

End of life care

(England)

May 2019

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.



“A friend didn’t feel safe talking about dying with people other than those of her own age. She felt that she might be patronised”.
Older person

Death and dying

Everyone has the right to expect services and support that help to achieve a ‘good death’ and to choose 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 supports physical, psychological and spiritual needs, respects personal choice (including where advance decisions are made) and maintains 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 England and Wales, 85 per cent are aged 65 or over and almost 70 percent (68.3) are aged 75 or over^{iv}. Only 16.4 per cent of

Key statistics

70%

of all deaths are people aged 75+ⁱ

18.4

Average number of days spent in hospital after an emergency admission in the last year of lifeⁱⁱ

16%

Deaths of people aged 85+ that occur at home, compared with 34% of people under 65ⁱⁱⁱ.

“In hospital, death is very clinical. The spiritual side is neglected.”

Older person

people gaining access to specialist palliative care services are 85 or over despite representing almost 40 per cent of all deaths^v. Research suggests that between 50 and 70 per cent of people would prefer to die at home,^{vi} however only 19 per cent of deaths in people aged 75+ occur at home, compared to 34 per cent of people aged 15-64.^{vii} 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 can 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 death^{viii}. 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.^{ix}

Dealing with complexity

In a 2015 report the Parliamentary and Health Service Ombudsman said that “End of life care is, sadly, a recurring and consistent theme in our casework”^x. 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.^{xi}

Most discussion of end of life care assumes that people will have a single condition, ignoring the fact that multi-morbidity (living with more than one long-term condition) 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.^{xii} 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 was at the centre of the National End of Life Care Strategy (2008), yet they persist.



Further complexity can arise when someone lacks mental capacity, i.e. when they are unable to understand the information and/or express their preference in relation to a decision. For example, this could be because they are unconscious or because a condition such as dementia prevents them from taking on relevant information or communicating. Some people may choose to elect a friend or family member to take decisions on their behalf, for example with regards to financial matters or health and welfare decisions, granting them what is called a lasting power of attorney (LPA).

The numbers of people choosing to do this has increased substantially, with one estimate suggesting the number of LPAs rose 192 per cent between 2013 and 2019^{xiii}. Part of this rise will relate to the growing numbers of older people and people living with dementia, however, it has raised potential safeguarding issues. Conversely, the Office for the Public Guardian (OPG) also found that people can assume that relevant decision making powers are automatically available to families^{xiv}, meaning people find out too late that this is not the case and cannot make appropriate arrangements. More information must be available to older people, families and carers to use LPAs appropriately, and health professionals can play an important role in supporting people through this process or sign-posting them to the appropriate place.

Achieving change

The NHS Long Term Plan, published in January 2019, promised to “introduce proactive and personalised care planning for everyone identified as being in their last year of life”. One of the aims of this is to see “a reduction in avoidable emergency admissions and more people being able to die in a place they have chosen”. End of life care further features in planned work dedicated to older people, covered by proposals to improve urgent care in the community, increase uptake of advance care planning and by improving the health of people living in care homes. Some of this work will play an integral part in wider improvements to the care of older people living with frailty, however, we are concerned that end of life care does not play a sufficiently large part of the overall plan.

Regional strategic bodies, known as Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) (for more see: <https://www.england.nhs.uk/integratedcare/>) should be clear how they are working to implement these proposals and how they will measure performance. In particular, ongoing work will need to demonstrate:

- upskilling the health and care workforce;
- guaranteeing specialist palliative care for those that need it, regardless of setting (e.g. access to specialist care in the community, 24 hours a day); and
- achieving robust care planning that recognises older people’s ongoing access to all relevant care but that can quickly adapt to changing needs.

At all times, this must be driven by the older person's wishes and preferences, including the extent to which they want to involve carers and family.

End of life care provision should be mindful of our own research with health professionals, which uncovered 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 common currency, but in our view this should 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.
- 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 Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) should have a clear strategy for meeting the requirements of the NHS Long term Plans 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, Primary Care Networks should take a leading role in formally incorporating end of life care into community services and work with the social care sector to ensure they are working in a fully coordinated way.
- 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.

End of Life Care England
May 2019

- Awareness of Lasting Powers of Attorney should be a core capability of all professionals working with older people. Those that play a clinical leadership role in the care of older people should have a good understanding of the process.
- 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.

Want to find out more?

Age UK has agreed policy positions on a wide range of issues, including money matters, health and wellbeing, care and support, housing and communities. There are also some crosscutting themes, such as age equality and human rights, age-friendly government and information and advice

Further information

You can read our policy positions here;
www.ageuk.org.uk/ourimpact/policy-research/policypositions/

Individuals can contact us for information or advice here;
www.ageuk.org.uk/informationadvice/ or call us on 0800 169 8787

Further information also see *policy positions on Health Care; Mental Capacity*

ⁱ ONS. Death registrations summary tables - England and Wales, Office for National Statistics, 2018

ⁱⁱ Emergency admissions data briefing, Marie Curie, 2018

ⁱⁱⁱ Public Health Profiles (Fingertips tool) – End of Life Care, Public Health England, accessed May 2019

^{iv} ONS. Death registrations summary tables - England and Wales, Office for National Statistics, 2018

^v National Council for Palliative Care, Hospice UK, Public Health England, National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2014-2015, 2016.

^{vi} *End of Life Care, National Audit Office, 2008*

^{vii} ONS. Mortality statistics: Deaths registered in England and Wales 2016, Office for National Statistics, 2017

^{viii} *End of Life Care, National Audit Office, 2008*

^{ix} National VOICES survey of bereaved people 2014, ONS, 2015

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

^{xi} Care of the Dying Adult in Hospital Audit, Royal College of Physicians, 2016

^{xii} 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

^{xiii} FT, Power of attorney rise leads to misuse concerns, 2019,

<https://www.ftadviser.com/pensions/2019/04/24/increasing-number-of-power-of-attorneys-leads-misuse-rise/>

End of Life Care England
May 2019

^{xiv} Lasting power of attorney: Your voice, your decision, Office of the Public Guardian, 2019,
<https://publicguardian.blog.gov.uk/2019/04/09/lasting-powers-of-attorney-your-voice-your-decision/>