

Dementia Gateway: End of life care

This summary highlights key messages from the research on end of life care for people with dementia.

Key messages

- There is not much research on end of life care for people with dementia,² with much of the research that does exist being based on descriptions.
- People with and dying from dementia are a particularly vulnerable group and their end of life care needs may be complicated by cognitive (thinking, memory, reasoning) problems, communication problems, the protracted nature of dementia, pain, and behaviour that implies discomfort, but is hard to interpret and respond to.¹
- People with dementia often get poor care at the end of their lives because it can be difficult to recognise when a person with dementia is approaching end of life and because they cannot communicate their needs and preferences.²
- The research literature to support advance care planning in dementia is limited.^{2,5}
- People with dementia are at higher risk of acute hospital admission than people without dementia, and, if they are admitted from their own homes, at high risk of being discharged to a care home rather than back home.⁷
- The quality of end of life care is an important issue that concerns family and friends.⁹ Information from the National Health Service shows that over half of complaints made about services concern end of life care.¹⁰ Nearly a third of people with dementia admitted to hospital have no record made of their dementia, which implies that it continues to go unrecognised.¹¹
- Staff do not always have the confidence to assess and manage care at the end of life for people with dementia.²⁴

Introduction

This summary highlights key messages from the research on end of life care for people with dementia. It is not intended to be a comprehensive review of the literature on this topic. The material on which this summary is based was identified through focused searching of the literature published from 2008 to 2012. Some material pre-dating 2008 is also referred to where relevant.

The status of research

There is very little research on end of life care that is specific to dementia,² with the exception of work by authors such as Sampson et al,³ Robinson et al⁴ and a SCIE research briefing by Moriarty et al.² Other recently published SCIE research provides an overview of end of life care, and makes reference to dementia.⁶

Research on end of life care is fragmented and largely descriptive, which means that the nature and challenges of particular interventions cannot be explored in any detail.⁸ There is a lack of interventions and outcome measures for providing end of life care in people's own homes.⁸

There is very little research exploring the views and experiences of people with dementia and their carers at the end of life,^{2,8} although this is changing, with recent work by Denning et al.¹² There is very little information on the ethnicity of residents in care homes and their preferences for end of life care.⁹

Studies on the assessment of pain in people with dementia at the end of life are limited, and mainly rely on the carer's ability to predict pain in the person with dementia, and the soundness and benefit that various assessment tools for end of life care are thought to have.⁸

Research on the availability of specialist palliative care support for people dying in care homes is limited.² Palliative care is described in more detail below.

What is end of life care?

End of life care supports people with advanced, progressive, incurable illness to live as well as possible until the time of death, while enabling the supportive and palliative care needs of both the person and their family to be identified and met through the last part of life into bereavement.¹³ As well as pain and symptom management, end of life care provides psychological, social, spiritual and practical support.¹³

End of life care and dementia

People with and dying from dementia are a particularly vulnerable group and their end of life care needs may be complicated by cognitive (thinking, memory, reasoning) problems, communication problems, the protracted nature of dementia, pain and behaviours that are difficult for other people to understand.¹ People with dementia are at higher risk of acute hospital admission than people without dementia, and, if they are admitted from their own

homes, at high risk of being discharged to a care home rather than back home.⁷

The quality of end of life care is an important issue that concerns family and friends.⁹ For example, information from the National Health Service shows that over half the number of complaints made about services are about end of life care.¹⁰ Nearly a third of people with dementia admitted to hospital have no reference made to their condition, which implies that it continues to go unrecognised.¹¹ Once admitted, people are more likely to remain longer, to be readmitted and to die there.¹¹

Palliative care

Palliative care describes care that is given in the last few months of an individual's life or the last few hours and it focuses on the comfort and quality of life of the person rather than on the treatment of any disease.² Palliative care is based on the sensitive and holistic care of terminally ill people and their families.^{2,14} But there are very few examples of specialist palliative care services for patients with dementia in the United Kingdom.^{14,15} The traditional model of palliative care, which is focused mainly around specialist palliative care and hospices, may not be suitable for people with dementia.¹³

Policy

Good end of life care depends on good clinical leadership, education for care staff and working together in partnership with families¹⁶. At the policy level, there have been plans to improve both end of life care^{17,18} and support for people with

dementia.^{19,20} Various guidelines such as the joint dementia guidelines produced by the National Institute for Care and Excellence and the Social Care Institute for Excellence²¹ and in 2008 the Department of Health End of Life Strategy,¹⁷ have brought dementia into the fold of palliative care through the development and trying out of end of life tools in various care settings including care homes.¹⁴

Challenges to providing good end of life care

Two key reasons for people with dementia receiving poor care at the end of their lives are communication problems and problems in recognising when a person with dementia is approaching the end of their life.² Other problems include staff skills and organisational issues.

Communication

Communication with people with end-stage dementia can be challenging¹ and requires patience, perseverance and openness from carers and care staff.¹⁴

Despite communication problems with people with end-stage dementia, it is possible through a combination of engaging with the person with dementia, family carers and staff, and observing the person with dementia, to get a sense of their thoughts about death and preferences for end of life care.²

Knowing how to recognise end of life

It is not always simple for care staff and family carers to recognise when the end of life is approaching,^{2,6}

despite assessment tools being available,^{8,22} because the symptoms of dementia can change over time and the course of the disease is not as predictable as it may be in other illnesses, such as terminal cancer.²³ People with dementia can then be denied the type of care that would give them the best comfort and support at the end of life.² But identifying and managing pain and discomfort should always be part of dementia care.

Staff skills

Many people with advanced dementia live in a care home. The end of life care of people with dementia can be compromised where staff do not have the skills to manage both dementia care and end of life care.¹ Staff often do not feel confident in assessing and managing care at the end of life for people with dementia.²⁴ Sometimes, they find it difficult to talk about end of life care issues with residents and their families because of the personal and emotional complexities of such a discussion.²⁵

Organisational barriers to providing end of life care

In one study of five care homes, where residents generally said that they received good care, there were common barriers to providing good end of life care.²⁵ These included insufficient staffing levels, and a lack of structured support for staff who may have experienced distress at the death of a resident.

Carer burden

Caring for someone who is terminally ill at home places an immense burden on carers.^{1,6} If they are unsupported they can become ill and their health can

deteriorate drastically, leading to unplanned emergency admissions to hospital or home care both for themselves and the person with dementia who they care for.²³

Assessing spiritual needs and providing spiritual care

Spirituality is a key part of the care of people who are dying² as emphasised in The National End of Life Care Strategy.¹⁷ Providing spiritual care involves offering time and compassion to dying people and their families, regardless of whether they have religious needs, but only three per cent of patients have these needs assessed before their death, according to research.^{26,27}

Promoting good end of life care

Advance care planning

Advance care planning within the framework of the Mental Capacity Act 2005 can make sure that people with dementia and their carers have been told about and have thought through their choices for the future, and can contribute to or even override decisions about care that are made by service providers.⁸ These decisions could be about the nature and extent of treatment the person wants when they approach the end of their lives, such as a preference for or refusal of resuscitation if their heart fails or being prescribed antibiotics at the sign of an infection.^{2,14} People with advanced dementia are not able to make such choices, so unless the choices were discussed in the early stages of dementia, family carers may have to make difficult choices in a stressful situation¹⁴. Specialist palliative care staff

should have the skills to help families cope with such issues.¹⁴ There is still very little evidence to support advance care planning in dementia.^{2,5}

Recognising protracted losses

People with dementia and their families may have to live with dementia over a long period of time. For example, a person with dementia can survive for 20 years or more after a diagnosis of dementia.¹⁴

Palliative care staff who are sensitised to this can help families to deal with their grief and reactions to loss and help make the period one where people gain strength to live with the experience.¹⁴

Catering for cultural and spiritual needs

The cultural and spiritual needs of people can be provided through activities that mirror the 'symbols and sensual elements of customs and rituals', including things that stimulate the senses such as music, sacred objects and those things that have importance and meaning for the person with dementia.¹⁴ In a hospital setting, chaplains are a valuable resource for both patients and families, but also for nurses and other care staff.²⁶

Avoiding hospital admission

Sometimes care home facilities cannot support the wish for residents to stay in a care home at the end of life, and they are transferred to hospital.⁹ This can be a traumatic and frightening experience for the person with dementia,⁶ their families and care home staff.⁹ There have been moves to improve the quality of end of life care provided in care homes to avoid unnecessary hospital admissions.⁹ This includes the use of the Gold Standards Framework, which

provides simple tools for care home staff to use in these situations.^{28,29}

Staff training

Care home and home care staff often do not have the knowledge, skills and training to support families of people dying with dementia. But training for staff does appear to improve satisfaction with end of life care for bereaved family members.³⁰

Views of people with dementia

In the first ever national survey of the palliative and end of life care needs of people with dementia and their carers, the three most common issues mentioned by people who responded to the survey were: care to meet physical needs; choice about place of care; and practical support.¹³ People described issues such as not knowing how a person in the late stage of dementia was going to die; when it would be right to stop antibiotics that were no longer of use; staff not having discussions with people about end of life; and giving carers the option for their relative to die within the care home with specialist services including palliative care brought into the home, instead of having their relative sent from the care home to die in hospital.¹³

Implications from the research

Future research could explore the areas that we still do not know much about such as: end of life care in care homes; the needs of carers as they support their relative as the end of life nears; dying with dementia in one's own home; and the impact of ethnicity on end of life support.

Improving end of life care for people with dementia affects both health and social care staff across disciplines and sectors. Commissioners and service providers need to focus more on: the effective use of specialist liaison and knowledge of dementia with palliative care providers; skills training in pain detection, management and relief; and end of life nursing care. Combining the knowledge and skills of specialist dementia nursing and palliative care nursing will be beneficial for people with dementia and their families.

The views and experiences of people with dementia and their families should be fed into training and support for care home and domiciliary staff to address end of life care issues.⁹ There is also a need for regular staff training around the promotion of choices in end of life care, especially for residents with more complex palliative care needs²⁵ and those at risk of going into hospital.

References

1. Cahill, S., Doran, D. and Watson, M. (2012) 'Guidelines for nursing homes delivering end-of-life care to residents with dementia across the island of Ireland', *Quality in Ageing and Older Adults*, vol 13, no 1, pp 60–70.
2. Moriarty, J., Rutter, D., Ross, P.D.S. and Holmes, P. (2012) *SCIE Research briefing 40: End of life care for people with dementia living in care homes*, London: Social Care Institute for Excellence.
3. Harrison Denning, K., Jones, L. and Sampson, E.L. (2011) 'Advance care planning for people with dementia: a review', *International Psychogeriatrics*, vol 23, no 10, pp 1535–1551.
4. Mukadam, N. and Sampson, E.L. (2011) 'A systematic review of prevalence, associations and outcomes of dementia in older general hospital inpatients', *International Psychogeriatrics*, vol 23, no 3, pp 344–355.
5. Badger, F., Pumphrey, R., Clarke, L., Clifford, C., Gill, P., Greenfield, S. and Knight Jackson, A. (2009) 'The role of ethnicity in end-of-life care in care homes for older people in the UK: a literature review', *Diversity in Health and Care*, vol 6, no 1, pp 23–29.
6. Healthcare Commission (2007) *Spotlight on complaints: A report on second stage complaints about the NHS in England*, London: Healthcare Commission.
7. Care Quality Commission (2013) *CQC care update issue 2: March 2013*, London: Care Quality Commission.
8. Goodman, C., Evans, C., Wilcock, J., Froggatt, K., Drennan, V., Sampson, E., Blanchard, M., Bissett, M. and Iliffe, S. (2010) 'End of life care for community dwelling older people with dementia: an integrated review', *International Journal of Geriatric Psychiatry*, vol 25, no 4, pp 329–337.
9. Sampson, E.L., Burns, A. and Richards, M. (2011) 'Improving end-of-life care for people with dementia', *The British Journal of Psychiatry*, vol 199, pp 357–359.

10. Robinson, L., Hughes, J., Daley, S., Keady, J., Ballard, C. and Volicer, L. (2005) 'End-of-life care and dementia', *Reviews in Clinical Gerontology*, vol 15, no 2, pp 135–148, doi:10.1017/S0959259806001833.
11. Social Care Institute for Excellence (2013) *Dying well at home: Research evidence*, London: Social Care Institute for Excellence.
12. Dening, H.K., Jones, L. and Sampson, E.L. (2012) 'Preferences for end-of-life care: a nominal group study of people with dementia and their family carers', *Palliative Medicine*, doi: 10.1177/0269216312464094 (Epub).
13. National Council for Palliative Care (2009) *Out of the shadows: End of life care for people with dementia*, London: National Council for Palliative Care.
14. Ghiotti, C. (2009) 'The Dementia End of Life Care Project (DeLcAP): supporting families caring for people with late stage dementia at home', *Dementia: The International Journal of Social Research and Practice*, vol 8, no 3, pp 349–361.
15. Treloar, A., Crugel, M. and Adamis, D. (2009) 'Palliative and end of life care of dementia at home is feasible and rewarding: results from the "Hope for Home" study', *Dementia: The International Journal of Social Research and Practice*, vol 8, no 3, pp 335–347.
16. Ryan, T., Ingleton, C., Gardiner, C., Nolan, M. and Gott, M. (2009) 'Supporting people with dementia to die with dignity', *Nursing Older People*, vol 21, no 5, pp 18–23.
17. Department of Health (2008) *End of life care strategy: Promoting high quality care for all adults at the end of life*, London: Department of Health.
18. National Institute for Health and Care Excellence (2011) *End of life care for adults (QS13)*, London: National Institute for Health and Care Excellence.
19. Department of Health (2009) *Living well with dementia: A national dementia strategy*, London: Department of Health.
20. Department of Health (2010) *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*, London: Department of Health.
21. National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, CG42, London: National Institute for Health and Clinical Excellence and Social Care Institute for Excellence.
22. Marie Curie Cancer Care (2012) *Committed to carers: Supporting carers of people at the end of life*, London: Marie Curie Cancer Care.

23. Brandt, H. and Ribe, M. (2005) 'The last days of life of nursing home patients with and without dementia assessed with the Palliative Care Outcome Scale', *Palliative Medicine*, vol 19, no 4, pp 334–342.
24. Harrison Dening, K., Greenish, W., Jones, L., Mandal, U. and Sampson, E.L. (2012) 'Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study', *BMJ Supportive and Palliative Care*, doi:10.1136/bmjspcare-2011-000178 (Epub).
25. Centre for Social Action (2008) *The standards we expect: Choices for end of life care*, Leicester: De Montfort University.
26. Pugh, E.J., Smith, S. and Salter, P. (2010) 'Offering spiritual support to dying patients and their families through a chaplaincy service', *Nursing Times*, pp 18–20.
27. Sampson, E.L., Gould, V., Lee, D. and Blanchard, M.R. (2006) 'Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study', *Age and Ageing*, vol 35, no 2, pp 187–189.
28. Wheeler, N. and Oyeboode, J.R. (2010) 'Achieving gold standard end-of-life care for people with dementia in care homes', *Journal of Dementia Care*, vol 18, no 1, pp 36–39.
29. Watson, J., Hockley, J. and Murray, S. (2010) 'Evaluating effectiveness of the GSFCH and LCP in care homes', *End of Life Care*, vol 4, no 3, pp 42–49.
30. Arcand, M., Monette, J., Monette, M., Sourial, N., Fournier, L., Gore, B. and Bergman, H. (2009) 'Educating nursing home staff about the progression of dementia and the comfort care option: impact on family satisfaction with end-of-life care', *Journal of the American Medical Directors Association*, vol 10, pp 50–55.

www.scie.org.uk/dementia/understanding-dementia/end-of-life/index.asp

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