

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

By Jo Moriarty, Deborah Rutter, Paul D S Ross and Pamela Holmes

Key messages

- Dementia is a progressive condition but it is not always easy for care staff and family carers to tell when the end of life is approaching. This means that people with dementia sometimes do not receive the end of life care they would have wanted.
- People with dementia may be willing and able to discuss preferences even when they are no longer considered to have the capacity to make advance decisions in their legal form.
- Advance care plans, or similar expressions of views, are important ways in which people with dementia can express their wishes about end of life care. Not enough is known about how to implement these wishes effectively, especially where there is disagreement between a person's advance care wishes and the views of family members or professionals.
- When a person moves into a care home, there should be opportunities to discuss advance care plans sensitively at a carefully chosen time or when the moment arises. However, it is also important to respect the wishes of people who do not want to specify in advance what end of life care they wish to receive.
- There is little research on the provision of specialist palliative care support and the integration of services for people dying in care homes. There is also a lack of research on the training of care staff to recognise and respond to the need for palliative care.
- Care staff may find it difficult to raise the subject of end of life care, but training and support will help them become more confident.
- Making treatment decisions on behalf of another person places an emotional burden on family carers, but care staff can help by informing them about what is happening and what to expect. Good communication with staff is highly valued by family carers.

Introduction

This research briefing is about the care provided in care homes to people with dementia in the period leading up to the end of their lives. It aims to provide an overview of a range of issues important to care home residents, carers and providers.

The term 'family carer' as used in this briefing implies a person or people identified by the person with dementia (if possible) as important to them, and is intended to cover a spouse, partner, child, other relative or friend and supporter.

What is the issue?

End of life care and dementia care are areas of growing prominence in health and social care policy^{1,2,3} and there have been a number of government initiatives in England aimed at improving both end of life care^{4,5} and support for people with dementia.^{6,7} Specifically, the Government intends that 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.’ (p 12)⁷

Similar policy objectives for end of life care exist in the other UK countries^{8,9,10} and elsewhere (e.g. Australian Department of Health and Ageing).¹¹

Care homes play an important role in end of life care for people with dementia. It has been estimated that they are the location for around 16–20 per cent of all deaths.^{12,13,14} This proportion is even greater if the 15 per cent of people dying in hospital after having been admitted from a care home are included.¹⁵ Although it is not known exactly how many deaths in care homes are attributable to dementia, the high proportion of residents with dementia means that end of life

care for people with dementia frequently takes place in a care home.^{16,17,18,19}

‘End of life care is generally used to describe care for those who are approaching death, with a key goal being to make the person comfortable and attend to their needs and wishes as the end of their life approaches. This approach recognises that much can be done to maintain quality of life, even when a cure is no longer an option.’ (p 4)²⁰

According to the General Medical Council (GMC), people are approaching the end of their life when they are likely to die within 12 months. However, there is no single universally agreed definition of end of life care. In some contexts it is used to describe the care given in the last few months of a person's life or when their death is no longer unexpected, whereas in others it refers to the final few hours of life or even death itself.^{21,22}

The term 'palliative care' is often used to describe care for people who are approaching the end of life. The World Health Organisation (WHO) defines palliative care as:

‘...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’²³

Palliative care 'concentrates on the individual person rather than on the specific disease, affirms life and regards dying as a normal process, and intends neither to hasten nor to prolong death'.²⁴ Although people with cancer still make up the majority of those receiving palliative care, it is now recognised that palliative approaches can benefit anyone with a life-limiting condition, including dementia.^{24,25,26,27,28} The equal focus that is placed on the psychological, physical and social aspects of a person's life is sometimes termed 'holistic care'. The phrase 'comfort care' is also used in the US to emphasise the priority placed on making the dying person comfortable, rather than attempting a cure.^{29,30,31}

Mostly, we use the term 'end of life care' in this briefing, but we sometimes refer to 'palliative care' in discussions about medical interventions, resuscitation and specialist palliative care services. We searched for research evidence on end of life care for people with dementia in care homes (with and without nursing), using a variety of international terms and explicit inclusion criteria. We did not include hospice care in our searches, since UK hospice care is not often available to people with dementia, although reference is made to US research about hospice social workers³² and hospice care in-reach teams in care homes.^{28,33}

Why is it important?

Much has been done in recent years to improve our understanding of dementia. Drugs have been developed that may improve its symptoms, and it has been demonstrated that people with dementia can continue to enjoy a good quality of life. However, dementia continues to be a terminal condition^{34,35,36} and results in a shortened life expectancy.³⁷ Around 700,000 people in the UK today have dementia,³⁸ and around 100,000 people with dementia die each year.³⁹ When this number is set against the total of 493,242 deaths registered in England and Wales in 2010⁴⁰ it becomes clear that people with dementia make up a very high proportion of all those needing end of life care each year. This number is set to rise as the number of people with dementia increases.^{38,41} By 2025, one in

three people over the age of 60 will have dementia when they die.³⁹

It is often said that there is only one chance to get an individual's end of life care right,^{20,22} and people with dementia often receive poor care at the end of their lives.^{15,21,24,26,27,35,42,43} There are two main reasons for this.

- In comparison with people with time-limiting illnesses whose ability to communicate is not affected by their condition, few people with dementia will be able to express their needs and preferences for end of life care at the time they require it.^{30,44} This means that staff in care homes need to rely on a combination of information from advance care planning (ACP), information about a person's preferences from their own knowledge and that of other people who know the person with dementia well, such as family carers, and their own observations of levels of comfort and absence of pain.^{43,45}
- The particular challenge involved in recognising when a person with dementia is nearing the end of their life. The overall estimated median survival time from onset of dementia to death has been reported to be 4.1 years for men and 4.6 years for women, but these figures are estimates which are influenced by the stage of the disease at diagnosis: a person diagnosed with dementia late in the illness will naturally approach the end of life earlier.^{46,47}

Findings

Advance care planning (ACP)

Some of the most important questions that need to be asked when people approach the end of their lives concern the extent and type of treatment they wish to receive, such as whether they want to be resuscitated if their heart stops or be prescribed antibiotics if they develop an infection. The National Institute for Health and Clinical Excellence (NICE) Quality Statement 3 for end of life care states that 'people should be given the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment'.⁵ However, unless

individuals with dementia die earlier as a result of an illness or event unrelated to their dementia, they will probably reach a stage at which they can no longer communicate their treatment wishes.^{30,37,48} This makes ACP, and possibly an advance decision under the provisions of the Mental Capacity Act 2005, which applies to England and Wales, particularly important. Separate guidance applies in Scotland and Northern Ireland.

ACP has been described as a:

‘...voluntary process of discussion and review to help an individual with a progressive condition who has capacity to choose to set on record choices about their care and treatment – including the circumstances in which they want to refuse a treatment – in the event that they lose capacity to make these decisions once their illness progresses. These plans can then be referred to by those responsible for their care or treatment.’ (p 6)⁴⁹

ACP is a dynamic process of discussing and recording people’s preferences and choices, and existing plans should be consulted and reviewed as an individual’s condition changes. One advantage of the slowly progressive nature of dementia is that, if a person wishes, there is generally some opportunity to discuss end of life care⁵⁰ in contrast to those situations where life-threatening illnesses develop very rapidly. However, to be effective, systems also need to be in place to enable everyone involved in an individual’s care to be aware of the existence of an advance care plan and the wishes documented in it.⁵¹

Research undertaken outside the UK^{30,34,52} sometimes refers to ‘advance directives’ rather

than ‘advance care plans’ or ‘advance decisions’. Whichever term is used, the aim of the process is to ensure that care is more likely to be centred on the individual’s wishes rather than on the assumptions of those providing care.¹⁵

Under the terms of the Mental Capacity Act 2005, formalised outcomes of ACP might include one or more of the following:⁵³

- advance statements to inform subsequent ‘best interests’ decisions (sometimes called ‘statements of wishes’)
- advance decisions to refuse treatment which are legally binding if valid and applicable to the circumstances at hand
- appointment and registration of lasting powers of attorney (‘health and welfare’ and/or ‘property and affairs’).

Despite the importance given to ACP in policy documents, there is currently very limited UK-based evidence on ACP for people with dementia.^{51,54} This is important as research undertaken outside the UK will have taken place in different contexts. For example, advance care plans in the Netherlands usually relate to euthanasia,⁵⁵ whereas in the US they usually specify whether a person agrees to be resuscitated or tube fed.^{30,56}

Another difference between UK and US research identified for this briefing was the role played by social workers in ACP. In the US, many nursing homes employ social workers who play a major role in meeting families and residents on admission, informing them about care and treatment, encouraging them to document wishes and helping to resolve family conflict.^{57,58} However, we found no published UK research about how social workers can support people with dementia at the end of their lives within care home settings.

Moving into a care home provides an opportunity to develop, or revise, an advance care plan.^{45,59} In the US, where systems for recording advance care wishes have been formally established for longer, advance care plans for people with dementia seem to be more frequent – although

still less common than among people with cancer.⁶⁰ In one study of residents with dementia in nursing homes, 66 per cent of participants had an advance directive in their medical notes, although these tended to be worded in a quite generalised way and did not mention specific issues like wanting or not wanting to be given antibiotics or placed on a ventilator. White educated women were most likely to have made an advance directive while unmarried African American men were least likely to have made one, leading the researchers to consider whether some groups of people with dementia are in some way excluded from the process of ACP.³⁰ Interviews with surrogates able to make decisions on behalf of those participants in the same study⁵⁰ highlighted the varied way in which people with dementia had expressed their preferences for end of life care, with some reiterating their wishes throughout their lives, while others referred to their wishes indirectly, rarely, or not at all. (Surrogates or proxies are people – usually relatives – appointed by individuals with dementia to make decisions on their behalf when they no longer have capacity themselves.)

Another US study⁶¹ suggested that care home residents who were known to have held religious beliefs over their lifetime were *less* likely to have made an advance directive. A study of views of older people in good health included people who felt that ACP was neither necessary nor beneficial.⁶²

While many care homes in England have policies encouraging residents to make advance care plans, practice is much more variable.⁶³ This is partly because some care home staff think that residents with dementia will be unable to express their views about end of life care⁶⁴ and partly because staff may be reluctant to raise the issue.^{44,63,64,65,66}

This reluctance seems to be shared by other health and social care professionals who worry that if they introduce the topic too soon after diagnosis it might engender distress or despair, but if they leave it too late the person with dementia might lack the capacity to make such decisions.⁴³ A lack of confidence in working with

the Mental Capacity Act 2005 among groups such as specialist dementia nurses and workers in voluntary organisations may also act as a barrier to developing advance care plans.⁶²

Even where advance care plans exist, concerns have been expressed about the extent to which they are followed.⁶⁷ Staff may not know about their content or feel confident enough to implement them. For example, a care plan might include a preference to die in the care home rather than in hospital, but staff may be anxious that litigation will ensue if the dying person is not sent to hospital.⁶⁵ Alternatively, care home staff report that it is not uncommon for family members to insist on transfer to hospital *in spite* of the resident's expressed wish to die in a care home.⁶⁴ In other circumstances, the wishes expressed in a care plan may be overruled by other professionals, such as general practitioners (GPs) or ambulance crews, although interventions to improve inter-agency cooperation may result in greater consensus being achieved.⁶⁸ In the US, high rates of adherence to do-not-hospitalise (DNH) orders among people with dementia were observed in a study of one large nursing home, especially among those who had been living there for some time.⁶⁹ However, the needs of people dying with dementia may sometimes be complex, especially if a person has other health problems in addition to dementia, and it should not be assumed that all hospital admissions are inappropriate.³

As well as seeking to ensure that a person with dementia receives the end of life care they want, advance care plans have also been reported to benefit family carers. A US study found that the more time they spent discussing advance directives with a health care provider, the more satisfied health care proxies were with the care that the person with dementia received.⁴² Satisfaction with care may increase because carers understand better the outcomes of the treatment choices involved in supporting a person who is dying with dementia, or because they feel the responsibility is shared with a knowledgeable professional.

The emphasis in ACP is on treatment decisions (and indirectly therefore on preferred place of death). However, holistic care planning should offer opportunities for people – those with dementia, family and carers – to discuss wills, environmental comforts and stimuli, religious and funeral arrangements and anything else important to them.

Views of people with dementia

NICE Quality Statement 2 for end of life care advocates that 'people approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences'.⁵ However, as mentioned earlier, most people with dementia at the end of their lives have difficulty communicating. Indeed – as will be discussed in the next section – loss of the ability to speak is often seen as an indicator of the need for end of life care.^{25,35}

Despite this, two studies have shown that people with dementia living in care homes are able and willing to talk about death and dying.^{21,66} Godwin and Waters'²¹ small qualitative study of end of life care in different communal settings involved people with dementia and their key workers. They concluded that while some residents with dementia might express their preferences for end of life care in a complicated or obscure way, it was possible – through a combination of talking to the person with dementia, family carers and staff, and through observation – to put together a picture about attitudes to death and preferences for end of life care and funeral arrangements. However, some staff admitted that they avoided the topic of death, and tried to deliver their own interpretation of a 'good death' (such as flowers, music, etc.) even though this may not have suited the individual concerned.

Mathie et al.⁶⁶ also emphasised the ability of participants with dementia to talk about end of life care, in a study in which they interviewed care home residents up to three times during a year. While some appeared to be reluctant to talk about the issue, others reported they had

already made plans and were all 'sorted out'. The majority said they did not want to talk with staff about end of life care and arrangements, and some considered that arrangements should be made by their relatives. This evidence challenges a policy preoccupation with ACP and advance decisions, which appears to build on an assumption that care home residents will welcome discussion of death. However, residents also commented on the lack of time staff had for conversation, and a significant number remarked that the interviews had been helpful. Some participants said they wanted to talk about dying and end of life care but felt that staff lacked the time or inclination to talk to them.

Where research evidence for care in a particular setting is limited or lacking, it is sometimes possible to look at the results from research in related settings. Tyrrell et al.⁷⁰ looked at five aspects of decision-making in their interviews with 21 pairs of people living at home with early-stage dementia and their family carers in France:

- information received
- being listened to
- expression of opinion
- time allowed to reflect on decision
- possibility of changing one's mind.

Participants were considering whether to accept help at home, attend a day centre or move into residential care. Those with dementia reported very mixed experiences in terms of their involvement in decision-making with some considering they had been listened to while others felt they had been given no opportunity to express their views. Most felt their time for reflection had been too short, and that choices would be difficult or impossible to modify. The family carers, on the other hand, felt that professionals had on the whole listened to their views and that they had had adequate time to form their opinions. The authors concluded that professionals were too ready to assume that the views of family carers and people with dementia coincided and that they sometimes made

decisions with family carers without informing the person with dementia.

Samsi et al.⁶² explored the experiences, opinions and attitudes of 37 older adults living at home regarding planning for their future in the context of the Mental Capacity Act 2005. They asked participants for their views on drawing up statements of wishes and documenting their decision-making preferences. They found that the tendency to plan, or not to plan, was a personal lifelong preference and that very few participants were familiar with the Act and the possibility of drawing up an advance care plan. People with family were more inclined to assume that their relatives would act in their best interests if they lost capacity, whereas those without kin were more aware of the need to record their wishes. The latter group were especially aware of the need for an advance care plan because their friends, being of a similar age, could develop health problems that would prevent them from acting on their behalf. This briefing cannot address the issue of who is accepted as an appropriate surrogate decision-maker, but friends, partners (including same-sex partners) and children of the person may all be contenders, and may not agree with one another about the best course of action.

Overall, available studies suggest that people with dementia may be willing and able to discuss ACP and more general issues concerning end of life care, but that this is a sensitive topic which requires careful and possibly staged introduction.

Recognising the need for end of life care

NICE Quality Statement 1 for end of life care calls for people approaching the end of life to 'be identified in a timely way'.⁵ However, the need for end of life care in dementia can easily go unrecognised^{21,56} simply because staff do not realise that a person is dying.^{1,25,26,71} For example, one US study found that just 1 per cent of a sample of people with advanced dementia moving into a care home were expected to live for less than six months, while 71 per cent went on to die within this period.⁶⁰ Care staff may be

more likely to recognise the approach of death if they have known the person for some time.⁶⁵ However, better knowledge of events in late-stage dementia might help to improve the quality of support that care staff can give, and help prepare family carers for what is likely to happen.^{2,72}

Studies of death^{73,74} have shown that – in contrast to illnesses where death is preceded by a short period of evident decline, as often happens with cancer – dementia can progress more gradually,^{2,74} often punctuated by steeper declines caused by bouts of acute illness.³⁵ The person with dementia may eventually die after an infection such as pneumonia⁷² or from complications following a fracture.^{35,74} Dementia is then a contributory factor, rather than the primary cause of death.

In the final months of their lives, people with advanced dementia may experience symptoms such as pain, depression, incontinence, constipation, appetite disturbance, breathlessness, difficulty swallowing, weight loss, dehydration and pressure sores.^{27,44} It has been suggested³⁵ that where signs of advanced dementia – for example, no longer being able to walk or hold a meaningful conversation, and being dependent in most or all activities of daily living (ADL) such as washing or dressing – are combined with developing complications such as weight loss, recurrent infections, multiple pressure sores, hip fracture or pneumonia, then it is likely that a person with dementia is approaching the end of their life. Identifying this stage is important to the provision of good palliative care. It is also important to carers (both professional and family members)^{3,75,76} that they recognise this stage, so as to prepare themselves and support the best possible death.

Access to specialist palliative care and support

Identifying the onset of death is important to the provision of palliative care, and may trigger greater vigilance and attention to the assessment of pain and the reduction of other treatments. Palliative care aims to improve quality of life for

patients and families by preventing and relieving suffering. NICE Quality Statement 10 highlights the need to ensure that people living in care homes are able to access specialist palliative care services by stating that: 'people approaching the end of life who may benefit from specialist palliative care [should be] offered this care in a timely way appropriate to their needs and preferences, at any time of day or night'.⁵

A distinction is sometimes drawn between palliative care provided in mainstream settings and that provided by workers in specialist palliative care teams.^{27,37,77} UK evidence suggests that people with dementia have very limited access to hospice care⁷⁸ as well as to specialist palliative care teams and medicines while in hospital.⁷⁹ The use of life-prolonging treatment, alongside or in place of palliative care, is another issue. There are US studies on the extent to which people with advanced dementia receive treatments such as resuscitation or antibiotics which may prolong life but make it more uncomfortable^{34,60,80,81,82} but we did not find comparable UK-based studies looking at this issue. The use of life-prolonging treatment may well entail moving the person from the care home to an acute hospital, and this is rarely considered beneficial for people with dementia in the final stage of life.^{67,69}

An alternative approach to admitting people resident in a care home to a hospital or hospice at the end of their lives is to provide specialist palliative support to care homes to enable them to continue to support the person with dementia until their death. However, there is limited evidence about the effectiveness of this approach.⁷⁸ A systematic review of interventions to improve palliative care in nursing homes²⁴ identified only three studies, all based in the US, that met all its inclusion criteria, two of which looked at access to specialist palliative support.^{33,83} Despite the methodological limitations of these studies, there is some evidence that staff in specialist palliative units report greater job satisfaction and empathy and less discomfort among residents⁸³ than do staff providing end of life care in general nursing home settings. There is also evidence that family

carers appreciate formal assessment of their loved one's end of life needs.³³

In the UK, people living in care homes are generally reliant on access to palliative care services mediated by their GP,^{1,84} but we know very little about whether this ensures that they receive appropriate specialist palliative care. A survey of care homes in England found problems in accessing support for end of life care, including variable support and reluctance to prescribe appropriate medication among GPs, lack of support from other agencies, including out-of-hours support, cost of equipment and inadequate training.⁸⁵ GPs themselves report difficulty in assessing a person they may never have met, and suggest that clear guidelines and protocols would help them to decide what the best approach should be.⁸⁶

A forthcoming study is testing how building relationships between organisations can improve teamwork between staff in care homes, community nurses, GPs and family carers, thereby improving continuity of care and outcomes.⁶⁸

Providing holistic care

NICE Quality Statements 4, 5 and 6 state that people in the last days of life should be offered timely and personalised care 'including rapid access to holistic support, equipment and administration of medication', 'support for their social, practical and emotional needs, which is appropriate to their preferences' and 'spiritual and religious support appropriate to their needs and preferences'. Holistic care at the end of life will include palliative care, and given the variability in access to palliative care specialists (see above), care home staff will often be responsible for delivering holistic palliative care. Unsurprisingly, concerns are frequently expressed about the quality of care provided in a range of end of life settings.^{15,25,29,43} Family carers in particular believe that attention to cleanliness, comfort, food and nutrition, along with management of pain, are crucial to ensuring that people with dementia receive good quality end of life care. However, they also feel that simply providing physical care is not enough and that

'getting to know' and caring about the dying person are essential as well, especially in the assessment of needs.^{43,87}

It is impossible to cover every aspect of holistic support here, thus we have singled out a few areas that are often problematic for carers of people with dementia. Nutrition becomes an important issue in end of life care because difficulty in swallowing is very common among people with advanced dementia. Concerns that the person with dementia is not eating or drinking enough can create anxieties for care staff⁸⁸ and family carers.⁴³ This can create pressures to use artificial methods of nutrition and hydration such as a nasogastric tube (a tube that is passed through the nose and into the stomach) or a percutaneous endoscopic gastrostomy (PEG) (where a feeding tube is inserted into the stomach and is accessed through a permanent incision in the abdominal wall). However, a Cochrane Review⁸⁹ concluded that there is no evidence to suggest that either type of tube feeding is beneficial for people with advanced dementia.

Joint advice from the Royal College of Physicians (RCP) and the British Society of Gastroenterology (BSG)⁹⁰ recommends using alternative approaches, such as ensuring that there are enough staff to help people with advanced dementia to eat and drink orally, adjusting the consistency and presentation of food so that it can be safely swallowed and increasing meal frequency to help improve the overall calorie intake. However, in the last few days or hours of life, a person with dementia may show no appetite for eating or drinking. In these circumstances it is important to maintain oral comfort, such as making sure that the lips are moist and clean and offering sips of iced water or juice if the person is still able to swallow.⁹¹

Pain relief is another problematic area. Self-report is often thought to be the 'gold standard' for assessing pain because it emphasises the importance of an individual's own perceptions.⁹² However, because memory, judgement and verbal communication have been affected, self-report is less reliable as a way of assessing pain in people with advanced dementia.^{28,35,59,93,94} There is no

evidence that people with dementia experience less pain, although they may be less able to verbally communicate it.⁹⁵ This has led to considerable concern that people with advanced dementia might be in pain that is neither detected nor adequately treated.^{25,27,59,93}

Good pain management depends on the ability of care staff to recognise signs of distress.^{25,94} These can include changes in facial expression and movements, the sounds a person makes (vocalisations) and behaviours, as well as physiological changes such as raised temperature, sweating or changes in pallor.^{43,48,93}

Spirituality is an essential component of the care of patients with life-limiting conditions and those who are dying, but there appears to be almost no published research looking at the spiritual needs of people with dementia at the end of their lives, although there is increasing interest in the topic in general.⁹⁶ Godwin and Waters²¹ found that very few staff had any knowledge of the end of life preferences of the people with dementia included in their study, and that knowledge was more likely to concern treatment decisions than wishes concerning access to religious support.

There is a long established literature (e.g. Field⁹⁷) suggesting that practitioners believe that 'being with' the dying person is an important part of providing good quality end of life care.^{21,76} Family carers want care that is delivered with empathy and goes beyond simply tending to their relatives' physical needs.⁴³ Two Canadian studies^{75,76} and one from the US⁹⁸ have commented on the difficulties of providing personalised care when there are not enough staff and where the physical environment is noisy and crowded.

Experience of family carers

NICE Quality Statement 7 for end of life care states that: 'Families and carers of people approaching the end of life [should be] offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences'.⁵ The limited evidence

available suggests that both the levels and quality of support for family carers whose relatives require end of life care are very mixed.

Hennings et al.² undertook a systematic review to identify what is currently known about family carers' needs and their experiences of end of life care. The accounts of carer experiences highlighted three broad themes:

- 'unfamiliar territory'
- making decisions
- the grieving carer.

The phrase 'unfamiliar territory' was used to describe family carers' lack of knowledge and experience about end of life care. Like care professionals themselves,^{35,73} many family carers find it difficult to recognise the significance of indicators of the end of life, such as worsening cognition or the inability to speak.⁹⁹ They are then unprepared for making decisions about nutrition and hydration, transfers to hospital, the use of antibiotics and resuscitation, all of which are highly emotional issues.¹⁰⁰ This highlights the importance of good communication between care staff and family members.³ The failure of staff to explain to family carers exactly what is happening and why can mean that carers sometimes decide that palliative care is second best and may opt for active treatments such as tube feeding or antibiotics, even when these may not be beneficial.²

Evidence from two studies, one Australian¹⁰¹ and one Canadian,³¹ suggests that information booklets are helpful for family carers. In the Australian study, staff in a dementia residential unit developed a booklet for carers which was evaluated very positively by almost all those who received it. In the Canadian study a booklet developed for staff as part of an educational intervention was also shared with family carers. The carers who received it seemed to be more satisfied with the end of life care given in one nursing home than those who did not.

While most family carers do wish to continue to be involved in making decisions about their relative's care, there are some who do not.²

Accounts suggest that some carers feel that they are expected to make decisions when they feel unprepared and ill-informed to do so, while others feel that they have been marginalised by care home staff and are 'getting in the way'.³

Wendler and Rid¹⁰² undertook a systematic review of the effects on surrogates of making treatment decisions for others. Not all surrogates are family carers – lawyers or medical staff may also act as surrogates – but in reality the overwhelming majority of surrogates are related to the person on whose behalf they are making decisions.^{50,69,72,100,102,103,104} From a total of 40 studies, Wendler and Rid found that making treatment decisions has a negative emotional effect on at least a third of surrogates, which is often substantial and typically lasts for months or even years. Examples of the most commonly reported stressors include:

- being unsure of the preferences of the person needing end of life care
- being uncertain about what is likely to happen to the person needing end of life care (prognosis)
- feeling uncomfortable in the care setting
- poor communication
- conflict within the family or with those providing care
- insufficient time to make decisions
- having a sense of sole responsibility
- uncertainty or guilt about decisions.

ACP may reduce, but not eliminate, the potential for stress in taking such decisions. Two studies^{50,105} reported that family carers found it easier to make decisions if they knew what views the person with dementia held, before losing capacity, about what they would want to happen at the end of their lives. Livingston et al.⁶⁵ also emphasised the benefits for family carers of having a clear idea of the person with dementia's prognosis and support from other family members.

Lawrence et al.⁴³ found that end of life care was evaluated positively by family carers if it was felt that practitioners also cared about their dying

relative. Families prioritised a 'warm atmosphere' where people with dementia were made to feel relaxed and safe, but found failures to attend to personal care or hygiene extremely distressing. An Australian study⁸⁷ suggested that family carers sometimes conflated quality of life and quality of care. Both studies concluded that, because perceptions of quality of life are so personal, it is essential for care staff to involve family carers as much as possible in all decisions. Wendler and Rid¹⁰² found that family carers sought to personalise relationships with caring staff in order to gain support, increased confidence in the care of loved ones and hopefully greater peace of mind. This presents opportunities to develop good communication between relatives and staff so that care decisions are shared and understood, and carers (informal and paid) feel that the best interests of the person with dementia are observed. However, staff may lack confidence in their own knowledge and ability to care for the dying person's holistic needs, which may hamper communication.⁴³ This issue is considered in the next section.

Hennings et al.² described family carers of people with dementia at the end of their lives as undertaking the 'dual role of grieving carer and decision-maker' (p 123) and highlighted the importance for care staff of responding to carers' needs for empathy and support, communication and guidance. The welfare of family carers is important in itself, but is not discussed further as our research briefing did not include interventions to support carers.

Training for staff delivering end of life care

NICE Quality Statement 15 for end of life care states that 'health and social care workers [should] have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers',⁵ but research suggests that many care staff feel they would benefit from additional training in providing end of life care.

Staff may feel ill-equipped and uncomfortable about broaching the topic of death.⁶⁵ Lack of

confidence in their knowledge may be one reason why they are sometimes reported to be reluctant to talk about end of life care^{45,65,71} and they are often aware of the limitations in their knowledge.⁴⁸ Knowledge gaps identified by staff include provision of everyday care (for instance, helping someone who has difficulty eating), management of ethical dilemmas (such as what constitutes withholding treatment)¹⁰⁶ and palliation (such as recognising and managing pain).⁴⁸ Without further training, care home staff may be unable to communicate sensitively to family carers the complexity, uncertainty and unpredictability of end of life dementia.⁶⁵

As well as training, care home staff may also need support to help them deal with their own grief as residents approach the end of their lives.^{65,67,75} Managers and nurses in one UK study⁶⁴ believed that some care home staff had difficulty with ACP because of their cultural beliefs.

Social workers play an important role in helping people with dementia take the decision to move into a care home, but we found little evidence that they were involved with this group and their carers thereafter, or of a palliative social work presence in UK care homes. As noted above, this contrasts with their documented involvement in similar US contexts.^{57,58} What these discrepancies suggest is that UK care home staff take on complex roles which in other contexts might be the responsibility of more highly qualified professionals.

Training interventions on end of life care for care home staff have generally reported positive results in terms of staff satisfaction and knowledge,^{106,107} greater willingness to discuss end of life care with residents¹⁰⁸ and satisfaction on the part of family carers with the care that staff have given.³¹

Measuring the outcomes of end of life care

Measuring the quality and outcomes of end of life care for people with dementia is difficult.^{24,26,109} Standard measures of quality and efficacy of care, such as survival times, may not be appropriate. People in the advanced stages of dementia may

be unable to use self-report quality of life rating scales, and reports from proxies such as care staff or family carers may not always be accurate.²⁶ Standard measures of disability that gauge how well a person can undertake ADL, such as washing and dressing, may be inappropriate for someone highly dependent on active support, and insufficiently sensitive to measure change because they tend to ask simply for 'yes' or 'no' answers.³⁶ It is important to use assessment tools designed for people with dementia, such as the FAST (Functional Assessment Staging Tool).¹¹⁰

Relief of pain and distress is a vital aspect of end of life care and recording the presence or absence of pain systematically is one way of trying to ensure that it is recognised and treated.¹⁰⁸ There is growing interest in developing suitable scales to measure pain or distress in people with dementia and other communication difficulties. These include the Abbey Pain Scale,⁹³ the Disability Distress Assessment Tool (DisDAT)⁹⁴ and Pain Assessment in Advanced Dementia (PAINAD).¹¹¹ However, it has been suggested that the psychometric properties of the most commonly used pain scales for people with dementia are limited¹¹² and opinions vary as to the best pain assessment tool that is currently available.

Hall et al. suggest that in view of the holistic nature of end of life care, measures concerning satisfaction with such care should cover improvements in physical symptoms, and how psychological and spiritual needs have been addressed, as well as satisfaction with care.²⁴ Family carers' satisfaction with care can also be measured through the Satisfaction With Care at the End of Life in Dementia (SWC-EOLD) scale¹¹³ which measures relatives' or proxies' satisfaction with the end of life care received by those who have died with advanced dementia.

*The end of life care strategy*⁴ and *Living and dying well*⁹ both recommend the use of tools such as the Gold Standards Framework in Care Homes (GSFCH)¹¹⁴ and the Liverpool Care Pathway (LCP) for the Dying Patient¹¹⁵ as a means to improve end of life care.³ Two studies undertaken in England⁷¹ and Scotland³ evaluated the effects of implementing the GSFCH and the LCP in care

homes. Both reported that these models led to better communication between care staff and family carers and greater confidence among care staff, GPs and other health professionals in implementing end of life care.

There is a distinction to be drawn between measures used to evaluate different approaches to care, and those used as part of care itself. A tool to measure or assess the experience of pain, and the need for pain relief, can fulfil both functions. Both types of measure are important in the care of people with dementia, where communication with the person is difficult.

Gaps in the research evidence

Research evidence on end of life care for people with dementia has developed comparatively recently and therefore, despite increases in knowledge,²⁷ there is still a need for further research.¹¹⁶ The majority of studies identified for this briefing were undertaken in the US, where service organisation, legal arrangements and funding are very different. Two major UK studies on end of life care in care homes⁸⁴ and ACP⁵⁴ are now nearing completion.

The views of people with dementia are strikingly absent from the majority of studies in this area. One review identified a total of 68 papers about end of life care for people with dementia, of which just six included direct evidence from people with the condition.¹⁵ While people in the early stages of dementia feel excluded from decision-making,⁷⁰ we know even less about how people with more severe dementia are helped to make decisions about the end of their lives.

Little research has focused on the detail of the experiences of people with dementia leading up to the last days of life. Particular deficits in the literature concern the important areas of spiritual and psychosocial support, and the extent to which 'spending time' with the dying person²¹ improves the experience of end of life care for all those involved.

The cost-effectiveness of palliative care and hospice interventions are rarely reported.¹¹⁷ Only

one study discussed the costs of implementing changes to end of life care,⁷¹ but pointed out that when a patient is admitted to an acute hospital from a care home, their place in the care home is kept open, even though they are not physically there. This highlights the need to identify agreed methods or models for costing different options for end of life care.

Two UK studies have raised the question of how the cultural background of staff impacts on attitudes to end of life care,^{3,64} while a US study shows variation in recording of residents' advance care plans according to ethnicity.³⁰ One UK study¹¹⁸ has suggested that Chinese older people would prefer to die in a hospital than in a hospice. Research should consider the sociodemographic characteristics of people with dementia (and care staff), as personalised care should reflect cultural differences and preferences.

Similarly, we know very little about the experiences of end of life care for people with dementia and an intellectual disability. This group may develop dementia at an earlier age and they and their family carers may require differently tailored support.^{88,106}

The role of social workers in supporting people with dementia at the end of their lives^{32,58,119} is strikingly absent from the UK literature, although they may make arrangements for people to move into a care home.

There is a need for more research evaluating whether the use of tools such as the GSFCH and LCP improves the support given to carers,^{3,71} and whether the provision of information in formats such as leaflets^{31,101} helps improve communication between care staff and family carers.

Conclusions

Although there is increasing interest in end of life care for people with dementia, UK-based evidence remains limited and the results from other countries with different funding systems and with different cultural approaches to death and dying may not be directly transferable.

There is evidence that people with dementia are able to talk about death and dying and make decisions about their end of life preferences. However, we know very little about the extent to which they are able to achieve their wishes and what happens if their wishes differ from those of their family carers or from health and social care professionals in charge of their care.

The support available to family carers of people with dementia living in care homes at the end of their lives is mixed, despite the fact that they may be under considerable stress, particularly if they are asked to take decisions that they suspect will shorten the life of the person for whom they care.

Care staff lack confidence in helping people with dementia to plan their end of life care, but training can help increase that confidence. The use of tools such as the GSFCH and LCP may help. Advance care plans can assist people with dementia to state their preferences about the end of life care they wish to receive, and the recording of such wishes can reduce family carers' stress if they are asked to make decisions according to their understanding of what the person with dementia would have wanted. However, it is important to respect people's wishes not to specify the end of life care they want. We need to know more about the complexities of cultural and personal preferences for different forms of end of life care.

Implications from the research

For the policy community

- The target for end of life care – that every person with dementia will be confident that their end of life wishes will be respected and that they can expect a good death⁷ – is extremely challenging, given the current evidence.
- There is a need to know more about how care homes access specialist palliative care services for their residents with dementia. This is an issue of equality and discrimination, and is of growing importance as the number of people

dying with dementia increases. Commissioners need to consider how care homes can be involved in and supported to deliver excellent end of life and palliative care.

- Care home staff and other health and social care professionals report their current knowledge of and competence in delivering end of life care to people with dementia as poor. If inappropriate admissions to hospital at the end of life are to be reduced, there is a need to ensure that health professionals working outside acute hospitals, as well as social care staff, have sufficient knowledge about the likely progression of symptoms and end of life care for people with dementia.
- The public could benefit from education about ACP in particular, and understanding about dementia in general.

For care home managers and care staff

- Care staff may be reluctant to discuss end of life care but there is evidence that training increases confidence in this area. Training needs to refer to ACP, progression of dementia, palliative and holistic care, and communication with residents and family carers.
- A range of tools have been developed to support care homes in delivering better end of life care. However, more information is needed on their effectiveness.
- Care homes should review residents' care plans to see if there is evidence of an advance plan, while accepting that not all people will want to make one.
- Many people with dementia are willing and able to talk about dying and their wishes for end of life care.
- Family carers value good communication and it is important that care home staff ensure that those who wish to be involved in the care of their relative are informed and supported, and know what to expect.
- Care home staff and managers also need to recognise and address the psychological impact on their own wellbeing when a resident dies.

- End of life care encompasses attention to psychological, social and spiritual needs as well as to a person's physical or treatment needs.

For people with dementia and family carers

- ACP allows a person with dementia to specify the end of life care they want. Family carers can help their relative discuss their preferences while they have the ability to do so, and can also highlight them to care staff.
- Being confident about what the person with dementia would have wanted helps family carers make decisions and may help the process of bereavement.
- Carers need to recognise that being involved in end of life decision-making can be stressful. They need to feel confident that they can discuss the progression of symptoms, and how they will be addressed, with care home staff, and that it may be helpful for them if such discussions begin before end of life is imminent.
- People with dementia and their carers should be encouraged to discuss and record psychological, social and spiritual needs and preferences, as well as treatment preferences.
- Residents and carers from varied ethnic and cultural backgrounds may have particular preferences for end of life care. They should be encouraged to discuss and record these.

For researchers

- Despite the increasing number of people dying with dementia in care homes, and a policy objective to reduce last-minute transfers to acute hospital settings, there is a lack of research on end of life care in the care home context.
- Research is needed to clarify what support, local arrangements and partnerships care homes need to improve end of life care for people with dementia. This research should take account of the experience and wishes of people with dementia and their families, and investigate cultural differences and preferences.

Useful links

National End of Life Care Programme for England

Includes material aimed at care homes:
www.endoflifecareforadults.nhs.uk/

Also includes a guide on ACP and capacity:
www.endoflifecareforadults.nhs.uk/

NICE

NICE Quality Statements for end of life care
www.nice.org.uk/guidance/qualitystandards/

Dying Matters

Coalition of health and social care organisations. The website has a number of free resources, including leaflets suggesting how to start conversations about end of life wishes:
www.dyingmatters.org/

National Council for Palliative Care

Has produced a useful document called *Difficult conversations: making it easier to talk to people with dementia about the end of life*:
www.ncpc.org.uk/

General Medical Council

Has published *Treatment and care towards the end of life: good practice in decision-making* online at: www.gmc-uk.org/

Liverpool Care Pathway

Information on the LCP can be found at:
www.liv.ac.uk/mcpil/liverpool-care-pathway/

Gold Standards Framework

The GSFCH can be found at:
www.goldstandardsframework.org.uk/

Alzheimer's Society

Leaflet explaining what is likely to happen in the later stages of dementia, including the end of life:
<http://alzheimers.org.uk/>

Related SCIE resources

The Social Care Institute for Excellence (SCIE) has produced a series of resources aimed at improving end of life care:
www.scie.org.uk/adults/endoflifecare/index.asp

The Dementia Gateway is especially designed for staff working with people with dementia in care homes and in home care:
www.scie.org.uk/publications/dementia/index.asp

Other SCIE briefings have specifically looked at care in care homes and dementia.
Communication training for care home workers: outcomes for older people, staff, families and friends:
www.scie.org.uk/publications/briefings/briefing34/

Black and minority ethnic people with dementia and their access to support and services:
www.scie.org.uk/publications/briefings/briefing35/

Aiding communication with people with dementia:
www.scie.org.uk/publications/briefings/briefing03/

Supporting people with dementia and their carers in health and social care:
www.scie.org.uk/publications/misc/dementia/

eLearning: Mental Capacity Act
www.scie.org.uk/publications/elearning/mentalcapacityact/index.asp

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About the development of this product

Scoping and searching

Three pre-scopes were undertaken in July 2011 due to the variety and amount of content on the topics of dementia, care homes and end of life care. A research analyst reviewed the data from the pre-scopes and drafted inclusion and exclusion criteria to inform subsequent searches. Full searching began in August through to November 2011. Additional searching was undertaken for user views and carer views, along with searching in key journals: both were completed in December 2011.

Peer review and testing

The authors have research and topic expertise. This research briefing was peer reviewed both internally by Professor Mike Fisher and externally by Professor Malcolm Payne. The authors would also like to thank, Professor Claire Goodman and the EVIDEM team, Professor Jill Manthorpe and Professor Steve Iliffe.

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Fifth floor
2-4 Cockspur Street
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