

Policy Position Paper

End of life care (England)

March, 2016

Everyone has the right to expect services and support that help them to achieve a dignified and pain-free death, with choice in how they are cared for in their final months and days, regardless of where they live or their diagnosis.

Key issues

Everyone has the right to expect services and support that help to achieve a 'good death' and to choice in how they are cared for in their final months and days. This should include access to high quality palliative care services (including pain management) which support physical, psychological and spiritual needs, respect personal choice (including where advance decisions are made) and maintain dignity. Diagnosis, place of residence, care setting or individual circumstances should not act as a barrier to receiving high quality end of life care.

Of those people who die in the UK, 91 per cent are aged 65 or over and three quarters are aged 75 and over¹. Only 15 per cent of people gaining access to specialist palliative care services are 85 or over². Research suggests that between 50 and 70 per cent of people would prefer to die at home,³ however only 18 per cent of deaths in people over 65 occur at home, compared to 31 per cent of people aged 15-64.⁴ It is, however, important to remember that dying at home is not the only indicator of good end of life care and some people's preferences about place of death change as they approach the end of life.

There is huge variation in the numbers of older people living in care homes who die in hospital, ranging from none to every resident death⁵. People over 80 experience the worst overall quality of care in the last two days of life compared with other age groups, covering such areas as pain relief, nutrition and emotional needs.⁶

¹ Mortality statistics: Deaths registration summary tables, Office for National Statistics, 2013

² National Council for Palliative Care (2013) National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2011-2012. Public Health England

³ *End of Life Care, National Audit Office, 2008*

⁴ *Review of the Mortality Statistics in England and Wales, Office of National Statistics, 2009*

⁵ *End of Life Care, National Audit Office, 2008*

⁶ National VOICES survey of bereaved people 2014, ONS, 2015

In a May 2015 report the Parliamentary and Health Service Ombudsman said that “End of life care is, sadly, a recurring and consistent theme in our casework”⁷. In spite of attempts to increase the availability of care closer to home at the end of life, the report went on to say that “people who are dying and their carers suffer because of the difficulties in getting palliative care outside normal working hours” . In the latest edition of the Care of the Dying Adult in Hospital Audit, the majority of hospitals only had face-to-face specialist palliative care teams Monday to Friday 9-5.⁸

Most discussion of end of life care assumes that people will have a single condition, ignoring the fact that multi-morbidity is the norm amongst people in later life. It can be difficult to predict the course of many of the conditions which affect people. In 2015, *Ambitions for Palliative and End of Life Care* was published, led by the National Clinical Director for End of Life Care.⁹ It identified “fragmented and disjointed care” and “poor communication” as key factors in failures at the end of life. These factors can lead to people in later life not being identified as entering an end of life phase and not receiving effective, joined-up care planning. Resolving these issues were at the centre of the National End of Life Care Strategy (2008), yet they persist.

In work we have recently completed with health professionals, there is evidence that the word “frailty” is strongly associated with end of life care. It can often be seen as justification on do not attempt cardiopulmonary resuscitation (DNACPR) forms. We are pleased that the concepts around frailty are gaining some common currency, but we would caution that wider use of both the word and the concept does not give permission to regard some older people as less appropriate for active treatment.

Public policy proposals

- GPs should work closely with Clinical Commissioning Groups (CCGs) in coordinating end of life care in the community. CCGs should drive take up of existing good practice such as the Gold Standards Framework.
- All part of the NHS and social care services should work towards embedding recommendations of *Ambitions for Palliative and End of Life Care*.
- The government, health professional bodies and commissioners should systematically incorporate end of life care into the wider narrative on multi-morbidity and frailty. A crucial first step will be to establish and disseminate a stronger evidence base on the progression of poor health in later life and living with multiple conditions.
- All health and wellbeing boards should have a strategy on end of life care. This should incorporate the promotion of long-term planning and ensuring all relevant health and care services merge seamlessly with palliative care pathways.
- As part of this, health and wellbeing boards should take a leading role in formally incorporating end of life care into social care planning and delivery.

⁷ Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care, PHSO, 2015

⁸ Care of the Dying Adult in Hospital Audit, Royal College of Physicians, 2016

⁹ Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, National Palliative and End of Life Care Partnership, 2015

- End of life support commissioned by CCGs should include comprehensive support for care home residents.
- Pre-registration training of all health and social care professionals should include sufficient time devoted to palliative care and the needs of people in late old age. Professionals should be expected to keep up to date with these issues throughout their careers and have the support to do so.
- There should be an investment in new approaches to advance care planning and talking about end of life care. Health and care services should explore how to use key transition points to promote these conversations e.g. changes in living circumstances.

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