Care towards the end of life for people with dementia
an online resource guide
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High quality care towards the end of life for people with dementia can support vulnerable individuals to live comfortably and as well as possible until they die.

It can also be of great help to families that care for them and help to avoid the distress of unnecessary, repeated, often lengthy and costly hospital admissions.

This guide is principally for professionals working in health and social care and allied professions. Its main aim is to provide links to information sources, resources and good practice in end of life care (EoLC) for people with dementia, particularly for those who work with people with dementia who are not EoLC experts and EoLC experts who are not particularly knowledgeable about dementia.

While the document is not principally written for patients and carers, some of the information will be relevant to them and professionals can make use of it to signpost them.

Further information about dementia care in general can be found through the Dementia Gateway.
The nature of dementia

Dementia is one of the most pressing challenges facing health and social care in the UK. The direct costs of Alzheimer’s disease alone exceed the combined costs of stroke, cancer and heart disease, and the overall economic burden has been estimated to be over £14 billion per year in the UK (Alzheimer’s disease in the UK, Lowin et al, International Journal of Geriatric Psychiatry, Dec 2001).

Dementia affects one person in 20 over the age of 65 years, and one in five of those over the age of 80. The number of people with dementia is increasing. There are estimated to be over 750,000 people in the UK with dementia and numbers are expected to double in the next thirty years (Quality outcomes for people with dementia: building on the work of the national dementia strategy, DH 2010). This would substantially increase the already considerable emotional, financial and social burdens of this condition.

About half a million people die each year in England, a third of them from frailty or dementia. Most people with dementia die in residential or nursing care homes or in hospital. Although some receive excellent care at the end of life, many do not. The last few months of life may often be dominated by pain and distress; physical deterioration and malnutrition; frequent, ineffective and costly admissions to hospital; and an absence of dignity and choice.

A step change in access to high quality care for all people with dementia approaching the end of life is needed. This was highlighted in the DH’s End of life care strategy (2008), national dementia strategy (Living well with dementia, 2009) and national carers strategy (Carers at the heart of 21st-century families and communities, 2008).

The wider impact of dementia in the community should not be underestimated. Informal family carers are at significant risk of social isolation, financial drain and physical and emotional exhaustion. Supporting carers through the last few years and months of the lives of people with dementia is critical, augmented by the provision of high quality nursing and residential care when needed, if those with dementia are going to be enabled ultimately to have a ‘good death’.

The Social Care Institute of Excellence’s (SCIE) Dignity in care guide was launched in 2006 to support the Department of Health’s Dignity in Care Campaign. The guide has always been one of SCIE’s most popular products and it has recently been updated.

Quality of experience for the carer and the person with dementia

High-quality end of life care for people with dementia can:

- Break down the stigma of dementia, which leads to barriers in accessing the care people need
- Enable people to live as well as they can until they die
- Increase choice for people with dementia by supporting them in their preferred priorities for care (PPC) through the implementation of advance care planning (ACP)
- Support and empower carers
- Reduce inequalities by improving access to information, advice and the range of available support services
- Optimise the psychological, physical and spiritual wellbeing of people with dementia and their carers through access to an appropriately trained workforce
- Ensure appropriate access to continuing healthcare provision
- Strengthen support for carers after the death of the loved one.
Why good end of life care for people with dementia matters

What is different about end of life care for people with dementia?

End of life care is normally defined as the care needed during the last year of life. Dementia has some similarities to but also differs considerably from diseases such as cancer, which may also be viewed as life limiting.

Given the slow progression of most types of dementia, identifying the time for a transition to EoLC will often be difficult. Several decades of cancer research have failed to find a set of indicators that predict prognosis, and dementia is just as difficult to predict. Consequently, carers of people with dementia commonly underestimate the likelihood that a person will die in the next few months.

In addition, many progressive conditions have crises, any one of which could bring about the death of the individual. In most progressive neurological conditions these crises are often respiratory tract infections but by the nature of these repeated infections patients will survive all of them except the last crisis. The difficulty is defining what is different about this last crisis.

A particular feature of dementia, however, is that the individual’s communication skills deteriorate so that the ability to express their views and wishes and to make choices is lost at an earlier stage than with other life limiting conditions.

Case study on involvement of patients and carers

- End of life care for people with dementia (NEoLCP, 2010) (Case study from report, End of life care for people with dementia in Haringey, Marie Curie Cancer Care, the National Council for Palliative Care, Dementia UK, NHS Haringey, Barnet, Enfield and Haringey NHS Mental Health Trust and Haringey Council, 2009).

Case study

- The National Council for Palliative Care’s (NCPC) dementia project.
Over the past few years the concept of a care pathway has been embedded for the planning, delivery, contracting and monitoring of services across a wide range of conditions. The EoLC pathway is outlined in the Department of Health’s *End of life care strategy* (2008).

This chapter links the particular characteristics/needs of people affected by dementia to the steps in the pathway, recognising that these should not be seen in isolation and that people should not be excluded from care because of factors such as co-morbidity, age (whether young or old), culture or ethnicity or co-existing learning disabilities.
Step 1  
Discussions as the end of life approaches

The deterioration in communication skills with dementia prevents people from expressing their views and wishes later in the disease pathway – particularly on how and where they wish to be cared for and to die.

So it is even more important for people to receive support to think and plan early for their future care. In particular there should be:

- Access to good quality information about advance care planning which can include wishes and preferences
- Advance decisions to refuse treatment (ADRT) and lasting power of attorney available as part of the commissioning of early diagnostic and assessment services for those with dementia
- Providers involved in the care of people with dementia should be aware of the provisions of the Mental Capacity Act 2005 and understand how to assess mental capacity. Guidance on helping people with decision-making is available
- The workforce should be equipped with the skills and confidence to enable open, honest communication about EoLC with individuals and their carers.

Identifying the need for a palliative care approach

Uncertainty in prognosis for people with dementia can make decisions around treatment and EoLC difficult. The emphasis should be on identifying a developing need for a more palliative care approach.

Tools to help include using:

- The ‘surprise’ question: “Would you be surprised if this patient were to die in the next 6–12 months?”
- The Gold Standards Framework’s (GSF) Prognostic indicator guidance
- The NCPC’s algorithm involving these questions:
  1. Does the patient have moderately severe or severe dementia?
  2. Does the patient also have:
     a. Severe distress (mental or physical) that is not easily amenable to treatment, or
     b. Severe physical frailty that is not easily amenable to treatment, or
     c. Another condition (eg co-morbid cancer) which merits palliative care services in its own right?

If criteria 1 and 2a, b and/or c co-exist, then the patient ought to have a full assessment of need and a focused analysis of why they are in distress and how best their symptoms can be improved and distress reduced (p17, The power of partnership: palliative care in dementia, NCPC, 2009). Additionally, tools such as the Reisberg FAST© scale can be used.

Useful resources

- The Dying Matters Coalition has produced a range of useful leaflets that can support early discussions about EoLC
- The This is me leaflet produced by the Alzheimer’s Society can be useful in supporting communication with people with dementia.
Step 2
Assessment, care planning and review

A case management approach is needed, built on a comprehensive multidisciplinary health and social care assessment of the individual’s needs. It requires access to a range of primary and secondary care professionals with expertise in dementia and palliative care.

Therefore dementia services must up-skill in palliative care issues and palliative care services must up-skill in dementia management. Partnerships between these services, as well as partnerships with district nursing teams, social care and community matron services, can be especially effective.

Holistic common assessment of supportive and palliative care needs for adults requiring end of life care (NEoLCP, 2010) is an excellent recent resource to support this.

Assessment should also include ongoing assessment of carers’ needs, as set out in the guidance on the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004. The Carers Recognition Act 2005 is also relevant.

The Princess Royal Trust for Carers joined forces with the Royal College of General Practitioners to publish Supporting carers (2008) to help GPs work with carers.

Help the Hospices has advice on how to request and prepare for a carer’s assessment.

Useful resources

- Planning future healthcare for people with dementia nearing end of life. If people would like to receive a copy of the flowchart, please email MEndofLifeCare@gstt.nhs.uk
- The GSF’s PEPSI COLA aide memoire.
Step 3
Co-ordination of care

There should be a single point of access for carers and people with dementia to offer a co-ordinated response from all care agencies, including care homes and the voluntary sector.

In line with the national dementia strategy there is a need to provide continuity as well as co-ordination in the range of health and social care support services available to:

- Manage presentation of physical symptoms/changes in behaviour (eg access to drugs and equipment and extra care housing)
- Facilitate early discharge if admitted (eg 24-hour rapid response services)
- Arrange for equipment to be available to support independent living
- Secure access to high quality out-of-hours advice and support.
Step 4
Delivery of high quality care from a range of settings

Most people living with advanced dementia are either in their own home or in residential or nursing homes and services should be delivered as close to 'home' as possible. The workforce must be skilled in the management of the health and social consequences of advancing disease. Up-skilling will be achieved through training as well as partnership working.

Greater emphasis on palliation and less on curative medicine is needed, with a particular focus on:

- Responding to difficult behaviour through individually tailored care plans that recognise the factors that may generate, aggravate or improve such behaviour, as well as securing access to appropriate medication
- The effective use of antipsychotic medicines, which recognises recent Department of Health commissioned research – this includes advice that although such medicines can be important for some with dementia and in palliative care for those who are dying, they should not be the sole focus of response to distress in dementia
- Informing family carers of the effects of antipsychotic medication and supporting them to be involved in decision-making with appropriate medical guidance
- Supporting the relief of pain and distress (whether mental or physical) by developing the skills and confidence of all staff to identify and prevent distress, as well as knowing when to access expert palliative and pain control services and psychiatric services

- The use of validated pain scales - eg DOLOPLUS 2 and Abbey – can help to increase the recognition of pain in people with dementia
- Informed use of telecare products
- Managing complications such as pneumonia, febrile episodes and swallowing and eating problems in the community - these are frequent complications in people with advanced dementia and are associated with high mortality, particularly in the first six months
- Safeguarding vulnerable adults by securing zero tolerance of all forms of abuse and by appropriate use of the the Mental Capacity Act (2005): deprivation of liberty safeguards and the Mental Health Act (2007).

Care should be provided by the expert dementia and EoLC teams already working in the community - including Admiral Nurses, community nurses, palliative care teams, dementia advisers, peer support and volunteers.

Hospital admission of people with moderate or advanced dementia is associated with an increase in mortality, complications and poor symptom control. Therefore the aim, apart from in exceptional circumstances, is to treat people in their own environment (home, residential/nursing care home, or extra care housing). This requires increased expertise and understanding within the primary healthcare team and from others involved in care at home, as well as out-of-hours services. Reducing unnecessary hospital admissions requires detailed written planning that is shared between all appropriate staff, the provision and prescription of emergency medication and the availability of contact.
details for further help when crises occur. It is important to improve hospital care for people with dementia when hospitalisation is necessary, through dedicated leadership and liaison with psychiatry services for older people.

Workforce education and training programmes should be carefully designed to develop skills in all care staff caring for those with dementia, particularly towards the end of their lives, whether at home, in extra care housing or in a care home, whether mental health professionals, general practitioner or generalist social care and healthcare workers.
Step 5
Care in the last days of life

The key care components that should be available to support people in the last days of life include:

- The recognition that many people with dementia will also have a co-morbidity that involves a separate life limiting condition, e.g. cancer or heart or lung disease. The characteristics of the dying phase may therefore be more in line with these other disease trajectories
- Access to 24-hour community services for all those approaching the end of life who need them - so supporting people to die in their home or preferred place of death
- Anticipatory planning within primary care to reduce unplanned hospital admissions in the last days
- Diagnosis of dying and a multidisciplinary team approach

- Where dying is not clearly imminent and where it has already been used, the Gold Standards Framework, preferred priorities for care and other validated tools should continue to be used
- Where death is clearly imminent, tools such as the the Liverpool Care Pathway for the Dying Patient (LCP) may also be used (see useful resources below)
- Physical symptom management
- Psycho-social and spiritual support to ease discomfort so both the person with dementia and the carer feel at peace, safe and secure
- Spiritual care, including religious care, should be specific to that chosen by the individual and outlined as part of an advance care plan
- Access to carer support and information.
Step 6
Care after death

The process of bereavement can differ for carers of people with dementia, as it can for others who have a long illness accompanied by changes to cognition or psychology, such as those with brain injury or alcoholism. Carers can experience various losses throughout the course of the disease (such as the loss of the person’s personality and character, loss of their abilities and of plans for a future together). Care after death therefore needs to be seen as part of an ongoing package of emotional and practical support.

Case studies

• *Supportive care pathway for use with older people in Birmingham and Solihull Mental Health Trust* (NEoLCP, 2010)
• *Hope for home care of dementia in Bexley and Greenwich* (NEoLCP, 2007)
• *Out of the shadows: end of life care for people with dementia* (NCPC, 2009).
Leadership is needed at all levels to provide direction, motivation and support and to demonstrate a commitment to staff working in this area. Steps that will facilitate this include:

- Implementation of the national initiatives to raise the profile of EoLC for people with dementia
- Implementation of ACP in practice
- Dementia workforce and palliative care workforce planning initiatives to take account of the EoLC needs of people with dementia
- Strategic commissioning of cross-organisational models of service for EoLC for people with dementia - including developments to enhance co-ordination of care and workforce education and training
- Partnership working between strategic health authority end of life care pathway leads, primary care trust end of life care leads (and their successors), local authority social services departments and dementia end of life care leads
- The establishment of local agreements with commissioners to ensure EoLC for people with dementia is adequately resourced
- The nomination of a member of the local palliative care team in each locality as palliative care lead for EoLC for people with dementia
- Mental health services should appoint a palliative care lead for dementia
- Recognition of the key role of patients’ and carers’ representatives on local and national EoLC steering groups
- The formation of integrated local groups to oversee development and implementation of local action plans for EoLC for people with dementia, and to encourage and facilitate other local initiatives. An example is the Peterborough Palliative Care in Dementia Group.

Chart on advance decisions

The National End of Life Care Programme has an ‘at a glance’ guide to the differences between general care planning and decisions made in advance.

The single page chart lists the essential components of general care planning and the three main types of decisions made in advance, i.e. ACP, ADRTs and do not attempt cardiopulmonary resuscitation (DNACPR).

Within each category the following questions are addressed:

- What is covered?
- Who completes it?
- What does it provide?
- Is it legally binding?
- How does it help?
- What risks are there?
- Does it need to be signed and witnessed?
- Who should see it?
The main difference between ACP and more general planning is that ACP is designed to make clear a person’s wishes and usually takes place in the context of an anticipated deterioration in the individual’s condition.

Definition: advance care planning

This is the process of discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose capacity to decide or are unable to express a preference. Key examples include their preferred place of care and who they would want to be involved in making decisions on their behalf. It seeks to create a record of a patient's wishes and values, preferences and decisions - helping to ensure that care is planned and delivered in a way that meets their needs and those of the people closest to the patient (Treatment and care towards the end of life: good practice in decision making, General Medical Council, 2010). The National End of Life Care Programme in partnership with NCPC has produced a guide for professionals on ADRTs.

Guidance on helping people to make decisions is also available.

Recognising dementia

- Around 30 per cent of older people in the general hospital population are affected by dementia
- No two patients with dementia will present in the same way
- Memory loss is an essential feature in the definition of dementia; however, the degree will vary and memory loss alone is not enough to define dementia – other cognitive problems also have to be present, the nature of which depend on the type of dementia
- Emotional, behavioural and physical changes can also occur. A person may experience changes in their ability to communicate and thinking and decision-making skills may be affected
- Symptoms with a sudden onset and with marked fluctuations are more likely to be due to delirium
- Older people with dementia are 50 per cent more likely to experience delirium
- Dementia is common and yet generally under-recognised and hospital admission may be the first opportunity leading to diagnosis
- Not all older people have dementia - but the risk increases with age.

How to communicate with someone with dementia

- Ensure you have the person’s attention before you address them
- Use the name the person prefers
- Are you at the right height? Standing over a person will not be helpful
- Speak clearly and not too fast
- Allow time for a response
- Use body language to help you communicate
- Be prepared to repeat information
- Ensure the environment is not too noisy
- Is the person ready to speak? If a person has been asleep they may not want to talk to you
- Does the person have a hearing aid? Is it switched on? Is it working?
- Does the person have dentures? If so, are the dentures properly in place to allow them to talk or are they too big or uncomfortable so that they impair their ability to communicate?
- Do not use too many words or offer too many choices
- Consider the use of non-verbal communication, ie pictures or writing
- Talking Mats® have also been developed
- Is there a carer who can advise you on the best way to communicate with the person with dementia?
Responding to the needs of people who challenge us

At certain stages of their illness people with dementia may behave in ways that make caring much more difficult. Some may walk in places that put them at risk or require carers or care workers to search for them. They might shout out, become verbally hostile or physically aggressive or exhibit disinhibition and repetitive conversation or behaviour. At times this may be caused or exacerbated by unmet need.

Some possible reasons are that the person is feeling or experiencing:
- Psychosis
- Hallucinations
- Delusions that they are not able to express
- Hot/cold
- Thirsty/hungry
- Pain
- Constipation
- Anxiety/fear
- Anger
- A sense of being abandoned
- Depressed
- Bored
- Lonely
- That they are being belittled
- Confused about reality.

Remember that the person with dementia is not being deliberately difficult. Ask yourself if the behaviour is really a problem. Also remember that all behaviour is a means of communication. Consider what the person is trying to communicate and try to imagine how it may feel for them.

Mental Capacity Act (2005)

The Mental Capacity Act provides a comprehensive framework for decision-making for the care and treatment of people who lack capacity to make decisions for themselves. This has particular relevance for anyone who wishes to make provision for their future care and welfare. It has particular relevance for individuals who may lose their cognitive function as a result of their illness or other decline.

The Mental Capacity Act is underpinned by five key principles:
- An assumption of capacity
- All practical steps must be taken to support people to make their own decisions
- People have the right to make unwise or eccentric decisions
- Any decision made on behalf of a person who lacks capacity must be in their best interests
- Rights and freedoms must be restricted as little as possible.

Capacity is a legal definition but means that the person has enough mental ability to make each particular decision. Each assessment of capacity will vary according to the type of decision to be made. The more complex or difficult the decision the greater the level of capacity required. The person making the individual decision needs to be able to:
- Understand what the decision is and why it needs to be made, and the likely consequences of making or not making the decision
- Retain the information long enough to make the decision
- Use or weigh up the information as part of the process of making the decision
- Communicate their decision (by whatever means possible).

The Mental Capacity Act requires any decision or act made on behalf of a person who lacks capacity to be made in that person’s best interests; strict criteria are in place for best interest decision-making. The starting position is to assess whether the individual has capacity to make the specific decision.
Putting end of life care into practice

All attempts should be made to encourage or support the individual to take part in the decision and also to take account of previous wishes and views if known. It is important to consult others involved with the person for their views. When considering options it is important to ensure that the least restrictive option for the individual is chosen where possible.

When do we assess mental capacity?

Those who lack the mental capacity to make decisions are entitled to both excellent and appropriate care as well as to protection from inappropriate care. Whenever a significant intervention is made an assessment of capacity may be required.

Within the Mental Capacity Act, capacity is also considered to be situation and decision specific, i.e. someone may still have the capacity to decide whether to have an operation but has lost the capacity to make complex decisions about investments.

Therefore a person who does not have the capacity to make a decision about their discharge may still be able to make decisions about the food they would like to eat or whether they wish to have a wash at a certain time or whether they wish to take medication.

But clinicians and carers must also ensure that any anxieties about their authority to treat do not lead to poor or delayed care.

Spiritual care

People with dementia may be unable to express their need for spiritual care. The Mental Capacity Act sets out that when people lack capacity, decisions about the provision of care must be made in their best interests. Best interest decisions include consideration of past beliefs and values. Consequently, good dementia care must include a component of spiritual care as no-one should die without access to the support that they would have chosen when they were able to.

Specific enquiry and consideration of spiritual needs is therefore recommended.

Case studies

- Improving end of life care for individuals with dementia in the North West (NEoLCP, 2010)
- Spiritual care assessment tool in Mount Vernon Cancer Network (NEoLCP, 2010)
- Addressing the spiritual needs of individuals nearing the end of life in St Michael’s Hospice, Hereford (NEoLCP, 2008)
- Arrangements for the supply of palliative care medicines in South Western Ambulance Service NHS Trust and Dorset Cancer Network (NEoLCP, 2010)
- Understanding distress in people with severe communication difficulties: piloting and assessing DisDAT (Journal of Intellectual Disability Research, 2006)
- End of life care for people with dementia (NEoLCP, 2010) (Case study from report, End of life care for people with dementia in Haringey, Marie Curie Cancer Care, the National Council for Palliative Care, Dementia UK, NHS Haringey, Barnet, Enfield and Haringey NHS Mental Health Trust and Haringey Council, 2009).

Useful resources

- Disability Distress Assessment Tool (DisDAT).
Recognised tools are in place to help the assessment and review of people with dementia during the end of life phase. These include:

- The use of palliative care registers, which are part of the Quality and Outcomes Framework in primary care
- Prognostic indicators in primary care, as introduced by use of the Gold Standards Framework
- Preferred priorities for care (PPC), an example of an advance care plan
- The use of an integrated care pathway such as the Liverpool Care Pathway for the Dying Patient, particularly in the last days of life
- The Care Programme Approach
- Caseload management tools
- Holistic assessment tools used by dementia care services.

The Gold Standards Framework

As an example, the Gold Standards Framework provides a valuable mechanism in primary and community care for effective person-centred planning during the last 12 months of life.

Proactive care planning and timely management of symptoms can enhance quality of life for individuals and their family and carers and help to prevent crises and unscheduled hospital admissions.

The framework encourages primary care teams to improve their knowledge and understanding of palliative care and underlines the need for effective communication, co-ordination and continuity of care. It emphasises the importance of:

- Case identification
- Holistic common assessment
- Care planning

- Individual case discussions and case management by a multidisciplinary team
- Family and carer assessment and support.

This approach has now been extended to ensure that patients with any condition, in any care setting, and their carers who have been assessed as having needs arising from the end of life care of their relative, benefit from the principles and practice exemplified by use of the Gold Standards Framework.

Preferred priorities for care

Preferred priorities for care is an example of an advance care plan in which individuals can write down their preferences and priorities for care during the EoLC phase.

The document is held by the individuals so that they can take it with them if they receive care in different places.

The approach aims to help people to prepare for the future by encouraging and helping them to think and talk about an area of care that is often not discussed. Not all individuals will wish to take part in these discussions but all should have the opportunity to do so.
People who have a preferred priorities for care or other advance care planning document should have this identified in their primary, secondary and out-of-hours records. This should be reviewed on a regular basis with the individual while they are still able to do so, or with their representatives when they are not.

**The Liverpool Care Pathway for the Dying Patient**

The Liverpool Care Pathway is an integrated care pathway designed for the care of patients who are in the last days/hours of their life to facilitate effective planning and provision of care during this important time.

The emphasis is on ensuring all aspects of care are considered, including symptom control, communication and spiritual or religious needs. Regular review of the patient and carer by the multidisciplinary team is recorded using a single document. Review of documentation is also carried out frequently.

The pathway continues after death, aiming to ensure good communication and care for the family and carers. The LCP has been adapted for use in hospital, hospice, home or care home.

Steps are under way to ensure that the LCP or its equivalent is implemented in all care settings for patients dying from any advanced progressive condition, including those with dementia.

**Case studies**


A useful tool is also available to health and social care professionals to help with planning future health care.
Going forward, consortia of GP practices will commission NHS services on behalf of individuals, including elective hospital care and rehabilitative care, urgent and emergency care (including out-of-hours services), most community health services, and mental health and learning disability services. Consortia will also have a responsibility to promote equalities and to work in partnership with local authorities.

Therefore, a real opportunity exists for GP consortia to be at the forefront of commissioning high quality EoLC services for people with dementia across the whole system and the care pathway.

Commissioners should ensure that they consider both the clinical and economic viability of the service - and any related services - and take into account patients’ and carers’ views and those of other stakeholders when making commissioning decisions. The National End of Life Care Programme has worked in partnership with the National Institute for Health and Clinical Excellence (NICE) to produce a commissioning guide for EoLC for people with dementia. Information is also available from the National End of Life Care Intelligence Network.

**End of life care services for people with dementia need to:**

- Be responsive to the needs of individuals and carers
- Provide treatment and care based on best practice, as defined in NICE–SCIE clinical guideline CG42 on dementia
- Deliver the required capacity (taking account of the anticipated growth in the number of people with dementia)
- Be integrated with other elements of care for people, eg palliative and EoLC support services
- Define agreed criteria for referral, local protocols and the care pathway for people requiring EoLC services
- Be person-centred and provide equitable access, ensuring that individuals are treated with dignity and respect, are fully informed about their care early in the pathway and are able to make decisions about their care in partnership with healthcare professionals for as long as possible; after that point decisions are supported by an agreed advance care plan
- Demonstrate how they meet requirements under equality legislation (guidance on equality can be found on the Joseph Rowntree Foundation website and via the Equality and Human Rights Commission)
- Demonstrate value for money.
Commissioning end of life care for people with dementia

Local quality assurance

Any mechanisms for quality assurance at a local level are likely to refer to the following:

- Service and performance outcomes
- Clinical quality criteria: appropriateness of referral, consenting procedures, clinical protocols and timeliness of support
- Audit arrangements: frequency of reporting, reporting route and format and dissemination mechanisms. This should include auditing the proportion of eligible people requiring EoLC, and monitoring of patient and carer experience and complications. See End of life care strategy: quality markers and measures for end of life care (DH, 2009)

- Meeting the requirements of the Mental Capacity Act (2005)
- Health, safety and security: infection control, waste management, confidentiality procedures, legislative requirements
- Equipment: testing and calibration
- Staff competences: individual and team baseline requirements, monitoring and performance. The NICE–SCIE clinical guideline CG42 on dementia recommends that staff involved in the care of older people in the healthcare, social care and voluntary sectors have access to dementia-care training (skill development) that is consistent with their roles and responsibilities. The implementation advice for NICE clinical guideline CG42 on dementia suggests that a sustained programme of training, education and awareness-raising for all staff, including GPs, would help to improve the end of life experience of carers and patients
- Information requirements, including both patient-specific information (NHS number, referring GP, provision of high-quality information to patients/carers) and service-specific information (quality markers, workload trends, number of complaints)
- The process for reviewing the service with stakeholders, including decisions on changes necessary to improve or to decommission the service
- Achieving targets associated with equality legislation.

Further information can be obtained from the following sources:

- The National Patient Safety Agency (NPSA) oversees the implementation of a system to report and learn from adverse events and near-misses occurring in the NHS (although the agency is to be abolished with safety functions transferred to the planned National Commissioning Board)

- The Care Quality Commission oversees standards for care homes for adults aged 18-65 and, separately, for older people

- NHS Alliance online resources enable PCTs to network and exchange best practice

- The DH commissioning framework provides guidance on the commissioning process in the context of the NHS reform agenda (Health reform in England: update and commissioning framework, NHS/DH, 2006)

- Implementation advice for NICE–SCIE clinical guideline CG42 on dementia

- NHS Institute for Innovation and Improvement support for commissioners, includes commissioning for health improvement products to accelerate the achievement of high quality commissioning; The Productive Leader programme to enable leadership teams to reduce waste and
variation in personal work processes; and
Better Care, Better Value indicators
to help inform planning, to inform views
on the scale of potential efficiency savings
in different aspects of care and to generate
ideas on how to achieve these savings

10 Steps to your SES: a guide to developing
a single equality scheme (DH, 2007) that
have a duty, as public authorities, to comply
with the race, disability and gender public
sector equality duties; and in anticipation of
new duties in relation to age, religion and
belief and sexual orientation

The Quality and Outcomes Framework (QOF)
sets out a range of national standards based
on the best available research evidence

Skills for Health works with employers and
other stakeholders to ensure that those
working in the sector are equipped with the
right skills to support the development and
delivery of healthcare services.

Case studies

- Strategic plan 2010-2015: position
  statement and action plan for learning
disability (Care Quality Commission, 2009)
- Improving end of life care for individuals
  with dementia in the North West
  (NEoLCP, 2010)
- End of life care for people with dementia
  (NEoLCP, 2010) (Case study from report,
  End of life care for people with dementia
  in Haringey, Marie Curie Cancer Care,
  the National Council for Palliative Care,
  Dementia UK, NHS Haringey, Barnet, Enfield
  and Haringey NHS Mental Health Trust and
  Haringey Council, 2009).
The following local stakeholders should be involved in determining what is needed to support the EoLC needs of people living with dementia:

- People with dementia and their carers
- Health and social care commissioners across a breadth of areas of expertise (e.g., dementia, end of life care, long-term conditions, cancer and coronary heart disease)
- 24-hour primary and secondary healthcare providers (GPs, mental health and dementia services, palliative care and community nurses)
- Local authorities with regard to social care, extra care housing projects and disabled facilities grants

- Telecare call centres
- The voluntary sector, e.g., Alzheimer’s Society and Dementia UK
- Care homes such as nursing and residential homes, NHS continuing care homes, hospices and housing agencies.

There is no single service specification for EoLC for people with dementia; rather a series of services commissioned across a number of different settings (e.g., hospital, community, at home, care home or hospice, criminal justice system, secure hospitals and hostels for the homeless), all working within an integrated commissioning framework and supporting the delivery of a high quality pathway of care.
The overarching principles for determining high quality EoLC for people with dementia are in line with the national dementia strategy and the end of life care pathway. We list those principles and how they can be approached below.

1) **People with dementia and their carers retain control and choice over their lives.**
   Vulnerable people with dementia are enabled to access timely, appropriate and excellent care. Achieving this requires commissioning aimed at personalisation of services - balancing investment between different services to respond to the specific dementia and/or EoLC needs of the individual. People should have the chance to describe their preferred priorities for care.

2) **Services are connected and provide a joined-up pathway for people with dementia and their carers.**
   Clear decision-making points and protocols to support EoLC should be built into core dementia and palliative care services specifications.

3) **Quality and dignity is built into every service.**
   This principle requires providers to recognise the spiritual, psycho-social, mental and physical needs of each individual.

4) **That the specific needs of certain groups of people with dementia are met (eg younger people, people with a learning disability).**
   This can be achieved by accessing information and audit data on the EoLC experience of both the person with dementia and their carer.

5) **People’s legal rights are maintained.**
   This principle requires monitoring of the use of key pieces of legislation, such as the Equality Act 2010, the Mental Health Act (2007), the Mental Capacity Act (2005) and the Human Rights Act (1998).

6) **Services maintain and enhance an individual’s abilities.**
   High-performing services will agree the required outcomes both in terms of patient and carer experience.

7) **Services are provided to all individuals affected by dementia in the local population.**
   This involves ease of access and range of service locations provided within a network of care available 24 hours a day every day.

**Case study**

**Monitoring services**

- *End of life care for people with dementia* (NEoLCP, 2010) (Case study from report, *End of life care for people with dementia in Haringey*, Marie Curie Cancer Care, the National Council for Palliative Care, Dementia UK, NHS Haringey, Barnet, Enfield and Haringey NHS Mental Health Trust and Haringey Council, 2009).
People nearing the end of life require care in a variety of different settings, including those explored in this chapter.

There is much that can be done to improve both the experience of care for people at the end of life and the memories of their carers and families. Central to this is the importance of providing care settings that emphasise dignity and respect for the individual. The Care Quality Commission oversees standards in these sectors.

The King’s Fund’s Enhancing the Healing Environment programme also highlights a number of key environments and environmental issues that affect the quality of end of life care. These are particularly important during the last days of life and following death.

The areas highlighted by the King’s Fund include:
- A room where the person and their family can go to talk privately
- Informal ‘gathering’ spaces where family and friends can meet to confer and talk with staff
- Guest rooms where close family and friends can stay overnight, with facilities for catering and communication.

Following the death, particular attention needs to be given to:
- The transfer of the body to the mortuary
- The location of the mortuary and how it is approached by family, friends and carers
- Rooms where the body is viewed by family, friends and carers
- Rooms where family, friends and carers can sit quietly and receive the deceased person’s property and collect the death certificate.

Acute hospitals

The challenge

At present over half (58%) of all deaths occur in acute hospitals. An even larger proportion of patients who die in any one year will have had at least one admission to an acute hospital in the year before death.

Despite most people’s expressed desire to die at home, hospitals will continue to be the most common place of death in this country for the immediate future. It is therefore imperative that actions should be taken to continue to improve the quality of EoLC that they provide.

Hospitals can be confusing places. People with dementia find hospital environments particularly difficult.

Challenges identified in acute hospitals are likely to relate to:
- A failure to recognise that one of the core roles of an acute hospital is to provide care for the dying
- A failure to recognise when continuation of treatment is of little or no effect, is becoming burdensome or is otherwise inappropriate
• A failure to take responsibility for enabling people to return home to die if that is their wish
• A lack of leadership on EoLC from senior managers and senior clinicians
• A lack of timely service provision or access to appropriate funding streams
• Staff at all levels not having the knowledge, skills and attitudes required to deliver high quality EoLC.

The factors crucial to achieving high quality EoLC in acute hospitals include:
• Establishing mental health liaison
• Dedicated dementia champions
• Training for staff in dementia awareness
• Training for staff in EoLC
• Dedicated EoLC champions
• Developing inter-disciplinary teams and partnership working
• Communicating and working closely with colleagues in social care, community and primary care.

Case studies on rapid discharge

• Rapid discharge pathway from hospital to home of the dying patient in Salford Royal Foundation Trust (NEoLCP, 2009)
• Integrated care pathway for the rapid discharge home of a dying patient in NHS Great Yarmouth and Waveney (NEoLCP, 2009)
• Palliative care rapid response service across care settings in Luton (NEoLCP, 2010)
• Meet and greet - supported discharge scheme for palliative patients (NEoLCP, 2010).

Useful resources

• The Liverpool Rapid Discharge Pathway for the Dying Patient has been developed by Marie Curie Cancer Care Palliative Care Institute, Liverpool.

This supports co-ordinated care to enable patients, where possible, to be discharged from the acute hospital to home in the last hours/days of life, if this is what the patient wants. This model of care provision can be adapted by other organisations as part of a continuous quality improvement programme for care of the dying.

Improving end of life care in acute hospitals

To improve EoLC, commissioners and providers will wish to ensure that all acute hospitals have:
• An appropriately constituted expert palliative care team (as set out in the 2004 NICE guidance on cancer services, Improving supportive and palliative care for adults with cancer). This team should, however, provide care based on patients’ needs rather than being limited to any specific diagnoses
• Mechanisms to ensure that people who may be approaching the end of life, or who are at substantial risk of dying on admission to hospital, are identified
• Mechanisms to ensure that relevant healthcare professionals have the necessary competences to initiate discussions regarding EoLC, elicit priorities and preferences and meet the individual’s physical, psychological, social and spiritual EoLC needs
• Mechanisms to ensure that people who are approaching the end of life have their needs assessed and are offered a care plan
• Mechanisms to ‘fast track’ assessments for NHS Continuing Health Care, so that decisions can be made quickly and services can be put in place to enable people to leave hospital and die elsewhere, including their own home if that is their wish
• A framework to ensure the delivery of appropriate care for people who are in the dying phase of their illness and after death. The LCP is an example of such a framework, whose use is being assessed in dementia
• Mechanisms for monitoring the demographics (including race, gender, age, religion/belief, disability and sexual orientation) of patients dying in hospital and the quality of care delivered.
Toilets and bathrooms that are readily recognisable, with signs that not only use words but pictorial images

- Signs that are highly visible and not too high – eye height is best
- Distinguishing toilet and bathroom doors by painting them a bold colour - people with cognitive impairment find pale, flat colours and surfaces difficult to decipher

- Toilet seats and grab rails in bright colours - all white bathroom fixtures are problematic for people with dementia

- Non-shiny floors

- Make the person’s bed area easily identifiable to them, using the name they prefer to be called by and consider the use of personal belongings and photos

- Meal times can be stressful for a person with dementia. Find out their likes and dislikes and don’t rush. Sitting at a proper table may provide a visual prompt. Ensure the cutlery used is recognisable to the person and use finger food if required

All people feel comfortable in their own clothes and this is important for people with dementia

- Find out about the person’s likes and dislikes. Involve families and carers and ensure care plans use their expertise in caring for the person with dementia

- Like other people, a person with dementia can get bored so ensure they are kept stimulated and engaged.

The following guidance is available:

- Oral feeding difficulties and dilemmas (RCP/BSG, Jan 2010)
- Swallowing problems and dementia in acute hospital settings (Smith et al, Clinical Medicine, Dec 2009)
- Gastrostomies in dementia: bad practice or bad evidence? (Age and ageing, Feb 2010)
- Compromised Swallowing: A Practical Guide to Nutrition, Hydration and Medication in Advanced Dementia (Peterborough Palliative Care in Dementia Group, 2010)

Acute awareness: improving hospital care for people with dementia (The NHS Confederation, 2010) looks at the key issues for NHS trusts in improving care for patients with dementia, the majority of whom will have been admitted for another condition. It showcases the innovative work that NHS trusts and cross-agency partnerships are undertaking to enhance patient care and describes how significant improvements can be achieved in both the quality and efficiency of patient care.

Useful resources

- The route to success in end of life care - achieving quality in acute hospitals (NEoLCP, 2010) sets out the key pathway steps and highlights practical resources for staff to use in supporting effective delivery of care

All people feel comfortable in their own clothes and this is important for people with dementia
People’s own homes

The challenge

Most people will spend the large majority of their last year of life in the community. More could do so through a reduction in avoidable admissions to hospital and good support in the community.

People may require a diverse range of health and social care services to enable them to continue living at home and to die there if that is their wish. These include primary care, district nursing, domiciliary care, social care, community pharmacy, occupational therapy, physiotherapy, dietetics and out-of-hours services.

Support for carers is essential if they are to continue providing direct support to a patient. Telecare products may help both carer and individual.

Admiral Nurses provide an important role in supporting carers and loved ones as well as providing practical support.

The key challenges in relation to the delivery of high quality EoLC in the community include:
- Poor identification, assessment and co-ordination of EoLC within some general practices
- Lack of availability of nursing services and personal care services on a 24-hour basis in some areas
- Slow provision of equipment and modifications to a person’s home
- Difficulty in accessing medicines outside routine working hours
- Lack of training and continuing professional development for some key staff groups
- Poor co-ordination between service providers in primary and secondary care and especially between daytime and out-of-hours services
- Inadequate information to carers about what to expect, and what to do.

There is increasing evidence that the lack of co-ordinated community-based care leads to avoidable admissions and to prolonged hospital stays. However, there is also increasing evidence that these deficiencies in care can be rectified through the introduction of innovative service models and approaches to practice.

Useful resources

- *Transforming community services: ambition, action, achievement transforming end of life care* (DH, 2009)
- *Important choices - where to die when the time comes* (NHS Institute for Improvement and Innovation, 2010).

An example key tool

The Gold Standards Framework is designed to care for people with advanced, progressive, incurable illness, mainly in the primary care setting. It enables GPs to identify patients for inclusion on the palliative care register, which attracts Quality and Outcomes Framework (QOF) points. The approach helps primary care teams to work together in optimising continuity of care, teamwork, advance care planning, symptom control and patient, carer and staff support.

The QOF has an indicator set for palliative care. Originally linked with cancer care, this indicator is now providing the impetus to improve EoLC for all those with advanced disease. Each GP practice establishes a supportive care register of all those who require EoLC. The ongoing care of those on the register is regularly reviewed at multidisciplinary planning meetings. The creation of the register enables the wider practice team to provide more appropriate and patient-focused care, such as reception staff being aware of the need to prioritise communication from relatives to clinical staff if the person is on the register. Currently eight sites across the country are testing the use of
the locality-wide EoLC registers with the aim of supporting improved managed care across organisational and professional boundaries.

Case studies - additional home care services

Several different models have been developed to provide individuals with the additional support they need to continue living at home if that is their wish. These include ‘hospice at home’ services and rapid response services, which enable patients to be assessed out of hours in their own homes and for services to be provided which otherwise might require a patient to be taken to an accident and emergency department.

For more about the different models see:

- **End of life care strategy** (DH, 2008):
  - Fair Havens Hospice at Home working collaboratively with SPDNS Nurse Care (p86)
  - Marie Curie Cancer Care Lincolnshire Rapid Response Team (p87)
  - Hampshire Initiative – out of hours service (p89)
- **Hope for home care of dementia in Bexley and Greenwich** (NEoLCP, 2007).

Guidance on the supply of and access to medicines, particularly controlled drugs, to those people who choose to die at home, is available in *Delivering the out-of-hours review: securing proper access to medicines in the out-of-hours period - a practical guide for PCTs and organised providers* (DH, 2004). Community pharmacists can provide additional support to people in their homes by delivering medicines, answering questions and providing advice.

Dementia services

Dementia services provide a specialised holistic assessment of dementia that will offer disease management where appropriate. Such services also offer advance care planning as well as EoLC of advanced dementia - including pain and symptom management.

Dementia services should be able to support and accompany patients throughout their illness from early diagnosis to advanced care both at home and in care homes.

Dementia services should also have access to specialist dementia assessment units, which provide a specialist setting to respond to some of the most difficult behaviours that may occur throughout the course of the condition.

NHS continuing care units for dementia may often be the setting where a primarily palliative approach is taken.

A recent Department of Health commissioned report stated that it must be clear why antipsychotics are being used *Report on the prescribing of anti-psychotic drugs to people with dementia*, DH, 2009). The guidance states that before prescribing it is essential that an assessment be done to look for all possible causes of distress and any treatment (often non-pharmacological) of the most likely cause should be given before using antipsychotics.

It is also important, particularly for those with dementia who may lack capacity to consent to the use of antipsychotics, that the
relevant next of kin/lasting power of attorney/independent mental capacity advocate (IMCA) are informed of the plan to treat with antipsychotics. This discussion, including an explanation of the side effects, should take place prior to commencing treatment.

Useful resources


Residential and nursing care homes and sheltered and extra care housing

The challenge

Homes where nursing is not provided, often known as residential care homes, are now often referred to simply as care homes.

A home registered for nursing will provide personal care (help with washing, dressing and giving medication), and will also have a qualified nurse on duty 24 hours a day to carry out nursing tasks. These homes are for people who are physically or mentally frail or people who need regular attention from a nurse. A significant proportion of the residents of residential and nursing care homes experience dementia. Recent research indicates that over 200,000 people with dementia live in care homes, which represents around one-third of all people with dementia.

Many people enter a care home because they are no longer able to live independently in their own home. For these people the care home becomes their normal place of residence and many would choose to stay there until they die. Others enter a care home for respite care, or for nursing care and rehabilitation, with a view to returning to independent living.

At present around 80,000 people die in care homes each year, representing around 16 per cent of all deaths. However, there is evidence that significant numbers of residents are being transferred from care homes to acute hospitals in the last days, or weeks, of life when this is not necessarily their wish, or in their best interests.

Several factors may contribute to suboptimal care being delivered in care homes, and sheltered and extra care housing, which include:

- EoLC not being discussed with residents or their representatives, with a consequent lack of advance care planning
- Inadequate recognition of the need for palliative care to begin and a failure to undertake, or arrange for, a holistic common assessment of needs and preferences
- Anecdotal concerns that some care homes fear that if too many residents die, this may reflect badly on the care being delivered
- Concerns about the impact on other residents of people dying within the care home, or in sheltered and extra care housing
Inadequate access to community-based NHS services, eg district nursing care, primary medical care, out-of-hours medical care, a community palliative care team
Inadequate review and management of medicines
Inadequate training of staff at all levels within the care home and sheltered and extra care housing sector. This is considered to be the single most important factor.

Costs of training also need to be recognised, both in terms of trainers/facilitators and the time of care home staff who need to be trained.

Improving end of life care in care homes

In recent years, significant new initiatives have been facilitated by the National End of Life Care Programme to support ongoing improvement in the quality of EoLC in the care home sector. In 2010 the programme published a straightforward guide for improving EoLC in care homes. The route to success in EoLC – achieving quality in care homes (NEoLCP, 2010) follows the generic six-step EoLC pathway (see useful resources below).

The approaches being adopted by the care homes reflect the different steps in the EoLC pathway, but also include specific support for carers and for other residents of the care home.

The National End of Life Care Programme has demonstrated that tools and approaches that were developed for use in other sectors can be modified for successful use in care homes. Approaches have also been developed from within the sector, such as those from the Anchor Trust and Methodist Homes Association Care Group.

In addition, a number of approaches have been developed in collaboration with expert palliative care providers.

The Hospice of St Francis, Berkhamsted, has developed a general service model to improve the quality of care provided to residents of care/nursing homes who are approaching the end of life.

There are now many examples of innovative practice on which to build. These include:

- Introduction of end of life care tools to improve care at Risedale Estates (NEolCP, 2010)
- Palliative initiative in neurological care (PINC) in Sue Ryder Care neurological care centres (NEoLCP, 2007)
- Peterborough Palliative Care in Dementia Group
- Housing 21
- Greater Manchester and Cheshire Cancer Network
- The Palliative Care in Dementia Project in Croydon
- See also End of life care learning resource pack: information and resources for housing, care and support staff in extra care housing (NEoLCP/Housing 21, 2009).

Useful resources

- The route to success in EoLC – achieving quality in care homes (NEoLCP, 2010)
- The route to success in end of life care series – additional resources
- St Christopher's Hospice, Sydenham.

Hospices

The challenge

The hospice movement started with the foundation of St Christopher's Hospice by the late Dame Cicely Saunders in 1967. From the outset, the aim of hospices has been to provide high quality physical, psychological, social and spiritual care for people at the end of their life and to provide care both for the person and their families. However, there are inequalities in access to hospice care for certain groups of society.
Hospices do far more than provide pain relief for those at the end stages of life. They provide multidisciplinary, holistic care both within the hospice itself and often within the local community. Many hospices provide:

- Community palliative care teams
- Hospice at home services
- Day care
- Bereavement care.

In addition to providing direct care for people with complex problems, hospices and palliative care services also provide advice, eg to district nurses and GPs. Many hospices also have an important role in providing education and training - both for staff who wish to specialise in palliative care and those working in other areas that have significant roles in the provision of EoLC.

Some experts in palliative care (physicians and nurses) work directly alongside other clinical staff. For example, they may hold joint clinics or ward rounds with cardiologists, respiratory physicians or neurologists. Some hospices provide leadership in research, development and evaluation related to EoLC.

There are some excellent examples of hospices delivering outreach services for people with conditions other than cancer. For example, St Christopher’s Hospice has developed a service for people with dementia, reflecting the fact that people are dying at an increasingly older age, often with multiple chronic illnesses complicated by dementia. This presents a considerable challenge for the UK’s care homes where currently one in five people die.

Community hospitals

The challenge

Community hospitals and other community-based centres provide a valuable but under-recognised resource in relation to EoLC.

There are over 330 community hospitals in England, which provide a range of facilities and resources, including inpatient care, outpatient care, day care and outreach services. Between 2001 and 2004, the Health Foundation funded a study to identify how community hospitals are involved in providing palliative and EoLC to older people with cancer and non-malignant diseases.

One part of this project involved collecting the views of bereaved relatives from six community hospitals in the south of England. A total of 51 bereaved carers were interviewed, all of whom were positive about the care they and the dying patient had received. The bereaved carers particularly appreciated the location of the hospital (close to home), the availability of parking, the pleasant environment and the familiarity with staff. The care and kindness shown by community hospital staff was commented on specifically.

Between January and February 2007, the NHS Institute for Innovation and Improvement undertook a baseline survey that provided an up-to-date database of all community hospitals (The productive community hospital). The database of 266 returns provided information on the profile, staffing, size, location and services provided, including palliative care; 181 community hospitals stated that they provide palliative care.

Community hospitals are actively involved in EoLC. Around 50 per cent of them have already adopted the Liverpool Care Pathway. Their role now needs to be fully recognised and integrated into local EoLC service planning and delivery.
This section is principally intended for professionals and provides some signposting information that they may wish to share with carers and patients.

A carer is someone who looks after and supports a friend, relative or neighbour who could not manage without their help because of old age, physical or mental illness or disability. It does not mean a professional care worker or personal assistant who gets paid for their work. Three in five people in the UK will become carers at some point in their lives.

Carers come from all backgrounds and can be any age. Caring can be rewarding, but it can be difficult too. People can get practical, financial and emotional support with their caring role.

Good EoLC involves assessing the needs of close relatives and/or other carers. Help the Hospices has produced a guide, *Identifying carer’s needs in the palliative setting* (2009).

The local council is the first place to go to for information about caring for someone.

There are also voluntary organisations to help carers, including national charities, and local groups, eg the Alzheimer’s Society and Dementia UK.

**Useful resources**


**Practical support**

People who provide care for someone aged 18 or over are eligible for an assessment by their local council to see if they are entitled to any services that could make caring easier.

Examples of assistance include help with housework or changes to the home.

**The practical support available that you might wish to tell carers about includes:**

- Carers’ education groups and courses
- Reminiscence groups
- Memory skills training
- Specialist dementia occupational health advice
- Advance care planning and open, honest communication
- Respite care
- Home care services
- Clear pathways to express concern and worry when the family feel that things are not going well
- Continence care and laundry services
- Equipment and adaptations
- Home adaptations and Disabled Facilities Grants
- Telecare
- Alarms
- Mobile meals on wheels.
Financial support

There is a range of financial benefits available to carers and also to the person who is cared for. This includes Carer’s Allowance, which is a taxable benefit for people who cannot work or have a low income because they are looking after someone who is ill or disabled. People may be eligible for the Carer’s Allowance if they spend at least 35 hours a week in a caring role.

Emotional support

Carers can become isolated and it is important to have contact with the outside world and time for themselves. There are groups, events, internet discussion forums and weekly telephone chats to join.

Carers UK provides information on your rights and how to get help.

Useful resources

- Supporting carers: an action guide for general practitioners and their teams (Princess Royal Trust for Carers/Royal College of General Practitioners, 2008)
- Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own (DH, 2008).
A workforce education and training strategy is central to achieving high standards of EoLC for people with dementia. The Department of Health commissioned Skills for Care and Skills for Health, working in collaboration with the National End of Life Care Programme, to lead a joint project to identify a set of common core competences and principles for EoLC.

The General Medical Council also recently published guidance for doctors, *Treatment and care towards the end of life: good practice in decision making* (2010), which includes guidance on advance care planning.

**The core common requirements for workforce development are:**
- Training in communication skills – basic, intermediate and advanced level as appropriate
- Assessment of the person’s needs and preferences
- Advance care planning
- Symptom management.

**The national end of life care strategy document classified the clinical workforce into three tiers according to their working exposure to end of life issues:**
- **Group A** – Staff working in palliative care services who essentially spend the whole of their working lives dealing with EoLC
- **Group B** – Staff in other specialties who frequently deal with EoLC as part of their role
- **Group C** – Staff working as specialists or generalists within other services who infrequently deal with EoLC.

In the dementia setting many clinical staff would fall into Group B, though some, such as the clinical leads and key workers, would belong to Group A.

Training in EoLC issues should form part of the curriculum for core medical training and for specialist training in dementia and specialist dementia nursing training.

Each strategic health authority, as part of the *NHS next stage review (High quality care for all, 2008)* end of life care workstream, is focusing on EoLC workforce development. It is important that staff caring for people with dementia are included in this. Dementia services should have a multidisciplinary group overseeing education and training about EoLC issues.

Regional training days should be developed for dementia, palliative care and primary care multidisciplinary teams.

General communication skills training is needed for all staff involved in EoLC. Advanced communication skills training could benefit most senior clinical and middle-grade clinical staff.

Training in palliative care and care towards the end of life as it applies to dementia should form part of appraisal discussions for all dementia clinical staff.
Learning resources should be developed, building on e-Learning for Healthcare’s EoLC modules (see section on e-ELCA below), with examples of good practice from different dementia services, electronic resources of patient voices and stories from families. Booklets on aspects of EoLC should be accessible to patients at clinics and on wards.

There are also training requirements for palliative care clinicians relating to the understanding of dementia and its management – multi-professional study days will provide mutual benefit for dementia and for palliative care clinicians.

The Alzheimer’s Society has developed a training programme for healthcare staff to support the EoLC planning process for people with dementia and their families. The two-day course, accredited by University of Surrey, is entitled *End of life care for people with dementia*, NCPC’s Care to Learn Training Pack has a dedicated dementia module.

The National End of Life Care Programme’s route to success series includes practical training resources available on the programme website.

A suite of e-learning modules, e-ELCA (End of Life Care for All), was launched in January 2010 and around 130 learning sessions are now available to many health and social care staff. The modules include communication skills and they are intended to support a variety of learning experiences, including experiential and face-to-face learning.

During the course of a working life many people who are not EoLC experts will find themselves supporting an individual who is in the final stages of their life.

In 2009 the DH, the NEoLCP, Skills for Care and Skills for Health published *Common core competences and principles covering:*

- Communication skills
- Assessment
- Advance care planning
- Symptom management, comfort and wellbeing.

The competences have subsequently been mapped to a *Knowledge set for end of life care* (Skills for Care, 2010) and *A framework of national occupational standards to support common core competences and principles for health and social care workers working with adults at the end of life* (NEoLCP/DH/Skills for Care/Skills for Health, 2010).
Possible evaluation routes include:

- Hospitals should participate in national audits, e.g., Liverpool Care Pathway national care of the dying audit.
- Future audits of EoLC in dementia should incorporate elements included in the DH’s 2009 consultation on quality markers for end of life care. The quality markers are based on the structures and processes of care most likely to yield good outcomes for people approaching the end of life, their families and carers. The markers are associated with suggested measures for assessment of compliance, which commissioners and providers should use to audit and evaluate services. Such a measure would be the availability of locality-wide registers.
- Use of the national public awareness assessment tool to assess trends and attitudes within specific communities. A tool to assess change in awareness/attitudes is being developed.
- Local EoLC plans to include actions on awareness/attitudes. (The NCPC has established the Dying Matters Coalition to lead this work supported by the Department of Health)
- Use of Voices questionnaires to bereaved relatives and carers with consideration of modification of Voices to address dementia-specific issues.
- The NICE dementia quality standard.
- Assessing progress against standard 7 of the National service framework for older people (DH, 2001). The scope of this framework extends to ‘conditions such as stroke and dementia [which] are not limited to older people’ and ‘the standards and service models will apply for all who need these services, regardless of their chronological age.’ While there is currently no national dataset for dementia, various organisations (including the Alzheimer’s Research Trust and the Alzheimer’s Society) engage in pertinent research on an ongoing basis.
- Establishment of collaborative cross-boundary audit and research and development in EoLC between dementia services, primary care and expert palliative care with collection of patient and carer-reported outcome measures including quality of life, control of symptoms and quality of death.

Research and evaluation case study

- End of life analyses: 3 scoping reports from Birmingham and Black Country SHA (NEoLCP, 2006).
A few examples of new ways of working are listed below, which go some way to show how the end of life needs of people with dementia are currently being met:

- Marie Curie’s Lincolnshire Palliative Care Coordination Service
- **End of life care for people with dementia** (NEoLCP, 2010) (Case study from report, *End of life care for people with dementia in Haringey*, Marie Curie Cancer Care, the National Council for Palliative Care, Dementia UK, NHS Haringey, Barnet, Enfield and Haringey NHS Mental Health Trust and Haringey Council, 2009)
- Sanctuary Care specialist dementia service
- **Our health, our care, our say** (DH White Paper)
- Care Home Learning Network (South West) (NEoLCP, 2007)
- St Christopher’s Hospice, Sydenham
- **Supportive care pathway for use with older people in Birmingham and Solihull Mental Health Trust** (NEoLCP, 2010)
- **Community matron in care homes - providing access to appropriate care in Nottinghamshire Community Health PCT** (NEoLCP, 2008)
- **Hope for Home care of dementia in Bexley and Greenwich** (NEoLCP, 2007)
- Housing 21’s Dementia Voice Nurse pilot project
- The Palliative Care in Dementia Project in Croydon
- Admiral Nurses.
End of life care historically has been neglected and undervalued. This resulted in patchy health and social care provision across the country and reluctance and awkwardness about discussing people’s wishes.

However, in recent years a substantial amount of work has been done to raise the profile of EoLC and to improve practice. This work has been both ‘top down’ from government and ‘bottom up’ from providers and users of services.

The White Paper, Our health, our care, our say, emphasised the importance of EoLC. This is followed by the end of life care strategy to bring about improved access to high-quality care for all adults approaching the end of life, equally available to all who need it and wherever that care is delivered.

End of life care was one of the eight clinical pathways developed by each of the strategic health authorities (SHA) in England as part of the NHS next stage review. The SHA end of life care clinical leads were able to draw on the emerging work from the end of life care strategy to further refine this and contribute substantially to the final strategy, which was published in July 2008.

The importance of EoLC for those with dementia is acknowledged in Objective 12 of Living well with dementia: a national dementia strategy (DH, 2009).

It says: “People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.”

The context for this resource also includes the NICE/SCIE clinical guidance CG42, Dementia: supporting people with dementia and their carers in health and social care (2006).

Guidance on commissioning of services can be found in the Joint commissioning framework for dementia (DH, 2009) and Information for commissioning end of life care (NEoLCP, 2008).

Palliative and end of life care is currently provided most often by primary care and dementia care services, often by acute hospital services and occasionally by expert palliative care services.

Dementia care, in particular, requires services spanning health and social care and effective co-ordination between these services. Also relevant therefore are policy developments promoting an integrated health and social care response, such as Putting people first: a shared vision and commitment to the transformation of adult social care (DH, 2007), which seeks transformational change and the delivery of personalisation leading to better care and support for all individuals.

The recent health White Paper, Equity and Excellence: Liberating the NHS, also emphasised the importance of integrated care and proposed measures for services to work in a more integrated manner.

The contribution of carers has been highlighted in the national carers strategy.

Finally, voluntary sector organisations, including the National Council for Palliative Care, Marie Curie Cancer Care, the Alzheimer’s Society and Dementia UK, have helped to remove the stigma from EoLC issues and to promote innovative practice.
Dementia

Dementia is a condition, usually but not always affecting the elderly, which causes an irreversible and progressive loss of memory accompanied by other cognitive and physical changes. These can include, for example, increasing difficulty in speaking and swallowing, a progressive loss of mobility, a loss of the ability to understand concepts and plan and execute responses to changes in the environment, etc. Dementia is a terminal illness, but also increases the likelihood of certain complications such as chest infections.

There are many types of dementia. Alzheimer’s disease is the most common, with 50 per cent of people with dementia affected by it. All forms of dementia involve a deterioration of cognitive and physical functions that is usually progressive and eventually severe.

End of life care

This is defined in the national end of life care strategy as being about the total care of a person with an advanced incurable disease. It does not just mean dying but means enabling people to live as well as they can until they die. It ends in death and care of the bereaved but knowing when the end of life phase has started can vary according to the perspectives of patient, carer and professional. It can be difficult to identify when a person is entering the timeframe for EoLC.

End of life care may last for weeks, months or years. Recognising when a person is entering the phase of EoLC is very important, since it enables the supportive and palliative care needs of the patient and family to be identified and addressed as early as possible.

Supportive care

This is defined as care that helps the patient and their family to cope with their condition and its treatment, from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement.

It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is accorded equal priority with diagnosis and ‘curative’ treatment. Although it is about cancer, NICE’s guidance document Improving supportive and palliative care for adults with cancer (NICE, 2004) could be useful in improving supportive and palliative care for people with dementia.
Palliative care

This includes many elements of supportive care and has been defined by the World Health Organization as the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support are paramount.

The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Care of the dying

This is the care of the individual and family in the last hours and days of life. It incorporates four key domains of care - physical, psychological, social and spiritual - and supports the family at that time and into bereavement.

Acknowledgements

The National End of Life Care Programme has worked in partnership with the DH Dementia Implementation Team to produce this resource guide. We would like to thank the members of the Dementia End of Life Pathway Advisory Group for their invaluable advice and guidance. We would also like to thank everyone else who gave their time and energy to the development of this document.
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