

# Good end of life care in care homes

**This briefing sets out the key findings of a research review on ‘good end of life care in care homes’ undertaken by Caroline Nicholson, in 2006, as part of the My Home Life programme<sup>1</sup>. The briefing also provides examples of promising approaches for improving practice within this area.**

**The full review providing further tools and examples of ‘best practice’ can be accessed at the My Home Life website ([www.myhomelife.org.uk](http://www.myhomelife.org.uk)). This review is currently being updated.**

## Introduction

High-quality end-of-life care for people living in care homes is both a necessity and a challenge. The quality of a person’s dying is, in many ways, as important as their quality of life. Many older people who are facing the end of their life begin to come to terms with their mortality in care homes. This may prompt a process where they become more aware that time is limited and become more preoccupied with focusing on the past rather than the future. They also want this aspect of their life to be good and may have a need to control their end.

Standards for those who are dying in care homes are present (see Standard 11 of the National Minimum Standards). However, the very nature of multiple, often chronic, health problems, such as many older people experience, makes it difficult to define when someone can actually be said to be dying. This uncertainty can sometimes lead to impersonal, reactive and inadequate care.

This lack of clarity as to when it is right to start providing care for the dying is perhaps a reflection of society’s reluctance to face mortality more generally. There is consensus

that a culture of care should be developed that values older people’s dying just as much as their living. Promoting end-of-life care in care homes requires an awareness of and openness to such a process.

Death and dying should not be denied or hidden in a care home. We propose five areas for consideration that address important aspects of care towards the end of life: developing a culture of openness, facilitation of the dying process, support for residents in their last days, leadership and support, and respecting and remembering.

## Developing a culture of openness

As already noted, we find it difficult at times to address the issues that dying and death bring us as care workers or relatives. It may be more useful to move away from trying to define a point of dying to making good care that supports people who are dying something that is integral and normal within the life of a care home, while also doing everything to enhance the quality of care for those who are not in this position.

Many of the practical approaches to enhancing someone’s sense of self and dignity may offer a way of encouraging more openness about dying. Care home culture does not always facilitate discussion with residents on their wishes and needs as they face the end of life. A conversation with each new resident that encourages them to express any thoughts or anxieties they have about their future, including dying, allows them to know that they will be supported by caring staff until the end. This may enable them to raise any issues they have in future.

<sup>1</sup>NCHR&D Forum (2007) ‘My Home Life: Quality of life in care homes. A review of the literature’, Help the Aged, London, available at: [www.myhomelife.org.uk](http://www.myhomelife.org.uk).

Staff need to know what they can do to make the process better. This includes being aware of their own attitudes; recognising the value of palliative care; being open in communication; supporting families who have a dying relative; ensuring that the dying person is not left alone; supporting other residents at this time; and supporting fellow staff.

## Facilitation of the dying process

A good death can be achieved only if staff recognise and take the necessary responsibility in managing the process of dying. There is a range of supporting principles and measures that can be helpful.

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards death as a normal process; integrates the psychological and spiritual aspects of care; offers support to help patients live as actively as possible until death and helps families cope during the relative's illness and in bereavement. It can be used early in an illness together with other therapies intended to prolong life, including managing distressing clinical complications.

A number of national initiatives are being used to improve the experience of dying in care homes: the Gold Standard Framework, the Integrated Pathway for the Dying, and the Preferred Place of Care Initiative. They have received clinical and government support and their effectiveness in care homes is currently being evaluated. Various other resources and training materials have been developed specifically for care homes. The aim is to acknowledge that a person-centred approach, based on the individual needs of all those living in a care home, is pivotal to the delivery of high quality end-of-life care.

## Staff support for residents in their last days

Alongside the delivery of good supportive and palliative care to residents who have such needs it is important that home staff recognise their role in the provision of appropriate care

to residents and their family members. This requires staff to:

- understand and be aware of their own attitude to death and dying, and how that may influence decisions about care;
- recognise and value the principles of palliative care and a good death;
- have an ability and willingness to involve outside support and understand what the local support services are (eg. GP, district nurses, palliative care and hospice services) and how to access them;
- make sure that communication is open and sensitive; accepting that death is coming, yet recognising that some residents and family may not want to talk openly about what is happening: family members may be reluctant to face the imminent death of their relative and can create problems for staff and resident alike;
- make sure that those relatives who may wish to be with a dying family member in the last few days are given the support they need: this means not only emotional support from staff but practical arrangements, such as providing refreshments or a comfortable chair;
- recognise the importance of not leaving the dying person alone and ensuring that, for example, enough staff are on shift at such a time for someone to sit with the person, or using volunteers for this purpose, either with or in place of a family member;
- support other residents when someone is dying: it is valuable to recognise formally that someone has died and offer bereavement support to residents and family members;
- offer family and friends the opportunity to gather at the home after a funeral, which makes it easier for residents to join them for the occasion if they wish to do so.

The process of dying is a significant one for all of us and the quality of care afforded at this time needs to be as high as for that afforded

to the living. Dying is a part of life and the care given at different times of life may be different but it is part of a continuum.

## Pain management

Research suggests that a significant proportion of older people do not receive adequate pain treatment, including effective interventions for chronic pain. Pain can impair movement, sleep, appetite, bowel and bladder functioning, grooming and socialising. Support is needed for care homes in establishing written pain management policies and in making use of pain assessment tools, along with access to multi-disciplinary input and staff education, which together can considerably improve pain management.

## Nutrition

Under-nutrition is reportedly widespread in care homes. This is partly attributable to age-related changes, coupled with impaired vision and hearing, dementia, confusion, depression, and loss of taste and/or smell. Specific illnesses or disabilities, such as stroke, Parkinson's disease and swallowing disorders complicate nutrition.

Under-nutrition contributes towards many problems, including infection, poor wound healing, skin problems, pressure sores, depression and mental confusion.

Often it is the little things that can improve nutrition among older people in care homes. For instance, a Liverpool care home is ensuring residents with dementia can focus on enjoying their meals by removing distractions such as leaving the television on and allowing mealtime visitors. Protected mealtimes have made an 'unbelievable difference. Best practice statements on nutrition and oral health, advice on dental care for people in care homes and information on improving the delivery of meals are now all widely available.

## Continence

The Royal College of Physicians estimates that about three quarters of care home residents are categorised 'as incontinent, but also

- recognises that a great deal could be done
- to improve the experience for older people
- through access to local continence services.
- The College notes that improved routine
- assessment, clear policies and documentation,
- along with appropriate staff training and
- greater emphasis on seeking to cure
- incontinences, rather than simply managing the
- problems, would make considerable difference
- to the quality of life of older people living in care
- homes.

## Falls prevention

- It is estimated that care home residents are
- three times more likely to sustain a hip fracture
- than older people living in their own homes.
- Effective falls prevention includes medication,
- nutritional reviews, environmental modification
- and appropriate walking aids. Most homes now
- provide balance and strength exercises for
- residents and there is strong evidence that this
- maintains muscle strength and mobility, even in
- advanced age.

## Rehabilitation and health promotion

- The would appear to be considerable potential
- for re-enablement of residents in care homes
- and research has identified that many residents
- moving into care homes have conditions that
- could benefit from rehabilitation. Much can
- be achieved if homes adopt a re-enablement
- approach to care. This helps to reduce
- dependency, reduce the risk of falls and
- promote general health.

- Especially because they have more chronic
- illnesses, older people can benefit enormously
- from health promotion. Many care homes
- aim to promote health but external support is
- largely absent. The annual health check for
- people over 75 offers an opportunity for early
- identification of changes or concerns. Older
- people living in care homes should have the
- same opportunities for health screening as
- those living at home.

## Moving forward

- There is no doubt that the quality of life of older
- people in care homes can be improved through

improved access to NHS services. Better interdisciplinary working and greater sharing across the care homes sector on promising approaches to care practice will undoubtedly make a difference in improving wellbeing of people in their care.

There is a real need to get greater support to care homes from the NHS. However, there are also good examples of inter-disciplinary work from which to build, for instance:

- One Community Health Support Team in London, comprising older people's specialist nurses, a mental health nurse, pharmacist, old age psychiatrist, two consultant geriatrician sessions, and sessions from a consultant nurse, worked with care home staff and was found to drastically improve outcomes for older people in care homes.
- Local falls champions in Dorset, including nurses, occupational therapists and physiotherapists, are providing on-site group training to staff in care homes. This includes information on current guidelines and evidence with experiential falls assessment.
- Group activities to promote physical wellbeing, address cognitive deficits and encourage social interaction through activity.

There would appear to be enormous potential for developing new ways of working in order to offer a range of multi-professional healthcare services to care homes. Such services could prove to be cost-effective and would contribute significantly to helping older people to maintain their health, functioning, potentials for enjoyment and ultimately their quality of life.

## Support and leadership for staff

The experience and effect of accumulated losses for older people and staff in care homes receives little attention, yet it is significant and has been termed living bereavement. Often there is a difficult tension between the professional and the personal in care homes.

- Staff often feel like 'family' to the resident, so when that person dies it is important to recognise the need of the staff to be supported.
- Working with loss requires a systemic approach within the care home. Clinical supervision and support of the managerial leadership are important in shaping care home culture and sustaining open awareness to dying. External support structures, such as access and availability of a GP, community nursing and palliative care teams are also needed.

## Respecting and remembering

- The respect paid to dying individuals, their bereaved family and friends and support staff is one indication of the extent to which a particular care home is open to the presence of dying in its midst. One way in which a culture of openness about dying and support for residents, relatives and staff can be facilitated is through the use of rituals of remembrance.
- Respecting the body of a resident who has died and maintaining their dignity, can be achieved through ways of remembering:
  - placing a favourite article of the deceased over the trolley and allowing the body to be removed through the front door of the home;
  - ensuring that the news of the resident's death is communicated sensitively to staff and residents. Some homes pin a photograph on the notice board, place a flower in a vase or have a candle with a photograph nearby;
  - providing opportunities for the home to stop for a moment of 'quiet' in order to respect the significance of the resident's life and death: for example, bedside prayer;
  - facilitating sharing memories of the deceased, for example, a book of remembrance;
  - allowing residents and staff personal acts of commemoration, such as attending a funeral or planting a flower in the care home garden.

Such commemoration facilitates mourning and powerfully voices the idea that remaining residents will be remembered when they die.

Annual services of remembrance for those who have died in the past year can be held and relatives invited. Homes could be made available to host receptions after funerals, which would allow other residents to attend.

## Resources

### Websites:

<http://www.endoflifecare.nhs.uk/eolc>

<http://www.goldstandardsframework.nhs.uk/>

[http://www.mcpcil.org.uk/liverpool\\_care\\_pathway](http://www.mcpcil.org.uk/liverpool_care_pathway)

A teaching resource is available through Macmillan's Professional Resources Quality Assurance Framework, including a rigorous peer review process. It enables care homes to address standard 11 of the National Minimum Standards for Care Homes for Older People.

Further information on resources is available within the **My Home Life** shared space.

This summary was written by Christine Moss in partnership with Katherine Froggatt for **My Home Life**.

The **My Home Life programme** is a UK-wide programme of work aimed at promoting the quality of life for those who are living, dying, visiting or working in care homes for older people.

**More information can be found on [www.myhomelife.org.uk](http://www.myhomelife.org.uk)**

