

Older people



A DIFFERENT ENDING: ADDRESSING INEQUALITIES IN END OF LIFE CARE

The independent review of the Liverpool Care Pathway, *More Care Less Pathway*, highlighted the care of older people at the end of life as a particular concern. Our review showed that older people's experiences of end of life care are mixed.

Attitudes of staff

Respect for older people and their individual needs, wishes and choices was a particular problem. Some people told us about poor communication in relation to people's treatment and care in care homes in the last year of life, with staff sometimes ignoring the observations and input of family members. One carer described how staff at her father's care home failed to make sure that he was eating and drinking by not helping him to feed himself, and said that they paid little attention to her father's preferences. She felt that there was a lack of compassion in communicating about her father, and said "they really weren't bothered".

While we have rated 96% of end of life care services in acute hospitals as caring, people told us that this was not always their experience of care for older people. Some people said they felt health and care staff viewed the lives of older adults as less valuable than younger adults, which had an impact on the care they received. One person told us that their partner, who was 90 and who died in hospital, had

received little medical care for his condition until he became acutely ill shortly before he died. She said: "Maybe at 90, I don't know, they think you've had your life..."

We also saw this attitude in the way health and care staff talked to people and their families, with people telling us that staff showed a lack of compassion in the way staff spoke to them. One person was told by staff "not to phone the hospital as they'd be busy", and another person was told in the presence of his mother that she "probably only had a day left". Recent research has highlighted the importance of communicating effectively with older people and their families at the end of life.¹ Where communication was ineffective, people felt unsure about what was happening with their relative and were distressed by the experience of their relative's end of life care.

Sometimes people and their families said they did not have a say in decisions about their care. For example, one person told us their mother was transferred from hospital to a nursing home without any discussion, and was not given the opportunity to look at the nursing home before she was discharged, "they basically told me, 'you have no say in it... she's going.'"

¹ Caswell G, Pollack K, Harwood R, Porock D, **Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study**, BMC Palliative Care, August 2015, 1;14:35

Personalised care

For people who are old and frail, identifying when they are approaching the end of life is challenging. This is highlighted by examples in which people told us they thought healthcare professionals were reluctant to move from continuing treating their family member's condition to starting palliative care. Families can sometimes interpret this reluctance as the health professional not understanding the person's wishes.

In some cases, people told us that their loved one only received the right care when they were moved from hospital to a care home, nursing home or hospice in the last weeks or days of life, where they received more supportive care.

"My 92-year-old brother-in-law was admitted to our local hospice for the last week of his life, and his care at the hospice was holistic and high quality. Prior to his admission, however, it was very difficult to get his end of life situation recognised and recorded, and my sister was left to try to care for him almost entirely alone for almost all of the last year or so of his life, with very little support from the local NHS or social services."

One person told us that treatment had been undertaken against a person's wishes, even though they had clearly and consistently stated their preferences.

"My mother, who died of old age at 86 ... wished to die at home in her sheltered accommodation. She was admitted to hospital two to three weeks before she died and, expressly against her repeated wishes, she was given intravenous fluids and fed. While my mother knew she was approaching end of life (and welcomed it...), the hospital consultants did not recognise that. The week before she died we were finally able to persuade the hospital to put her on the end of life register and we moved her to a palliative care bed in a local nursing home where she finally received the morphine she needed two to three days before she died."

We found some good examples of care homes providing person-centred care for people in the last days of life, which are illustrated in our document on good practice case studies. Some local areas are identifying end of life care for frail older people and people with dementia, including people who are living in care homes, as a priority for improvement, for example, as part of initiatives to reduce unnecessary hospital admission.

On our visits to local areas, we also found some good examples of GPs having links with care homes, and carrying out weekly visits and regular reviews of people's health needs. This helped to identify people over 75 or those with dementia who were in the last phase of life, and led to relevant personalised care plans being developed.

End of life care can also be improved through proactive care for older people. This is already happening in some of the enhanced health in care home vanguard sites, which are leading the development of new models of care nationally.² We saw a number of examples of this care model working well in our local area fieldwork. Care home support included providing training to care staff and improving access to specialist palliative care. Health and care staff told us about outcomes including reduced hospital admissions, improved confidence and increased use of advance care plans in care homes, and said that they were supporting more older people to die at home.

Training and support for staff

People living in care homes are not always able to access good, personalised end of life care because staff may lack the skills and confidence to care for them or they are not able to access the wider health and care services they need. Sometimes people who live in care homes may be admitted to hospital frequently during the last months and weeks of their life, and may die in hospital when they would have preferred to die at home.³

2 NHS England, **Enhanced health in care homes vanguard sites**.

3 Care Quality Commission, **The state of health care and adult social care in England: an overview of key themes 2011/12**, November 2012

“Care home staff also find it difficult to deal with dying individuals and they send them into hospital rather than letting them stay in their home.”

Training is sometimes provided to care home staff by specialist palliative care teams, specialist nurses or local hospices, as well as external providers. We found several local areas using the Six Steps Programme⁴ as the basis for training care home staff. Commissioners and providers in a number of areas told us that they had funded training from the Gold Standards Framework (GSF).⁵ In Dorset, there was a comprehensive GSF training programme in place across the nursing and care home sector to support care homes to carry out advance care planning and have conversations with people and their families about end of life as part of their routine care planning.

CQC ENCOURAGES:

- Commissioners and providers to develop systems to support care homes to care for people well at the end of life. This is to help reduce avoidable hospital admissions and to enable people to die where they choose.
- Commissioners and providers to make sure that staff who care for people who are likely to be approaching the end of life in any setting to have appropriate training and support to enable them to care for people approaching the end of life.

4 National End of Life Care Programme, 2010, **Route to Success: achieving quality in care homes**
See also our **good practice case studies document**.

5 **Gold Standards Framework**

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OVERVIEW REPORT

GOOD PRACTICE CASE STUDIES

PEOPLE'S EXPERIENCE BRIEFINGS:

- People with conditions other than cancer
- People with dementia
- People from Black and minority ethnic (BME) groups
- Lesbian, gay, bisexual or transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and Travellers

