NHS

National End of Life Care Programme

Improving end of life care

The route to success

in end of life care - achieving quality in domiciliary care

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Introduction

According to the the Department of Health's 2008 *End of life care strategy*, high quality end of life care "should be available wherever the person may be: at home, in a care home, in hospital, a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money."

This strategy poses particular challenges in relation to those domiciliary care workers, often described as carers, who support people to remain in their own home. Domiciliary workers are often overlooked when policies are developed and are often not engaged in service development.

Core principles for delivery of end of life care

- Care is client-centred and integrated
- Treat individuals with dignity and respect
- Identify and respect people's preferences
- Provide care after death.

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The importance of getting this care right has never been greater at a time when care standards and flexibility of care organisations is so much to the fore. The health secretary Andrew Lansley and care services minister Paul Burstow have set out their vision for adult social care, promising personal budgets for eligible people by 2013. This is underpinned by a new legal framework, more outsourcing of local authority services and emphasis on reducing council back-office costs, portability of care assessments, plans for new workforce development, personal assistants' strategies and a greater role for local communities.

United Kingdom Homecare Association (UKHCA) chair, Mike Padgham, said "The challenge now for providers is to mould their services to the government's vision, but with true entrepreneurial flair I am confident they will seize the opportunity."

There is already evidence of adult social care services' increasing responsiveness and flexibility. A recent report published by the Care Quality Commission found that the proportion of homecare agencies rated "good" or "excellent" rose from 72% in May 2008 to 80% in 2010, with the most significant change being the number of agencies moving from "adequate" to "good" ratings. However it is end of life care delivery that remains a challenge for many organisations.

Background and Care Quality Commission context

The Department of Health issued national minimum standards for domiciliary care in 2000. These have now been replaced by essential standards *(Guidance about compliance: essential standards of quality and safety)* published in March 2010 by the Care Quality Commission (CQC). See appendix 1.

The purpose of these essential standards is to guarantee the quality of personal care and support which people receive while living in their own home. All are relevant and, although not always explicitly linked to end of life care in the standards, they are all particularly relevant to provision of good end of life care.

It is useful to consider how CQC frame end of life care and below are definitions of some of the terms used in the CQC document:

End of life The last phase of a person's life, when a judgement has been made by an appropriately qualified person that the person has an advanced,progressive, incurable illness, or that the person's death is imminent.

End of life care The care, treatment and support that is provided to enable a person with an advanced, progressive, incurable illness to live as well as possible before they die. End of life care also covers the management of pain and other symptoms, the provision of psychological, social, spiritual and practical support, and support for the family into bereavement.

Palliative care The active, holistic care of people who use services with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount.

The goal of palliative care is to achieve the best quality of life for people who use services and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with other treatments.

These standards establish the minimum required. In other words, they identify a standard of service provision below which an agency providing personal care for people living in their own home must not fall.

While broad in scope, these standards acknowledge the unique and complex needs of individuals and the additional specific knowledge and skills required in order to deliver a service that is tailored to the needs of each person.

These standards will be applied to agencies providing personal care to the wide range of people who need care and support while living in their own home.

They include:
- Older people
- People with physical disabilities

- People with sensory loss, including dual sensory impairment
- People with mental health problems
- People with learning disabilities
- Children and their families
- Personal or family carers.

The message is that care and support workers may be directly providing the care themselves but they are more likely to be providing the care jointly with the person needing assistance, encouraging them to do as much as possible for themselves to maintain their independence and physical ability. In addition, it is important to recognise that care and support workers will be helping people with a range of disabilities, which will include end of life issues. With the emphasis on caring for people with complex health and personal care needs living in their own home instead of in residential or nursing homes or long stay hospitals, the provision of personal domiciliary care services is evolving rapidly and reflects changes at the interface between health and social care.

Access to domiciliary care

There are many ways in which those wishing or needing to access domiciliary care can do so. This can be a very confusing and complex process dependant on the individual's financial situation and engagement with health and social care services. Individuals may need to have advice and help in order to navigate successfully through the different options to obtain the care they need. This will also include those that are accessing the care privately, ie paying and contracting directly with the care provider themselves without any interaction with health or social care. The process via health or social service provision continues to be somewhat complicated, and providers find that more and more they need to have an understanding around the funding stream the person and/or carer are linked into. This is not to say this is an expectation on them; rather it is a reflection of the reality many providers face. This proves particularly relevant when changes are needed to the care package identified by either the provider, the person or the carer. One common issue with the current systems in place is that people can have to change providers according to who is providing funding for the care and this can be difficult for both the cared for and the carers in terms of continuity. Care workers can also find this difficult as often they have established relationships with individuals and would prefer to continue to provide their care. Agreements with regard to seamless funding transition processes would go some way to eliminate this issue.

The summary below is intended to provide some basic information. It is recommended that this a key part to providing care to someone and that the funding source is identified accurately to ensure smooth transition of any information or changes needed to someone's care package. (See also appendix 2: Statutory provisions and guidance regarding funding for domiciliary care.)

Summary of funding information

Care providers

There are many different types of care available within the market, offered by a broad spectrum of providers ranging from small local companies through to larger national companies. The cost of care varies from provider to provider and will depend on the care services the person requires, how often they need the care and when it is delivered. The person may be entitled to free domiciliary care if they meet the local authority's eligibility criteria.

Personalisation

Personalisation is the new initiative that allows people to choose their own care provider and to manage the relationship directly, including payment. If an individual is eligible for funded care via the local authority they can opt to take a direct payment and will then be able to select their care provider. Another option is to have a personal budget where they can choose the care provider but the finances are managed by the local authority.

Self-funded care

Many people pay for their own care and it is important that they are informed and able to select a care provider with the best skills and experience to meet their needs or those of a loved one. The contract with that self-funding client should be as robust as the contract with other commissioning authorities (for instance, health and social care).

NHS continuing care and NHS-funded nursing care

A cared for person may be eligible for NHS-funded health and personal care, known as continuing care. If they are not eligible for continuing care, then they may be entitled to NHS-funded nursing care. This should be explored and taken forward by either the health or social care commissioner involved with the person.

Making decisions for others

Choosing care and working out how best to fund it can be very complicated, and older people can sometimes find this difficult. A Lasting Power of Attorney/Continuing Power of Attorney (Scotland) can help people deal with property and financial affairs or their health and care matters. People can seek information from professional advisers who are authorised to advise about setting up a Power of Attorney.

(Adapted from Mears Group information on funding care)

Aim of guide

The aim of this publication is to provide a practical guide which supports domiciliary care organisations and their staff to engage with key professionals in ensuring that those who may be in the last months of life receive high quality end of life care. The guide may also be useful to health professionals who work or link with care staff in clarifying what measures need to be taken to ensure that people can access appropriate care. It also provides further information on the role of care staff in the end of life care arena.

Individuals approaching the end of their life need high quality, accessible care if they are to make genuine choices about how they are cared for and where they wish to die. Competent and compassionate care is also critical to giving people the opportunity to have a dignified death and offering bereavement support to families, staff and other representatives following a death.

This care should be of the same high quality regardless of diagnosis and of whether the care is carried out at home, in hospital, in the community or in any other setting. This guide is intended to support organisations, carers and practitioners working in this arena to develop their awareness and understanding of the end of life care pathway and how it relates to people in the domiciliary setting who have life-limiting conditions. Of course, care staff are not usually health care providers. Few care staff possess specialist palliative care skills while some care agencies will not be able to manage people with physical conditions or those approaching end of life, due to funding issues and/or skill sets within that organisation. So this guide also offers signposting to more appropriate resources.

The document is intended to work in two distinct ways. At each stage, the 'Questions for your organisation' section is about the whole organisation. The 'Your role – as a care worker' section is about and intended for the individual care worker. The top tips and quality markers identified are intended to offer some best practice tips and links to the relevant quality markers identified for good end of life care (Reference can also be made to the relevant quality markers for end of life care. See appendix 3 for full list.)

Key considerations for the organisation

- Acknowledge the unique lone worker position – the United Kingdom Homecare Association has produced guidance for lone workers.
- Do other professionals fully understand the role of domiciliary staff?
- Misconceptions about roles can lead to mistaken assumptions.
- What can be done to assist understanding?

The guide will reflect the need to work with other professionals in health and social care and assist staff 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 may be affected by the death of a client and identify some measures to support them and provide information.

This guide has been developed by the National End of Life Care Programme in conjunction with a range of organisations working with people receiving domiciliary services at home, as part of its *route to success* series. It is intended to be a practical tool offering advice on what domiciliary organisations and their staff can do as well as how and when to access specialist help.

End of life care pathway

End of life care pathway

The guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death.

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

Social care

Spiritual care services

Support for carers and families

Information for patients and carers

Step 1
Discussions as the end of life approaches

Allowing an individual to die with dignity in the comfort of their own home with their own family around them is a key measure of good end of life care provision. A key challenge for domiciliary home care workers is the extent to which it is appropriate for them to become involved in an individual's discussions about their personal wishes and preferences for care

Questions for your organisation

- Do you liaise with local health and social care teams to identify those in your care approaching end of life?
- Can your care workers identify if the person they care for is approaching end of life?
- Do your care workers recognise some of the signs which may indicate end of life is approaching?
- Do they feel comfortable with participating in any discussion the person may wish to have about approaching death?
- Are there training needs, such as communication skills, which would help care workers feel more comfortable having end of life discussions or dealing with family dynamics?
- Are you following the essential standards in relation to issues such as having appropriately trained staff?

Your role – as a care worker

- Recognise when changes in an individual's signs and symptoms indicate their condition is deteriorating
- Ask yourself, would you be surprised if this individual were to die in the near future?
- Be ready for the possibility that changes in circumstances – such as the death of a close friend or relative or increased hospital admissions - may prompt the individual to want to talk about the future
- Consider whether it is appropriate for you to take part in an individual's discussions about the future. Do they just want a listener or to make specific plans?
- Be prepared to recommend that discussions about specific plans should be carried out with a more appropriate person - for instance, a GP, district nurse, social worker or family member
- Do not pressurise an individual to have discussions but offer support and relevant advice when asked.

Top tips

- Recognise that greater attention and support may be required by those individuals who have difficulty communicating their needs
- Death and dying is not something to be hidden. Building a trusting relationship may help an individual to have open conversations
- As a care-giver it is important to recognise that your own attitudes to death and dying might influence the care you provide or your ability to have open conversations
- End of life discussions with people who have dementia may need to take place earlier while they still retain mental capacity. (See appendix 4.)

Quality markers

- Have an action plan/policy in place which will support workers caring for those approaching the end of life
- Have a mechanism in place which identifies and records which people may be approaching the end of life.

Step 2
Assessment, care planning and review

As the end of life approaches it will be essential that an assessment of an individual's needs has taken place and that the care worker is familiar with its requirements. The assessment should include physical, psychological, spiritual and cultural and, where appropriate, environmental and financial needs.

Questions for your organisation

- What involvement do you have in local joint care planning and assessment?
- Are you aware of the care/support plan which has been written with the individual?
- Do you feel you have sufficient confidence and skill to support the requirements of the care/support plan or might further advice or training be required?
- Are you aware of any personal wishes and preferences the individual may have expressed about their future care should they lose the capacity to express them for themselves? (See also appendix 4)
- Do you know if the relatives or advocate has any particular wishes or concerns that need to be considered?
- Do you have systems in place to manage any emergency changes to care plans?

Your role – as a care worker

- Ensure you are aware of the holistic care plan which is in place for the individual
- Respond sensitively to the social, psychological and spiritual needs and wishes of the individual as well as to their physical needs
- If appropriate, and with the individual's permission, offer your input into the ongoing assessment/review of the person's needs made by the other professionals involved in their care
- Be aware of any previously expressed or recorded wishes and preferences (known as an advance care plan or advance statement)
- Note any new specific wishes and preferences the individual may raise and discuss with you and, with their permission, bring them to the attention of the appropriate person
- If an individual expresses a wish to discuss the refusal of future treatment, recommend to them that this should be discussed with the professionals who can best advise them such as GPs
- As long as an individual has the mental capacity to do so, always encourage them to participate in any decisions about their own care
- Identify any changes which indicate the need to review care/support plans and refer this to the appropriate person.

Top tips

- Decisions about not wanting treatment should be recorded as an advance decision to refuse treatment. This requires a specific format to make it valid in particular circumstances and therefore legal
- Encouraging individuals to talk about their life and viewing old photographs may prompt discussions about personal beliefs and preferences
- Think of ways that may help you communicate with someone who has difficulty expressing themselves - for instance, picture cards.

Quality markers

- Ensure an holistic assessment has been carried out and those who need to be are aware of the resulting care plan
- If wishes and preferences about future care have been expressed they should be communicated, with permission, to the appropriate people.

Step 3
Co-ordination of care

Once a care/support plan has been agreed it is important that all services are effectively co-ordinated, especially across service boundaries, and good communication systems are in place.

Questions for your organisation

- Is there a communication system in place to keep all relevant people, such as a district nurse, GP or social care worker, informed of developments?
- Is there a key person within the domiciliary care organisation who takes responsibility for supporting care workers dealing with end of life care issues?
- Is there a system in place for the organisation to respond rapidly to any sudden change of circumstances as end of life approaches?
- What other local support services are available, what can they provide and what is the method of referral?

Your role – as a care worker

- Ensure you inform the relevant health and social care professionals if you note changes which indicate approaching end of life
- Make sure good communication systems are in place with all associated services
- Discuss with the other health and social care providers how your role should continue or should be reviewed due to the client's deterioration
- Ensure you are aware of who the key contacts would be in other services and you have their contact details to hand
- Be aware of any specific drug regime or equipment use that is introduced as end of life approaches, ensure any appropriate training is received and identify who the family should contact if they need support
- Do not carry out any new duties for which you are not qualified or have not received instructions.

Top tips

- Find out which pharmacies are open out-of-hours in case a relative needs to collect drugs urgently
- Build a strong working relationship with other services so that you may be able to support them and the families as end of life approaches
- It may be helpful to let the family carer know that they too are eligible to have their own needs assessed
- Find out if the commissioning agent has handover procedures in the event of funding changes.

Quality markers

- Consider the needs of the carer
- A mechanism should be in place to co-ordinate care across organisational boundaries 24/7
- Have essential services available and accessible 24/7 as end of life approaches.

Step 4
Delivery of high quality care in domiciliary care

Individuals may be receiving a complex combination of services. They are entitled to receive a high level of quality care regardless of their care setting and who is providing the services.

Questions for your organisation

- Does your organisation have an end of life care management policy?
- Can all staff access any internal or external training for end of life care?
- What systems are in place to monitor, evaluate and review the delivery of end of life care in your organisation?

Your role – as a care worker

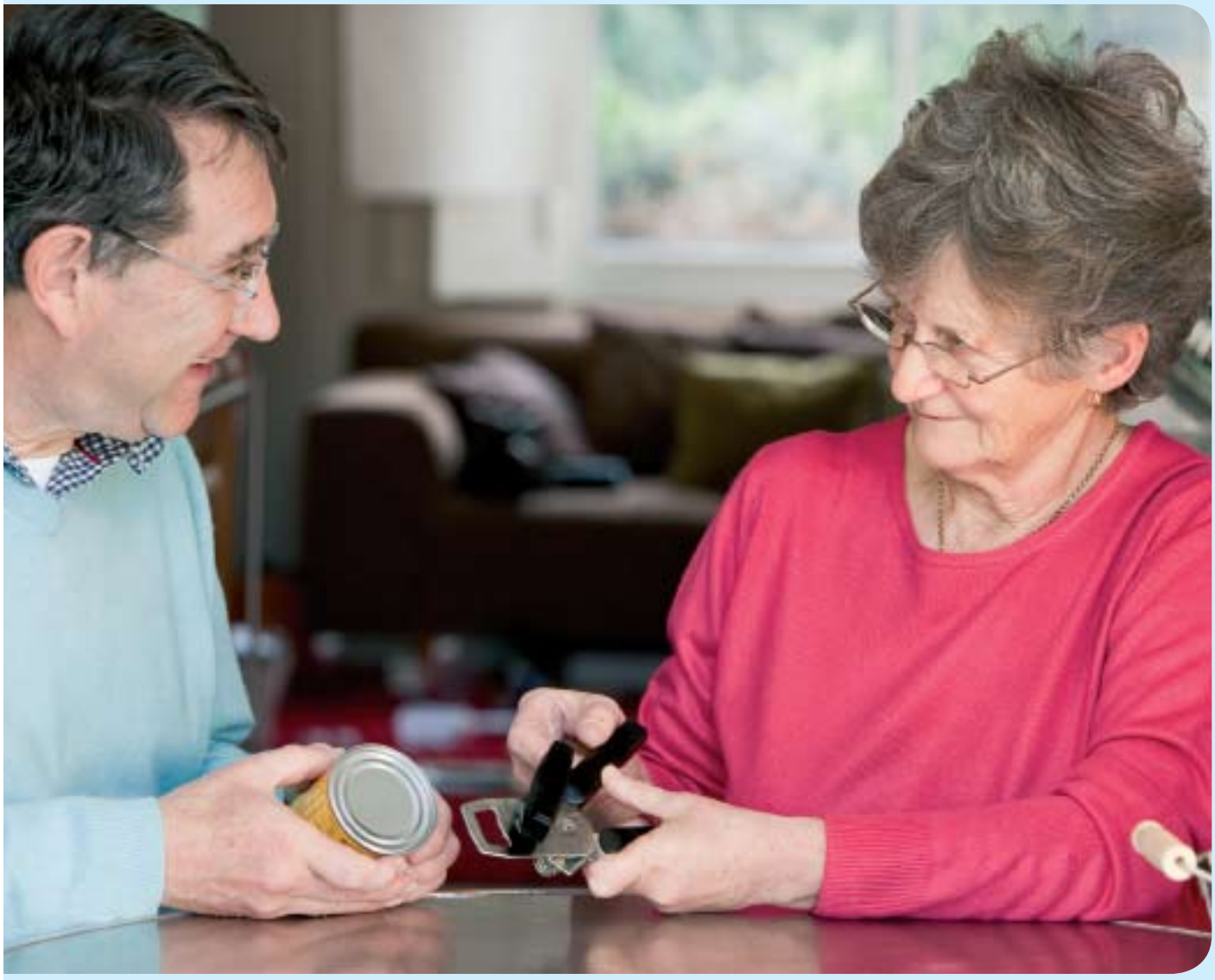
- Be aware of the organisation's end of life care policy
- Be aware of the basic end of life care core principles and values
- Promote or participate when possible in any end of life care training which may be available to you
- Where possible, access training about communication skills
- Give consideration to the environment in which end of life care is provided and if necessary carry out sensitive negotiation with relatives which may improve the care delivery area
- Respect the knowledge of the family carer and treat them as equal partners in care delivery
- Use the experience of the family to provide constructive feedback to support continuous practice improvement
- Be aware of symptom changes which can occur as end of life approaches and know what you can do within your remit to offer comfort and relief
- Support the individual and their family in understanding some of the changes which will occur as end of life approaches.

Top tips

- Do not forget the role that others can play in supporting someone approaching the end of life. Eg, friends, neighbours, children and pets. (See appendix 5 for further ideas of what kinds of services may be in your area)
- Staff training is not just about physical care but also about understanding psychological and spiritual needs
- Allow the client the maximum level of independence, choice and control for as long as possible.

Quality markers

- Access relevant training opportunities



Step 5
Care in the last days of life

It is vital that care workers can recognise the dying phase and take appropriate action. How someone dies remains a lasting memory for the relatives, friends and care workers.

Questions for your organisation

- Are your care workers familiar with the bodily changes which may occur during the dying phase and how to manage them?
- Are your care workers able to allow the family to be involved in care-giving as death approaches?
- Are you aware of any specific wishes that have been expressed by the client for what is to happen at this time?
- Can you help in any way in the response to any spiritual or cultural needs which have been part of the end of life care planning?
- Are your care workers familiar with the Liverpool Care Pathway which the district/ Macmillan nurses may implement at this time?
- Do you keep other services informed of approaching end of life?
- Be aware a syringe driver may also be introduced for administering drugs. What support do staff need to work with this?

Your role – as a care worker

- Be aware of the physical changes, which may occur during the last days of life and how to manage them
- Be prepared to support the family in their understanding of these changes which may cause some distress
- Be aware that someone who appears to be approaching the end of life may show an unexpected improvement in their condition
- If the individual wishes it, be open in your discussions with friends and relatives about the approaching death
- Familiarise yourself with the Liverpool Care Pathway (or equivalent) which the nurses may apply in the last few days so that you understand the process
- Act professionally and with sensitivity at all times with everyone associated with the end of life care
- Care routines may be altered at this time. Be prepared for your caring role to be altered once the Liverpool Care Pathway has been introduced.

Top tips

- It may be helpful to offer to support the district/Macmillan nurses by communicating with them should you identify any change in symptoms
- Support the client and their family with the same dignity and respect you would want for yourself or a member of your own family
- If you have established a strong relationship with the client you may need to establish your own coping mechanisms once death has occurred.

Quality markers

- Be aware of the process involved in introducing the Liverpool Care Pathway.

Step 6
Care after death

Good end of life care does not stop at the point of death. When someone dies all care workers need to follow good practice in the care of the body and in supporting those close to them.

Questions for your organisation

- Are you or the care workers aware of the actions that need to be taken should they be present at the time of death?
- Have the relatives been provided with any supportive information they may require?
- Are mechanisms in place to support care workers who may have had strong relationships with the family and the deceased?
- Is it appropriate for care workers to attend the funeral?
- Are systems in place for the sensitive retrieval of any equipment?

Your role – as a care worker

- Make yourself familiar with local policies on verification and certification of death
- It may be helpful to the family if you can provide useful information on what to do after death. (See references and resources)
- Does your organisation provide a comfortable and private environment in which care workers can discuss their feelings?
- Acknowledge that you as a worker may wish to have the opportunity to pay your respects
- Have any wishes expressed by the individual about actions to be taken at the time of or after death been addressed?
- Have any anticipated concerns or needs of the relatives been addressed?

Top tips

- Use the experience learnt from the provision of end of life care to support and enhance future care provision
- Create a portfolio of written evidence of the delivery of good end of life care – eg, policies and systems of approach
- Organisations should ensure good support mechanisms are in place for their staff.

Quality markers

- Ensure systems are in place to monitor and evaluate the provision of end of life care.

Appendix 1

Excerpts from Care Quality Commission essential standards

(*Guidance about compliance: essential standards of quality and safety,* CQC, 2010)

Outcome 2 Consent to care & treatment

How to respond to advance decisions sits under regulation 18 of the Health and Social Care Act 2008 (regulated activities) regulations 2010).

from 2C:
Staff knowing the circumstances in which an advance directive or advance decision regarding the refusal of treatment by a person using services may be lawfully over-ruled.

Outcome 4: Care and welfare of people who use services

4K: **People who use services who are at the end of their life will have their care, treatment and support needs met because, wherever possible:**

- They are involved in the assessment and planning for their end of life care and are able to make choices and decisions about their preferred options, particularly those relating to pain management
- There are systems in place to ensure further assessments by specialist palliative care services and other specialists, where needed
- They have information relating to death and dying available to them, their families or those close to them
- There are arrangements to minimise unnecessary disruption to the care, treatment, support and accommodation of the person who uses the service, their family and those close to them
- They are able to have those people who are important to them with them at the end of their life
- They have a dignified death, because staff are respectful of their needs for privacy, dignity and comfort
- The plan of care records their wishes with regards to how their body and possessions are handled after their death and staff respect their values and beliefs.

Appendix 2

Statutory provisions and guidance regarding funding for domiciliary care

Local authorities (LA) have the power to make arrangements for providing domiciliary care in a disabled person's home under section 29 of the *National Assistance Act 1948.* This general power is turned into a duty under section 2 of the *Chronically Sick and Disabled Persons Act 1970.* The duty upon the LA to assess a disabled person's needs arises from section 47 of the *National Health Service and Community Care Act 1990*. Once a person's needs have been assessed, the LA can then either provide those care services directly or offer the individual direct payments. The power to make direct payments is derived from section 57 of the *Health and Social Care Act 2001*. Section 7 of the *Local Authority Social Services Act 1970* (LASSA) states that LAs should exercise their social service functions, including any discretion, under the general guidance of the Secretary of State. The Local Authority Circular *Fair access to care services: guidance on eligibility criteria for adult social care* (LAC(2002)13) was issued under section 7 of LASSA. This established criteria for LAs to determine eligibility for the provision of care services according to need. The policy guidance document also called *Fair access to care services: guidance on eligibility criteria for adult social care* (DH, 2003) provides for four bands, namely critical, substantial, moderate and low. This guidance was updated in February 2010.

The provisions relating to charging service users for domiciliary care provided by way of direct payments are contained in regulation 5 (2) of the *Community care, services for carers and children's services (direct payments) (England) regulations 2003*. Guidance on charging for domiciliary care can be found in the 'FCP' (*Fairer charging policies for home care and other non-residential social services: guidance for councils with social services responsibilities*, DH, 2003). This guidance does not provide information as to how the service users' unearned income should be treated. In relation to savings or other capital, the FCP states that LAs may take into account savings and capital belonging to the service user. It then states that where savings are taken into account, the tariff income should be calculated on the same basis as set out in the Department of Health's *Charges [or charging] for residential accommodation guidance* (CRAG). Users with savings of more than the upper limit (as set out in CRAG) may be asked to pay a full charge for the service. CRAG states that damages paid into trust will be disregarded in the assessment of means. The FCP does not say whether CRAG should be followed in respect of the treatment of income.

Appendix 3

Quality markers for end of life care

(*End of life care strategy: quality markers and measures for end of life care*, Department of Health, Jun 2009)

1. Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.

2. Institute effective mechanisms to identify those who are approaching the end of life.

3. Ensure that people approaching the end of life are offered a care plan.

4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.

5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.

6. Have mechanisms in place to ensure that care for individuals is 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* by Julie Foster, end of life care lead, Cumbria and Lancashire End of Life Care Network

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)?

Appendix 5

Guidance on other support options

These examples are taken from the 'baker's dozen' in the Joseph Rowntree Foundation's briefing paper *The older people's enquiry: 'That little bit of help'* (2005)

A) Handy Help - This section of Trafford Care and Repair is a local charitable trust providing help with small repairs around the house. Handy Help is funded by grants from the business sector and carried out 402 small jobs during 2003/2004. There is a charge of £10 per visit and the user also pays for materials (which can be bought at cost through Handy Help).

B) Welcome Home - Volunteers help people returning from hospital – for example, by doing the shopping, or giving them a lift home. They also help them to settle back at home by tidying up, putting the heating on, sorting post, etc. No charge is made for this.

C) Help at Home - Services including cleaning, ironing, accompanied shopping, collecting pensions, etc. Help at Home aims to provide the same worker at the same time each week. Users pay £8.25 an hour for domestic support. The Gardening and Home Maintenance Service was re-launched in March 2004. Users pay £12.50 an hour for this.

D) Primary Night Care - Staff 'pop in' to people in their own homes during the night – for example, helping with toileting, medication, or to check all is well. Most visits are planned but staff can respond to emergencies. People can be supported through the night if the usual carer is taken ill. Users are charged for routine night visits but not for emergency calls.

E) Befriending Service - Provides companionship and support through regular visits. Befrienders have undertaken training, are CRB-checked and are supported by the Community Volunteer Service. Volunteers also provide a phone buddy service.

F) Sole Mates - Provide a footbath and a foot massage for people over 50 who cannot cut their own nails safely. The same volunteer visits each time. The charge is £3.50 a visit plus a one-off charge of £10 for their nail-clippers.

G) Cinnamon Trust - A national charity helping older or terminally ill people care for their pets. They provide help by walking and grooming dogs, taking pets to the vet, cleaning cages or short-term fostering. Life-long fostering can also be arranged.

H) Digging Deep - This scheme involves older people teaching school children how to grow vegetables in school-based allotments. Volunteer older people tend to stay working with the school.

I) RISE - A community outreach project to 'Reach the Isolated Elderly'. It provides transport to people to attend the regenerate.com lunch clubs four days a week. It also provides transport to take part in outings and other activities. There is an optional £10 membership and a £3 charge for eating at the lunch club.