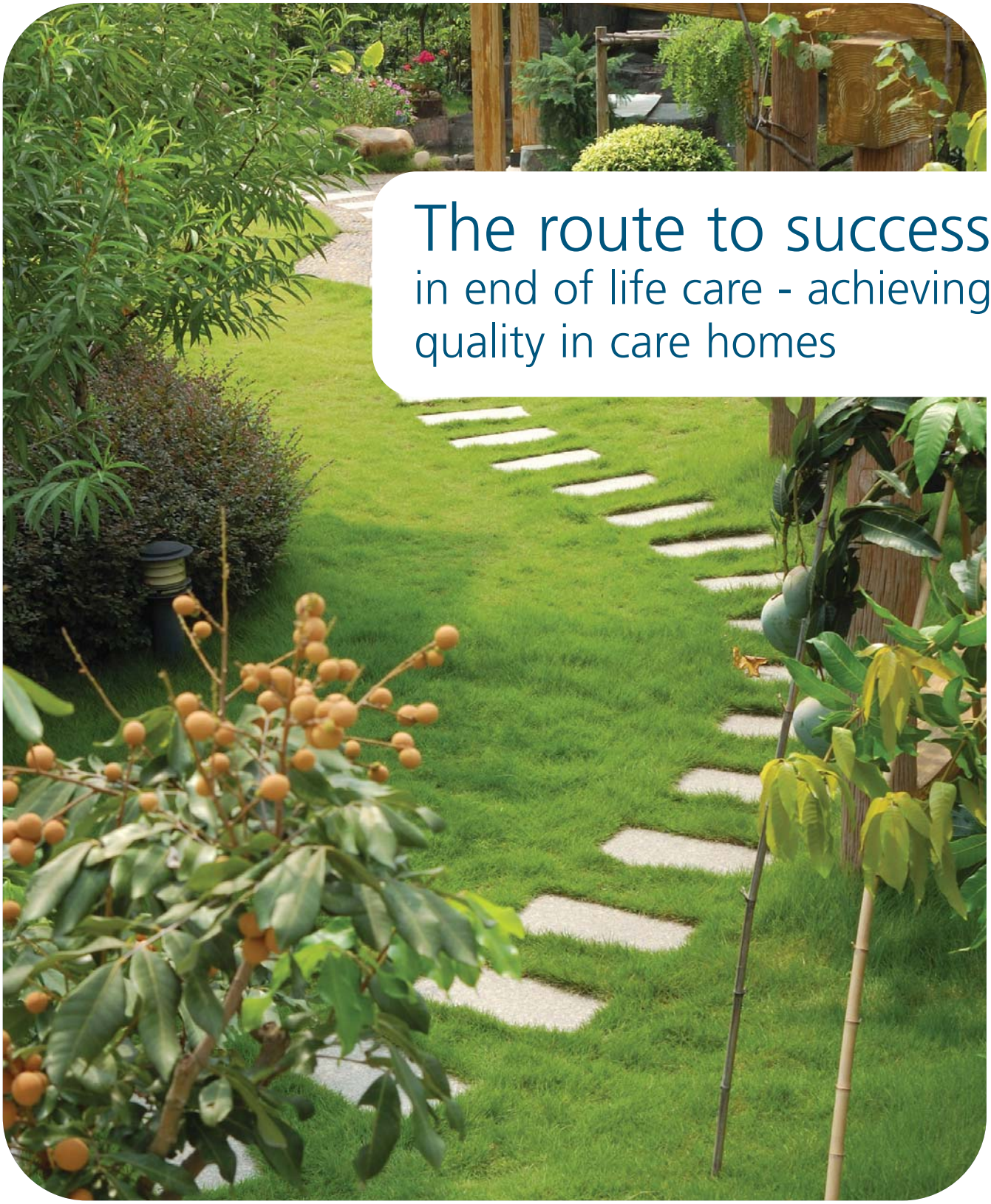
NHS

National End of Life Care Programme

Improving end of life care



The route to success

in end of life care - achieving quality in care homes

Contents

Introduction

The Department of Health's *End of Life Care Strategy*, published in 2008, emphasised the need to raise the quality of care provided to dying people and their loved ones in a variety of settings – including care homes.

"Many of the residents in this home have no more than days or weeks to live and appreciate the time, patience, care and expertise of staff to help them cope with the journey to death."

Although many care homes are enthusiastic about enhancing the quality of care they provide at the end of life, many of their residents die in hospital after an emergency admission just hours or a few days before their death.

The strategy identifies the need for care home staff to receive the training and support necessary to ensure the provision of good end of life care. It sets out an ambitious staff development agenda which the National End of Life Care Programme and its partners have taken forward. That includes the publication of core competencies and principles for end of life care (July 2009) and pilots in the key area of communication skills.

The national strategy also called for more co-ordinated services, which could see NHS and statutory social care authorities providing more support to care home staff and managers and their residents. Such support would reduce the number of unplanned hospital admissions, ensuring more people can die in their care home if that is their expressed preference.

This guide follows the six steps of the pathway laid out in the national strategy. The pathway leads from initial discussion about death and future care, on to assessment and the provision of high quality co-ordinated care and support through to the final days and end of life.

It includes questions staff and managers should ask about end of life care provided in the home and the employees' role in that care. This guide is linked to the National End of Life Care Strategy Quality Markers.

Care homes which embrace the guide and the pathway approach, while using the training resources which are available now or coming on stream, will see well-trained and motivated staff working to ensure more residents have a "good death". This will mean that the residents' wishes and preferences - recorded through advance care planning – are met wherever possible.

Delivering end of life care quality and productivity

KEY LEVERS FOR RAPID IMPROVEMENT IN THE QUALITY OF END OF LIFE CARE IN CARE HOMES

- Co-ordinated care based on assessed need
- Good communication and access to all relevant services when required
- Training and education as appropriate to each team member's role
- Strong managerial overview
- The use of a recognised tool for the last hours and days, such as the Liverpool Care Pathway, by competent and confident staff well-trained in use of that tool
- Provision of good care after death.

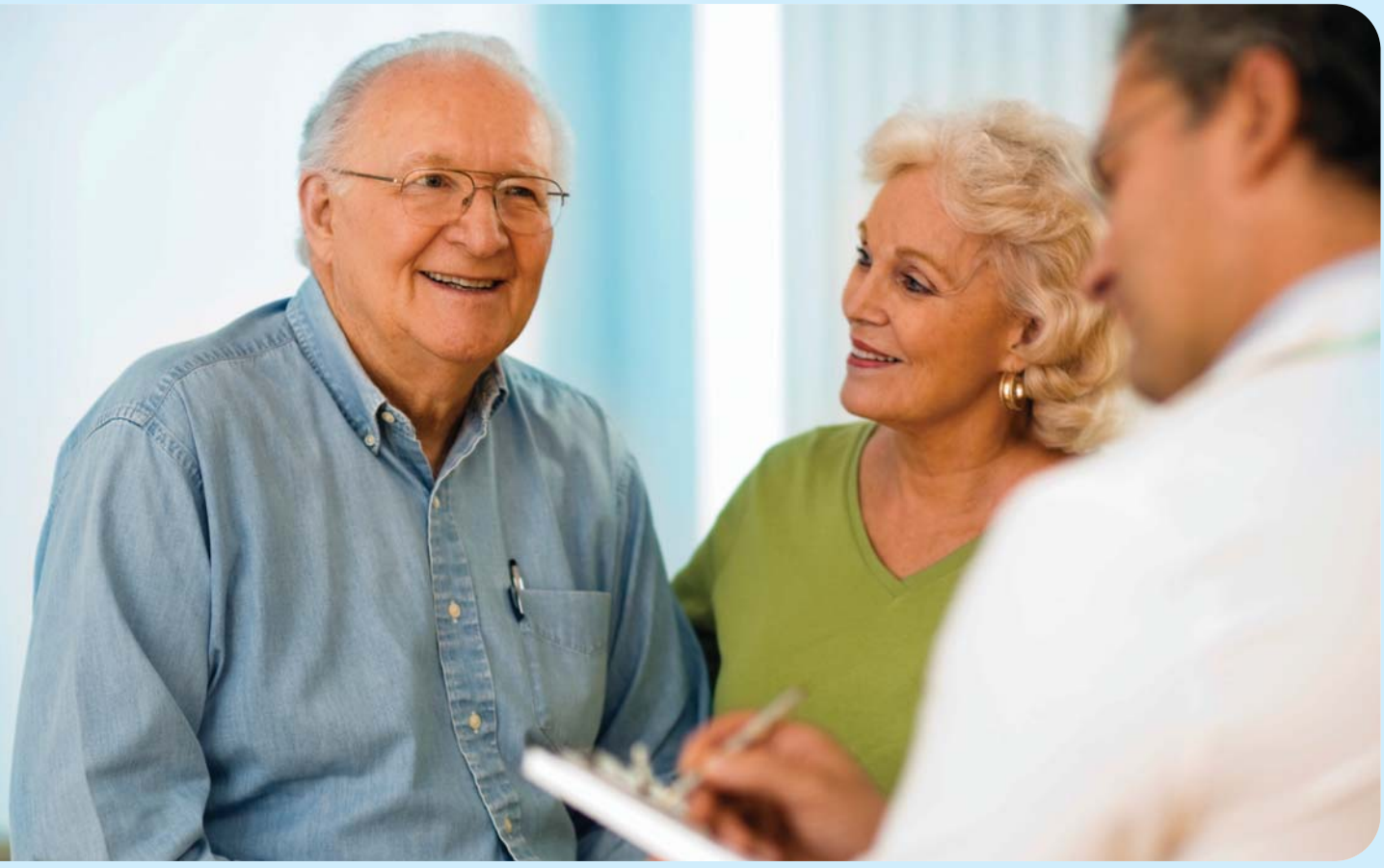
IMPROVED OUTCOMES

- More people having a "good death" in their preferred place of care
- Fewer complaints about end of life care from relatives or friends
- An improved reputation for the home
- Fewer unplanned hospital admissions
- A skilled workforce with improved morale and retention.

Step 1
Discussions as the end of life approaches

Enabling residents to die in comfort and with dignity is a core function of care homes. One of the key challenges for managers and staff is knowing how and when to open up a discussion with individual residents (and relatives) about what they would wish for as they near the end of their life. Agreement needs to be reached on when discussions should occur, who should initiate them and what skills and competencies staff require to take on this role.

"Care homes are increasingly at the forefront of good practice in providing care for those who are approaching or reaching the end of their life."



Ask yourself

- Can you identify those in your care who are approaching the end of life?
- Have you noted triggers that might indicate it is an appropriate time for discussion?
- Are you certain you know whether a resident does or does not wish to have a conversation about their future care?

Your role

- Recognise when a resident's signs and symptoms have increased or his or her condition has deteriorated
- Ask yourself: "Would I be surprised if this resident were to die in the near future?"
- Identify those who need to be receiving end of life supportive care
- Remember to take into account triggers such as recent changes in circumstances. Triggers could be the death of a spouse, increase in hospital admissions or a change in care setting, eg a move from a residential to a nursing home
- Identify whether it is appropriate to open a supportive discussion with the resident and/or their family about their wishes for end of life care and the best time or circumstances in which to do that
- Consider carefully whether the individual wishes to have open discussions about prognosis and possible future care options
- Provide any relevant information that may be required by the resident or their family.

Relevant national quality marker

Families and carers are involved in end of life decisions to the extent that they and the resident wish.

Top tips

- Recognise that greater attention and support may be required for those residents who struggle to communicate their needs because of dementia or other health problems
- Death and dying should not be hidden from residents, relatives and carers. Building a trusting relationship will help facilitate conversations that may include end of life care
- As care givers it is important that you recognise how your own attitude to death and dying may influence the care you provide or your ability to talk openly.

Step 2

Assessment, care planning and review

An early assessment of a resident's needs and wishes as they approach the end of life is vital to establish their preferences and choices, as well as to identify any areas of unmet need. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs and wishes of each resident.

"One of the key challenges that we have is when there is a conflict between a resident's wishes and what a relative feels they would like to happen at the end of life. Building strong relationships with the relatives from the start can really help when we try to resolve these situations."

Ask yourself

- Does your care plan assessment include an exploration of all aspects of end of life care?
- Do you feel sufficiently confident and skilled in supporting residents to identify their wishes and preferences about their future care? Might additional training and support be valuable?
- Have the wishes or concerns of the relatives or advocates been considered?
- Have you considered how you might gather information from, or about, those of your residents who struggle to communicate, perhaps because of dementia or stroke?

Your role

- Undertake a holistic assessment for end of life needs and preferences in partnership with your residents and, where appropriate, their relatives and friends
- Assess and respond sensitively to the social, psychological and spiritual needs and wishes of a resident, as well as their physical care needs
- If necessary, support an assessment of the resident's ability to make decisions about their care
- Identify, record and respond to a resident's personal wishes and preferences about their future care and implement regular reviews (advance care planning) and verify this with their local GP if necessary
- If requested, you should support a resident in the recording of an Advance Decision to Refuse Treatment document in an appropriate format (see resources page 17)
- Communicate information about personal wishes and preferences (with permission) to relevant people, eg the GP out-of-hours service.

Relevant national quality markers

- There is a mechanism in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life
- The resident's needs for end of life care are assessed and reviewed on an on-going basis.

Top tips

- If residents make an advance decision to refuse life-sustaining treatment it must be in writing, signed by that person (or representative) and witnessed
- Holding an open discussion meeting with residents and relatives can be a way of raising awareness about the possibility of expressing personal wishes and preferences
- Creating "life books or collages" may prompt discussions about personal beliefs and preferences.

Step 3
Co-ordination of care

Once a care plan has been agreed it is important that all the services the resident needs are effectively co-ordinated. A lack of co-ordination can mean the resident's needs and preferences are not met.

"Friendship and teamwork in a home can help with good quality end of life care, because success is often all about integration and linking up with colleagues."

Ask yourself

- Is there a communication system in place to keep all members of the care home team and others outside of the home (relatives, friends and health and social care professionals) fully informed of the end of life care plan?
- Has a key worker been identified within the home who can develop a strong working relationship with those key professionals who may be needed in order to meet the end of life care plan?
- Are systems in place for services to respond rapidly and appropriately, (out-of-hours as well as working hours), to changes in circumstances as end of life approaches? Examples include anticipatory drug prescribing and access to special equipment.

Your role

- Ensure local health and social care professionals are aware of those approaching the end of life. Some GP practices may be implementing an end of life care register
- Make sure good communication systems are in place with all relevant services
- Ensure you know who your key contacts are across the provider services, voluntary bodies and social care sectors
- Make sure there is a key worker within the home for the individual approaching end of life, who can also act as the link between services
- Ensure timely access to relevant equipment and any drugs that may be required is possible
- Inform out-of-hours services of anticipated care needs
- Inform ambulance services of anticipated care needs.

Relevant national quality markers

- Have an action plan for end of life care which is congruent with the strategic plan developed by the local PCT
- Nominate a key worker, if required, for each resident approaching end of life.

Top tips

- Find out which pharmacies your local hospice uses; these are more likely to offer out-of-hours delivery of drugs
- Building strong relationships with other services – eg GPs, palliative care teams and social care - can help you provide the resident with good end of life care
- Remember: good communication systems need to work in both directions.

Step 4

Delivery of high quality care in care homes

Residents and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless of whether they are living independently at home or in a care home.

"Our local council offers a forum where we can talk openly to GPs, staff from the local hospital and the end of life care teams, about all kinds of issues including end of life care. It really helps to put a face to a name, and means that I can pick up the phone to any of them if I need some advice or to talk about a resident's needs."

Ask yourself

- Has a policy for the management of end of life care been developed within your organisation? For example, does the team know what to do in various end of life scenarios such as at a weekend?
- Can all staff access any internal or external on-going training and support programme for end of life care?
- Does the environment within the care home offer privacy, dignity and respect for individuals and their families as end of life approaches?
- What systems are in place to monitor and evaluate the quality and delivery of end of life care?
- Can you ensure that any transition from the care home to a hospital is well co-ordinated and minimises any distress?

Your role

- Establish or be aware of the operational policy for implementing end of life care in your care home
- Ensure you have awareness and understanding of end of life care core principles and values
- Promote or participate in the different aspects of end of life care training that may be available to you. There is no one set format for the delivery of training
- Where possible, access training around communication skills, assessment and care planning, advance care planning, symptom management and comfort and wellbeing
- Give consideration to the environment in which end of life care and support are delivered, eg is there access to a quiet room or facilities for relatives?
- Use the experience of a relative, staff member or advocate to help provide constructive feedback to support continuous practice improvement.

Relevant national quality markers

- A process is in place to identify the training needs of all workers
- Take particular account of the training needs of those involved in discussing end of life care with residents, families and carers
- Be aware of available end of life care training including around the use of the Liverpool Care Pathway or equivalent.

Top tips

- Do not forget the role that other residents, particularly those who have developed a close relationship with the person who is dying, may be able to play in the planning and delivery of care
- Staff training needs will include not only the physical aspects of care but also psychological and spiritual care
- Enable residents to maintain the maximum level of independence, choice and control for as long as possible.

Step 5
Care in the last days of life

The point comes when a resident enters the dying phase. It is vital that staff should recognise that this person is dying and take the appropriate action. How someone dies remains a lasting memory for the resident's relatives, friends and care staff involved.

"After training in the use of the Liverpool Care Pathway, staff feel confident in discussing issues about dying, and are better placed to make appropriate preparation when a resident's condition begins to deteriorate."

Ask yourself

- Are you aware of the changes that may occur in a resident's condition during the dying phase?
- Are systems in place for involving families and friends in some aspects of the care-giving or in discussions as death approaches?
- Have any specific wishes or preferences been identified by the resident for this time?
- Has the Liverpool Care Pathway for Care Homes or other equivalent pathway been implemented?
- Have you responded to any particular spiritual or cultural needs that have been recorded as part of the end of life planning?

Your role

- Be aware of the processes that occur during the last days of life and be alert to the possibility that on occasions a resident's condition may improve
- Have open discussions with relatives, friends and other members of staff to ensure you all know what to expect during the last days of life, and offer support where needed
- Where possible, adhere to a resident's stated wishes and preferences
- If a person lacks mental capacity, try to identify what they would take into account, if they could make their own decisions
- With appropriate training, follow a "validated integrated care pathway" for the last days of life such as the Liverpool Care Pathway
- Where possible, have anticipatory prescribing systems in place or a system for rapid access to necessary medication.
- Anticipate and be prepared for any specific religious, spiritual or cultural needs a resident might require.

Relevant national quality markers

- A process is in place to review all transfers into and out of care homes for residents approaching end of life
- Residents who are dying are entered on to a care pathway.

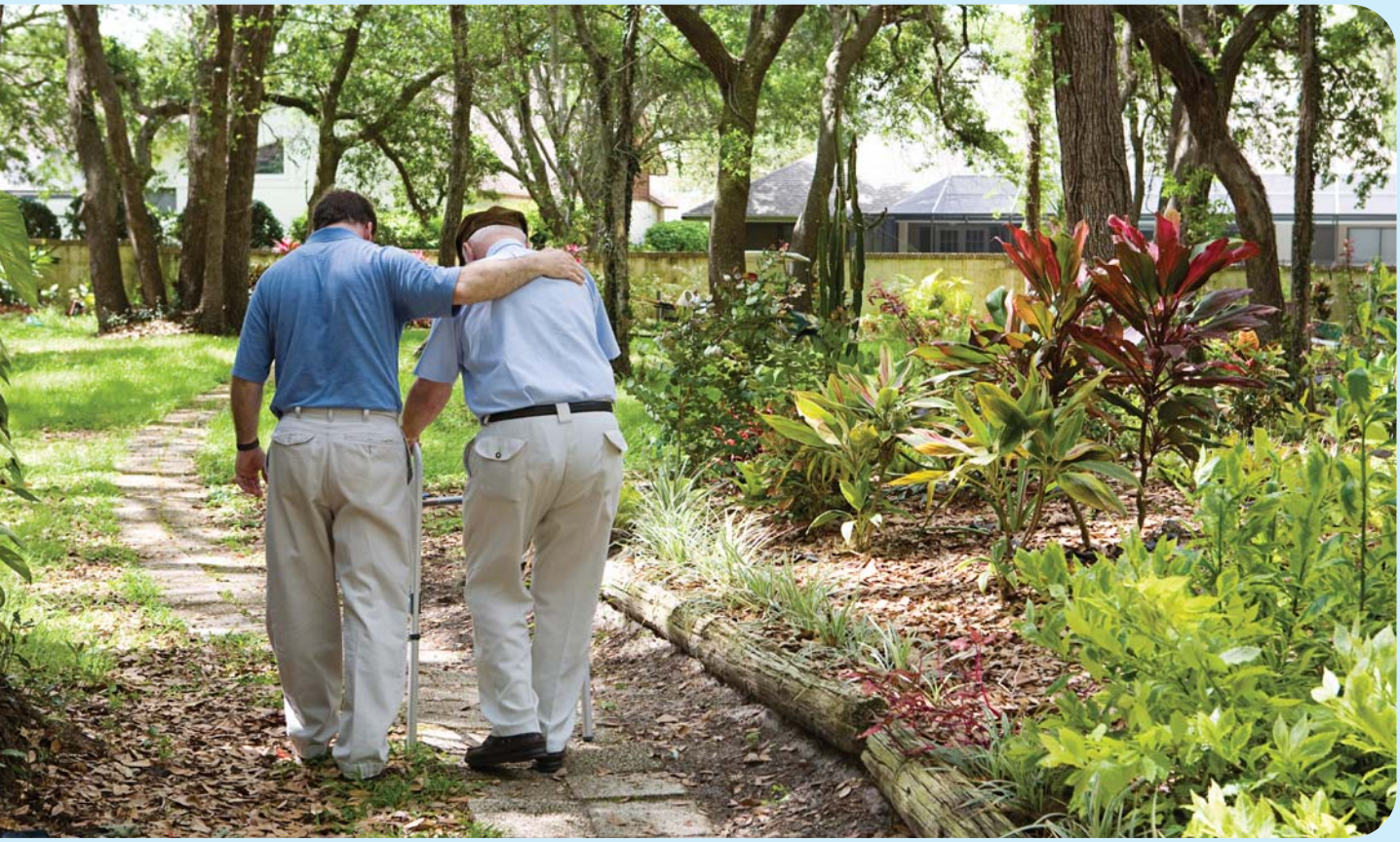
Top tips

- Where possible, plan to have someone - a member of staff or a volunteer - available to sit with the dying resident. This will provide them with comfort and reassurance
- Consider ways to support the relatives that the resident wishes to have present by providing, where possible, transport, accommodation, meals and emotional support
- Support people with the same respect you would wish to have for yourself or a member of your own family.

Step 6
Care after death

Good end of life care does not stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to family wishes. The support and care provided for relatives will help them to cope with their loss and is essential for achieving a "good death". This is important too for staff, many of whom will have become emotionally connected to the resident.

"Residents are remembered through a memory book of poems and photos. We have also created a memorial garden with trees planted to remember those who died."



Ask yourself

- Have the relatives been provided with appropriate support information?
- Are systems in place for advising on or offering bereavement support?
- Do mechanisms exist to support non-family members, such as staff, other residents and friends, who may also be affected by a death?

Your role

- Respect individual faiths and beliefs and take steps to meet their requirements
- Be aware of verification and certification of death policies
- Provide appropriate information to relatives and carers about what to do after a death
- Offer information about bereavement support services if required
- Provide a comfortable environment in which staff and, where appropriate, other residents, can discuss or share their feelings
- Provide staff, residents and relatives with the opportunity for remembrance and to showi their respect.

Relevant national quality markers

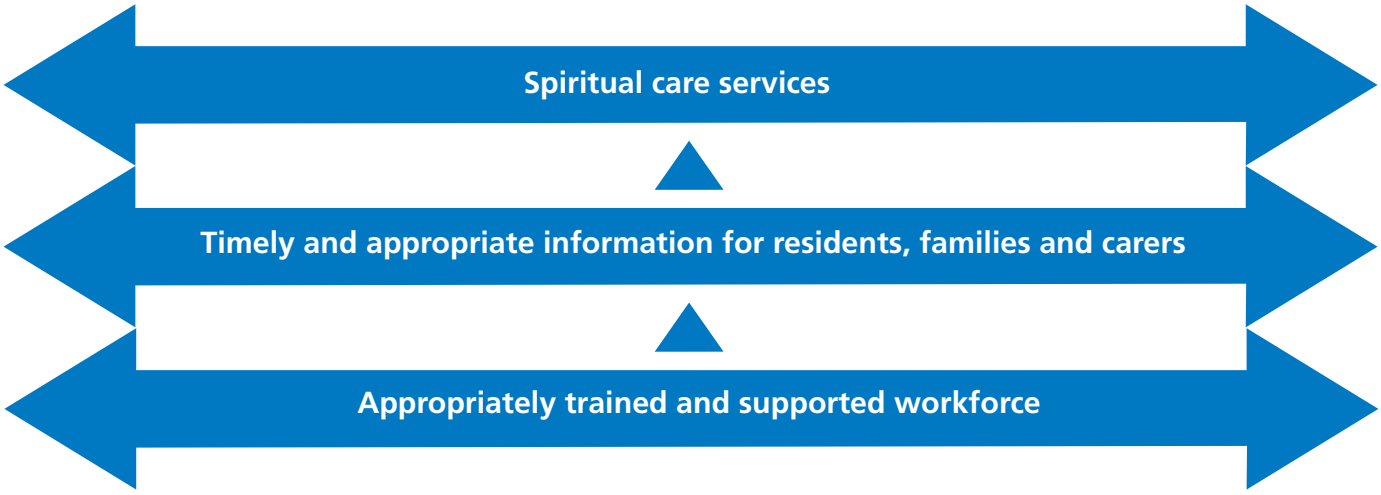
- Other residents are supported following a death in the home
- The quality of end of life care in the care home is audited.

Top tips

- Be open and provide residents, relatives and staff with the opportunity to acknowledge that a resident has died and allow them to pay their respects in their own way
- Recognise that a resident's death may be more significant to some than to others and they may require additional support.

The pathway to quality end of life care in care homes

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 a care home**	**Care in the last days of life**	**Care after death**
• Open, honest communication • Identifying triggers for discussion.	• Conduct a holistic assessment • Agreed care plan and regular review of needs and preferences • Assessing needs of carers.	• Co-ordination working with primary and community health services, ambulance/ transport services and social care • Co-ordination of individual patient care • Create adequate communication systems across care settings.	• Dignified environment • Treat with dignity and respect • Access support from other health and social care services • Making best use of resources.	• 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.



Useful resources

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

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

The support sheets already available include:

Support Sheet 1: Directory of Key Contacts
Support Sheet 2: Principles of Good Communication
Support Sheet 3: Advance Care Planning
Support Sheet 4: Advance Decisions to Refuse Treatment
Support Sheet 5: Quality Markers for Care Homes
Support Sheet 6: Dignity in End of Life Care
Support Sheet 7: Models/Tools of Delivery
Support Sheet 8: The Dying Process
Support Sheet 9: What To Do When Someone Dies
Support Sheet 10: Flow Chart for Supportive Care: Care Homes/Sheltered Housing
Support Sheet 11: Quality Markers for Acute Hospitals
Support Sheet 12: *Mental Capacity Act (2005)*
Support Sheet 13: Decisions Made In a Person's 'Best Interests'
Support Sheet 14: Using the NHS Continuing Health Care Fast Track Pathway Tool

Other web-based resources can be found on the same webpage. These include information on the Liverpool Care Pathway, Preferred Priorities for Care and the Gold Standards Framework.

Full documents that can be found through the same page include:

Advance care planning: a guide for health and social care staff NEoLCP, National Council for Palliative Care (NCPC), University of Nottingham and DH (2008) http://tiny.cc/6asvu

Advance decisions to refuse treatment: a guide for health and social care professionals NCPC, DH, Help the Hospices and the Social Care Institute for Excellence (2008) http://tiny.cc/k9ok2

The differences between general care planning and decisions made in advance NEoLCP (2010) http://tiny.cc/j331a

Planning for your future care: a guide NCPC, NEoLCP and the University of Nottingham (2009) http://tiny.cc/2yild

End of Life Care Learning Resource Pack: Information and resources for housing, care and support staff in extra care housing Housing 21 and NEoLCP (2009) http://tiny.cc/h9ntw

Mental Capacity Act (2005) Code of Practice Department for Constitutional Affairs (2007) http://www.dca.gov.uk/menincap/legis.htm#codeofpractice

* The NEoLCP would like to acknowledge the My Home Life team (Age UK, City University and the Joseph Rowntree Foundation) who worked in conjunction with the programme to produce the initial draft of the Route to Success for distribution via the My Home Life bulletin. We are also grateful for their permission to incorporate some of their 'Top tips' for care homes into this extended version.

www.endoflifecareforadults.nhs.uk

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