.

## **End of life care in the UK**

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Caring for people at the end of their lives is an important role for all health and social care staff. When asked, over half of all people express a wish to die at home, although currently only about 20% are actually achieving this (Healthcare for London, 2007 p79). Many health and social care staff also feel that they have not had the appropriate training to help care for people at the end of their lives.

'Building on the Best, Choice, Responsiveness and Equity,' (Department of Health, 2003) committed the Department of Health to take forward training programmes, so that all adult patients, nearing the end of life, would have access to high quality palliative care and be able to live and die in the place of their choice.

The NHS End of Life Care Programme (Department of Health, 2004) was part of an overall strategy to address some of these challenges. The aim of the programme was to improve end of life care for all patients, irrespective of diagnosis, and it sought to provide greater choice for patients in their place of care and death. It also sought to reduce the number of emergency admissions to acute care, for those who expressed a wish to die at home, and to reduce the number of patients transferred from care homes to acute care, in the last week of life.

A total of £12 million, over three years, was committed from November 2004, specifically to help support the implementation of best practice in end of life care, by widening the pool of trained staff. This was to be achieved via implementation of tools, highlighted in Improving Supportive and Palliative Care for Adults with Cancer (National Institute for Clinical Excellence, 2004), which we will look at in the next section.

### **End of life care developments in England**

Since 2007, a number of publications, in England, have specified what best practice in end of life care is and what health and social care organisations should do to achieve that. Those documents are:

- High Quality Care For All: NHS Next Stage Review Final Report (Department of Health, 2008)
- NHS National End of Life Care Strategy (Department of Health, 2008)
- National Audit Office (NAO) Report, End of Life Care (NAO, 2008)
- House of Commons Public Accounts Committee Report on End of Life Care (2009)
- NHS End of Life Care Strategy: Quality Markers and measures for end of life care (Department of Health, 2009)

These documents, together with the requirement in the Department of Health Operating Framework 2007/8 that Primary Care Trusts (PCTs) undertake a Baseline Review of End of Life Care, has significantly heightened awareness of the need to improve quality of care in this area.

### **High Quality Care For All: NHS Next Stage Review Final Report (DoH 2008)**

Strategic Health Authorities across England were charged, in 2008, with planning eight pathways of care, one of which was End of Life Care. Local visions were developed addressing the “necessity for greater dignity and respect at the end of life... as well as the desire to have round the clock access to palliative services.”

### **National End of Life Care Strategy (for England)**

The Department of Health’s ‘National End of Life Care Strategy: Promoting high quality care for all adults at the end of life’ was finally published, in England, in July 2008. The strategy is intended to enable a step-change in the provision of, and access to, high quality end of life care, as a follow-on to the work of the End of Life Care Programme.

The body of the strategy is divided up into eight chapters, grouped into three sections:

- The introduction covers a synopsis of the demographics and issues around death and dying in the UK, today; particularly the impact of society’s reluctance to acknowledge and discuss such issues and the great need to address this.
- The section on care delivery details: the proposed end of life care pathway, issues peculiar to individual care settings, the vital importance of carer support and the many workforce-planning issues.
- The final section deals with current issues, in terms of accessibility, availability and quality of services and how best to take this forward, including some detailing of responsibilities at national, regional and local levels.

### **National Audit Office (NAO) Report, End of Life Care (NAO 2008)**

Following investigation into the state of end of life care and developments across England, the National Audit Office expressed a number of concerns:

- The wishes of people, approaching the end of their life, are not always conveyed to those who need to know.
- There are significant gaps in the education and training curricula for health and social care professionals.
- Few care home staff have sufficient training in providing end of life care.
- Little is known, however, about the direct patient benefits associated with the use of the recommended tools, such as the Gold Standards Framework (GSF) and Liverpool care pathway (LCP).
- There is a limited understanding of the national picture of demand and supply of end of life care services, particularly among PCTs who are charged with commissioning it on behalf of their populations.
- A lack of coordination between services or a single point of contact can lead to frustration for patients and carers.
- PCTs generally contract with independent hospices on an annual basis, leading to uncertainty in planning and, sometimes, financial pressures on those hospices.
- Hospitals will continue to have an important role to play in end of life care, but these services do not always meet the needs of patients and carers.
- There is considerable variation in how specialist palliative care services are commissioned and in the availability of such services to the local population.

- People’s preferences for place of care are generally not being met and access to hospice services is primarily for people with cancer.
- The current reviews of medical and nursing education present an opportunity to improve the level of basic training, which doctors and nurses receive, in end of life care.

### **House of Commons Public Accounts Committee Report on End of Life Care (2009)**

Similar concerns were expressed by the Public Accounts Committee, when they looked into end of life care in England, after the NAO presented their report to Parliament.

While they echoed concerns around communication, coordination, levels of training, PCT commissioning and contracting with hospices, they also expressed further concerns:

- There is a risk that the additional £286 million committed to improving end of life care will not be used as intended.
- Most people express a preference to die at home, but 60% die in an acute hospital, even when there is no clinical need for them to be there.
- People who die in hospital are not always afforded the end of life care they deserve, including effective pain management and being treated with dignity and respect.
- More people could be supported to die in their homes or in a care home if there was a more responsive system for providing the equipment and support services needed.

### **National Quality Markers for End of Life Care**

The National End of Life Care Strategy heralded the development and publication of national quality standards for end of life care.

From these standards, a document was published in 2009, comprising of 126 markers, covering nine types of end of life care provider and the PCT commissioning body. Each care setting has between 4 – 14 quality markers and each marker is accompanied by at least one proposed measure of compliance, designed to demonstrate achievement of the specific marker. The markers emphasise issues such as action planning, communication, coordination and training, at the individual, as well as organisational, level.

There is an expectation of investment plans for training among provider organisations, utilisation of national common core competencies and end of life care training for all workers (not just qualified staff), ongoing training needs assessment, access and provision. The care that should be delivered by district and community nursing staff is also specified.

Given the wide range of markers and diversity of providers an attempt has been made to prioritise the ‘Top Ten’ quality markers for providers (see Table 1)

**Table 1: ‘Top Ten’ Quality markers for all end of life care providers.**

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.
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.
6.	Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
7.	Have essential services available and accessible 24/7 to all those approaching the end of life that needs them.
8.	Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9.	Adopt a standardised approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10.	Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

It is recognised that there are some gaps in the areas covered within the document, such as bereavement and spirituality, which, it is hoped, will be addressed in the next iteration. The quality markers are conceived as an evolving piece of work that will be reviewed and amended over time to reflect emerging evidence.

### **Implementation of the Quality Markers**

In accordance with Department of Health policy, implementation of these national Quality Markers has been devolved to local NHS organisations, rather than been centrally directed. It is suggested that the markers would be of use for (PCTs), working with their local partners to formulate their plans for end of life care.

They are not, however, mandatory. Individual provider organisations need to decide which of the Quality Markers they wish to adopt, depending on their local needs and circumstances. It is acknowledged, though, that commissioners may use the Quality Markers, and an expectation of improvement against them, in their contracting.

While these national quality markers are generally supported by those involved in end of life care provision, some have reservations: *“Some (markers) may remain slightly controversial and will develop over time. For example the term 'keyworker' is not clearly defined in terms of the practicalities of what this means for each organisation; and locality registers are at the stage of piloting so the best models are not yet known. It is also not clear at this stage how influential the quality markers and measures will be.”* (Gold Standards Framework website, 2009).

Despite all the progress and inquiry, in regard to end of life care, in England, in the last five years, the home death rate (the only indicator, universally used, just now) remains low: 19%, nationally, in 2006 (ONS 2008). Despite the work on their Baseline Reviews of End of Life Care, most PCTs are still lacking a comprehensive, valid and reliable assessment of end of life care need for their populations, which can be benchmarked against other similar populations, in order to drive up the quality of care.

This service development is being led, nationally, by the National End of Life Care Programme at the Department of Health, in conjunction with other national bodies, such as the National Council for Palliative Care.

While the current financial downturn has put pressure on organisations investment plans, there is still a drive to make significant changes in the delivery of end of life care.

A paper from Abel et al (2009) found that 44% of all patients, who died within the district general hospital, in the course of a year, had chronic life threatening illnesses, which would suggest their death could have been planned for. They proposed that a maximum of one third of all hospital deaths could have been looked after at home if excellent end of life services were in place.

## **Other ‘end of life care’ strategy developments in the UK**

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Since the devolution of powers to the Scottish Parliament, the National Assembly for Wales and the Northern Ireland Assembly, each country has moved to develop a strategy for end of life care that meets the particular health, social and economic needs of that country.

### **Scotland**

The Scottish Government action plan for health and wellbeing, Better Health, Better Care, published in December 2007, stated a commitment to the delivery of high quality palliative care to everyone in Scotland who needs it, on the basis of established principles of equity and personal dignity and of clinical need rather than diagnosis.

Living and Dying Well, published in September 2008, represents a cohesive and collaborative approach to the development and maintenance of equitable, high quality and sustainable palliative and end of life care services for the future. It is based on the principles of equality, dignity and quality and supports the national policy of empowering the diversity of patients, carers and the voluntary sector to be full partners in planning, improving quality and enhancing the experience of care.

### **Wales**

While the Welsh Assembly has formally adopted the All Wales Care Pathway for the Last Days of Life, based on the Liverpool Care Pathway, it is still in the process of developing a comprehensive strategy document. This follows on from a report to the Minister for Health and Social Services, in June 2008, chaired by Vivienne Sugar, which aimed to “specify the elements of a core palliative care service including end of life care for adults and children”.

### **Northern Ireland**

On 29th May 2009, Northern Ireland’s Health Minister announced the development of palliative and end of life care strategy by the end of 2010. As with the other strategy plans, it is planned that this will “help ensure palliative care services, wherever possible, will be provided in a way that meets the particular needs and wishes of patients, their carers and families.” (Northern Ireland Executive Press Release, May 2009). A consultation document was published in December 2009 (Department of Health Social Services and Public Safety, 2009)

#### **Thinking Point:**

Does your organisation or your organisational partners have an end of life care strategy? If so, to whom is it accountable for delivery of that strategy?

## Activity 2 (allow 2 hours)

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**Task 1:** Review the DoH Quality Markers document:

([http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_101681](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681)) and pay particular attention to your own type of care setting. How does your organisation compare? Do you know if that requisite information is available? Who is responsible for gathering the information and to whom does it go?

**Allow 1 hour**

**Task 2:** Does your organisation have a local end of life care strategy? Is it aligned with the other organisations you work closely with? Find out which organisations in your healthcare sector have an end of life care strategy.

**Allow 1 hour**

### Resources required to complete this activity

#### Useful websites

The National End of Life Care Programme  
[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

Department of Health:

<http://www.dh.gov.uk/en/Healthcare/IntegratedCare/Endoflifecare/index.htm>

Gold Standards Framework

[www.goldstandardsframework.nhs.uk/](http://www.goldstandardsframework.nhs.uk/)

National Council for Palliative Care

[www.ncpc.org.uk](http://www.ncpc.org.uk)

#### Background reading

Abel, J., Rich, A., Griffin, T. & Purdy, S. 2009. End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year. Palliative Medicine, 00, 1-7. Available from: <http://pmj.sagepub.com/cgi/content/abstract/0269216309106460v1> [Accessed 18th February 2010]

Department of Health (2003a) Building on the best: Choice, responsiveness and equity in the NHS. Department of Health (CM 6079), London. Available from:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4075292](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4075292) [Accessed 18th February 2010]

Department of Health (2008b) The End of Life Care Strategy: Promoting high quality care for all adults at the end of life. Department of Health (284109), London. Available from:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_086277](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277) [Accessed 18th February 2010]

Department of Health (2008a) High Quality Care For All: NHS Next Stage Review Final Report. Department of Health, London. Available from:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085825](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825) [Accessed 18th February 2010]

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Department of Health Social Services and Public Safety, 2009. Palliative and End of Life Care Strategy for Northern Ireland Consultation Document. Department of Health Social Services and Public Safety, Belfast. Available from: [http://www.dhsspsni.gov.uk/palliative\\_and\\_end\\_of\\_life\\_care\\_strategy\\_-\\_consult.pdf](http://www.dhsspsni.gov.uk/palliative_and_end_of_life_care_strategy_-_consult.pdf) [Accessed 18th February 2010]

Healthcare for London, 2007. *A Framework for Action*. London: Healthcare for London  
House of Commons Public Accounts Committee. 2009. End of Life Care: Nineteenth Report of Session 2008-9. House of Commons Public Accounts Committee, London. Available from: <http://www.publications.parliament.uk/pa/cm200809/cmselect/cmpubacc/99/99.pdf> [Accessed 18th February 2010]

National Audit Office (2008) End of Life Care. National Audit Office, London. Available from: [http://www.nao.org.uk/publications/0708/end\\_of\\_life\\_care.aspx](http://www.nao.org.uk/publications/0708/end_of_life_care.aspx) [Accessed 18th February 2010]

National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. National Institute for Clinical Excellence (N0474), London.  
Office for National Statistics, 2008. Mortality Statistics: Deaths registered in 2007. Office for National Statistics, Newport. Available from: [http://www.statistics.gov.uk/downloads/theme\\_health/DR2007/DR\\_07\\_2007.pdf](http://www.statistics.gov.uk/downloads/theme_health/DR2007/DR_07_2007.pdf) [Accessed 18th February 2010]

The Scottish Government. 2007. Better Health Better Care: Action Plan. Edinburgh. Available at: <http://www.scotland.gov.uk/Publications/2007/12/11103453/0> [Accessed 18th February 2010]

The Scottish Government, 2008. Living and Dying Well: A national action plan for palliative and end of life care in Scotland. Edinburgh. Available at: <http://www.scotland.gov.uk/Publications/2008/10/01091608/0> [Accessed 18th February 2010]

Welsh Assembly, 2008. Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services. Welsh Assembly Government, Cardiff. Available at: <http://wales.gov.uk/topics/health/publications/health/reports/palliativecare/?lang=en> [Accessed 18th February 2010]

## End of life care tools

### Gold Standards Framework

The tool designed to improve end of life care in primary care settings was the Gold Standards Framework (GSF) (DH, 2004). GSF is used, across much of the United Kingdom, when people are likely to be in the last six to nine months, or more, of life. It was started to help GPs plan care for these patients and to make sure that information about their likely needs was shared with others involved in their care. This helps with managing symptoms and by giving the patient and their family confidence in their care, especially by planning ahead for what might happen.

Alongside the implementation of end of life care registers and regular multi-disciplinary team meetings, GSF in primary care addresses symptom management, discussions with the patient about their preferred place of care and death, continuity and out-of-hours management, carer and staff support and management of the dying phase.

The Gold Standards Framework has been adapted for use in care homes. Through coding of all the residents in a home, better identification of end of life care needs is supported and through better communication processes and an emphasis on robust training throughout the home, including staff, residents and families, the planning and quality of care needed is optimised. While the focus has been on care homes with nursing, this programme is beginning to be spread across residential homes also.

A pilot is taking place also across England currently attempting to implement GSF in the acute sector, in an attempt to better manage those approaching the end of their lives, who are not yet dying. The aims of this development are to improve the hospital experience for such patients, to improve cross-boundary communication, and to reduce the overall number of hospitalisations for these patients.

Further information on these initiatives and on other developments, including the Prognostic Indicator Guidance, which helps in the better identification of end of life care needs, particularly with non-cancer patients, can be found on the Gold Standards Framework website:

[www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

### **Liverpool Care Pathway for the Dying**

Another important tool, developed to improve the consistency of care of the dying in the last hours or days of life, is the Liverpool Care Pathway for the Dying (LCP). The LCP is a nationally-recognised evidence-based tool, intended to help clinicians give appropriate and high-quality care to people, who have reached the last few hours or days of life. Its purpose is to promote the comfort of dying people and to address the needs of their informal carers.

The LCP has been developed for use in different settings, once the multiprofessional team has agreed that the patient is dying, and two of the following apply:

- The patient is bedbound
- Only able to take sips of fluids
- Semi-comatose
- No longer able to take tablets

Key domains considered in the LCP are: physical issues or symptoms (for example, pain, nausea or vomiting, respiratory function, agitation), psychological issues, social issues (for example family relationships and understanding of patient's condition) and spiritual issues (includes involving chaplaincy services). The documentation to be used with the LCP has been adapted for a number of care settings: hospice, hospital, care home, and community, with plans for intensive care units (ITU), units delivering care for those with advanced chronic kidney disease or heart failure and for children.

There has been some media interest in recent times around the implementation of the LCP, with some criticism that it led to "tick box medicine".

A statement from the National Council for Palliative Care, in response to the media coverage, declares: "The LCP is only used when a team of doctors and nurses have agreed that a person is dying and that all reversible causes have been considered. It enables frequent assessment of care and includes discussion with relatives and carers. It is only one of a range of tools

available to support good end of life care, and does not encourage “tick box medicine” which can never be justified. Like all tools, it should be used by people who are skilled and competent.

In September 2009, the results from the second National Care of the Dying Audit were published. The audit covers the use of the LCP in 155 hospitals, looking at the records of almost 4000 patients. The audit was led by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in collaboration with the Clinical Standards Department of the Royal College of Physicians (RCP) supported by Marie Curie Cancer Care & the Department of Health End of Life Care Programme.

The Audit demonstrated increased spread of the LCP in Round 2 (2008/2009) compared with Round 1 (2006/2007): The number of participating hospitals increased in Round 2 by 31% (from 118 to 155). The number of patient data sets submitted increased by 46% (from 2672 to 3893). Further information can be found at:

<http://www.mcpcil.org.uk/pdfs/LCP%20V12%20New%20Documents/What%20is%20the%20LCP%20-%20Healthcare%20Professionals%20Nov%202009.pdf>

### **Preferred Priorities for Care**

A third tool recommended for use from the NICE guidance (2004) was the Preferred Place of Care, now Preferred Priorities for Care (PPC). This is an example of Advance Care Planning, originating in Lancashire. It can commence at the point, when discussions are first had with the patient, about their preferences for their care, once it is identified that they are entering the final phase of their life. The PPC document can be found at:

[http://www.endoflifecareforadults.nhs.uk/eolc/files/F2110-Preferred\\_Priorities\\_for\\_Care\\_V2\\_Dec2007.pdf](http://www.endoflifecareforadults.nhs.uk/eolc/files/F2110-Preferred_Priorities_for_Care_V2_Dec2007.pdf)

### **Activity 3: (allow 1 hour)**

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**Task 1:** Review the three end of life care tools above. Which tool would be most appropriate to your workplace and why?

**Allow 1 hour**

### **Resources required to complete this activity**

#### **Useful websites**

The National End of Life Care Programme  
[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

Gold Standards Framework  
[www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

Liverpool Care Pathway for the Dying:  
<http://www.mcpcil.org.uk/liverpool-care-pathway/index.htm>

Preferred Priorities for Care:  
<http://www.endoflifecare.nhs.uk/eolc/ppc.htm>

## Advance care planning

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Advance Care Planning is key to good end of life care. It involves discussion (and documentation of those discussions) around both what the patient would prefer to experience leading up to their death, which, while not legally binding in the UK, may lead to a better quality of experience for the patient and what the patient does not wish to have happen to them. This pre-emptive refusal of certain types of intervention, under specific conditions, is now referred to as 'advance decisions' in the UK. Previously, and in other countries, they have been termed 'Living Wills' or 'Advance Directives'. When carefully drawn up, advance decisions can be legally binding.

### An advance decision to refuse treatment

- Can be made by someone over the age of 18 who has mental capacity
- Is a decision relating to refusal of specific treatment and may be in specific circumstances
- Can be written or verbal
- If an advance decision includes refusal of life sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'
- Will only come into effect if the individual loses capacity
- Only comes into effect if the treatment and circumstances are those specifically identified in the advance decision
- Is legally binding if valid and applicable to the circumstances.

Because of issues around capacity and consent in such a sensitive area, care must be taken to adhere to the requirements of the Mental Capacity Act 2005 ([http://www.opsi.gov.uk/acts/acts2005/ukpga\\_20050009\\_en\\_1](http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1) )

The jargon of such legal documents can make them difficult for professionals to interpret, in order to be able to apply them to real-life situations. A guide to advance care planning and the issues around Advance Decisions to Refuse Treatment and the application of the Mental Capacity Act 2005, can be found at [http://www.endoflifecareforadults.nhs.uk/eolc/files/F2023-EoLC-ACP\\_guide\\_for\\_staff-Aug2008.pdf](http://www.endoflifecareforadults.nhs.uk/eolc/files/F2023-EoLC-ACP_guide_for_staff-Aug2008.pdf)

Further guidance is available at:

<http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>

<http://www.goldstandardsframework.nhs.uk/Resources/Gold%20Standards%20Framework/Test%20Content/ACPTThinkingAheadTemplate.pdf>

To be effective, good Advance Care Planning should be implemented by a sufficiently competent staff member. The staff member should be sufficiently confident in their communication skills, to have a potentially difficult discussion with the patient, perhaps around sensitive areas such as nutrition and hydration support and resuscitation status, once the prognosis is discussed.

The following sections will inform on developments across England around:

- End of life care competencies
- End of life care training

- Nutrition and hydration considerations
- Resuscitation issues with end of life care patients

### **Development of Competencies for Staff Working in End of Life Care**

In England, the National Audit Office (2008) has calculated that around 5,500 staff work in specialist palliative care services; the National End of Life Care Programme has estimated that the size of the workforce who actually deliver end of life care is approximately 2.5 million. (National End of Life Care Programme website).

In order to develop competencies for those 2.5 million, to determine who is capable and responsible, for delivering which level of care, the national team, have been working alongside other statutory and non-statutory bodies.

A guide "[Common core competences and principles for health and social care workers working with adults at the end of life](#)" was therefore published in 2009. Further work will take place to clarify specific levels of competencies for individual staff groups.

### **End of life care training**

Allied with the development of competencies, is the development of training to enable staff to be able to meet those competencies and provide the requisite level of care.

Training and education needs to be given not just in the physical, social, psychological and spiritual aspects of end of life care, but also in their ability to initiate end of life care discussions or to appropriately handle any discussion, prompted by the patient.

In England, advanced communication skills training has been running now, for a number of years, for those who specialise in the cancer arena (for information see the Connected website: [www.connected.nhs.uk](http://www.connected.nhs.uk)). This was as a result of the NHS Cancer Plan (2000), which required that advanced communication skills would form part of continuing professional development. The National End of Life Care Programme has been working to ensure equitable access to training across the cancer and non-cancer fields of cancer and among generalists and specialists:

- Across England, a one year pilot is running across twelve sites to explore and develop communication skills training, for those working in end of life care, who are unable to access the courses previously run by Connected.
- In January 2010, two websites were launched, providing access to e-learning packages, devised by Dr Bee Wee, clinical lead for the project and Consultant/Senior Clinical Lecturer in Palliative Medicine at Sir Michael Sobell House and Harris Manchester College, Oxford University.
  - On [www.endoflifecareforall.com](http://www.endoflifecareforall.com) there are is a package for social care workers administrative and clerical staff and volunteers, addressing the four core components of advance care planning, assessment, communication skills and symptom management.
  - On [www.e-ELCA.org.uk](http://www.e-ELCA.org.uk) there is a wider package accessible only to health and social care professionals in the UK.

Regional events have been planned for staff to see these programmes in action. There are plans to link completion of these modules with the electronic staff record for NHS staff, so that they are accredited for the extra learning.

## Activity 4: (allow 30 minutes)

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**Task 1:** Review the website [www.endoflifecareforall.com](http://www.endoflifecareforall.com) and, depending on your role, attempt one of the modules.

**Allow 30 minutes**

### Resources required to complete this activity

#### Useful websites

End of Life Care for All (e-ELCA)

[www.endoflifecareforall.com](http://www.endoflifecareforall.com)

e-Learning for Healthcare (e-LfH)

[www.e-ELCA.org.uk](http://www.e-ELCA.org.uk)

Mental Capacity Act (2005)

[http://www.opsi.gov.uk/acts/acts2005/ukpga\\_20050009\\_en\\_1](http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1)

Royal College of Physicians – advance care planning

<http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>

Gold Standards Framework – advance care planning

<http://www.goldstandardsframework.nhs.uk/Resources/Gold%20Standards%20Framework/Test%20Content/ACPTThinkingAheadTemplate.pdf>

End of Life Care – advance care planning

[http://www.endoflifecareforadults.nhs.uk/eolc/files/F2023-EoLC-ACP\\_guide\\_for\\_staff-Aug2008.pdf](http://www.endoflifecareforadults.nhs.uk/eolc/files/F2023-EoLC-ACP_guide_for_staff-Aug2008.pdf)

#### Background Reading:

National Audit Office, 2008. End of Life Care. National Audit Office, London. Available from:

[http://www.nao.org.uk/publications/0708/end\\_of\\_life\\_care.aspx](http://www.nao.org.uk/publications/0708/end_of_life_care.aspx) [Accessed 18th February 2010]

## Specific issues in end of life care

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### Nutrition / hydration

The issue about whether and when to withhold or withdraw artificial nutrition and hydration, when a patient, approaching the end of their life, can either no longer take enough food and fluids by mouth, or is deemed to have a compromised swallow, has caused a great deal of controversy and concern to patients, families and all staff involved.

This was addressed in the recent Royal College of Physician's report: *'Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life'* (RCP, 2010). Fundamentally, this report stresses the importance of maintaining an oral route for food and drink, for as long as possible. It emphasises that for any patient, particularly one approaching the end of their life, deciding that they should be 'nil-by-mouth' should be a last resort.

The report recommends:

- “A multidisciplinary nutrition support team of healthcare professionals, ideally, but not inevitably, led by a doctor, with special expertise in nutrition, should be available to work with patients and their families when oral feeding difficulties occur. A member of the team should be available by telephone at weekends as well to provide advice.
- Such teams should be collaborative in nature and not be made up of independent professionals who are focussed only on their area. The patient should be at the centre of their efforts.
- The first question should be ‘what are we trying to achieve’?
- Oral intake, modified as necessary, should be the main aim of treatment. Nutrient-dense foods or special provision of food (in hospital the ‘red tray’ system) is helpful.
- Even when tube feeding is necessary, this should be additional, whenever possible. At the end of life, even if deemed to have an ‘unsafe swallow’, a risk management approach may offer the patient the best quality of life. If in doubt, a trial of nasogastric feeding, with clearly agreed objectives, may be appropriate. Tube feeding should then be withdrawn, if failing to achieve the objectives. ‘Nil by mouth’ should be a last resort, not the initial default option.
- When artificial nutrition and hydration are required for the medium term or longer, this should be managed by the multidisciplinary team, together with other health professionals, the patients themselves and their family/carers, at home if possible. The setting may be a care home, if the patient has other medical problems.
- All trusts and care homes should ensure there are sufficient staff, especially at mealtimes, to assist and feed those patients who require a long time to eat an adequate meal.
- The full facts of the situation should be understood by all involved, to enable a patient-centred decision about artificial nutrition and hydration and the means of delivery. This should never be based on the convenience of the staff or carers, or be required as a criterion for admission by any institution. We believe that to be unethical practice.”

A moving account of the feelings of a patient, who was nil-by-mouth for an indeterminate period of time, is available at: <http://www.nursingtimes.net/nursing-practice-clinical-research/how-it-feels-to-be-nil-by-mouth/206032.article>

## Resuscitation

There has been considerable media interest in the issue of resuscitation over the last number of years:

- “BMA debate ‘do not resuscitate’ orders” (2000): <http://news.bbc.co.uk/1/hi/health/806623.stm>
- “Should doctors play God?” (2000): <http://news.bbc.co.uk/1/hi/uk/757067.stm>
- “Legal threat over hospital notes” (2000): <http://news.bbc.co.uk/1/hi/scotland/753641.stm>
- “Pensioner’s ‘Do Not Resuscitate’ Tattoo” (2003): <http://news.bbc.co.uk/1/hi/health/2819149.stm>
- “Nurses to decide on resuscitation” (2007): <http://news.bbc.co.uk/1/hi/uk/7065010.stm>

Given this degree of public concern and the pressing need for some consistency in practice, the British Medical Association and the Royal College of Nursing published ‘*Decisions relating to cardiopulmonary resuscitation: A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing*’.

This guidance was designed to support organisations in decision-making around the ethical implications of cardiopulmonary resuscitation (CPR), especially in regard to those approaching the end of their lives.

In regard to the prolongation of life in all circumstances, the document states: “It is not appropriate to prolong life at all costs with no regard to its quality or to the potential burdens of treatment for the patient. The decision to use any treatment should be based on the balance of burdens, risks and benefits to the individual receiving the treatment, and that principle applies as much to cardiopulmonary resuscitation (CPR) as to any other treatment.”

This guidance does make this proviso: “Uncommonly, some patients for whom a DNAR [Do Not Attempt Resuscitation] decision has been established may develop cardiac or respiratory arrest from a readily reversible cause such as choking, induction of anaesthesia, anaphylaxis or blocked tracheostomy tube. In such situations CPR would be appropriate, while the reversible cause is treated, unless the patient has specifically refused intervention in these circumstances.”

It is acknowledged that the patient’s wishes and the patient’s prognosis may not always be known or clear: “If no explicit decision has been made in advance about CPR and the express wishes of the patient are unknown and cannot be ascertained, there should be a presumption that health professionals will make all reasonable efforts to attempt to revive the patient in the event of cardiac or respiratory arrest.

In such emergencies there will rarely be time to make a proper assessment of the patient’s condition and the likely outcome of CPR and so attempting CPR will usually be appropriate. Medical and nursing colleagues should support anyone attempting CPR in such circumstances.” In this situation, it continues: “There may be some situations in which CPR is commenced on this basis, but during attempted resuscitation further information comes to light that makes continued CPR inappropriate. That information may consist of a DNAR order or a valid and applicable advance decision refusing CPR in the current circumstances, or may consist of clinical information indicating that CPR will not be successful. In such circumstances, continued attempted resuscitation would be inappropriate.”

In circumstances where it is clear that CPR is inappropriate for the patient “for example a patient in the final stages of a terminal illness, where death is imminent and unavoidable and CPR would not be successful, but for whom no formal DNAR decision has been made. In such circumstances, healthcare workers who make a considered decision not to commence CPR should be supported by their senior colleagues and employers.”

In cases where the family are demanding that a patient be resuscitated, when it may be futile to do so, the document states: “Neither patients, nor those close to them, can demand treatment that is clinically inappropriate. If the healthcare team believes that CPR will not re-start the heart and breathing, this should be explained to the patient in a sensitive way. These discussions informing the patient of the healthcare team’s decision may be difficult and where possible should be carried out by experienced senior clinicians.

If the patient does not accept the decision and requests a second opinion, this should be arranged whenever possible. Similarly, if those close to the patient do not accept a DNAR decision in these circumstances, despite careful explanation for its basis, a second opinion should be offered.”

While this document has been available now for some time, only some organisations have employed it in developing local policies. NHS Lothian did however use this document in drawing

up their Do Not Attempt Resuscitation (DNAR) Policy and this version is gaining acceptance in a number of regions.

### **Activity 5: (allow 1½ hours)**

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**Task 1:** For your patient group, consider the risks and benefits, physical, social, psychological and spiritual, of being placed nil-by-mouth.

How would adherence to the recommendations laid out in the Royal College of Physicians working party report affect practice in your care setting, if it were to be implemented there?

**Allow 30 minutes**

**Task 2:** Review your organisation's resuscitation policy. Does it consider end of life care patients and DNAR decisions?

What experience have you had of involvement with DNAR discussions with patients and families? Reflect back on the last occasion, on what went well and what could be improved.

**Allow 60 minutes**

#### Resources required to complete this activity

##### **Useful websites:**

British Medical Association

[http://www.bma.org.uk/ethics/end\\_life\\_issues/Withdrawwithhold.jsp](http://www.bma.org.uk/ethics/end_life_issues/Withdrawwithhold.jsp)

[http://www.bma.org.uk/ethics/cardiopulmonary\\_resuscitation/CPRDecisions07.jsp](http://www.bma.org.uk/ethics/cardiopulmonary_resuscitation/CPRDecisions07.jsp)

Royal College of Physicians

<http://www.rcplondon.ac.uk/pubs/contents/3fc70478-ef13-4df2-a836-1304250b8a50.pdf>

The Resuscitation Council (UK)

<http://www.resus.org.uk/pages/dnar.htm>

##### **Background reading:**

British Medical Association, 2007. Withholding and Withdrawing Life-prolonging Medical Treatment. 3<sup>rd</sup> eds. British Medical Association, Oxford.

Royal College of Physicians, 2010. Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life: Report of a Working Party. Royal College of Physicians, London.

British Medical Association & Royal College of Nursing, 2007. Decisions relating to cardiopulmonary resuscitation: A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing. British Medical Association & Royal College of Nursing, London.

NHS Lothian, 2007. Do Not Attempt Resuscitation (DNAR) Policy. NHS Lothian, Lothian. Available from:

[http://www.nhsllothian.scot.nhs.uk/ourservices/palliative/documents/nhsllothian\\_DNAR\\_policy\\_12\\_07.pdf](http://www.nhsllothian.scot.nhs.uk/ourservices/palliative/documents/nhsllothian_DNAR_policy_12_07.pdf) [Accessed 18th February 2010]

## Discussion Board

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The discussion board is a forum in which you can exchange ideas with other participants. This activity relates to the work you will have completed in earlier tasks and provides an opportunity for you to explore the difference in perspectives between the participants.

### Discussion Board

**When will it take place**

For a 3 month period from date of publication of this article.

**Which discussion thread**

End of life care

**What is expected of you as a participant**

This module has examined end of life care. By sharing your experience and questions of the various issues surrounding end of life care, we can build on the current body of knowledge.

### Summary of this module

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In this module you have learned about the history of 'end of life care' in the United Kingdom in the last five years, the application of tools to improve such care and the strategies across the UK to ensure improvements are driven forward. It also has introduced the developments in ethical issues around nutrition/hydration and resuscitation.

### On completion of this module you will have had the opportunity to:

- Consider personal experiences of death and dying and their impact on clinical practice
- Understand the different terminology in use in this field
- Learn about the history of end of life care in the United Kingdom
- Understand the application of End of Life Care tools
- Consider developments in ethical considerations around nutrition/hydration and resuscitation in end of life care.

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