



End of life care for people with dementia living in care homes

Key messages

- It is not always easy to tell when people with dementia are approaching the end of life. This means they sometimes do not receive the care they would have wanted.
- We have limited knowledge of successfully carrying out people's wishes in advance care plans. This is particularly difficult if their advance care wishes are not the same as those of family members or professionals.
- Even when they are no longer able to make advance decisions to refuse treatment under the Mental Capacity Act, people with dementia may still be able to discuss their wishes as they approach the end of life.
- People should be given the chance to discuss advance care plans when or before they move into a care home. But if they do not want to express their wishes, this should also be respected.
- Care staff may find it difficult to talk about end of life care but training and support can help. It is also important to keep carers informed, especially if they would like to be involved in making decisions.
- Making treatment decisions for someone else puts an emotional burden on family carers and others involved in those decisions.

Introduction

This At a glance briefing summarises the research briefing *End of life care for people with dementia living in care homes* (SCIE 2012). Research briefings provide a concise, narrative summary of the research knowledge on a particular topic and signpost routes to further information.

At the moment around 16–20 per cent of all deaths take place in care homes. A high proportion of these deaths are likely to involve people with dementia.

Around 100,000 people with dementia die each year in the UK. By 2025, one in three people over 60 are predicted to die with dementia. So it is clear this group makes up a high – and increasing – proportion of those needing end of life care.

'By 2014, every person with dementia living in England should agree with the statement: "I am confident my end of life wishes will be respected. I can expect a good death."' (Department of Health 2010)

Our understanding and treatment of dementia has improved in recent years. However, people with dementia often continue to receive poor care. This is partly because the nature of dementia means that few people are able to say what their needs are. It is also because it is hard to know when someone with dementia is approaching the end of life.

The findings

Advance care planning (ACP)

Most people with dementia will probably reach a stage where they can no longer say how they want their treatment to continue. This makes advance care planning particularly important.

ACP usually involves discussions between the individual, professionals and – sometimes – carers, and leads to

‘Being able to plan in advance has given him the chance to remain in control in the future when he knows he will deteriorate.’

recording the individual’s wishes and choices at the end of life. Advance care planning can help to meet the decision-making requirements of the Mental Capacity Act 2005. It can also include advance statements to help future ‘best interests decisions’, an advance decision to refuse certain treatment and appointing lasting powers of attorney.

Moving into a care home is a good opportunity to develop or revise an individual’s advance care plan. Most care homes in England have policies that encourage residents to make these plans. This is not the case in all care homes. This is partly because staff think people with dementia are not able to give their opinion, and partly because they are reluctant to raise the issue.

Example: Robert's story

Robert (not his real name) has had Parkinson’s disease for 12 years and Lewy Body dementia for the past two years. He understands very well how his illness is likely to progress, and can say what he wants at the present time. It was his decision to record his choices of where he wants to be cared for during the rest of his life as well as some of the arrangements at his funeral. He also chose to nominate lasting power of attorney (health and welfare) if he lost the ability to make a decision about his care or treatment.

The conversations with professionals and his children were difficult and the process took time. But he says he trusts his children to honour his wishes and is glad to have had the opportunity to discuss things so openly. Being able to plan in advance has given him the chance to remain in control in the future when he knows he will deteriorate. The family say that knowing they did the best for their father will help them face whatever the future holds.

Even when someone has a statement of wishes and preferences it is not always followed. Staff may not know about it or they may not have the confidence to put it into practice. They may be afraid of legal action if they do not call an ambulance in an emergency. Or a family member may insist on sending the individual to hospital. Also, another professional may over-rule the individual’s wishes – and some hospital admissions are entirely appropriate.

Research suggests that making a statement of wishes and preferences also helps family carers.

The views of people with dementia

Studies show that people with dementia may want to discuss death and dying. But this sensitive topic may need to be introduced in stages.

One care home study showed that although people might say how they want to be cared for in complicated and vague ways, it was usually possible to work out what their wishes were. However, in another study, some residents seemed reluctant to talk about death and dying, while others said their plans were already ‘sorted out’. Some residents said that discussing this issue with staff had been helpful. However, staff often did not have enough time or simply did not want to get involved in these discussions.

A French study suggests that some professionals are too ready to believe that people with dementia feel the same about their care as their family carers. Sometimes, they were likely to make decisions with family carers without telling the individual with dementia.

Recognising the need for end of life care

The need for end of life care for people with dementia can easily go unrecognised – simply

‘Evidence shows that people with dementia are able to talk about death and dying and make decisions about their care.’

because staff do not realise that an individual is dying. In one US care home, for example, staff estimated that only one per cent of people with advanced dementia were likely to die in the next six months. In fact, 71 per cent died in this period.

Dementia can involve a long period of poor health punctuated by shorter periods of severe illness. It has been suggested that if an individual shows signs of advanced dementia combined with complications such as weight loss and multiple infections, then it is likely they are approaching the end of life. It is important for carers to recognise this stage so that they can offer 'palliative care' – where individuals are cared for and made comfortable only – and can prepare themselves.

Providing holistic care

Good end of life care should not just be about physical care. Family carers think that cleanliness, food and nutrition, and pain management are crucial. They also think that staff 'getting to know' the dying person is important.

Issues include:

Nutrition

Nutrition can be a problem as many people with advanced dementia can have problems swallowing. There is no good evidence that tube feeding is beneficial in this situation. Other solutions include: making sure that enough staff are available to help residents eat and drink orally; making food easier to swallow and having meals more often. Even when the individual has stopped eating, it is important to keep the lips moist and clean and offer sips of iced water or juice if they are still able to swallow.

Pain relief

There is no evidence that people with dementia suffer less pain. But as their condition advances they become less able to recognise pain and tell someone about it. In these circumstances, pain management depends on care staff using the appropriate tools to assess pain or recognising signs of distress. These can include physiological changes as well as changes in facial expression, movement and behaviour.

Spirituality

Most carers think that being with the dying person is an important part of good end of life care. Family carers also value empathetic care. However, staff shortages and a noisy, crowded environment can make it difficult to give this personalised care.

Experience of family carers

There seems to be an inconsistency in the level and quality of support for family carers of people with dementia.

The study identified three areas that were particularly difficult:

1. Unfamiliar territory

Family carers may not recognise the signs that an individual is approaching the end of life – for example, worsening cognition and not being able to speak. It is important that care home staff explain exactly what is happening. If they do not, carers may continue to decide on active treatments and see 'palliative care' as second best. It can be helpful to use information booklets to explain the situation.

2. Making decisions

Most carers want to be involved in decisions about their relative. However, some seem to feel they are expected to make decisions without enough information and preparation. Others feel they are marginalised by care home staff and are 'getting in the way'.

Carers are more positive if they think practitioners care about their dying relative. They value a 'warm atmosphere', and find any neglect of personal care and hygiene distressing. However, there is a tendency to confuse quality of life with

Example: Carers' story

A study of family carers of people with dementia shows the difficulty of some of the decisions they have to make. Carers often faced resistance from the person with dementia. They also had to become a patient manager and advocate, while remaining a family member.

Carers highlighted the benefits of getting a fresh perspective on decisions from other family members and organisations. But they often experienced role conflict and guilt. This was made worse if there were family disagreements, and is particularly evident in decisions about end of life. Those who chose more life-prolonging treatment seemed to be more likely to express regret. One carer recalled: 'My brother and sister ... wanted the drip, antibiotics and the oxygen reinstated ... and the doctor said "it will flood her heart" and she died a horrific death ... but my brother always said, "oh, where there's hope" ... There was no hope.'

quality of care so it is essential that carers are involved as much as possible in all decisions.

3. The grieving carer

At the end of life, carers have the dual role of grieving carer and decision-maker. Staff need to understand this and respond to their need for empathy, support, communication and guidance. The welfare of family carers is important in itself.

‘Resuscitation was the biggest decision ... I consulted with my children and my wife’s sisters and they were all in agreement ... she has gone through enough.’

Husband of young onset patient

Carers need to feel confident they can discuss their relative’s care in detail. It helps if these discussions begin before the end of life is imminent.

Training for staff

Many care staff feel that their knowledge and competence on end of life care is poor. They say they would benefit from additional training.

Most training seems to have positive results. Evaluations suggest they lead to greater staff satisfaction, a greater willingness to discuss end of life care issues and higher satisfaction among family carers. See *Further information*.

Measuring the outcomes of end of life care

A number of tools have been designed to measure pain or distress in people with dementia. These include the Abbey Pain Scale, the Disability Distress Assessment Tool (DisDAT) and the Pain Assessment in Advanced Dementia (PAINAD).

There are also tools to measure carers’ satisfaction such as the Satisfaction with Care at the End of Life in Dementia (SWC-EOLD) scale.

Studies show that using models leads to better communication between care staff and family carers, and greater confidence among all staff. However, more information is needed on the effectiveness of these models.

Further information

1. SCIE (2012) *End of life care for people with dementia living in care homes* (Research Briefing 40).
2. National End of Life Care Programme includes material aimed at care homes, www.endoflifecareforadults.nhs.uk
3. SCIE (ongoing) Dementia Gateway, www.scie.org.uk/dementia
4. SCIE (2011) End of life care hub includes Social Care TV films, www.scie.org.uk/endoflifecare

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