

People with conditions other than cancer



A DIFFERENT ENDING: ADDRESSING INEQUALITIES IN END OF LIFE CARE

People with a non-cancer diagnosis tend to have less access to supportive and palliative care and may have a poorer experience of care in the last phase of their life.¹ An analysis of data from the National Survey of Bereaved People (VOICES), revealed that people with cardiovascular disease, respiratory or other non-cancer diagnoses were less likely to experience 'outstanding' and 'excellent' care in their last three months of life, and less likely to experience 'excellent' care from their GP, compared with people who had non-haematological cancer.² This document outlines the barriers that we found in our end of life care review that prevented people with conditions other than cancer from receiving good care.

Unequal access to care

People told us that they felt that appropriate end of life care was not always available, and that the care they received was not as good as the care for people with cancer. This was seen as discrimination, with access to care based on diagnosis rather than need.

"[People with] cancer... seem to have better end of life care... better discussions, support, choices, information; other conditions such as [chronic obstructive pulmonary disease (COPD)] seem

left out in the cold even though they have clear prognosis of terminal illness and palliative care."

Although cancer was the cause of only 29% of deaths in England and Wales in 2014, just 7.7% of all deaths in hospice inpatient units between 2008 and 2012 were from conditions other than cancer.³ Our review found that people from some groups are not always able to access specialist palliative care services when needed, and that generalist care is not always good enough.

Not receiving the right care and support could mean that people died in hospital when they would have wanted to be cared for elsewhere. It also had a significant impact on carers, family and friends, who sometimes said they pulled together to look after the person themselves. Some carers told us they felt overwhelmed by caring for their loved one 24 hours a day, but felt there was no alternative:

"End of life care was not discussed, because it wasn't cancer. I have cared for people with end stages of COPD and renal failure – neither got any end of life care and their lives and mine as carer was adversely affected, even though it was known they would shortly die. Only cancer sufferers appear to be included in end of life care."

1 Boland J and Johnson M J, End-of-life care for non-cancer patients, *BMJ Supportive and Palliative Care*, (3):2-3, 2013

2 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, 2015

3 Sleeman KE et al, The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993–2012 *Palliative Medicine* 1-9, 2015

Identifying the end of life phase

The health professionals that we spoke to said that it was difficult to identify when a patient is in the terminal phase of their illness, and whether they need end of life care. As one hospice nurse stated:

“It’s incredibly difficult to identify last year of life without cancer. When we opened the respite unit, the two first patients had advanced COPD. [If I had been] asked at the time I would have expected both to be in the last year of life, but both lived for three years. There are indications that people are at the end but it’s incredibly difficult to know when they’re in the last year...”

Fear of getting it wrong was another reason GPs gave for not always identifying people with a diagnosis other than cancer at an early stage. For doctors, judging how long a person may have left to live is one of the key challenges in delivering good end of life care.⁴

A number of tools have been developed to help recognise people who are likely to be in the last 12 months of life.^{5,6} However, given the difficulty in identifying when a person is entering the last year of life, and the need to talk about end of life care earlier in some cases, the importance of having a definitive prognosis may be overstated. There needs to be a shift in focus away from only identifying people who clearly have less than 12 months to live, towards having conversations about a person’s wishes and preferences for care during the last phase of their life. This may lead to people having conversations about end of life care earlier, which could address some of the issues with communication outlined below.

Talking about end of life care

Talking to people about the last phase of life early is important to give them the opportunity to make choices and plan their care. Some people, including people with conditions such as COPD, heart failure, Parkinson’s disease and frailty, felt that their

healthcare professional was reluctant to talk about end of life care. This was echoed by many of the health and care staff we spoke to during our local area visits, including GPs, who told us that they found conversations about end of life care difficult to start.

As a result, some people did not feel fully informed about their condition. In some cases, they felt that health professionals did not even understand it. People told us that they did not always know what to expect in the last months of life, and that not being diagnosed or identified as being in the end of life phase played a part in this.

One carer told us about the experience of her husband, who had Parkinson’s disease for 10 years before he died in July 2015. Although she felt that staff on the palliative care unit at the hospital were very caring, none were very knowledgeable about his condition:

“There’s not enough publicised about it, everything’s about cancer and there are other diseases which are more horrible... Parkinson’s is just pushed aside because it’s an old person’s disease.”

Conversations with patients where the prognosis is more uncertain were particularly difficult. This could mean that advance care planning is delayed or conversations about end of life care do not happen at all. One person told us,

“After he came out [of hospital] in April, and went back to the home, it was only then that I saw on his notes that he was receiving palliative care... nobody actually talked to me about end of life care, I was just left to work that out for myself.”

Some health and care staff also mentioned that the negative media coverage of the Liverpool Care Pathway could get in the way of having conversations about end of life care.

Training in communication skills was highlighted as a way of supporting health and care staff to develop their skills and help them to talk about end of life care. Some hospices told us they provided training in holding difficult conversations. In one area, a local GP was leading a training programme for staff in care homes and nursing homes, which included good communication about end of life and life limiting illness.

4 British Medical Association, **End of life care and physician assisted dying: public dialogue research**, 2016

5 Gold Standards Framework: **Prognostic Indicator Guidance**.

6 **Supportive & Palliative Care Indicators Tool (SPICT™)**: www.spict.org.uk

Coordination of care

Coordinating care around the person is essential to good end of life care. It may be particularly important for people with conditions other than cancer who are likely to have more complex needs. Their greater need for coordinated care increases the impact when coordination is absent or poor. People with conditions other than cancer may be less likely to have an identified professional coordinating their care, meaning they have little continuity of care, no forward planning, and less access to services.

Uncoordinated care also has a significant impact on carers, who may have to step in and attempt to coordinate health and care staff and services themselves. People told us about the impact of poor coordination, including a loss of focus on the person and their wishes.

Care in the last days of life

From other reports, including the review of the Liverpool Care Pathway and *Dying without dignity*, we know that care in the last days of life is not always good enough.^{7,8}

7 Independent review of the Liverpool Care Pathway, **More care less pathway**, 2013

8 Parliamentary and Health Service Ombudsman, **Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care**, 2015

However, the people we spoke to who had conditions other than cancer sometimes described a good experience of care in the last days of their life, despite a lack of good care in the preceding months.

Compassion from health and care staff was highlighted as fundamental to good care in the last days of life. One person said, “they cared for him the way I would’ve wanted to care for him myself.” People were often confident that staff had done their utmost to ensure that the person had a comfortable and peaceful death, even when the care leading up to the last days had been poor.

“My 92 year old brother-in-law was admitted to our local hospice for the last week of his life (non-cancer patient, he died from heart failure), and his care at the hospice was holistic and high quality. Prior to his admission, however, it was again 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.”

THE IMPACT OF POOR CARE COORDINATION

One woman told us about her uncle who had vascular dementia and end stage renal failure. He was 90 and died in hospital. She was told that her uncle would be moved to the local hospice, but this never happened. The palliative care team advised that they were unable to get a definitive answer from staff at the hospital.

She felt that everyone had different opinions regarding her uncle’s prognosis, and said that, “There were varying opinions ... when I did ring the palliative care team, I was told that the communication with medical staff wasn’t very good.”

Initially they were told he would likely die within a week, then that he could live on for a number of months. The woman and her family were unclear about whether they should find a nursing home for her uncle or not. She also felt that because her uncle did not really have much capacity to communicate and was asleep a lot, he was not really at the centre of his own care, but that was difficult to change.

She felt that coordination of her uncle’s care could have been much better if one person or team had been able to coordinate all the information at one time.

National Council for Palliative Care interview

CQC ENCOURAGES:

- Providers of specialist palliative care services in all settings to take a proactive approach to meeting the needs of people with conditions other than cancer. This should be reflected in the proportion of people with non-cancer conditions using the service.
- Health and care professionals, including GPs, to have early and ongoing conversations about care in the last phase of life as part of wider treatment and care planning.
- Health and care staff to give people who may be approaching the end of life the opportunity to make advance care plans to record their wishes and choices about their care.
- Commissioners and providers to support staff by providing appropriate training in communication skills for end of life care.

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GOOD PRACTICE CASE STUDIES

PEOPLE'S EXPERIENCE BRIEFINGS:

- Older people
- 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

