**Keywords** Dementia/Palliative care/End-of-life care

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## In this article...

- What dying with, or as a result of, dementia might involve and why good palliative care is needed
- Why recognising pain is important in palliative dementia care
- How to reconsider goals of care when a person with dementia nears the end of life

# Dementia 7: palliative and end-of-life care for people with dementia

### Key points

**People can die both with or from dementia**

**Determining when a person with dementia is dying is not easy**

**Impeccable assessment of the needs of people with advanced dementia is essential to ensure good palliative care**

**Dementia and frailty often coexist and both are considered life-limiting conditions**

**Family carers of people nearing the end of life need support in their own right**

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**Abstract** Having a diagnosis of dementia can significantly reduce a person's survival time from the onset of symptoms, such as pain, dyspnoea and terminal agitation, and has been shown to be similar to that of some cancers. With growing numbers of cases of dementia expected over the coming decades, we can also expect to see an increase in the number of people who die with dementia (when another comorbid condition causes their death) or from dementia (when there are no other contributing diseases). Supporting good-quality palliative care for people with dementia will be required of all nurses and clinicians in all care settings. This seventh and final article in our series on dementia emphasises that greater awareness of the palliative and end-of-life care needs of people with dementia, and of the needs of family members who are close to them, can improve outcomes as well as the quality of life and death.

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The global population is ageing and people are living longer (World Health Organization (WHO), 2022). However, with these extra years comes an increase in general ill health and disability (Rechel et al, 2020). The higher disability rates among older people are as a result of an accumulation of health risks across a lifespan of disease, injury and chronic illness (United Nations, nd).

The increased ageing and morbidity of the UK population is driven by several factors, such as improvements in life expectancy, resulting from a decrease in the number of deaths in early life from infectious disease, and an improvement in the management of other conditions, such as cardiovascular disease (Office for National Statistics (ONS), 2018).

The treatment and survival rates of some cancers is also improving, so more people are living to old age. This has led to an increase in the number of people living long enough to develop a range of conditions that are associated with old age, in particular neurodegenerative diseases such as dementia (Sampson and Harrison Dening, 2020).

## Dying with, and from, dementia

Dementia has not traditionally been seen as a 'terminal' or 'life-limiting' syndrome but a median survival time of 4.5 years from symptom onset of dementia to death has been reported (Xie et al, 2008) and Rait et al (2010) found that the median survival time from the diagnosis of dementia was 3.5 years. However, the data is based on an average life span, so the survival time will very much depend on the stage at which the diagnosis of dementia is made. Some people, especially those with a young-onset dementia, may experience marked delays in gaining a diagnosis, so the time from diagnosis to death is reduced (Loi et al, 2022).

In their longitudinal cohort study, Xie et al (2008) also went on to conclude that one in three people (around 30%) aged ≥65 years will die with, or from, dementia.

When we consider people who are in the advanced stages of dementia – as defined by a Functional Assessment Staging Tool (Reisberg, 1988) score of ≥7c) (Box 1), the median survival time is 1.3 years. Thus, to contextualise this, the life expectancy of a person with advanced dementia is similar to that of well-recognised terminal diseases, such as metastatic breast cancer (Mitchell et al, 2009).

People with advanced dementia will experience a range of symptoms, similar to those found in the terminal stages of cancer, for example:

- Pain;
- Dyspnoea;
- Pressure sores;
- Terminal agitation;
- Eating problems.

These are all very common as the end of life approaches. However, in people with dementia, these are often poorly assessed and managed due to a lack of recognition when a person stops living with dementia and starts to die with dementia (Sampson and Harrison Dening, 2020).

## Recognising when a person with dementia is dying

Recognising when a person with dementia is reaching the end of their life can be challenging. Many researchers have attempted to identify the prognostic indicators and tools that may guide nurses and other clinicians as to when to adopt a palliative approach to the person's care. However, such tools are often felt to be more reliable in identifying people with dementia who are at low risk of dying rather than those who are at a high risk of death (Sampson and Harrison Dening, 2020; van der Steen, 2010).

Van der Steen (2010) suggested that clinical judgment, discussions with family members and carers, and taking the opportunity to reassess or shift the goals of management towards palliative care at times of intercurrent illness (such as pneumonia or urinary tract infections) or transitions in care may be a more practical and reliable approach.

It is essential to consider that people can die both with, or from, dementia. Some people may have dementia only and no other conditions, but some may have multiple conditions as well as their dementia – such as cancer or heart failure – that may be the primary cause of any decline and subsequent death (Sampson and Harrison Dening, 2020). These differing scenarios – dying with or dying from dementia – do not make it easy to identify when a palliative approach to care and a shift in goals is appropriate.

### Box 1. Functional Assessment Staging Tool (FAST)

**Stage 1**
No difficulty, either subjectively or objectively

**Stage 2**
Complains of forgetting the location of objects. Subjective work difficulties

**Stage 3**
Decreased job functioning that is evident to co-workers. Difficulty travelling to new locations. Decreased organisational capacity

**Stage 4**
Decreased ability to perform complex task – for example, planning dinner for guests, handling personal finances (such as forgetting to pay bills)

**Stage 5**
Needs help to choose appropriate clothing to wear for the day, season or occasion (may wear same clothing repeatedly)

**Stage 6**

- 6a – difficulty putting clothes on properly without help
- 6b – unable to bathe without help
- 6c – unable to handle mechanics of toileting
- 6d – experiences urinary incontinence (occasional or more frequent)
- 6e – experiences faecal incontinence (occasional or more frequent)

**Stage 7**

- 7a – ability to speak is limited to approximately six intelligible words or fewer
- 7b – speech is limited to the use of a single intelligible word in an average day
- 7c – ambulatory ability is lost (cannot walk without personal help)
- 7d – cannot sit up without help
- 7e – loss of ability to smile
- 7f – loss of ability to hold up head independently

Source: Adapted from Reisberg (1988)

## Palliative care in dementia

The WHO (2020) defines palliative care as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual".

The European Association of Palliative Care (EAPC) published a consensus statement defining the principles of palliative care for people diagnosed with dementia (van der Steen et al, 2014). Leading this EAPC taskforce, van der Steen and colleagues undertook a Delphi consensus of experts in the field of dementia and palliative care to develop a set of recommendations for optimal palliative care in older people with dementia. The resultant recommendations have been valuable in terms of:

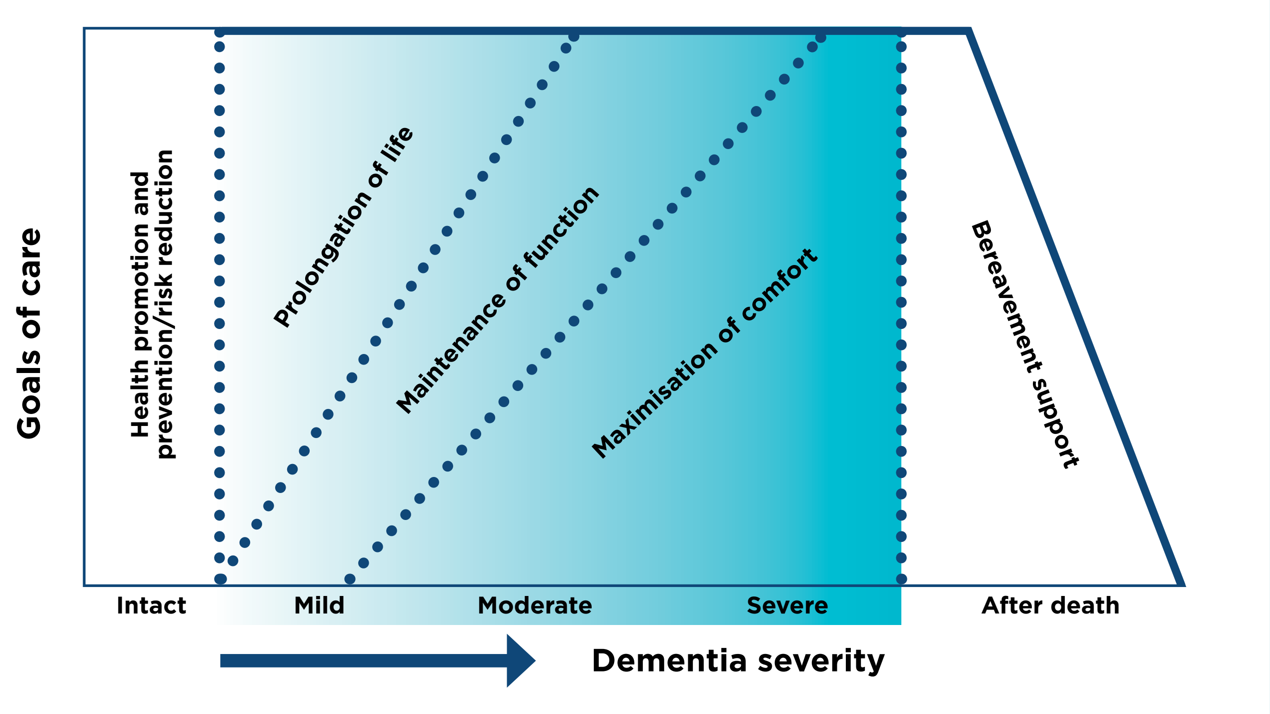
- Guiding clinicians to support people who have dementia with their palliative care needs;
- Considering how best to meet their needs, both in light of other comorbidities and also as their dementia advances.

Part of van der Steen's Delphi consensus study was on developing a figure that can support clinicians when considering a shift in goals of care through interventions aimed at:

- Prolonging life;
- Maintaining function;
- Maximising comfort (Fig 1) (van der Steen et al, 2014).

While the central premise to palliative care is to maintain the quality of life, which includes the quality of dying and the concept of a good death (Read and MacBride-Stewart, 2018), this is often still

Fig 1. **Goals of care**



Source: van der Steen et al (2014)

lacking in the care of people with dementia (Sampson and Harrison Dening, 2020) – many spend their last days, or even die, in acute hospital care (Sleeman et al, 2014).

### Hospital admissions and people with dementia

Admission to an acute hospital is often harmful for people with dementia, resulting in high levels of distress for them and their family carers and supporters, so avoidance of unnecessary admissions is a priority (Sleeman et al, 2014). In their population-based study linking ONS mortality data with regional variables, in England between 2001 and 2010, Sleeman et al (2014) found that the majority of people die in a care home or acute hospital, with deaths in their own home or hospice being rare. This is despite policy drivers to avoid hospitalisation for this population (Sampson et al, 2011).

Shepherd et al (2019) carried out a systematic review to understand hospitalisation rates of people with dementia; ascertain whether these differed from people without dementia; and identify sociodemographic and clinical predictors of hospitalisation. They found that the risk of people with dementia being admitted to hospital was 1.5 times higher than that of people without dementia. They also found that those at highest risk were people with dementia who were older and living with physical comorbidities.

### Impact of a hospital admission

A hospital admission for a person with dementia can be both confusing and distressing; acute hospital wards and departments are very hectic and noisy places at the best of times and not an ideal environment for anyone with a cognitive impairment (Aldridge and Harrison Dening, 2022). We know that people with dementia who are admitted to hospital have a higher risk of developing iatrogenic illnesses (defined in Box 2) and experience other adverse effects, compared with those without dementia or cognitive impairment. These include:

- Polypharmacy;
- Delirium;
- Functional decline;
- Fall-related injuries;
- Hospital-acquired infections;
- Mortality;
- Longer length of hospital stay;
- Reduced quality of life (Afonso-Argilés, et al, 2020).

Box 2. **What is an iatrogenic illness?**

An iatrogenic illness is one that is caused by the harmful complication or other ill effect of any medical activity, including diagnosis, intervention, error or negligence

Source: Barr and Kauffmann (2014)

There is also evidence to suggest that acute physical illnesses requiring emergency hospital admission, such as pneumonia or urinary tract infections, may be an indicator that a person with advanced dementia is approaching the end of their life (Sampson and Harrison Dening, 2020).

Sampson and colleagues undertook a prospective cohort study focusing on unplanned medical admissions of people aged ≥70 years old (n=616) in a large urban acute general hospital. They found that people with dementia had half the survival time of those without dementia (Sampson et al, 2013). This research implies that people with advanced dementia are being admitted for intercurrent conditions that would probably benefit from a palliative approach and a shift in goals of care, as outlined by van der Steen (2010).

Moreover, there is a lack of evidence to suggest that many active medical interventions – for example, artificial hydration and nutrition (Davies et al, 2021) or hospital admission (Sampson et al, 2009) – prolong or improve the quality of life in people with advanced dementia (van der Steen, 2010). There is increasing research and clinical interest in understanding how a palliative approach may be beneficial, not just for frail, older people with advanced dementia but, perhaps, in the moderate stages, especially when other serious or life-limiting conditions coexist (Livingston et al, 2017).

### Reviewing goals of care

When reviewing the goals of care for a person who is in the advanced stages of dementia, we need to weigh up the costs and benefits of any treatments considered. As discussed, it is difficult to prognosticate when a person is dying with dementia, but there are signs of when a person is considered to be in the final stages (Box 1, stage 7). Thomas et al's (2016) *Gold Standards Framework Proactive Identification Guidance* advises nurses and clinicians to ask themselves the 'surprise question': "For patients with advanced disease or progressive life-limiting conditions, would you be surprised if the patient were to die in the next year, months, weeks, days?"

As we have also discussed, prognostic tools and indices have a limited evidence base (van der Steen, 2010), but may support nurses and clinicians:

- In being mindful when determining an individual patient's goals of care;
- Facilitate timely communication and understanding about serious illness with their families (Secunda et al, 2020).

However, there are some signs and symptoms that might require further consideration, rather than simply determining a score on a measure. Although a person in the advanced stages of dementia may have limited or no speech, they may still make spontaneous noises that might indicate distress, pain or discomfort, either during a care intervention or outside of it. Other possible signs of distress arising from pain in a person with dementia may be:

- Facial grimacing;
- Agitation;
- Restlessness (Abbey et al, 2004).

### Assessing and managing pain in advanced dementia

Opinion is divided on how much is known about pain and dementia. In their review, Corbett and colleagues (2014) claim that we have come a long way in the past 20 years. However, conversely, in their review, Bullock and colleagues (2019) conclude there is still a dearth of high-quality research exploring pain assessment and treatment for people with dementia.

### Box 3. WHO's three principles of pain management applied to people with advanced dementia

**By the clock**

To maintain a person's freedom from pain, analgesia should be given by the clock or around the clock, rather than only on demand (pro re nata). In other words, it should be given on a regular and scheduled basis. Using analgesia on a PRN basis in people with dementia can result in them receiving too little or even no analgesia to keep them pain free and comfortable; this may be largely due to their difficulties in communicating their pain.

**By the mouth**

The oral route is usually the preferred route in various care settings because it is often the easiest. However, it may not be possible for all people with advanced dementia – for example, if they have difficulty swallowing. When the oral route is unfeasible, the least-invasive route should be considered; this might include using skin patches.

**By the ladder**

If pain occurs, there should be prompt administration of medications according to the stepped approach detailed in the WHO's Analgesic Ladder.

Source: Anekar et al (2023)
WHO = World Health Organization

Some nurses and clinicians may believe that people with dementia do not feel pain. However, many studies have found that people with dementia continue to feel pain but may have difficulty understanding what they are feeling, and describing and locating the pain (Achterberg et al, 2013). They may also be unable to remember that they have been in pain and so may not report this (Achterberg et al, 2013). There is limited evidence to suggest that people with dementia experience less pain than others (Closs et al, 2016). Instead, they are less likely to report their pain (Zwakhalen et al, 2009) due to the cognitive deficits they experience as their dementia progresses. Thus, pain in a person with advanced dementia – especially when there is expressive and/or receptive aphasia – may require assessment using an appropriate behavioural pain assessment tool, such as:

- The Abbey Pain Scale (Abbey et al, 2004);
- The Pain Assessment in Advanced Dementia Scale (Achterberg et al, 2013).

Undetected and undermanaged pain can markedly affect quality of life and increase morbidity in a person with dementia (Sampson and Harrison Dening, 2021).

Once pain is detected or suspected, it is essential that it is effectively managed. Managing pain in people with dementia often requires a multifaceted approach and may include:

- Non-pharmacological approaches – these can often be underused but can have great value, especially if taken alongside analgesia. Consider the use of heat or cold, music therapy, aromatherapy and massage, and therapeutic touch (De Vries, 2014). Some of these may be used in combination – for example, music therapy and massage;
- Pharmacological approaches – the Analgesic Ladder (Anekar et al, 2023) provides a three-principle framework for managing pain in palliative care (Box 3), but it can also be used in managing pain in people with dementia (Sampson and Harrison Dening, 2020).

### Family experiences of a person with dementia nearing end of life

Family carers provide most of the care and support to people with dementia (Wimo et al, 2018). Such care is varied and can include 24-hour supervision and providing basic physical needs if the person with dementia is living in their own home, or providing emotional and financial support if they live in a care home.

Caring can be a positive experience and lead to an enhanced relationship with the person with dementia or to a sense of accomplishment (Li and Loke, 2013); however, declining functioning of the person with dementia as end of life approaches can also lead to high levels of carer burden, depression and anxiety (Mo et al, 2021; Moore et al, 2017). Given this, as well as there being good management of care of the dying person, support of the relatives

It can be difficult knowing when a person with dementia is nearing the end of life but there are tools that can help identify when a change in the goals of care may be needed

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is crucial to the whole family group that is affected by dementia.

## Conclusion

People diagnosed with dementia can die with it or from it. Determining when a person with dementia is dying is not easy, but there are some prognostic tools and indices that may act as a guide for nurses and clinicians. It is important to be aware, however, that these resources are not 100% accurate and many serve more as a guide to indicate when a person is *not* dying rather than when they are.

People dying with dementia can often have complex physical and mental health needs that require impeccable assessment, not just of their physical symptoms but also of their spiritual and emotional needs. Family carers of people with dementia may also need support as the person they care for nears the end of life. **NT**

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