

EXPERIENCES OF END OF LIFE CARE

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Exploring the quality of End of Life care for people with cancer

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Background

An independent Review of Choice in End of Life Care (Choice Review) was published last year. It set out in detail what needs to be done to improve end of life care in England. One year on, a coalition of seven charities has urged the Government to respond to the recommendations which would ensure good quality care for everyone approaching the end of their life¹. To deliver this, the coalition is calling for: well-funded high-quality care; investment in specialist and generalist professionals; access to good quality advice and support; fully coordinated care across all teams and services; training for professionals and greater medical research.

As part of this work, Macmillan Cancer Support sought to better understand the issues for patients who died with cancer through further analysis of the data from the 2014 National Survey of Bereaved People (VOICES).

Methodology

VOICES is a national survey in England that is sent annually to bereaved relatives and carers about the end of life care of people. The survey is carried out by the Office for National Statistics (ONS) for NHS England. In 2014 it included a large cohort (6,703) of people who died from cancer.²

Macmillan Cancer Support analysed the publicly available data set to identify key published statistics and areas for further investigation. The relevant additional cancer-specific data from the ONS was then sourced, from which our conclusions were drawn.

'Don't know' answers were excluded from the analysis and the data requested from ONS are based on people who died from cancer only (ICD-10 codes C00 to D48.9; this includes non-malignant neoplasms).

Results

Care and choice is not as consistent as it could be

The original analysis by ONS of VOICES data found that almost **1 in 10 (9%)** of those dying from cancer experience poor care at the end of their life.³

Further bespoke analysis highlighted that many people dying from cancer are not dying in their preferred place, and that those who want to die at home or in a hospice are least likely to get their wish.⁴

1 IN 3 

(35%) people with cancer who had said where they would prefer to die, did not die in their preferred place.

Of those dying with cancer, 64% who wanted to die at home and 66% who wanted to die in a hospice were able to do so, compared with 82% who wanted to die in hospital and 87% who wanted to die in their care home.

More than one in five (22%) with cancer who wanted to die at home died in hospital.⁵

Fragmented care results in poorer experiences

Furthermore, care can be fragmented and variable. Services do not always work well together at the end of life. There are poorer experiences reported from relatives of those who die in a hospital compared to those dying at home on a number of aspects of care including pain relief and evening and weekend care:

At hospital



Among those who experienced inadequate pain relief when treated at home, twice as many died at hospital (46%) than at home (23%).⁶

At home



Among those who experienced poor quality of out of hours care in the last 3 months of their lives, 60% more died at hospital (44%) than at home (28%).⁷

Good care shows positive associations with choice...

Those with well-coordinated care at the end of life are more likely to die in the place of their choosing. People whose care at home is well coordinated are **57% more likely to die in their preferred location** compared with people whose care is poorly coordinated:

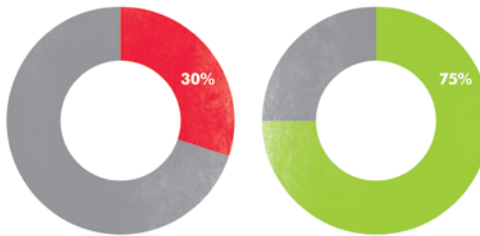


52% of people whose home care services did not work well together died in their preferred place...

...compared with four in five (81%) of those whose services did work well together.

...and specialist support can facilitate dying in one's preferred place.

People who receive specialist nursing support at home during their last three months of life are **more than twice as likely to die in their preferred place** compared with those who receive no care at home:



one in three (30%) of those who did not receive any support at home died in their preferred place...

...Three in four (75%) people who received support at home from a Macmillan nurse, hospice home care nurse, or specialist died in their preferred place.

What about support to die at home?

For the majority, the preferred place to die is at home—not just for cancer patients, but across all conditions: **82%** of those who stated a preference on where to die wished to die at home.⁸



However there needs to be a better support structure for those who want to die at home. Current levels of care could be improved across a number of areas including, but not limited to:



Better involvement in decisions about their care: Among those with cancer who wanted to die at home, more than 1 in 10 (11%) wanted to be more involved in decisions about their care in the last three months.



Better records of patient choices: Even among those who had stated they wanted to die at home, one in eight (13%) had no record of their preferred place of death by healthcare staff, yet evidence supports that having a record of where they want to die makes a difference. 74% of those cancer patients where staff held a record of where they would like to die, died in their preferred place, compared to just 39% of those who did not have a record.⁹

Conclusion

There are a range of factors that influence quality of care at the end of life and the results here highlight that there are still a number of people for whom care needs to be improved during these important last three months of their lives.

The Choice Review highlights the lack of choice and variable quality of care available to dying people and their families and carers. The evidence in this analysis builds upon existing knowledge to support the call to ensure everyone has greater choice and control at this point of maximum vulnerability in their lives. Specifically, this means people receiving the right services, at the right time, in the right place, and people's preferences being heard, recorded, shared and acted upon.¹⁰

In highlighting these statistics for people dying with cancer, we build a greater understanding of the need to give all cancer patients better support in their final weeks. This refers not only to making choices about their care and place of death where possible – a key element of the 'choice offer' – but also in receiving well-coordinated, high-quality care whether at home, hospice or hospital.

References

1. On the basis: The future of end of life care. A Coalition Report, 2016. Available here: <http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-Web.pdf> [accessed April 2016]
2. Each year a sample of approximately 49,000 adults in England are selected from ONS' registration database. Deaths were selected from those registered between January 1 and April 30 in 2014. Respondents are excluded from the sampling frame if the death was due to accident, suicide or homicide or where the death had occurred 'elsewhere' than the designated locations (home, care home, hospital or hospice) or where address details of the informant or deceased were missing. 2014 data presented here is about the end of life care for those who passed away in England between 1st January 2014 and 30th April 2014.
3. Office for National Statistics. National Survey of Bereaved People (VOICES) Dataset, 2014. Available here: <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcare/systems/beliefs/national-survey-of-bereaved-people/voices/2015-07-01/index.html> [accessed April 2016]
4. Office for National Statistics. Quality of end of life care for cancer patients, VOICES, 2014. Available here: <http://webarchive.nationalarchives.gov.uk/20160505140709/http://www.ons.gov.uk/ons/doi/doi.html?business-transparency/freedom-of-information/what-ops-i-request/published-at-hoc-data/health/december-2015/index.html> [accessed December 2015]
5. All statistics are taken from those who died with cancer as the cause of death unless otherwise stated
6. In total 2,555 respondents reported their loved one's pain was only partially or not at all relieved when treated at home
7. Excludes 'Don't know'; in total 4,397 respondents received out of hours care and 610 (15%) noted this as 'poor' when asked if it was excellent, good, fair or poor

8. As per reference 3. 82% of those who expressed a preference on where s/he wanted to die (all conditions) said they would prefer to die at home, as reported by relatives/carers. 8% wanted to die in a hospice, 6% in a care home, 3% in a hospital, and 1% somewhere else. The numbers are too small to break this down into condition-specific figures.
9. In total 2,397 respondents whose loved one had expressed a preference for where they wanted to die answered 'yes' or 'no' to whether staff had a record of where they would like to die. Of the 2,186 who had a record, 74% died in their preferred place, 26% did not. Of the 211 who did not, 39% died in their preferred place, 61% did not.
10. Campaign calls as detailed in The End of Life Care Coalition report. For the full report see reference 1.

Acknowledgements



Macmillan Cancer Support would like to thank ONS for the analysis conducted without which these results would not be possible. We would also like to thank the 6,703 carers and relatives who filled in and returned the 2014 survey to give us this data and valuable insight into end of life care. June 2016



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