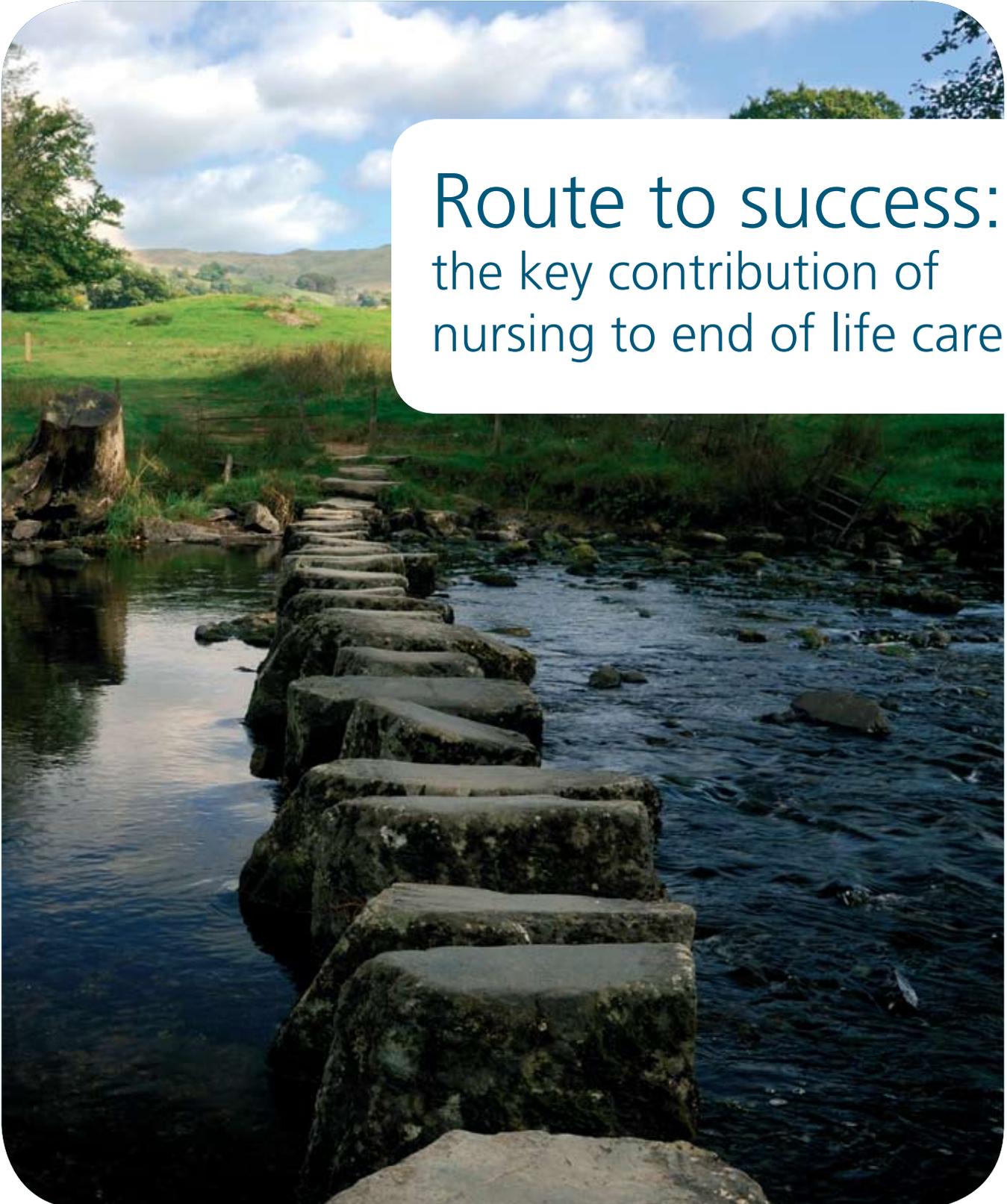




Royal College  
of Nursing



National End of Life  
Care Programme  
*Improving end of life care*



Route to success:  
the key contribution of  
nursing to end of life care

To be reviewed: July 2014



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The roles and responsibilities of the nursing profession continue to grow and to develop. The word 'nurse' is an extremely broad descriptor of an essentially diverse and intricate role. There are several definitions of nursing; the International Council of Nurses (ICN) offers the following:

“Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the

promotion of health, prevention of illness, and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles.”

<http://www.icn.ch/about-icn/icn-definition-of-nursing/>

Within end of life care (EoLC) individuals and their families may experience input from a wide range of professionals and organisations. Amongst the diversity of professionals who may be involved during this stage, it is often the nurse who is contacted when the individual or their family wish to seek guidance, discuss issues or raise concerns. Nurses are also predominately the key provider and co-ordinator for individuals during this time, linking and communicating across the health and social care teams. For many individuals and their families nurses are the 'key' within their care co-ordination and planning; the one who holds the key that fits all the locks and opens all the doors.

All individuals approaching the end of their life are entitled to high quality, accessible care and respectful, sensitive relationships with their nurses, enabling individuals to make genuine, informed choices about how and where they are cared for. Competent and compassionate care is also critical to facilitating a dignified death and offering bereavement support where appropriate to both family and staff.

The role of the nurse is unique to each individual and is a vital component within the delivery of good end of life care.



# Aim of the guide

This guide has been developed by the National End of Life Care Programme (NEoLCP) in conjunction with a range of organisations and nurses as part of its *route to success* series. The guide highlights the key nursing contributions within the six steps of the end of life care pathway. Given the diversity and intricacies of the role, the guide provides an overview; it is not meant as a definitive description of the role and may not cover all settings where a nurse practices.

The guide predominately focuses on how nurses can and do contribute to planned (and unplanned) end of life care for adults in England. It focuses on general adult care

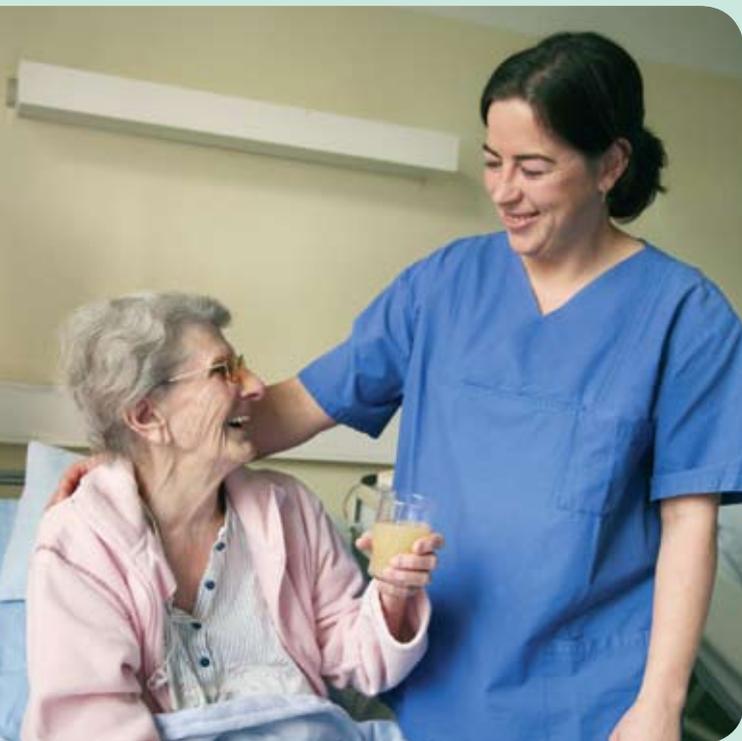
and acknowledges that these principles and steps apply to all those individuals who also may have mental health needs and learning disabilities. It is important to note that specialist support and care may also be needed. There is additional information relating to those with learning disabilities at end of life within *The route to success in end of life care: achieving quality for people with learning disabilities* (NEoLCP, 2011). Other guides in the series are also applicable to staff including nurses, and links and information can be found on the National End of Life Care Programme website (<http://www.endoflifecareforadults.nhs.uk/tools/core-tools/rtsresourcepage>).



It is acknowledged that nurses make a major contribution in a 'sudden death' situation – for example, those that occur within accident and emergency or intensive care, or a sudden death within a ward situation. In these circumstances the core principles and steps 5 and 6 are especially relevant.

This guide highlights some of the many key contributions that nurses make to facilitating good end of life care. It is a practical tool offering suggestions on what nurses can and do contribute to make a positive difference to the experience of individuals, their families and carers. It will also highlight exemplars of good practice and signposts to further useful resources.

The definition of 'nurse' used within this guide means a registered nurse as set out by Nursing and Midwifery Council (NMC) requirements. This therefore is inclusive of nurses within *all* care settings – eg, nursing homes, private hospitals, community providers, acute trusts, prisons and hospices.



The core principles for nurses delivering high quality end of life care are described in the nursing and midwifery code of conduct produced by the NMC (*The code: standards of conduct, performance and ethics for nurses and midwives*, NMC, current version 2008 <http://www.nmc-uk.org/Publications/Standards/> - see Appendix 1 for a summary).

Detailed guidance on the quality of care that patients, families and carers can expect from nursing is provided in the Principles of Nursing Practice published by the Royal College of Nursing (RCN) (<http://www.rcn.org.uk/development/practice/principles>).

This guide will also explore the nursing roles with reference to the nursing careers framework developed by the Department of Health (DH) for both unqualified and qualified healthcare practitioners, available as a poster entitled *Care for your future in nursing* (see the chief nursing officer's information page at [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_108369.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108369.pdf)). The entry level for a registered nurse or midwife is stage (level) 5.

### The stages and nursing contribution this guide reviews are:

- Stage 5: Practitioner (registered nurses – ie staff nurses)
- Stage 6: Senior practitioner (ward sister, district nurse level)
- Stage 7: Advanced practitioner (specialist nurse)
- Stage 8: Consultant practitioner (nurse consultant)
- Stage 9: Senior leader – ie director of nursing

The term 'senior nurse' refers to stages 5 and 6, 'specialist nurse' and 'consultant nurse' refers to stages 7 and 8, and 'senior leader' refers to stage 9.

# The key drivers and levers for nurses today

“All those who work on the frontline should be thinking carefully, and imaginatively, about how we can do things differently. The QIPP process is a home for this in the NHS and the way that we can implement the best and brightest ideas across the service. As the Prime Minister said: ‘Don’t hold back – be innovative, be radical, challenge the way things are done.’” Andrew Lansley, secretary of state for health, 2 July 2010 [http://www.dh.gov.uk/en/MediaCentre/Speeches/DH\\_117103](http://www.dh.gov.uk/en/MediaCentre/Speeches/DH_117103)

## Quality, Innovation, Productivity and Prevention (QIPP)

“QIPP is working at a national, regional and local level to support clinical teams and NHS organisations to improve the quality of care they deliver while making efficiency savings that can be reinvested in the service to deliver year on year quality improvements.

QIPP is engaging large numbers of NHS staff to lead and support change. At a regional and local level there are QIPP plans which address the quality and productivity challenge, and these are supported by the national QIPP workstreams which are producing tools and programmes to help local change leaders in successful implementation.

There are 12 national workstreams in total. Five deal broadly with how we commission care, covering long-term conditions, right care, safe care, urgent care and end of life care. Five deal with how we run, staff and supply our organisations, covering productive care (staff productivity), non-clinical procurement, medicines use and procurement, efficient back office functions and pathology rationalisation. There are two enabling workstreams covering primary care commissioning and contracting



and the role of digital technology in delivering quality and productivity improvement.”

Information page on DH website (<http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPP/index.htm>)

## Details of the QIPP workstream that specifically relates to end of life care

**Summary:** The end of life care workstream will focus on improving systems and practice for identifying people as they approach the end of life and planning their care. It will focus especially on high risk groups – such as those in residential and nursing homes.

## Working with NHS, social care and voluntary sector colleagues the workstream aims to:

- build a social movement for a good death
- change national levers to support good end of life care
- support the development of better intelligence about end of life care
- help clinicians know when and how to start the conversation about end of life care
- support systematic care planning, including advance care planning, for people approaching the end of life
- identify and share successful good practice.

Taken from DH website information page at [http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/DH\\_115469](http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/DH_115469)

## High Impact Actions: Important choices - where to die when the time comes

The High Impact Actions for Nursing and Midwifery were developed following a 'call for action' which asked frontline staff to submit examples of high quality and cost effective care that, if adopted widely across the NHS, would make a transformational difference.



Information taken from (and further information available at) [http://www.institute.nhs.uk/building\\_capability/general/aims/](http://www.institute.nhs.uk/building_capability/general/aims/)

## Energise for Excellence in Care

Energise for Excellence in Care (E4E) is a quality framework for nursing and midwifery that aims to support the delivery of safe and effective care, creating positive patient and staff experiences that build in momentum and sustainability; this is underpinned by 'social movement thinking' principles.

### Aims

- Patients reporting a positive experience when accessing healthcare
- Nurses driving the delivery of high quality and job satisfaction
- Commissioners using quality indicators to drive improvements in safe, efficient and effective care
- Inform boards in their decision making about nursing and patient care.

Information taken from (and further information available at) <http://www.dh.gov.uk/en/Aboutus/Chiefprofessionalofficers/Chiefnursingofficer/Energiseforexcellence/index.htm>

## Commissioning

We are in a significant period of change for both health and social care. Not least are the changes that are proposed for the commissioning of services in the future and current plans around commissioning boards and clinical commissioning groups. Considered within this must be the planning and delivery of good end of life care.

Central to the successful provision of improved end of life care is how the move away from primary care trust commissioning to that of commissioning groups is managed. Once the health reforms are implemented the groups will commission health services on behalf of their local community and design services

aimed at reflecting the needs and preferences of local people. Nurses are ideally placed to influence the development and provision of new and improved services. They have a wealth of knowledge and unique experiences that can inform and drive the commissioning process.

### **This will assist with the delivery of:**

- Increased numbers of individuals experiencing a 'good death' in their preferred place of care
- Seamless transitions of care
- Reduced numbers of inappropriate admissions and clinical interventions
- Reduced numbers of complaints
- A skilled and motivated workforce
- Improved reputation of local services whether in acute or community settings, including care homes
- Improved joint training and working opportunities throughout the care community
- Ensuring that end of life care is a priority for the clinical commissioning groups.

### **What do individuals want from professionals?**

The Patient Opinion report *In their words: what patients think about our NHS* (2011) sheds light on what the public want from professionals within the healthcare services. Analysing a sample of patient comments posted on the PO website over the past five years, the report identified sixteen areas of concern. In many of these areas, nurses can make a key contribution to improving patient experience.

### **The issues identified in the report include:**

- Staff attitudes
- Care and compassion
- Service to patient communication
- Negative health outcome
- Cleanliness
- Staffing levels
- Dignity



- Inclusivity
- Communication between staff, departments and services.

Full report available at [www.patientopinion.org.uk/resources/POreport2011.pdf](http://www.patientopinion.org.uk/resources/POreport2011.pdf)

In addition to this, the recent white paper *Equity and excellence: liberating the NHS* (DH, 2010) firmly places the individual at the centre of care. The principle "no decision about me without me" should underpin all health and social care, meaning that practitioners need to work as partners with individuals and their carers. This means being inclusive and respectful at all stages of care. ([http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_117353](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353))

A charter for the care of people who are nearing the end of life (Appendix 2) has been developed by the Patient Partnership Group and the EoLC English Working Group of the Royal College of General Practitioners (RCGP), working with the RCN. The charter represents best practice that individuals should be able to seek from their primary healthcare teams. Copies of the charter and the relevant guidance information can be downloaded at [www.rcgp.org.uk/endoflifecare](http://www.rcgp.org.uk/endoflifecare).

# End of life care context

The national end of life care strategy is a ten year strategy aimed at improving care and choices for all people regardless of their diagnosis and place of care. The principal aims are to improve the quality of care for those approaching the end of their life and to enable greater choice and control about where they die.

The strategy document states that high quality end of life care "should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money." (*End of life care strategy: promoting high quality care for all adults at the end of life*, DH, 2008 <http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy>)

The strategy focuses on the role of *all* health and social care staff in the delivery of high quality end of life care. For many individuals

and their families that role is fulfilled by the nursing profession.

Currently, most adults in England are not dying where they choose to; most say they would prefer to die at home. Current data highlights that 58% of people die in the acute setting, 17% in a care home (which is also their home), 4% in a hospice and only 18% at home. It has been further highlighted that the last century has seen a complete reversal in where people die; at the turn of the 19<sup>th</sup> century about 85% of people died at home. They argue that if the current focus and trends continue only one in ten individuals will die at home by 2030 (*Where people die (1974—2030): past trends, future projections and implications for care*, B Gomes/I Higginson, Palliative Medicine, Jan 2008).

The National End of Life Care Programme (NEoLCP) was developed in 2008 to implement the strategy. The programme's work focuses on supporting services to shift this balance and increase opportunities for people to die well in their place of choice. Within this the core principles of good end of life care are very much at the forefront of all end of life care planning and delivery.

## Core principles for delivery of end of life care

- Treat individuals with dignity and respect
- Identify and respect people's preferences
- Provide information and support to families and carers
- Recognise and respect an individual's spiritual and religious needs
- Provide effective pain and symptom management
- Provide care after death
- Ensure care is person centred and integrated
- Provide a safe, comfortable environment for care.



### Improved training will enable good quality end of life care

It is recognised generally that prognostication is uncertain which means that it is often difficult to predict when an individual is approaching the last six to twelve months of their life. Identifying end of life care needs at an early stage can be beneficial as it allows more time to prepare and plan services which offer the individualised support required by individuals and their families.

### Evidence shows that those people who have had discussions about their end of life care around three months prior to death:

- Are significantly less likely to have inappropriate aggressive medical treatment
- Have significantly reduced levels of depression
- Have significantly better caregiver adjustment post bereavement.

*(Making a difference: Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups, C Shipman et al, British Medical Journal, 11 Oct 2008)*

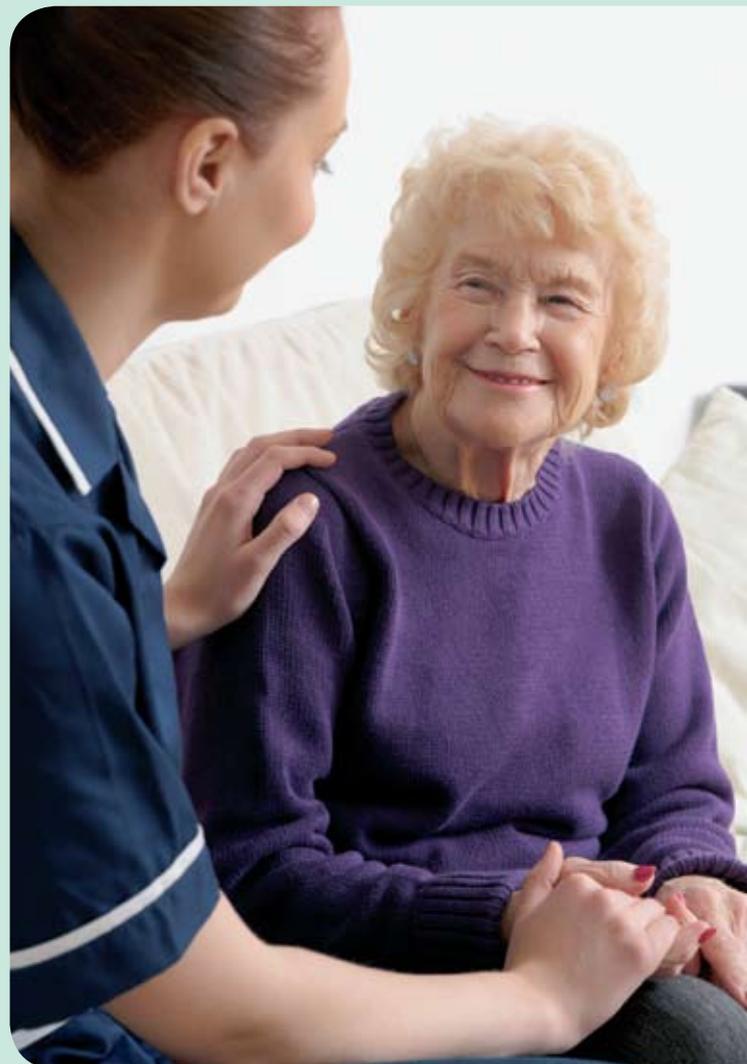
Providing effective, good end of life care can be challenging. Without the right training, support and information, staff and carers can find the experience overwhelming.

### By providing staff with the information, training and tools to enable the provision of good end of life care, an organisation will have:

- Confident staff who are able to engage in early conversations with individuals who are entering the last year of their life
- Staff trained and confident in using recognised tools such as the Gold Standard Framework (GSF), the Liverpool Care Pathway (LCP), Preferred Priorities for Care (PPC) and/or other locally agreed tools
- Effective multi-disciplinary team (MDT) communication with clear processes to access resources as necessary
- Seamless transitions of care

- Strong and engaged managerial understanding and support
- Access to specialist support 24/7
- Training and education plans appropriate to each team member's role and the level of competency required
- Raised staff awareness as to the importance of the provision of good care after death.

There are a variety of educational tools that are available to assist with this process, many of which are free. These include the end of life care core competences and principles, the communications skills benchmarking tool, end of life care for all - eLearning (e-ELCA) and many other resources and links which can be found at <http://www.endoflifecareforadults.nhs.uk/education-and-training/learningresources1>.



# The end of life care pathway

This guide is based on the end of life care pathway six key steps and aims to highlight the key contributions made by registered nurses in delivering this agenda, in all care settings.

The end of life care pathway (illustrated on page 10) begins with initiating discussions and concludes with care provided after death.

## **The pathway focuses on six steps:**

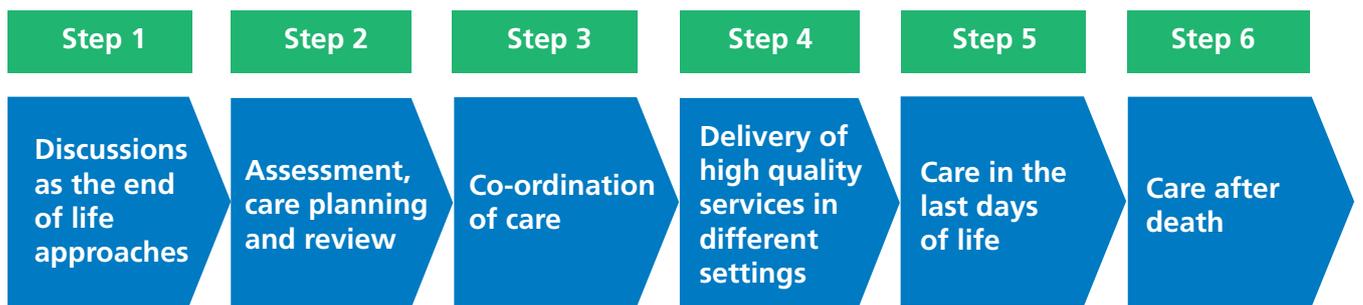
1. Discussions as the end of life approaches
2. Assessment, care planning and review
3. Co-ordination of care
4. Delivery of high quality care in different settings
5. Care in the last days of life
6. Care after death.

Each section in this guide outlines the relevant step of the pathway and questions to ask about both the individual's care and the nurse's role in that care. Quality markers for end of life care have been developed which can be used to measure quality and the delivery of care (see Appendix 3).

## **The guide is also intended to reflect the need for effective team working across all care settings in order to:**

- Identify when someone is approaching the end of life phase
- Assess needs and develop a care plan
- Review care planning
- Help to review practice
- Support communication and team working
- Understand that staff and fellow residents may be affected by the death of an individual and identify appropriate measures to provide support and information.





- Open, honest communication
- Identifying triggers for discussion.

- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers.

- Strategic co-ordination
- Co-ordination of individual patient care
- Rapid response services.

- High quality care provisions in all settings
- Acute hospitals, community, care homes, extra care housing, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services.

- 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.

- 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.



# Further considerations as to the contribution nurses can make

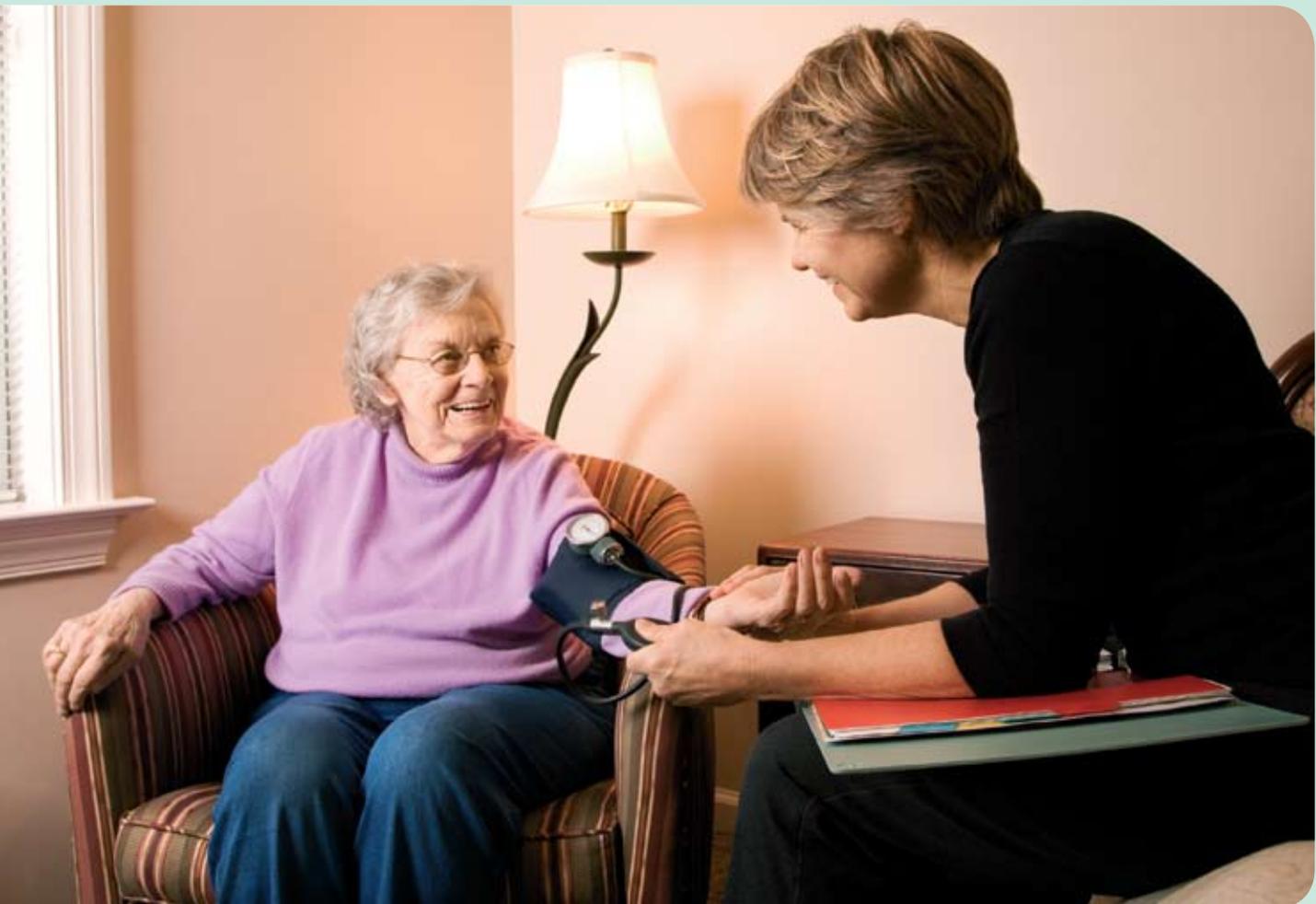
The publication of the white paper *Equity and excellence: liberating the NHS* (DH, 2010) has delivered new commissioning arrangements. This is an opportunity for nurses to influence and drive the changes needed to deliver high quality care. Senior nurses should start building relationships with the newly formed clinical commissioning groups to ensure that intelligent commissioning is taken forward.

This guide lists the key contributions that can be made by *all* nurses. It is important to note that within each of these steps there may be highly experienced nurses providing high quality care and there may be those who

would benefit from further training, support and guidance through personal development plans.

Equally, it is important to recognise that we all bring our life experiences to our work which can often enhance our ability to deliver high quality, sensitive, empathic care.

The additional contributions and considerations that can be made by senior nurses, advanced nurse practitioners, nurse consultants and senior nurse leaders across the end of life care pathway are listed below.



### Senior nurses can:

- Provide strong, effective leadership and support to their team
- Ensure that all nurses within the team are equipped to identify clinical triggers and take the correct action
- Identify gaps in services and staff training
- Ensure that staff and colleagues are aware of and trained in the use of agreed tools
- Be an advocate for the individual and provide clarity to other clinicians who may be unsure about the individual's wishes
- Support staff to understand the changes that can happen as someone dies, enabling them to communicate those changes to family and carers where possible
- Monitor quality standards of care within their area of responsibility
- Work with colleagues to ensure that there is that there is a suitable environment for individuals and their families and carers in relation to privacy
- Ensure that processes are in place so that decisions centred on advance care planning (ACP) and Do not attempt cardio-pulmonary resuscitation (DNACPR) are clearly identified and all staff are aware of these
- Input into holistic care assessment, planning and review as necessary for individuals
- Co-ordinate multi-disciplinary teams if required
- Ensure implementation of the NHS continuing healthcare fast track pathway tool
- Encourage and support reflective practice among the team, reflecting upon and learning from what worked well, what did not work so well, what could be done differently, and adapting services in the light of the reflections
- Provide empathy for the individual and their family
- Be aware of emotional and support needs of the professionals
- Provide clinical supervision.

### Specialist and consultant nurses can:

- Provide specialist advice and leadership
- Be a key co-ordinator between care settings, teams and organisations
- Provide specialist training, leadership and support to staff in all relevant settings, including care homes
- Drive research/audit/data analysis in relation to end of life care
- Utilise research to support improvements in end of life care and challenge practice that is not beneficial
- Publish relevant work across a wide range of publications/websites etc
- Encourage and actively support reflective practice
- Work with commissioners to ensure there is 24/7 support available
- Advocate and signpost family and carers to appropriate support.

### Senior leaders can:

- Be a champion for EoLC and lobby, influence and shape the development of good quality services
- Ensure organisational support and commitment in terms of commissioning services, staff training and support
- Work across organisations and ensure senior partnership engagement
- Work with other senior clinicians to ensure governance arrangements are in place especially around ACP and DNACPR
- Review and monitor the uptake and effectiveness of available tools in care settings
- Ensure that blended learning opportunities are available
- Work with other organisations to ensure that there are clear guidelines in place to share information
- Work with partners to identify gaps in resources, and review and amend the design of pathways and the development of clear policies and protocols
- Ensure that there are robust governance

arrangements in place, including monitoring complaints and compliments and acting as necessary

- Encourage and support reflective practice throughout the pathway
- Ensure that *all* mortuary viewing areas are appropriate
- Ensure that those in all settings are included in the pathways – eg, those in temporary housing, prisons and shelters – and that where possible the individual is at the heart of the care planning
- Ensure that local communities are involved in service redesign.

### **Nurses can also influence commissioning decisions by:**

- Being a champion and a 'voice' for good quality end of life care: promoting what is available and raising concerns around gaps in service provision
- Working with other professionals and organisations to ensure a clear narrative of what is needed around the end of life care with clear roles and responsibilities mapped out
- Ensuring that clinical commissioning groups are aware of end of life care key performance indicators (KPIs)
- Raising the profile by linking end of life care with other priorities – for example, long term conditions, dementia care and the urgent care agenda including admission avoidance and patient choice
- Actively contributing to, informing and driving forward local care pathway redesign
- Monitoring accessibility and use of equipment and identifying gaps in equipment provision
- Monitoring the effectiveness of the pathways ensuring that the six steps are met – for example, reduction of inappropriate admissions and unnecessary medical interventions, increase in preferred place of care being met, and improvements in levels of compliments and complaints

- Analysis and understanding of the local demographics, how end of life care needs will potentially change in the next three, five and ten years, and the impact on service requirements
- Regular analysis of feedback from carers and relatives; use of individuals' and carers' narratives can be extremely powerful
- Awareness of the experiences and views of staff involved in the care of individuals at the end of their lives and ensuring that those are considered and incorporated into future pathway design as appropriate
- Identifying gaps in training and supporting development of training resources at all levels
- Providing research and audit analysis to support changes in the various processes
- Including use of a recognised EoLC tool in service specifications, and monitoring and auditing the use of that tool
- Ensuring that the EoLC register is kept at GP practice level.



# Step 1

## Discussions as the end of life approaches

Enabling people to die in comfort and with dignity is a core function of the NHS. One of the key challenges is knowing how and when to begin a discussion with an individual and those involved within their care about what they would wish for as they near the end of life. Agreement needs to be reached on when discussions should occur, who should initiate them and what skills and competencies staff require for this role.

### Key contribution of nurses

A key challenge for all staff is knowing how and when to open up a discussion with individuals, their relatives and others involved within their care, about what they wish for as they near the end of their life. Agreement needs to be reached by the MDT caring for the individual on when discussions should occur and who should initiate them.

Nurses are ideally placed to identify the various clinical triggers that indicate when someone could be in their last year of life therefore enabling and facilitating effective care planning.

### All nurses should

In relation to the individual:

- Be aware of the clinical triggers that may indicate when individuals are potentially within the last six or twelve months of life. Some individuals may present later in their disease pathway and many within weeks or months of death. (See GSF guidance (including prognostic indicator guidance) at <http://www.goldstandardsframework.org.uk/TheGSFToolkit/Identify/TheThreeTriggers>.)



- Listen to and notice subtle changes in the individual and record and report as necessary
- Be able to initiate, undertake and document a holistic assessment of an individual's needs and ensure relevant reviews
- Empower and support individuals to make informed choices when they are able and willing to do so
- Be an advocate in supporting individuals in relation to their choices
- Ensure that individuals have sufficient space and time to reflect and discuss their concerns
- Acknowledge that individuals' wishes, desires and beliefs may vary over time and ensure that communication is always sensitive
- Recognise that sometimes the individual and their families and carers may struggle to consider the future and therefore conversations and care should be guided appropriately

- Recognise that there may be ethical and moral dilemmas
- Be aware of the various tools available to them and follow any local policies as necessary. Eg, Gold Standards Framework (<http://www.goldstandardsframework.org.uk/>), Liverpool Care Pathway (<http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>) and Preferred Priorities for Care (<http://www.endoflifecareforadults.nhs.uk/publications/ppcform>).

In relation to family and carers:

- Support family and carers appropriately whilst always considering the wishes of the individual, how much information is shared and with whom
- Refer to local adult social care for a carer's assessment when appropriate
- Highlight local carer support groups.

In relation to other professionals:

- Facilitate communication with the multi-disciplinary team (MDT) and other relevant services, ensuring that all discussions are documented and, with permission, shared with other services to ensure that all have a common understanding of the individual's wishes
- Gather relevant information from those services (with consent from the individual) as to history, social situation, current care, etc
- Support other members of the team to recognise relevant clinical triggers
- Support other care workers to notice and report changes in the person – for example, withdrawing from social events, talking about getting their affairs in order, indicating a time frame
- Inform colleagues of training opportunities.



### Top tips

- Ensure effective engagement with the individual and their family in discussions about the planning of care and the effectiveness of their needs being met
- Ensure that information is provided in various formats to meet the needs of the individual
- Identify and create training opportunities within your area to support staff and ensure that they are trained and are confident and competent to hold end of life discussions with individuals and their families
- If you feel, or someone working for you (such as a home care assistant) feels, unsure about how to approach these conversations, identify someone within either your team or the wider team who can provide guidance and mentorship
- Join the Dying Matters coalition ([www.dyingmatters.org.uk](http://www.dyingmatters.org.uk))
- Liaise with local social services to ascertain what is available to support carers.



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# Step 2

## Assessment, care planning and review

Early assessment of an individual's needs is vital to establish their preferences and choices and 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 includes physical, psychological, social, sexual, spiritual, cultural and, where appropriate, environmental and financial needs. This can be more complicated for those within the prison system, and maybe exacerbated if they have learning difficulties or mental health needs.



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### Key contribution of nurses

Undertaking an assessment, either during a single visit or over a period of time, is essentially about building a relationship of mutual trust and respect with the individual, family and carers.

It is recommended that the MDT appoint a key worker (often a nurse) for the assessment and review, which would reduce duplication and the need to repeat the same information to a variety of people and facilitate a smooth transition throughout the care pathway.

### All nurses should

In relation to the individual:

- Carry out a baseline holistic nursing assessment upon referral
- Be competent to build on that baseline assessment in a dynamic, sensitive and consistent manner and observe and record subtle changes
- Communicate with others who may contribute to this assessment or build upon it from their area of expertise – eg, clinical nurse specialist (CNS), community psychiatric nurse (CPN), occupational therapist (OT), speech and language therapist (SaLT) or social worker

- Keep the individual informed and involved at all times during the planning of care to meet their needs and wishes
- Where possible, maintain conversations with the individual around their care needs and choices, ensuring that changing needs are met
- Contribute to the MDT with regard to the nursing assessment, care planning and reviews
- Ensure that the assessment takes sufficient account of uncertain prognosis and records how crisis and deterioration will be managed
- Update the end of life care register
- Seek specialist support specifically in relation to symptom management, psychological and spiritual support and refer as necessary
- Ensure that all of the above is documented and available to share (with permission of the individual), thereby ensuring effective co-ordination of care.

#### In relation to family and carers:

- Ensure that, where appropriate, the family and carers' views are considered and recorded
- Be aware of and openly acknowledge any family and carers and their role
- Offer and refer the carer for an assessment if this is appropriate; signpost to local carer support groups

#### In relation to other professionals:

- Facilitate the decision making process and advance care planning. Be specific as to who is the best person in the team to do this
- Liaise with other professionals and share information as appropriate
- With consent, work with other agencies to enable individuals to make proactive choices (see Appendix 4: Support sheet Mental Capacity Act).

#### See also:

- *Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff*, NEdLCP, 2011 (<http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>)
- *Support sheet 3: advance care planning*, NEdLCP, 2010 (<http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet3>).

### Top tips

- It is recommended that a keyworker be appointed for assessment and review; this can avoid duplication and achieve consistency in care for the individual
- Remember to consider the individuality of each person in the context of the situation that faces them; know what it is that really matters to them as an individual
- Ensure that the individual is central to the process of assessment and planning at all times
- Always seek help from others when what is required is outside your current skill base
- With the person's permission, involve/inform other professionals of key conversations around PPC
- Remember that you are there primarily for the individual; be mindful of how easy it can be at times to be influenced by the wishes of family members, especially if they have strong beliefs or are opposed to what the individual has indicated are their wishes.



## Step 3 Co-ordination of care

Once a care plan has been agreed it is essential that all the services the individual requires are effectively co-ordinated. This should include all providers - for example, community and acute health providers, GPs, the local hospice, transport services and social care. A lack of co-ordination can ultimately mean that a person's needs and preferences are not met. Individuals should always give permission for information to be shared with other services.

### **Key contribution of nurses**

Nurses are often in a key position to take the lead in co-ordinating care and working

in partnership with the individual and their family/carers to review their care plan, and adapt it as necessary to ensure that needs and wishes are being met.



## All nurses should

In relation to the individual:

- Ensure that all the appropriate team members contribute to the care planning process and any following reviews
- With permission of the individual disseminate relevant information to those who are key within the co-ordination process
- Make appropriate referrals as required to other professionals and services
- Work with GPs and appropriate others to ensure that symptoms are effectively managed
- Ensure that all involved are aware of the individual's needs and wishes
- Ensure that there are effective mechanisms in place for co-ordination and information sharing.

In relation to family and carers:

- Ensure that family and carers' concerns are noted and addressed within the care plan
- Communicate with family and carers as appropriate and in the best interests of the individual
- Ensure that family and carers are aware of whom they can contact for advice and support on a 24/7 basis.

In relation to other professionals:

- Be an advocate for the individual and their family/carers in working with partners to deliver high quality care
- Ensure that all other relevant professionals are kept up-to-date and that referrals are made early.

## Top tips

- Ensuring that all relevant personnel are aware of an individual's wishes and preferences means the plan is more likely to work
- Ensure that all decisions are documented, kept updated, regularly reviewed and shared with all relevant professionals
- End of life care registers are extremely valuable in ensuring effective communication and co-ordination of care and that the individual receives their wishes and preferences
- Seek and ensure that each person has key worker assistance
- Record contact details for anyone the person would like notified if there is a change in circumstances
- Have a good understanding of discharge and transfer of care pathways across all settings, including the NHS continuing health care fast track pathway tool and local admissions and referral guidance if necessary
- Care co-ordination within end of life care is primarily the responsibility and role of the nurse. Nurses often choose to 'go the extra mile' on behalf of the individual, making a significant difference and enabling individuals to die in their place of choice
- Establish/build relationships with others across the care community and understand what it is that each care setting/agency is able to offer the individual.

# Step 4

## Delivery of high quality care in different settings

Individuals, their families and carers may need access to a complex combination of services across many different settings. They should be able to expect the same high level of care regardless of where they are. Individuals should be treated with dignity and respect and given as much choice as possible about the care they receive as they approach the end of their lives.

### **Key contribution of nurses**

The delivery of good quality end of life care in different settings will require proactive working to ensure that people die in their preferred place of care, in familiar

surroundings and with those they know. For individuals who are being cared for in the community (either at home or in a care home) access to specialist palliative care and 24/7 advice and support is vital.



## All nurses should

In relation to the individual:

- Promote and ensure that individuals' dignity and respect is maintained at all times
- Be creative and courageous and have a sense of tenacity in their desire to meet the individual's choices
- Be aware of the various procedures and processes around ensuring that the individual is transferred or maintained where they are, in accordance with their preferred choice
- Be aware of any ACP and DNR agreements in relation to the individual (See <http://www.endoflifecareforadults.nhs.uk/publications/differencesacpadrt>)
- Contribute to, review and maintain the care plan, alerting the MDT and other professionals as necessary
- Access specialist palliative care as necessary
- Ensure that access to spiritual care is available
- Ensure that the individual has the appropriate equipment to meet their needs (nurses in either the community or a care home setting need to be aware of how to access equipment)
- Be aware of the various models of care and implement agreed organisational tools including pain assessment tools.

In relation to family and carers:

- Ensure that family and carers are supported as necessary, including highlighting how people die, the changes that may occur and potential signs and symptoms
- Ensure that there is an appropriate place in all care settings for the family/carers to have privacy.

In relation to other professionals:

- Keep other team members informed as necessary.

## Top tips

- Communicate the person's wishes and reassess at regular intervals
- Remember to support the family; provide information in varied formats
- Be aware of the care network supporting the individual
- Ensure that there is a private, quiet space available for families and carers
- Take time to build relationships with professionals in other care settings, and be aware of the services that are available
- Promote joint education and reflective practice across the health and social care economy. This assists with building relationships, mutual understanding and respect, enabling the individual to die with dignity in their preferred place of care
- Be creative and courageous and have a sense of tenacity in the desire to meet the individual's choices.





# Step 5

## Care in the last days of life

The time comes when an individual enters the dying phase. For some this may seem to happen suddenly and without warning but for many others it can be a gradual process. It is vital that those caring for them recognise they are dying and take the appropriate action. How someone dies remains a lasting memory for their relatives and carers as well as for the health and social care staff involved.

### Key contribution of nurses

One of the key contributions made by nurses is the ability to recognize that the needs of individuals will differ. It is important that nurses acknowledge and are aware of their own beliefs and values whilst recognising that it is what is important to the individual that is paramount.

When an individual is known to the team and the previous steps of the EoLC pathway have been followed, reviewed and communicated, it would be hoped that there will be no surprises at this point, and that the individual's wishes will be met; however, contingency planning is an essential part of this process.

### All nurses should

In relation to the individual:

- Be able to identify when an individual is entering their dying phase
- Be respectful and implement prior wishes
- Be respectful of any preference around place of death and ensure that it is honoured where possible
- Ensure that the individual's comfort takes precedence over other nursing and clinical procedures – eg, if the person is comfortable and asleep do not turn or move them unnecessarily

- In relation to the above, be aware of the assessment and procedures of the NHS fast track tool, and implement that procedure at an appropriate time (see [http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH\\_073912](http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH_073912) and <http://www.e-lfh.org.uk/projects/e-elca/index.html>)
- Engage with the MDT to ensure that the above are honoured
- Ensure that clear pain and symptom management plans are in place and regularly reviewed
- Ensure that anticipatory medication is available across all care settings
- Ensure that key contact information is documented
- Commence the LCP or similar local care pathway
- Ensure that everyone is aware of the changes in the individual's condition
- Recognise the value and importance of the care and compassion shown to the person who is dying
- Ensure that spiritual and religious needs are addressed and appropriate referrals made.

In relation to family and carers:

- Support family and carers where appropriate, ensuring that they are guided step by step through the dying process and that changes in treatment (especially

withdrawal of treatments) are fully explained and understood

- Be clear about the individual's prognosis with the family and carers thus enabling them to have the opportunity to say any final things that have not yet been said and perhaps to say their final goodbyes
- Ensure that the family and carers have some privacy and a quiet space for reflection (See <http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet15> and the King's Fund Enhancing the Healing Environment programme at <http://www.enhancingthehealingenvironment.org.uk/>)
- Recognise the emotive and challenging time for the family and the importance of 'being there' for them
- Refer as necessary for support.

Note: In a care home, nursing home, group home, prison or shelter setting, other people/residents may have concerns and questions



which should be answered in a sensitive way. They may wish to visit/spend time with their friend who is dying and this should be arranged.

In relation to other professionals:

- Be aware of their own and other colleagues' emotional needs
- Support others in the team, especially those who are newly qualified.

### Top tips

- Ensure that all staff caring for an individual in the last days of life are aware of the Liverpool Care Pathway or similar local tool
- Communicate to all relevant agencies that the individual is dying and reinforce their wishes to, eg, GP and out-of-hours services
- Liaise with the ambulance service to ensure they are aware of the person's wishes, particularly if that wish is to remain at home
- Provide families with written information explaining what happens during the dying process (see <http://www.mcpcil.org.uk/patients-carers/index.htm>)
- Ensure that the care of individuals who are dying is shared amongst the team and does not solely become the responsibility of one of two team members
- We only have one chance to make this right for the individual; remember the difference that you can make.

A photograph of a river with several large, flat stepping stones leading across it. The water is dark and reflects the surrounding greenery.

# Step 6

## Care after death

Good end of life care does not stop at the point of death. When someone dies all staff need to follow 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 is essential to achieving a 'good death'. This is also important for staff, many of whom will have become involved with the person.

### **Key contribution of nurses**

Roles may vary widely and may be restricted by local circumstances and logistics at the time of death (eg, out-of-hours arrangements).

Nurses are pivotal to ensuring that the person is treated with the same dignity and respect in death as they were in life.



## The role may include

In relation to the individual:

- Performing last offices, ensuring that the environment promotes dignity and respect at all times and in all settings.

In relation to family and carers:

- Providing clear information and guidance as to the next steps that the family/carers need to take whilst recognising that this can be a confusing and overwhelming time
- Ensuring that the family and carers have sufficient privacy and that if they wish they have time with their loved one after death to say their goodbyes in the way that they want to
- Taking care to provide a sensitive and dignified environment
- Ensuring and facilitating access to any religious and/or spiritual support they need
- Ensuring that the family and carers know how to access assistance in the future if they are struggling following their bereavement
- Ensuring that all belongings are returned to relatives in a sensitive, appropriate and respectful manner. For example, black bin bags are not appropriate for returning a person's belongings to family or carers
- Being aware of the needs of other individuals in acute or community hospitals or living in a care home and offering support as appropriate
- Within a care home setting, making arrangements for other residents to attend the funeral
- Making appropriate follow up visits and/or phone calls as necessary.

In relation to other professionals:

- If appropriate, making arrangements and supporting staff to attend a funeral if that is their wish. See [www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death](http://www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death)

- Informing the primary care team, making a direct referral/telephone call if necessary
- Arranging for any equipment to be collected in a sensitive and timely manner
- Being supportive of your colleagues.

## Top tips

- (Senior nurses) Ensure that all staff have access to and support in implementing guidance for staff responsible for care after death (last offices)
- Ensure that there are policies and procedures in place to support nurse verification of death
- Be aware of the local services people can access for bereavement support
- As teams, ensure that there is reflective time scheduled into the day to acknowledge and learn from what went well and what could have been done differently
- In amongst the business of the day, being sensitive, compassionate and showing the smallest acts of kindness can make an enormous difference; we do only have one chance to get this right
- As professionals we also need to take care of ourselves in order to continue to care for others.

### Key contribution of nursing within education: raising the profile of palliative and end of life care

**Overview:** Over a two year period a range of educational programmes have been embedded in practice to support professionals in their delivery of palliative and end of life care.

**Key nursing contribution:** Nurse-led and nurse-designed palliative and end of life care education packages

Within the organisation it was recognised that there was very little palliative and end of life care education available for staff; in response to this need, in 2009 the post of palliative care education co-ordinator was created. Apart from training on syringe driver management, no other form of palliative/end of life care education was available in-house to staff; there was literally a blank canvas.

Coming from a community Macmillan nursing background and working in the local area for four years, the priorities for palliative and end of life care education and support for staff had been apparent to me for some time. Working at ground level you are exposed to the real issues.

Initially, I wanted to find out staff education priorities; I conducted a mini training needs analysis to enable me to identify the key priorities. A whole range of subject areas were highlighted but there were obvious key themes. These included symptom management, communication skills, the palliative and end of life care services available locally to support patient care, commonly used drugs in palliative and end of life care, and drug conversions from oral to injection form. Using these results, I then went on to develop and deliver a range of educational programmes to support staff and improve the quality of patient care; all of these programmes are nurse-designed and nurse-led initiatives. Education packages developed include:

- A 2 day foundation programme which aims to give staff a basic overview of palliative and end of life care. This includes the history of palliative care, an update on what's happening locally and nationally in palliative and end of life care, an overview of long term conditions, basic communication skills, an update on the Gold Standards Framework (GSF) and Liverpool Care Pathway

(LCP), and symptom management (including an overview of the 4 common palliative care emergencies)

*Over the last 2 years 94 staff members have completed the training*

- A 1 day introduction to palliative care services was also developed; this day aims to update professionals on the local services available to support patients during the palliative and end of life phases of their illness. The day provides staff with an overview of contact details, referral forms and service-specific referral criteria

*Over the last 2 years 155 staff members have completed the training*

- Syringe driver management session 1 which provides staff with theoretical knowledge on syringe driver management

*Over the last 2 years 126 staff members have completed the training*

- Syringe driver session 2 which provides staff with an overview of the commonly used drugs in palliative and end of life care. The session includes drug doses, drug compatibilities and drug conversions from oral to injection form

*Over the last 2 years 39 staff members have completed the training*

- Over the last year I have also been responsible for rolling out the LCP across community services; an awareness session was delivered to staff highlighting how to complete the pathway in practice

*A total of 291 staff members have completed the training.*

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## A collaborative approach with the ambulance service

Within my role as education facilitator for end of life care I was invited to assist with providing information to train emergency care practitioners (ECPs) from the East of England Ambulance Service, who work across Essex. The training took place at St Francis Hospice and included best practices in end of life care. The training included knowledge of the three tools recommended within the *End of life care strategy*: GSF, PPC and LCP. The education also include the Just In Case emergency drug boxes available within west Essex which include guidance on the drugs, how to use them alongside a syringe driver, and how to set up and troubleshoot a syringe driver.

The opportunity to work together in this way enabled both nurse and ECPs to promote partnership working and to link with champions within the ECP service to improve care at the end of life. Working as a nurse in this context provided a key opportunity for me to share my knowledge and skills and reflect on how our practices work together. It also provided us with a perspective on our roles and how they link together, as well as providing us with mutual respect for the value of utilising services within the community to prevent unnecessary hospital admissions. The ECP service has developed an information booklet for their staff with relevant symptom management and troubleshooting information, together with out-of-hours hospice helpline numbers and community services contact details.

Following on from the training we have had a number of scenarios in which individuals who were receiving end of life care required urgent assistance, or a carer who required help or support may have resorted to dialling 999. As a result of the training, individuals have had the opportunity to die with dignity in the place of their choosing. The following scenarios briefly highlight the impact of the training programme.

### Scenarios

A young 22 year old had expressed his wish to die at home and be cared for by his family. It was recognised that he could potentially require emergency symptom management, as his diagnosis meant that with an acute episode his death could become both distressing and painful. The ECP team were informed of his prognosis and a plan of care was established with the young man's family. The family were provided with direct contact details for the ECP if rapid treatment was required; this would prevent a normal 999 response which could mean an ambulance potentially taking him to hospital. With the support of the local nursing team and the ECP the young man died at home with his family and with an ECP holding his hand.

An ECP car was called to a dying lady whose daughter was very distressed by her mother's condition. The ECP contacted the community services who were able to attend to the needs of the family and prevent the lady being admitted to hospital. The ECP assisted in providing symptom management to settle the lady. The lady died peacefully at home eight hours later.

A gentleman who was due to be admitted for symptom management to the local hospice was extremely unwell when the ambulance arrived to transport him. The ambulance man discussed with the gentleman and his wife the effects of moving him at this stage and, with agreement, contacted the community services and the Macmillan clinical nurse specialist. The Macmillan nurse came to the house to meet the ambulance team and review the gentleman's condition. Together they were able to provide symptom management and arrange a home visit from the hospice consultant. The gentleman died peacefully at home that same afternoon with his family by his side.

**Contact**

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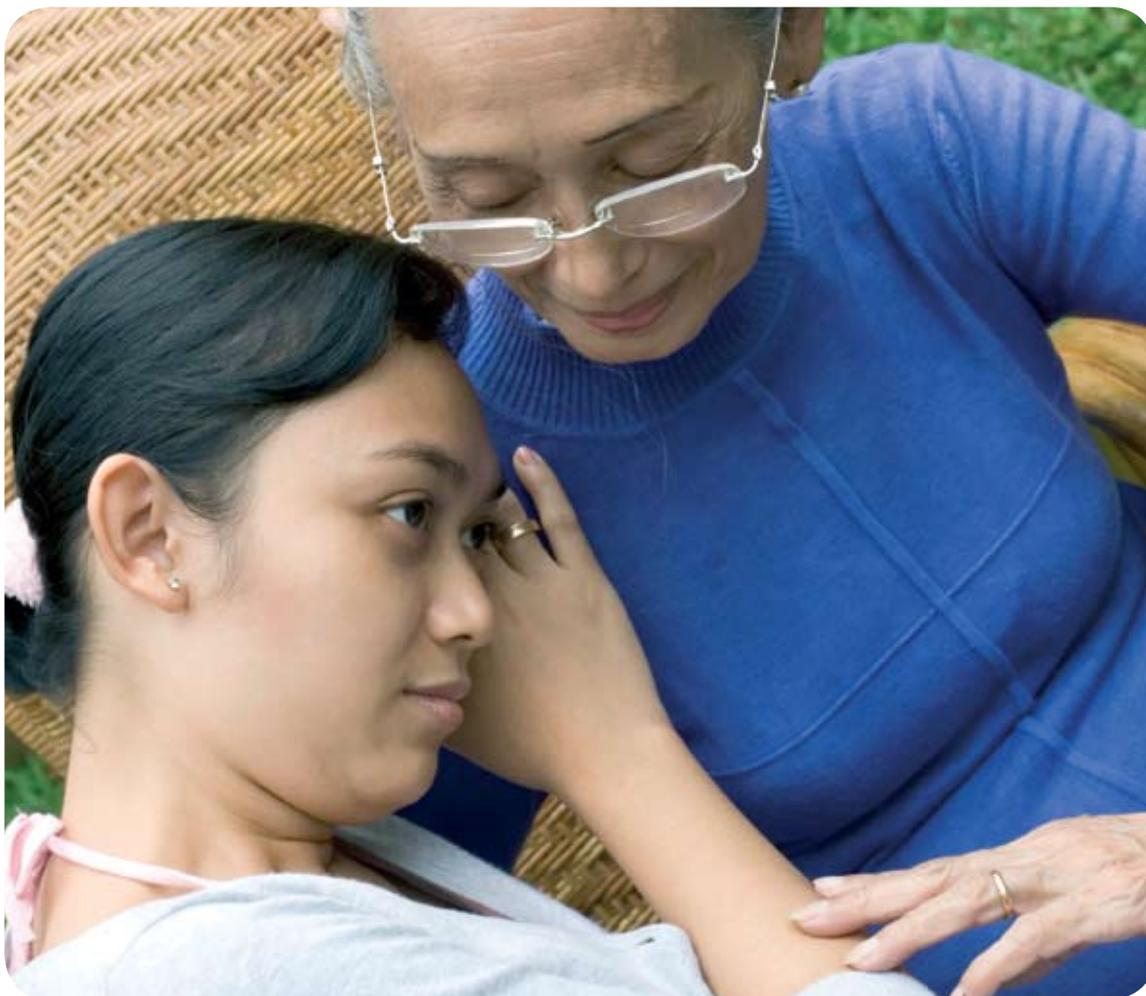


## Supporting individual choice regarding preferred place of care

Rachel was a 22 year old woman diagnosed with renal cancer, metastatic at the point of diagnosis following a short protracted history. The phrase “no decision about me without me” (*Equity and excellence: liberating the NHS*) could have been written with her in mind.

Rachel was transferred out of the hospice to her home, where she spent the last weeks of her life.

Rachel was assessed and managed by the district nursing team supported by the clinical nurse specialist (CNS) and GP. However, contact with the hospice continued as outreach physiotherapy and occupational therapy were arranged, and Rachel actually got out of bed into her wheelchair to attend a family party. Both Rachel and the family relaxed and we were able to focus on her quality of life, changing



her medication routine to make life more normal for her. Rachel did not feel as overwhelmed and had control of visitors as she was in her own domain.

Also as a consequence of being home, Rachel had the opportunity to talk to family and friends about her wishes for her funeral – ie, everyone in pink and no black, not even the men! At one point an oncology appointment was made as her condition stabilised; this improvement was short lived.

Utilising the Gold Standards Framework meant that the multi-disciplinary team were all aware of Rachel's preferred priorities for care. They were able to anticipate and plan, ensuring that end of life medication would be available at the point of need and avoiding delay and distress.

The out-of-hours GP and nursing service were updated and the expected death section of the documentation was completed. District nurses were able to show Rachel's mum the LCP document and the syringe driver in order to allay any fears and misconceptions she may have had. Rachel's dad was concerned that he would not be there for her, as he lived 200 miles away. In recognising the dying phase the CNS and district nurse were able to discuss the change in Rachel's condition with him and she died peacefully in his arms at home.

**Contact**

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## Key contribution of nursing to the discharge process

**Service:** End of Life Discharge Home Service ('fast track'), St George's Healthcare NHS Trust (SGH) palliative care team

To support individuals who are at the end of life to die in their preferred place of death, the palliative care team launched the End of Life Discharge Home Service in June 2009.

### **The main features of the service at SGH are:**

- The palliative care clinical nurse specialist (CNS) discusses preferred place of death with the individual and ensures that family/carers are informed and involved. In most cases a family meeting is arranged (step 1)
- The CNS liaises with continuing care, GP, district nurse, community palliative care and London Ambulance Service as soon as it has been established that the patient wants to go home (step 2). In areas where they have an end of life (EoL) locality register the CNS enters the patient on the register (step 2)
- We have wide representation on our stakeholder group from commissioners and providers from the PCTs, voluntary organisations and a range of departments from the acute trust (including transport) (step 3)
- The team has received funding from Sutton and Merton PCT and Wandsworth PCT for a band 6 nurse to increase the capacity of the team to offer this service
- The CNS from the palliative care team leads on the discharge and the liaison with the community services. All CNSs in the team are trained to do this, so we can provide a seven day week service (step 3)
- The CNS from the palliative care team escorts the patient in the ambulance and hands over to community staff in the patient's home (step 4). We provide a leaflet for the carers on how to care for someone at the end of life and including local contact numbers (step 5)
- We invite members of the family to a memorial service at the hospital six months after the death (step 6)
- The service is evaluated, including carers' views.

### Results

- 132 patients were fast tracked from April 2010 to March 2011
- Only 4 patients have been readmitted to SGH
- The average time to set up an EoL discharge home (fast track) is 3 days, compared to 27 days for a non-fast track
- Closer links with community services have been established
- Carers' evaluations rate the hospital transport home as excellent. Prior to involving the transport department in the new service discharges were often delayed due to transport problems.

### Contact

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## Our NHS campaign: the nurse's perspective and key contribution

In Worcestershire over 2,000 people die in our acute trust each year; this is nearly half of all deaths in the county. A recent survey of a citizen's panel in Worcestershire revealed that 80% of people would prefer to die at home, a stark contrast to the reality of only 21% achieving this.

Many of the individuals who die are not being given the opportunity to express or discuss their choices. At times this happens because some staff do not know what is available to patients; one of the staff nurses explained that she kept people in hospital for 'TLC' because it is safer on the ward. Some do not recognise when the time is right to have a conversation with the individual and, even when asked directly, staff can easily avoid the conversation.

It was recognised that nurses have a central part to play in initiating and maintaining dialogue with individuals to ensure that their wishes can be voiced.



Nurses can proactively enable people to realise their wishes by communicating outcomes of discussions with the person with other members of the multi-disciplinary team.

In NHS Worcestershire a campaign supported by a central leadership team has started to recruit nurses and other members of the multi-disciplinary team to commit to asking two questions of individuals and recording the answers in their notes and also on a reflective practice pro forma. The two questions were devised by Libby Mytton of Primrose Hospice. Whilst they are simple when asked, the intention behind the questions was to enable a dialogue to begin that is appropriate to the individual's understanding of where they are in their disease trajectory and whether they are ready to talk about their end of life care.

**The two questions are:**

- What do you understand about your illness?
- What is your greatest concern at the moment?

As the campaign develops it is the nurses who are key: they have taken the lead and started asking the questions. The nurses have found the questions to be a helpful tool to initiate these difficult conversations. Nurses' reflections on the process have been revealing, highlighting that although the nurses have the skills to talk to individuals they often do not have the confidence to initiate these sensitive conversations, sometimes because of fear of how the individual will react. Asking the two questions has developed confidence and enabled nurses to empower individuals to make appropriate, informed choices.

It is early days for the campaign, which is based on an organising methodology advocated by Marshall Ganz, but it appears that the intention of developing leaders at all levels of the acute trust to take forward the work is beginning to have an impact. Nurses are proactively suggesting and developing further tools that they want to support them with their conversations, and a group of nurses have also developed a complex discharge pathway for individuals at the end of life using a Map of Medicine® care map which will be rolled out across the acute trust.

The campaign has started in one ward of Worcestershire Royal Hospital but the positive impact it has had on individuals so far means that nurse leaders are stepping up to roll out the campaign across Worcestershire Acute Hospitals NHS Trust and beyond.

**Contact**

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## Key contribution of the community matron within end of life care

The role of community matron supportive and palliative care was a partnership project between NHS Oxfordshire and Sue Ryder care. The pilot commenced in 2006 and is now a permanent service. The key aims of the role are to place the individual at the centre of care, to ensure that every person has access to palliative care services appropriate to their needs, to ensure that all can exercise choice about their place of care at the end of life, to provide adequate symptom management, to support patients with long term conditions within the community and to reduce the number of acute spells by 5%.

Referrals into the service are accepted from GPs, district nurses, specialist nurses, social services, continuing care, community hospitals, the acute sector and nursing and residential homes, as well as from relatives.

The community matron is a nurse advanced practitioner and has clinical assessment and non-medical prescribing skills as well as advanced communication skills. This enables robust assessment of the patient's needs and clear discussions regarding future care. The important role carers play is acknowledged and care plans are developed with the patient and/or relative.

The community matron works with existing services to support both the individual and the carers. The co-ordination of care is encouraged, with a named key worker for all patients and communication between all parties involved. The matron will investigate issues and complaints that occur in order to disseminate learning from incidents and smooth the patient pathway.

### **An evaluation of the service over a 12 month period revealed that:**

- 78 people had died who have been on the community matron caseload
- Of these, 51 people identified where they wished to die and 49 achieved their wish
- 6 people were unable to express a preference, but all 6 died where the people closest to them believed they wished to be.

Cross-boundary working is a key element of the role; assessing patients in hospital and facilitating discharge can hasten discharge. The ability to prescribe within the community hospitals also smooths the individual patient pathway by addressing symptom issues quickly. A close working relationship with out-of-hours and the ambulance service provides a whole system approach.

Proactive planning and open discussion regarding patient options and wishes and the competency to complete the DNACPR paperwork facilitates patient choice.



The post holder has an in-depth knowledge of the services available to people in Oxfordshire and makes referrals as appropriate. The community matron will discharge patients from her caseload to other services. When an individual on the case load dies, the question of who will provide bereavement support is decided between the professionals involved. It may be more appropriate for the district nurse who has known the individual and relatives longer to provide this support, or it may be that the community matron is best placed.

The community matron's caseload is approximately 50% cancer diagnosis and 50% non-cancer. Recently Liz Clements (the community matron) has focused on working with South Central SHA on a dementia pathway and on raising the profile of dementia across Oxfordshire, within both the community and hospitals. Education is a vital element of disseminating good practice across the locality and the community matron provides educational sessions within the local university.

**Contact**

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## Professional support and advice for care home staff and residents: Warrington Community Services Unit

Warrington Community Services Unit has set up a care home team to provide professional support and advice to staff, carers and residents in a number of homes in the area.

The results are that residents are being given greater choice about where they die and the number of unnecessary hospital admissions has been cut. Between April 2009 and March 2010, the number of A&E attendances from care homes in Warrington has dropped by 250, emergency admissions have fallen by 288 and a total of 8,836 hospital bed days have been saved.

The service, which provides a comprehensive health needs assessment for all its patients, began in 2002/03 when NHS Warrington undertook a pilot by seconding two specialist nurse practitioners (district nursing) with initial aims of reducing demands on GPs from inappropriate requests and call-outs and also supporting and educating care home staff. Initially three nursing homes were invited to take part in the pilot.

Now, all care homes in Warrington are involved in the scheme. They now have a single point of access that can triage, prioritise referrals and offer advice. The service has also been expanded from a five day to a seven day service available from 8.00 am until 7.00 pm.

One of the biggest challenges was getting care home staff to adapt to a change in their everyday practice. Involving staff and GPs at every step of the journey has helped to build trust and establish good relationships.

As a result of the project, residents and families are now given a choice about where they wish their loved ones to spend the last days of their lives. In addition, implementing the Gold Standards Framework and involving the clinical nurse educator have helped to raise levels of education and skill among care home staff.

Training will be delivered to all organisations and to all levels of staff on a rolling programme over the coming months and years. A work programme is currently being devised to facilitate this and work will begin shortly. The team are working closely with commissioners to develop the education programme to be rolled out next year.

**Key points:**

- A scheme to support and advise care home staff in Warrington has cut hospital admissions and given residents greater choice about where they die
- The care homes collectively have reduced emergency admissions by 288 and saved 8,836 bed days in the last year
- It is planned to extend the GSF programme to the remaining 22 homes in the area.

**Contact**

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## Spirituality and end of life care in the West of Sussex Community NHS Trust

A local audit of the Liverpool Care Pathway in the community demonstrated a significant gap in the provision of spiritual care.

Nursing teams voiced a lack of confidence in discussing spiritual issues and were unclear as to the limits of their role. An already successful model operating at St Richard's Hospital in Chichester was adopted as the basis for our own project.

Our working definition of 'spiritual care' is when illness threatens a person's sense of meaning, worth and purpose. Nurses are encouraged to use a conversational style of spiritual assessment using open questions such as:

"How are you coping with your illness?"

"What generally helps you cope with problems?"

"What things are particularly meaningful for you?"

Religion may or may not form part of a person's spirituality; we emphasise the importance of listening in a supportive and open environment. It is important that nurses are confident that they have further or specialist support to call upon if needed. Permission is sought from the individual to refer on to the community pastoral care team under the management of the chaplaincy at the local acute trust.

Referrals are made through the nursing team rather than directly via the patient. This is in order to manage both clinical responsibility and risk assessment.

This project will give nurses confidence in assessment and referral of spiritual matters, and the ability of individuals and carers to share their hopes and fears will reduce spiritual pain

### Contact

Sandra Vargeson, end of life care co-ordinator  
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## Key contribution of nursing within care after death

“Mrs S was being cared for by the local district nurse (DN) team. She was a lady in her late seventies at the end of her life following a long illness. Her daughter, T, was single and was staying with her mother to care for her, with regular input from the DN team.

“One week after Mrs S died the DN visited T. She was clearly very sad but, more than this, she seemed lost. The DN was aware that she may need additional support and decided to visit again a month later, and to take with her a collection of general bereavement booklets to enable T to access help.”

This case study was provided by a community nurse and echoed other reflective discussions with nurses and practitioners working within end of life care. It was these reflective practice discussions within the nursing teams that highlighted the need for a local resource to assist and guide families immediately following bereavement. This in turn prompted the potential for the development of a bereavement booklet for use across acute and primary care services in East and Central Cheshire. The booklet would serve the local population by signposting families to local and national organisations and would also provide guidance on the tasks to be done in the initial period following the death.



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A multi-professional working group, with representation from health and social care, the voluntary sector and service users, was brought together to consider how the booklet could best address the identified needs. Chaired by the end of life programme lead for East Cheshire, the group worked closely together to formulate a bereavement booklet that can be given to families at the time of death. The nurses' role was key to providing local information and highlighting the needs of the families. The booklet contains information and guidance around bereavement irrespective of whether their relative died in hospital, at home or within another care setting.

This booklet is provided free of charge with the cost of printing being covered by advertising, facilitated by a reputable national printing organisation.

In addition, to assist with gaining further insight into families' experiences of end of life care, a feedback form was designed and is included to aid with evaluation, inform future developments and guide best practice. Once again the nursing staff are the key contacts for the dissemination and return of the questionnaires.

**Key contributions of the nurses within this project:**

- Due to reflection on their practice, the nurses were initially responsible for highlighting the need for a local resource that could be given out to people following bereavement
- The nurses took a key part in the group that formulated the booklet by both identifying needs and providing important local information
- It will be nurses who will play a major role in cascading the bereavement booklet as they follow up many bereaved relatives. They are required to do this in a caring and sensitive manner
- The nurses will be the point of return for the relative satisfaction surveys, which will give them the opportunity to further develop best practice.

**Contact**

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## The nursing and midwifery code

*(The code: standards of conduct, performance and ethics for nurses and midwives, Nursing and Midwifery Council (NMC), May 2008)*

The introduction to the code appears below. The full text, along with links to related resources and information, is available at <http://www.nmc-uk.org/Nurses-and-midwives/The-code/>.

Other formats (pdf, hard copy and mp3) are available at <http://www.nmc-uk.org/Publications/Standards/>.

### **Introduction to the code**

The code is the foundation of good nursing and midwifery practice, and a key tool in safeguarding the health and wellbeing of the public.

The people in your care must be able to trust you with their health and wellbeing.

### **To justify that trust, you must**

- make the care of people your first concern, treating them as individuals and respecting their dignity
- work with others to protect and promote the health and wellbeing of those in your care, their families and carers, and the wider community
- provide a high standard of practice and care at all times
- be open and honest, act with integrity and uphold the reputation of your profession

As a professional, you are personally accountable for actions and omissions in your practice and must always be able to justify your decisions. You must always act lawfully, whether those laws relate to your professional practice or personal life.

Failure to comply with this code may bring your fitness to practise into question and endanger your registration.

This code should be considered together with the Nursing and Midwifery Council's rules, standards, guidance and advice available from [www.nmc-uk.org](http://www.nmc-uk.org).



# End of Life Care Patient Charter

## A charter for the care of people who are nearing the end of their life

*"You matter because you are you, you matter to the last moment of your life and we will do all we can, not only to let you die peacefully, but to help you live until you die"* Dame Cicely Saunders

We want to offer people who are nearing the end of their life the highest quality of care and support. We wish to help you live as well as you can, for as long as you can. Therefore, if and when you want us to, we will:

- Listen to your wishes about the remainder of your life, including your final days and hours, answer as best we can any questions that you have and provide you with the information that you feel you need.
- Help you think ahead so as to identify the choices that you may face, assist you to record your decisions and do our best to ensure that your wishes are fulfilled, wherever possible, by all those who offer you care and support.
- Talk with you and the people who are important to you about your future needs. We will do this as often as you feel the need, so that you can all understand and prepare for everything that is likely to happen.
- Endeavour to ensure clear written communication of your needs and wishes to those who offer you care and support both within and outside of our surgery hours.
- Do our utmost to ensure that your remaining days and nights are as comfortable as possible, and that you receive all the particular specialist care and emotional and spiritual support that you need.
- Do all we can to help you preserve your independence, dignity and sense of personal control throughout the course of your illness.
- Support the people who are important to you, both as you approach the end of your life and during their bereavement.

We also invite your ideas and suggestions as to how we can improve the care and support that we deliver to you, the people who are important to you and others in similar situations.

*For more information from your Practice Team please contact*

Name : .....

Phone Number.....

Leading the Way: High-Quality End of Life Care Through General Practice

## Quality markers for end of life care

(*End of life care strategy: quality markers and measures for end of life care*, Department of Health, 2009 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_101681](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681))

(See also the End of Life Care Quality Assessment Tool (NEoLCP/National End of Life Care Intelligence Network) at [www.elcqua.nhs.uk](http://www.elcqua.nhs.uk).)

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 an individual's 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 coordinated across organisational boundaries 24/7.
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 enable relevant workers to access or attend appropriate programmes dependent on their needs.
9. Adopt a standardised approach (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.

## Support sheet Mental Capacity Act

Compiled from the *Mental Capacity Act 2005 code of practice* (Department for Constitutional Affairs, 2007) by Julie Foster, end of life care lead, Cumbria and Lancashire End of Life Care Network (See <http://www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm>)

The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so.

### **The five statutory principles are:**

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

### **How should people be helped to make their own decisions?**

To help someone make a decision for themselves, check the following points:

#### **Providing relevant information**

Does the person have all the relevant information they need to make a particular decision? If they have a choice, have they been given information on all the alternatives?

#### **Communicating in an appropriate way**

Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)? Have different methods of communication been explored if required, including non-verbal communication? Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

**Assessing capacity**

Anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity. Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.) If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

**Assessing ability to make a decision**

Does the person have a general understanding of what decision they need to make and why they need to make it? Does the person have a general understanding of the likely consequences of making, or not making, this decision? Is the person able to understand, retain, use and weigh up the information relevant to this decision? Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

**Assessing capacity to make more complex or serious decisions**

Is there a need for a more thorough assessment (perhaps by involving a doctor or other professional expert)?

A variety of publications and web-based resources can be found on the **National End of Life Care Programme** website at <http://www.endoflifecareforadults.nhs.uk/>. These include:

A 'useful resources' page 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/](http://www.endoflifecare.nhs.uk/routes_to_success/)

e-ELCA (end of life care for all): an e-learning project providing interactive modules aimed at a broad range of health and social care professionals including nurses. (Commissioned by the DH and delivered by e-Learning for Healthcare (e-LfH) in partnership with the Association for Palliative Medicine of Great Britain and Ireland) <http://www.endoflifecareforadults.nhs.uk/education-and-training/eelca>

Condition-specific resources such as *End of life care in advanced kidney disease: a framework for implementation*, NEOFPC/NHS Kidney Care, 2009 <http://www.endoflifecareforadults.nhs.uk/publications/eolcadvancedkidneydisease>

*End of life care strategy: promoting high quality care for all adults at the end of life*, Department of Health (DH), 2008 <http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy>

*Common core competences and principles for health and social care workers working with adults at the end of life*, NEOFPC/DH/Skills for Care/Skills for Health, 2009 <http://www.endoflifecareforadults.nhs.uk/publications/corecompetencesguide>

Preferred Priorities for Care (PPC), NEOFPC, 2007 <http://www.endoflifecareforadults.nhs.uk/publications/ppcform>

*Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff*, NEOFPC, 2011 <http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>

*Advance decisions to refuse treatment: a guide for health and social care professionals*, NEOFPC/National Council for Palliative Care, 2008 <http://www.endoflifecareforadults.nhs.uk/publications/pubadrtguide>

*Planning for your future care: a guide*, NEOFPC/National Council for Palliative Care/University of Nottingham, 2009 <http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare>

*Best interests at the end of life: practical guidance for best interests decision making and care planning at end of life (relating to the Mental Capacity Act (2005) England and Wales)*, C Hutchinson/J Foster, East Lancashire PCT/Central Lancashire PCT, 2008 <http://www.endoflifecareforadults.nhs.uk/publications/bestinterestseolguide>

## Other resources

NHS Choices (patient information) <http://www.nhs.uk/aboutNHSChoices>

*Mental Capacity Act (2005) code of practice*, Department for Constitutional Affairs, 2007 <http://www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm>

*Our health, our care, our say: a new direction for community services*, DH, 2006 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH\\_4127552](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4127552)

*Where people die (1974—2030): past trends, future projections and implications for care*, B Gomes/I Higginson, Palliative Medicine, Jan 2008

*Making a difference: Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups*, C Shipman et al, British Medical Journal, 11 Oct 2008

*Living and dying with dignity: the best practice guide to end-of-life care for people with a learning disability*, Mencap, 2008 <http://www.mencap.org.uk/page.asp?id=9753>

*Transforming community services: ambition, action, achievement transforming end of life care*, DH, 2009 <http://www.dh.gov.uk/en/Healthcare/TCS/index.htm>

Out-of-hours toolkit, Macmillan Learn Zone (online learning resources for professionals) [www.macmillan.org.uk/learnzone](http://www.macmillan.org.uk/learnzone)

Gold Standards Framework (GSF) <http://www.goldstandardsframework.nhs.uk>

The Liverpool Care Pathway for the Dying Patient (LCP) <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

*Can you see me?* (DVD), National Council for Palliative Care (NCPC), 2010 (DVD available from NCPC at <https://www.committedgiving.uk.net/ncpc/publications/>)

*Making nursing visible: valuing our contribution to high quality patient-centred care* (RCN, 2011) [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0003/372990/003877.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0003/372990/003877.pdf)

## Useful websites / organisations that have contributed to this publication

National End of Life Care Programme (NEoLCP) <http://www.endoflifecareforadults.nhs.uk>

National Council for Palliative Care (NCPC) [www.ncpc.org.uk](http://www.ncpc.org.uk)

Dying Matters Coalition ([www.dyingmatters.org](http://www.dyingmatters.org))

Royal College of Nursing ([www.rcn.org.uk](http://www.rcn.org.uk))

# Acknowledgements

We would like to take this opportunity to thank all those who have contributed to this guide.

Thank you also for the abundance of wonderful case studies. We have not been in a position to include all of them within this guide; we plan for others to be available on our website: [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk).



