

Health select committee inquiry

End of life care

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1. Introduction

- 1.1. Of the 569,024 people who died in the UK in 2012, 91 per cent were aged 65 or over; three quarters were age 75+¹. One third of all deaths are people aged 85 and over², yet only about 15 per cent of people gaining access to specialist palliative care are in this age group³.
- 1.2. This last fact should be central to consideration of this inquiry. Despite these numbers, the NHS continues to struggle to properly identify people who are in the last stages of life, unless they have a terminal or otherwise life-threatening condition. This in turn means people are not able to plan properly or encouraged to discuss decisions about their future care. The health and care system is then typically in a reactive mode so that changes in someone's wellbeing are dealt with in inappropriate ways, often resulting in dying in hospital or short stay in a care home.
- 1.3. A failure to understand multi-morbidity and frailty and the trajectory of people's health living with either (or often both) means the NHS is not agile, failing to allow care and support to switch tracks quickly when someone is approaching the end of life. Not in terms of stopping treatments, but changing priorities so that people can have as good a quality of life for as long as possible.
- 1.4. Improving end of life care is central to the NHS as a whole, not just those responsible for specialist palliative care. All professionals working in the NHS will care for people who are dying, yet training in end of life care remains poor. Geriatricians can deliver a wide range of care to people at the end of life, yet are not always included in considerations around commissioning end of life care.
- 1.5. Underpinning improvements in end of life care must be a much stronger understanding of the care of older people and the need to deliver whole-person care rooted in individual preferences and wishes. The following sections explores these issues alongside relevant evidence

2. Link with older people's experience of care

- 2.1. Older people's experience in hospital is linked to poor performance in end of life care. The Age UK/NHS Confederation/Local Government Association Dignity Commission⁴ found frequent examples of poor end of life care at the root of poor practice around dignity and respect. A number of the Commission's recommendations specifically address these issues.
- 2.2. The Parliamentary and Health Service Ombudsman reported that "the reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital, is not being fulfilled"⁵ following a detailed investigation of a number of serious complaints. The Francis report,

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

² ONS (2013) Mortality Statistics: Deaths Registered in 2010 (Series DR) Table 5

³ 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

⁴ <http://www.ageuk.org.uk/home-and-care/improving-dignity-in-care-consultation/>

⁵ *Care and compassion?*, Parliamentary and health service ombudsman, 2011

published in February 2013, highlighted end of life care as an area of particular concern

2.3. A 2011 article in the journal *Age and Ageing* examined the issue in the context of acute hospitals, concluding that many issues arose because of “attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources” as well as “uncertainty over the roles of specialist and generalist palliative care providers in acute hospitals”⁶.

3. Inequalities

3.1. The first national survey of bereaved people did report positive overall results for all age groups experiencing end of life care. However, it also found that “in the hospital setting, patients who died at 80 years or older were rated lowest [for dignity and respect] compared with both the under 65 and 65 to 79 years age groups”⁷. The same survey also shows that “having enough choice was lower among older people (80+ years)”⁸.

3.2. The latest survey said the overall “quality of care has not changed significantly between 2011, 2012 and 2013” but that “quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home”⁹. People over 65 are most likely to die in hospital compared to other age groups¹⁰ and least likely to die in a hospice¹¹.

3.3. People 65-79 in care homes have a poorer experience with regards to dignity and respect at the end of life compared with other age groups, though it is slightly better for people over 80¹². A report by the Nuffield Trust showed a two-fold difference between certain areas of the country in the proportion of people using social care in the month prior to death, suggesting that your access to services is highly dependent on where you live.

3.4. One third of all deaths are people aged 85 and over¹³, yet only about 15 per cent of people gaining access to specialist palliative care are in this age group¹⁴.

3.5. A report by Help the Aged from 2006 looked in detail at the importance of discussions around end of life and the findings remain highly relevant. It found that “people’s apprehension about discussing the topic frequently was overridden by their desire to know more about the decisions and choices available to them at this time”. Participants reported being “without sufficient and accurate information” and “were unable to challenge decisions made on their behalf”¹⁵.

⁶ Gardiner, C., et al, *Barriers to providing palliative care for older people in acute hospitals*, *Age and Ageing*, 2011

⁷ First national VOICES survey of bereaved people: key findings report, Department of Health, 2012

⁸ First national VOICES survey of bereaved people: key findings report, Department of Health, 2012

⁹ National Survey of Bereaved People (VOICES) 2013, Office for National Statistics, 2014

¹⁰ Review of the Mortality Statistics in England and Wales, Office of National Statistics, 2009

¹¹ End of life care strategy: Equality impact assessment, Department of Health, 2008

¹² National Survey of Bereaved People (VOICES) 2013, Office for National Statistics, 2014

¹³ ONS (2013) Mortality Statistics: Deaths Registered in 2010 (Series DR) Table 5

¹⁴ 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

¹⁵ *Listening to Older People: Opening the door for older people to explore end-of-life issues*, Help the Aged, 2006

3.6. This remains an issue. The most recent national survey of bereaved people showed that people over 80 were least informed about the fact they were likely to die. This age group, perhaps unsurprisingly, were also least likely to have said where they would like to die and relatives were less likely to say the person had enough choice over place of death¹⁶.

3.7. The Care Quality Commission (CQC) has recognised these issues, focusing its recently announced thematic review of end of life care on “people with a diagnosis other than cancer; [and] people aged over 75”¹⁷.

4. Dying at home

4.1. Dying at home has traditionally been seen as a proxy for good end of life care. It can reflect coordinated, well-planned care that has helped to avoid admissions to hospital or support at home that has enabled people to manage their health away from health care settings. 80% of people say they would prefer to die at home¹⁸.

4.2. However, there are limits to using dying at home in isolation as an indicator of a good death. Attitudes to place of death can change over time so people’s stated preference in good health may be very different closer to death. While in some circumstances planned and coordinated care can deliver a good death at home, it could equally mean that people feel unsupported and alone. For example, the 2013 National Survey of Bereaved People revealed that pain is relieved “least effectively at home (18%)”¹⁹.

4.3. People may also prefer to avoid “over-medicalising” their home or associating it with a person’s death, particularly when the spouse/partner would afterwards continue living there.

4.4. The National Institute for Health and Care Excellence (NICE) quality standard for end of life care, reflects some of these additional elements with overarching outcomes that include “increased length of time spent in *preferred place of care* during the last year of life” and a “reduction in *unscheduled care* hospital admissions leading to death in hospital”²⁰ (emphasis mine).

5. Benefits of coordinating care

5.1. The Nuffield Trust’s recent reports on patterns of care and the use of home nursing services have demonstrated the difference coordinated care can make. They showed that “individuals with the highest social care costs had relatively low average hospital costs [suggesting] that use of social care may prevent the need for hospital care”²¹. They also found that “more than three quarters (76.7%) of those who received Marie Curie Nursing Service (MCNS) care died at home, while only 7.7% died in hospital”²².

¹⁶ National Survey of Bereaved People (VOICES) 2013, Office for National Statistics, 2014

¹⁷ <http://www.cqc.org.uk/content/themed-review-end-life-care> (accesses December 2014)

¹⁸ National Survey of Bereaved People (VOICES) 2013, Office for National Statistics, 2014

¹⁹ National Survey of Bereaved People (VOICES) 2013, Office for National Statistics, 2014

²⁰ Quality standards for end of life care for adults, NICE 2011

²¹ *Understanding patterns of health and social care at the end of life*, Nuffield Trust, 2012

²² *Understanding patterns of health and social care at the end of life*, Nuffield Trust, 2012

5.2. In terms of cost saving, the mean hospital activity costs per patient who received home nursing care were £610, versus £1,750 for those not receiving this care, largely due to reductions in emergency admissions. The Nuffield Trust also said “the impact of MCNS care in terms of more home deaths and lower hospital use was greater for people without a recent history of cancer”²³. This suggests that older people, traditionally less likely to receive specialist palliative care, are more likely to benefit.

6. Frailty

6.1. Caring for older people, particularly the oldest old, means having a strong understanding of sometimes complex needs and having the skills to deliver proactive, planned support. This can mean constantly negotiating the pathway of active treatment (for example surgery; aggressive cancer therapies); management of long-term conditions and other challenges to wellbeing such as frailty; and where necessary an end of life care pathway (even if this is ultimately over a prolonged period). All the time, quality of life goals and individual preferences should be the guide to care and support.

6.2. These pathways (active treatment; management; end of life) are fluid, often unstable and can be experienced at the same time. The ability to plan and move between them is a crucial feature of high quality care for older people. However, much of the discrimination older people experience both in end of life care and wider NHS services, can be attributed to the failure of the system to achieve this. Older people can find they are pigeon-holed, often without a detailed assessment of their needs, as either for active treat or not appropriate for active treatment. However, there is still no guarantee such a moment that end of life care discussions would take place.

6.3. In part this is captured by the use of the word “frailty”, a word increasingly used in government and wider health policy. In work we have recently completed on health professional perceptions of frailty (not yet published) there is evidence that the word is currently very aligned with end of life care in isolation. It can often be seen as justification on do not attempt cardiopulmonary resuscitation (DNACPR) forms.

6.4. Age UK shares the view with older people’s specialists that frailty should be used as an identifier for people with high risk of sudden deterioration of health and people who would particularly benefit from whole person assessment and care²⁴ (while also acknowledging that older people themselves strongly reject the word^{25;26}). The gap between this and the description in 6.3 reveals one of the significant tensions in the care of older people – not always allowing complex care needs to prompt proactive and coordinated support designed to absolutely maximise quality of life, particularly where that includes end of life planning.

²³ Chitnis, X., et al, *The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life*, Nuffield Trust, 2012

²⁴ Fit for frailty, British Geriatrics Society/Age UK/RCGP, 2014

²⁵ Understanding the live of older people living with frailty, Age UK/Ipsos MORI, 2014

²⁶ I’m Still Me: a narrative for coordinated support for older people, Age UK/National Voices/UCLPartners, 2014

6.5. We are pleased that the concepts around frailty are gaining some common currency, with the secretary of state for health frequently referring to “the frail elderly” as a priority area. However, we would also add caution that wider use of the word does not entrench the issue described in the preceding paragraphs. Or, most importantly, give the impression that older people are less appropriate for active treatment.