

### **BGS End of Life Care Key Messages**

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'Ordinary' dying at the end of the life course is not well understood by the public.

Coverage of the Assisted Dying Bill has skewed the debate, leaving people with a distorted understanding of when and how most people die. Death is a natural process at the end of life and the large majority of people die in older age at the end their natural lifespan. Better provision of end of life care could enable more people to die well with supportive care in a place of their choosing.

#### 1. The vast majority of those who die each year do so in older age

There are approximately 670,000 deaths every year in the UK,¹ of whom around 65% are people aged over 75.² ¾ Most people die when they are old or very old. In England, those dying over the age of 75 are dying of or with one of the four major conditions (cancer, dementia, cardiovascular disease and respiratory disease). These account for 212,000 deaths in those over the age of 85; 157,000 deaths in those aged 75 to 85; and 180,000 deaths under the age of 75.5

However, dementia is now the leading cause of death, accounting for 74,731 deaths in the UK in 2023 (11%).  $^{1\,6\,7}$  The number of people dying of dementia will increase in the next ten years numerically and proportionally, whilst other causes of death decrease. After a dementia diagnosis, a third of remaining life expectancy is lived in a care home on average.

# 2. Those who die in older age often have multiple long-term conditions, including frailty resulting in health and social care needs

The majority of those who die each year have multiple long-term conditions and/or frailty, rather than a single condition such as cancer or motor neurone disease. Over 60% of people over the age of 85 have more than one **long-term condition**<sup>9</sup> which is associated with a higher risk of hospital admission and death. Up to half of people over the age of 85 years live with **frailty** and people with severe frailty are five times more likely to die within a year than older people without frailty. 12

Those with frailty and multimorbidity have an uncertain non-linear dying trajectory, making it hard to predict when someone will die, but expert understanding of these conditions can help to identify people who may be in the last year of their lives. This group of people are likely to require significant health and social support over a considerably longer period than those dying of a single condition, especially as 30% of people aged over 65 years live alone and 40% live with a partner of equivalent age, also likely to have health or social care issues.

## 3. What matters to people at the end of their lives should drive planning of EOLC services and support

Awareness that the end of life may be close should inform all clinical care for people with multiple long-term conditions, taking a needs-based approach. This enables proactive and compassionate communication with people and their families about how to spend their remaining time and where they wish to die. This can be documented and respected through Advance Care Planning. Most (78%) of the public are unaware of the term 'advance care planning'<sup>13</sup> and one study revealed that less than a third of respondents discussed end of life wishes in the last year of their life or formally documented their wishes. <sup>14</sup> Uptake is particularly low among older people living with frailty<sup>15</sup>, as well as ethnic minority groups, with cultural differences and language barriers often cited as a barrier to engagement with advance care planning services and resulting in inequitable access to quality end of life care. <sup>16</sup> Honest conversations about the approaching end of life can facilitate consideration of realistic treatment options and shared decision-making to avoid over-medicalisation. Instead, people can be supported to live their remaining days in the right place for them with appropriate health and social care support focussed on their individual needs.

### 4. People should be supported to die in their preferred place of death

Over half (56%) of people dying over the age of 65 indicate that they would prefer to die at home with their loved ones around them. However, at present 75% of people do not die where they would prefer. However, at present 75% of people do not die where they would prefer. Of those over the age of 65, around 40% die in hospital, 30% die at home, 20% die in a care home, and 5% die in a hospice. People express different reasons for their preferred place of death, but it appears that many end up in hospital as an emergency, dying there, when better recognition and provision of end of life care might have enabled them to remain at home, avoiding interventions that do not deliver better patient reported outcomes. One in eight people spends more than 30 days of their last three months in hospital and more than half are conveyed to hospital by ambulance as an emergency at least once in the last three months of life.

#### 5. The workforce supporting end of life care needs upskilling

Delivering quality end of life care for the majority of people who die in the UK requires skills in supporting people with multiple long-term progressive conditions, frailty and dementia, underpinned by a patient-centred, evidence-based approach. These skills include recognising when people may be entering the last year of life; delivering shared decision making focussed on realistic treatment options; ensuring access to timely, responsive care; considering alternatives to hospital admission when appropriate; communicating about and documenting Advance Care Planning. Delivery of such care requires professionals who are confident in managing risk in the community, are able to traverse health and social care and who can address physical, cognitive, psychological and social needs. Generalist skills are needed, rather than specialist skills focusing on only one condition. Currently, end of life care is provided predominantly by the generalist workforce, rather than palliative care specialists. Half of all people who die, largely older adults, have no contact with specialist palliative care.<sup>20</sup> We advocate for greater recognition of the role of other specialists in providing palliative and end of life care, in particular GPs and geriatricians, as well as emphasising the need to upskill the wider workforce in this important aspect of health and social care.

<sup>1</sup> Office for National Statistics, 2023. *Vital statistics in the UK: births, deaths and marriages*. Available:

https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/vitalstatisticspopulationandhealthreferencetables. (Accessed 22 January 2025).

<sup>2</sup> Office for National Statistics, 2024. Deaths registered in England and Wales: 2023. Available at: <a href="https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2023">https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2023</a> (accessed 22 January 2025).

- <sup>3</sup> National Records of Scotland. *Birth, deaths, marriages and life expectancy.* Available at: <a href="https://www.nrscotland.gov.uk/statistics-and-data/births-deaths-marriages-and-life-expectancy/">https://www.nrscotland.gov.uk/statistics-and-data/births-deaths-marriages-and-life-expectancy/</a> (accessed 22 January 2025).
- <sup>4</sup> Northern Ireland Statistics and Research Agency, 2024. *Registrar General Annual Report 2023 Cause of Death*. Available at: <a href="https://www.nisra.gov.uk/publications/registrar-general-annual-report-2023-cause-death">https://www.nisra.gov.uk/publications/registrar-general-annual-report-2023-cause-death</a> (accessed 22 January 2025).
- <sup>5</sup> Office for Health Improvement & Disparities, 2024. Palliative and end of life care factsheet: Patterns of care, England 2022. Available: <a href="https://fingertips.phe.org.uk/documents/peole">https://fingertips.phe.org.uk/documents/peole</a> patterns of care factsheet 2022.html (accessed 22 January 2025).
- <sup>6</sup> National Records of Scotland, 2024. *Alzheimer's and other dementia deaths.* Available: <a href="https://www.nrscotland.gov.uk/publications/alzheimer-s-and-other-dementia-deaths/">https://www.nrscotland.gov.uk/publications/alzheimer-s-and-other-dementia-deaths/</a> (accessed 29 January 2025).
- <sup>7</sup> Northern Ireland Statistics and Research Agency. *Cause of Death*. Available: <a href="https://www.nisra.gov.uk/statistics/births-deaths-and-marriages/cause-death">https://www.nisra.gov.uk/statistics/births-deaths-and-marriages/cause-death</a> (accessed 19 January 2025).
- <sup>8</sup> Brück C C, Mooldijk S S, Kuiper L M, Sambou M L, Licher S, Mattace-Raso F, and Wolters F J, 2025. Time to nursing home admission and death in people with dementia: systematic review and meta-analysis. *BMJ*. Jan 2025;388. doi: <a href="https://doi.org/10.1136/bmj-2024-080636">https://doi.org/10.1136/bmj-2024-080636</a>.
- <sup>9</sup> Age UK, 2023. *The State of Health and Care of Older People, 2023.* Available: <a href="https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/health-wellbeing/age-uk-briefing-state-of-health-and-care-july-2023-abridged-version.pdf">https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/health-wellbeing/age-uk-briefing-state-of-health-and-care-july-2023-abridged-version.pdf</a> (accessed 29 January 2025).
- <sup>10</sup> Coalition of Frontline Care, 2024. *End of life care is everyone's business.* Available: <a href="https://www.goldstandardsframework.org.uk/cd-">https://www.goldstandardsframework.org.uk/cd-</a>
- <u>content/uploads/files/Coalition%20of%20Frontline%20Care%20Report%20November%202024%20-%20compressed%20-%2026.11.24%20edits.pdf</u> (accessed 29 January 2025).
- <sup>11</sup> Clegg A, Young J, Iliffe S, Rikkert M O, and Rockwood, K, 2013. Frailty in elderly people. *Lancet*. Mar 2;381(9868):752-62. doi: <a href="https://doi.org/10.1016/s0140-6736(12)62167-9">https://doi.org/10.1016/s0140-6736(12)62167-9</a>
- <sup>12</sup> Clegg A, Bates C, Young J, Ryan R, Nichols L, Ann Teale E, Mohanned M A, Parry J and Marshall T, 2016. Development and validation of an electronic frailty index using routine primary care electronic health record data. *Age and Ageing*. 2016;45(3):353-60.
- <sup>13</sup> Marie Curie, 2021. *Public Attitudes to death, dying and bereavement in the UK*. Available: <a href="https://www.mariecurie.org.uk/globalassets/media/documents/policy/public-attitudes-to-death-and-dying-report-final.pdf">https://www.mariecurie.org.uk/globalassets/media/documents/policy/public-attitudes-to-death-and-dying-report-final.pdf</a> (accessed 29 January 2025).
- <sup>14</sup> Marie Curie, 2024. Available: <a href="https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2024/n401b">https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2024/n401b</a> padd briefing final.pdf (accessed 24 January 2025).
- <sup>15</sup> Hopkins S A, Bentley A, Phillips V and Barclay S, 2020. Advance care plans and hospitalized frail older adults: a systematic review. *BMJ Support Palliat Care*. Jun;10(2):164-174. doi: <a href="https://doi.org/10.1136/bmjspcare-2019-002093">https://doi.org/10.1136/bmjspcare-2019-002093</a>.
- <sup>16</sup> Clabburn O, Stone T, Anwar N, et al. Co-production in practice: A qualitative study of the development of advance care planning workshops for South Asian elders. *Palliative Medicine*. 2025;39(1):126-138. doi:10.1177/02692163241302678.
- <sup>17</sup> Higginson I J, Daveson B A, Morrison R et al. Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. *BMC Geriatr* **17**, 271 (2017). doi: https://doi.org/10.1186/s12877-017-0648-4
- <sup>18</sup> Office for Health Improvement & Disparities, 2025. *Palliative and end of life care profiles January 2025 update:* statistical commentary. Available: <a href="https://www.gov.uk/government/statistics/palliative-and-end-of-life-care-profiles-january-2025-update-statistical-commentary">https://www.gov.uk/government/statistics/palliative-and-end-of-life-care-profiles-january-2025-update-statistical-commentary (accessed 24 January 2025).</a>
- <sup>19</sup> Johansson T, Pask S, Goodrich J, Budd L, Okamoto I, Kumar R, Laidlaw L, Ghiglieri C, Woodhead A, Chambers R L, Davies J, Bone A E, Higginson I J, Barclay S, Murtagh F E M, and Sleeman KE, 2024. *Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales*. Available: <a href="https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2024/beol-2024-time-to-care-report.pdf">https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2024/beol-2024-time-to-care-report.pdf</a> (accessed 24 January 2025).
- <sup>20</sup> Marie Curie, 2024. *Time to care: Finding from a nationally representative survey*. Available: <a href="https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2024/beol-2024-time-to-care-report.pdf">https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2024/beol-2024-time-to-care-report.pdf</a> (accessed 24 January 2025).