

People with dementia



A DIFFERENT ENDING: ADDRESSING INEQUALITIES IN END OF LIFE CARE

As our population ages, conditions that are more likely in old age are becoming increasingly common. Dementia and Alzheimer's disease are the leading cause of death for women, and research shows that 30% of people aged 65 or over will die with dementia.¹

The Prime Minister's Challenge on dementia 2020 highlights the importance of end of life care to people who have dementia. Good end of life care supports people and those important to them to have a good quality of life, with pain and other symptoms well-managed. Dignity and choice are central to this.

Our review supports existing evidence that there are a number of barriers that prevent people with dementia receiving good end of life care, including lack of identification and planning, unequal access to care, and poor quality of care.²

Identifying the end of life phase

Although dementia as a cause of death is increasing, health professionals do not always recognise it as a life limiting condition. As a result, the end of life phase is not always identified early enough or planned for effectively. In some areas we saw

that the national initiative to improve diagnosis of dementia was having an impact. However, it was not always clear how these practices improved end of life outcomes for people with dementia.

This is supported by feedback from families and carers of people with dementia who were sometimes unsure about when the end of life phase began, suggesting that people were not clearly identified as approaching the end of life. For some people, the end of life phase can start much earlier than the last year of life. One person told us:

"I guess I would've known when she first had her diagnosis of dementia that it was a journey towards her death, so that would probably have been 15 years ago."

Identifying dementia early, so that people have the opportunity to consider advance care planning and make meaningful choices at an appropriate time, is particularly important as the person will progressively lose the mental capacity to make decisions about their end of life care.

Communication

Talking to people and families about advance care planning can be challenging and sensitive. However, people who have dementia have a greater need for early and ongoing conversations about end of life care in the last phase of life as part of their wider treatment and care planning. This is supported by conversations with family as well as health and care

1 Dixon J, King D, Matosevic T, Clark M and Knapp M, **Equity In Palliative Care In The UK**, PSSRU, London: London School of Economics/Marie Curie

2 Marie Curie and Alzheimer's Society, **Living and dying with dementia in England: barriers to care**, 2014

staff, and can start when people are well and able to make decisions.

We found that communication with people with dementia, their carers and families, can be poor or non-existent. In our case note review, 53 out of 70 (76%) of the overall sample showed that health and care professionals had considered the individual's communication needs. However, this dropped to only five out of 11 (45%) people with dementia whose individual communication needs had been considered.

Some of the GPs we spoke to said that this was because the person lacked the mental capacity to make decisions. The Mental Capacity Act (MCA) 2005 is a crucial safeguard for the human rights of people who might (or might be assumed to) lack mental capacity to make decisions, in particular about consenting to proposed care and treatment. Although people with dementia may lack the capacity to make some decisions, they should be supported to communicate and express their wishes and preferences about their care where possible through communication that meets their needs.

We found that health professionals' understanding of the MCA is patchy, and varied in relation to assessment and decision making. Only four out of 11 (36%) people with dementia in our case note review had evidence of a mental capacity assessment in their records. This supports our previous findings that the MCA is not well understood.³ GPs and other providers of health and social care should have a good understanding of the MCA to make sure that they can act in the person's best interests.

Deciding Right is an initiative that supports advance care planning through providing a framework to support decision-making.⁴ It supports health and care staff to help people approaching the end of life make advance care planning decisions, and ensures that the requirements of the MCA are considered. In North Tyneside, its use has contributed to 87% of people in nursing homes being able to remain there to die, and an increase from 58% to 79% of people being able to die in their care home.

3 Care Quality Commission, **Deprivation of Liberty Safeguards 2011/12**, 2013

4 Northern England Strategic Clinical Networks, **Deciding Right**

Unequal access to care

People told us that their loved one had sometimes not been referred to the right services by their GP, and that they did not always know what services were available locally. Some people felt that training and awareness raising about dementia and end of life care planning for GPs, district nurses, care agencies, hospital and hospice staff would help. As with people with conditions other than cancer, it was perceived that people with dementia did not have access to the same services.

“Dementia is a terminal illness and sufferers should be given the same help as someone with terminal cancer. I had to battle for everything my mum received and it was exhausting.”

Access to hospice care varied for people with dementia. Some hospices were working with local groups, such as Dementia Action Alliance, to improve staff knowledge and improve access to their service. However, others told us that they “only accept dementia patients who are ‘able to cooperate’.” We expect hospices to provide appropriate training for staff, support people whose behaviour challenges, help people to make decisions, and communicate appropriately with people with dementia and those who are important to them.

Hospice UK has identified dementia care as a key issue that hospices need to consider. It has published guidance on ‘hospice-enabled dementia care’ to support hospices in developing their role and to make sure that people with dementia can access their services.⁵

Poor quality of care

Staff not having the right skills to care for people with dementia, even in dementia-specific care homes, was seen as another barrier to receiving good, personalised end of life care. Several people highlighted problems such as a lack of staff training, staff not supporting people to eat and drink, and a lack of understanding. This supports the findings of our review of dementia care, *Cracks in the pathway*, which found that staff do not always have enough support or training to care for people with dementia.⁶

5 Hospice UK, **Hospice enabled dementia care: the first steps**, 2015

6 Care Quality Commission, **Cracks in the pathway**, 2014

People told us that the lack of skills and support for care home staff sometimes led to people with dementia being admitted to hospital unnecessarily, and that their experience of care in hospital was often poor.

“I have no doubt that my mother was failing and getting towards the end of her life but there was no need for her to be in hospital.”

People said that being cared for in the right environment, with staff who have the right skills, is crucial.

“We need more social care services willing and able to care for people at the end of their lives – we were very fortunate to find an amazing care home for my father for the last two weeks of his life. I think that people with dementia who are approaching the end of their life often experience poor care due to lack of understanding and training about dementia and end of life. Hospices often aren’t an option for people with dementia, and if a suitable care home or care-at-home package can’t be arranged, they may well languish in hospital.”

A lack of skills and understanding can mean that the dignity of people with dementia is not always respected at the end of life, particularly in hospital. One person told us about his uncle who was admitted to hospital in the last week of his life, and was left on a main ward to die in a very public and visible way because he had dementia and staff wanted to keep an eye on him. This meant he had no privacy and dignity in the last days of his life. This supports the findings from the Alzheimer’s Society that people with dementia in hospital experience variable and poor care.⁷

Dementia awareness

While there is a long way to go, overall awareness about dementia was relatively good in many of the areas we visited, with references to the Dementia Friendly Hospital Charter, dementia champions and ‘dementia proofing’ of services. Some clinical commissioning groups are recognising the barriers that people with dementia face and are putting measures in place to address these. For example, in one area training for GPs was delivered by Admiral nurses (specialist dementia nurses), while other areas had dementia teams and a dementia link nurse or lead practitioner. The Greenwich Advanced Dementia service, highlighted in our good practice publication, supports people with dementia to live and die in their own homes. Identifying and improving care for people with dementia can help people to remain at home and improve their experience at the end of life.

CQC ENCOURAGES:

- Health professionals, including GPs, to facilitate early conversations with people with dementia and those who are important to them about their wishes and choices for end of life care, and help them to contribute to an advance care plan wherever possible.
- Commissioners and providers to make sure that staff have the training and support they need to care for people with dementia who are approaching the end of life, and to understand and implement the requirements of the Mental Capacity Act 2005.
- Hospices to consider to what extent they are meeting the end of life care needs of people with dementia, and take action where required in line with our definition of good end of life care in hospice services.

⁷ Alzheimer’s Society, **Fix dementia care: hospitals**, 2016

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- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
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