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Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey

Policy briefing, October 2024

Key messages

- Up-to-date insights into the UK public's views on dying, death and bereavement are key to informing improvements to support for people at the end of life.
- There is a consistent and pressing need for more open conversations about the end of life, as despite many people feeling comfortable discussing death and dying, such conversations rarely happen.
- A principal reason why people don't plan for the end of life is a belief that their wishes won't be acted on – health and social care providers need to consider how they ensure that advance care plans are not only completed, but also that they are listened to and followed.
- Urgent improvements are needed in psychological support services for people at the end of life. Respondents – particularly those approaching the end of their life – identified psychological support as a key priority.
- Joined up health and social care is essential to meeting the end of life care needs and priorities of the UK public.

Who is this briefing relevant for?

This briefing is relevant for parliamentarians, health and care sector civil servants and local commissioners across the four UK nations who want to develop evidence-led policy and services that are in line with the priorities and needs of the public.

Key survey findings

- Most people in the UK want to die at home: 56% of all respondents and 42% of people with a terminal illness in their last years of life chose home as their preferred place of death.
- Being free from pain and other symptoms is people's top priority for their final year (36%) and days (38%) of life.
- Most people feel comfortable talking about their end of life treatment and care wishes (68%) and death (70%), yet far fewer have done so with anyone (14%) or with a healthcare provider specifically (7%). Over a third of people (38%) feel that expressing their wishes wouldn't make a difference to the care they receive.
- Around one in three (29%) of people consider feeling safe to be one of three top priorities for their final days of life.

- Psychological support is among people's top three selected needs in the final days of life for people with terminal illnesses (41%), their family and friends (47%), and those recently bereaved (46%).
- Many people wouldn't know what administrative and practical tasks need to be completed (20%) and how to access support from bereavement services (19%) after someone close to them dies.
- Most parents are in favour of including grief education in school curriculums for older primary school (54%) and secondary school (72%) children and young people. Support for grief education is even higher amongst parents of bereaved children.

What did we do?

In 2021, Marie Curie commissioned a survey to assess public attitudes to dying, death and bereavement in the UK – and the findings were striking.[1] In 2023 we revisited the topic with a new survey, the results of which we're now publishing to provide up-to-date insights. The survey was refined, based on advisory group feedback, to explore additional areas, including barriers to expressing future healthcare preferences in advance of serious illness, coping with practical tasks and reaching out for support after bereavement, and grief education in schools.[2]

Adults aged 18 years and over and living in the UK were eligible to participate in the survey and 10,500 responses were received: 8,561 from England (82%), 1,076 from Scotland (10%), 489 from Wales (5%) and 374 from Northern Ireland (4%). Data was weighted to ensure representativeness of the sample for age, gender and UK region. Most respondents (59%) described themselves as members of the public with an interest in the survey topic. Over a fifth (22%) indicated that they had personal experience of end of life and/or bereavement due to illness.

What did we find?

24/7 access to support and care (including medicines) in the community

Home is the most common place people want to die, followed by hospice (Figure 1). More than twice the proportion of respondents in the last years of life would prefer to die in hospice (20%) compared with respondents overall (8%), showing how preferences evolve near the end of life. Moreover, wherever they die, people want a comfortable, symptom-free death as their top priority (Figure 2).

Fig. 1: Preferred place of death

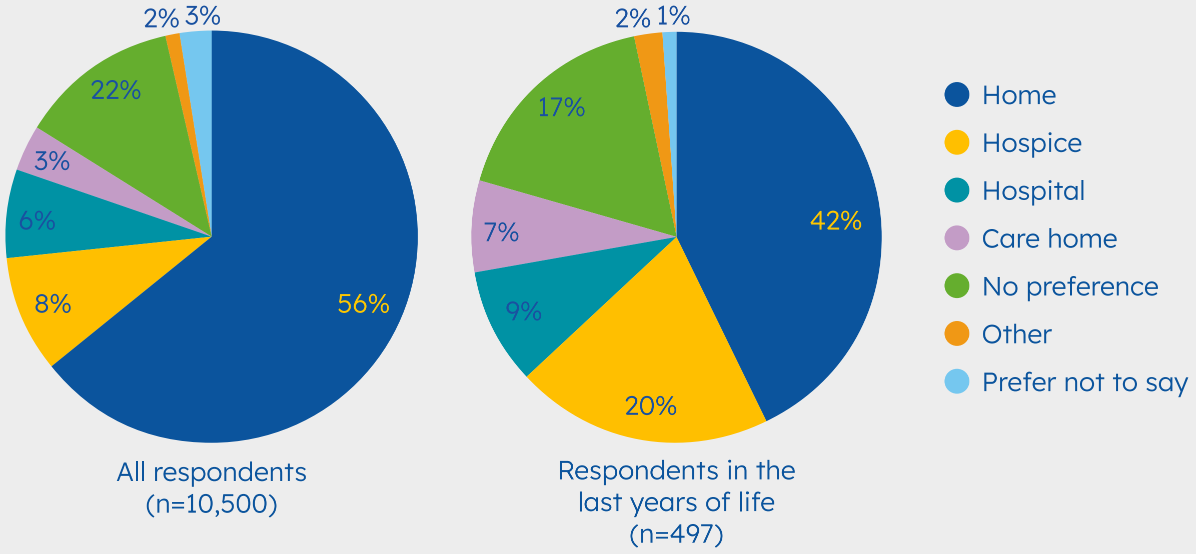
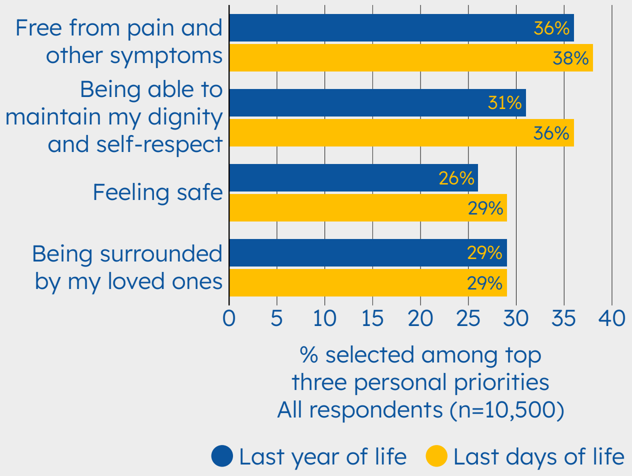


Fig. 2: Top priorities for the last year and days of life



Findings in context: **Most people want to receive care and die in the community, but 24/7 palliative and end of life support in community settings is often inadequate.** Patients and families may need support at home at any time – day or night – yet over a quarter of the UK doesn't have a designated single point of contact palliative telephone advice line operating out of hours.[3] Timely symptom management requires prompt access to medicines, but numerous barriers, including an insufficient community prescribing workforce, and a lack of community pharmacies consistently stocking palliative medicines, restrict this.[4] When people can't access the support and medicines they need at home, they resort to using acute and emergency services, which can be distressing and are costly. A&E visits increase in the last three months of life, with the greatest rise out of hours and in the most deprived areas.[3]

Advance care planning

Most people feel comfortable talking about death and dying (60%) and think that, as a society, we do not discuss the topic enough (59%). Furthermore, being involved in decision-making near the end of life is a top priority for respondents in the last years of life. Despite this, most people have not discussed death and dying or made any plans for the end of life.

These discussions are infrequent even amongst people living with a terminal illness, with less than a third of respondents in the last years of life having discussed their end of life wishes with anyone (31%) or formally documented their preferences (29%). Lack of trust and knowledge contribute to poor advance care planning, with over a third of people (38%) saying they don't think their wishes would be considered, and over a quarter (27%) saying they don't know where to find information on planning for future care.

Findings in context: **Without advance care planning, patients' preferences may not be known, leading to missed opportunities to put anticipatory measures in place that would reduce the likelihood of needing more urgent, distressing and costly care.** Advance care planning has numerous patient, family and system benefits.[5,6] Despite this, advance care plans are too rare, with less than 5% of patients presenting to A&E having one.[7] Poor public awareness of advance care plans and lack of confidence, training and time amongst healthcare professionals contribute to poor uptake.[8]

86%
of people haven't discussed end of life wishes with anyone

93%
of people haven't discussed end of life wishes with healthcare providers

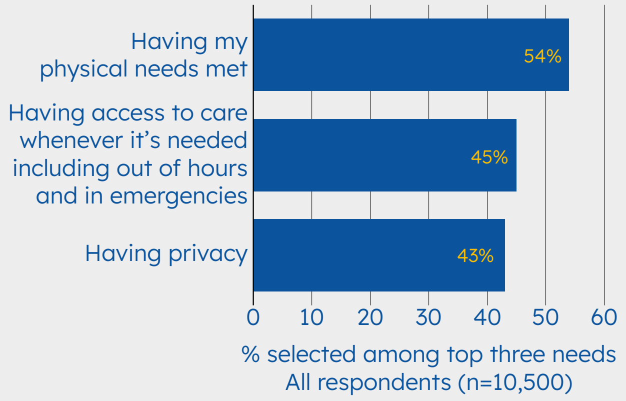
38%
of people think expressing end of life wishes wouldn't make a difference to the care they receive

Feeling safe, whenever and wherever care is delivered

29% of people consider feeling safe to be a top priority in their last days of life (Figure 2). Moreover, having access to care whenever it's needed – including out of hours and in emergencies – is considered the second most important need that people want to have addressed in their final days of life (Figure 3).

Findings in context: **People prioritise feeling safe at the end of life, yet poor coordination and communication across settings and providers hinders the quality and safety of care patients receive.** The introduction of integrated care systems sought to improve patient outcomes, including safety, by joining up care and improving collaboration across health and care organisations.[9] Patients often receive care from multiple providers across settings, including out of hours. This is increasingly common with the rise of complex, comorbid conditions often necessitating urgent care and input from various specialities.[10] Safe transitions of care 24/7 require seamless communication and information exchange. For integrated care to deliver its ambition of enabling safe care, it must be coordinated, collaborative and person-centred; it must prioritise shared electronic health records, education and training for health and care professionals; and it must have sufficient community resources.[11]

Fig. 3: Top needs during last days of life



Mental health and wellbeing

Among respondents in the last years of life, their family and friends, and those recently bereaved, support with psychological needs is considered a top-three priority at the end of life. Psychological support is considered the fourth most important need amongst all respondents, showing how perceived importance of psychological support increases near the end of life and bereavement.

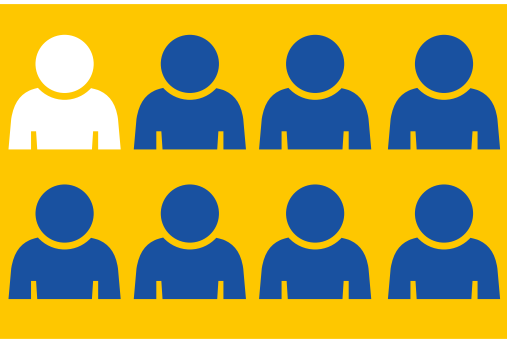
Findings in context: **Inadequate psychological support services mean patients' and their families' mental health and wellbeing needs are not being addressed.** Research shows that many healthcare professionals within hospices feel inadequately trained in providing psychological support.[12] Furthermore, in-house clinical and counselling psychologists are only staffed in 19% and 9% of UK hospices respectively, and only 16% of

Having psychological needs met was considered a top-three priority for:

41%
of respondents in the last years of life

47%
of family and friends of people in the last years of life

46%
of respondents recently bereaved



1 in 8 people

would feel uncomfortable seeking grief support

hospice staff feel that their patients' psychological needs are being completely met.[13] More psychological support training for health and care professionals delivering palliative care is needed.

Bereavement

After someone's death, one in ten people would feel uncomfortable reaching out to family and friends for help and one in eight would feel uncomfortable seeking grief support. Practically, around one in five people don't know what administrative steps would need to be taken after someone close to them dies.

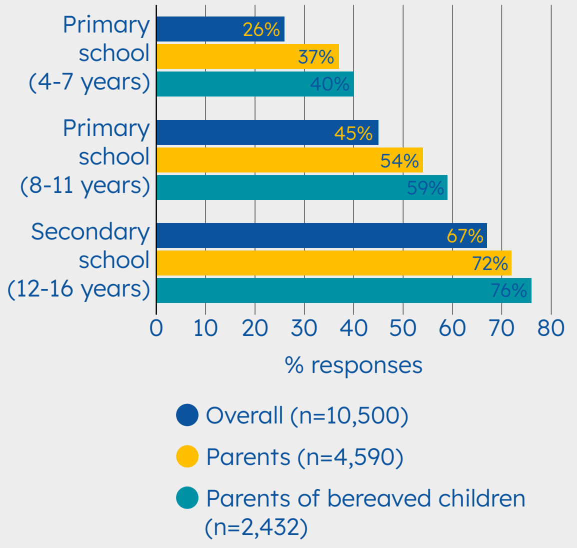
Findings in context: **Family and friends of people nearing the end of life and those who have died often don't have access to the support they need due to inadequate available resources or insufficient information.** According to the UK Commission on Bereavement, 33% of people who wanted to access bereavement services found that no support was available, and 37% said they didn't know how to access support.[14] Over 40% of those who wanted formal bereavement support didn't get any.[14] Over half (61%) of bereaved people said they experienced difficulties with practical or administrative tasks related to their family member's death.[14]

Grief education in schools

Many agree that learning about grief should be included in school curriculums, with the highest levels of support for grief education amongst older child age groups and respondents whose child had experienced a bereavement (Figure 4). Most agree that appropriate training for teaching staff would be critical to delivering sensitive, supportive education on bereavement.

Findings in context: **There is public and parental support for including grief education in school curriculums for older primary-aged and all secondary-aged students.** Research shows there is currently inadequate support for bereaved children and young people within schools, and that there are potential benefits of introducing grief education.[14,15,16,17] Learning about grief and bereavement at school could help children cope with future bereavements and enable them to better understand and support their bereaved friends. These benefits underline the need for bereavement policies, staff training, and a process for supporting bereaved children and young people in educational settings.

Fig. 4: Respondents who agreed that grief education should be included in school curriculums



Recommendations

In order to ensure people are able to die at home where this is their preference:

- Health commissioners must ensure 24/7 access to palliative and end of life care, including through a single point of access in every local area offering advice, guidance and support.
- Governments across the UK must act to improve 24/7 access to medicines through more pharmacies stocking palliative medicines and more professionals trained to prescribe them in local communities.

In order to ensure adequate access to palliative care to meet local need:

- Governments across the UK should deliver a new funding solution for palliative and end of life care to end the postcode lottery in access.

In order to ensure people's end of life needs and preferences are central to the care they receive:

- Governments across the UK should ensure that every individual reaching the end of their life has a legal right to personalised care and support planning, with plans being shared so they're accessible to all health and care professionals at the point of care.
- Health commissioners should consistently involve people with direct experience of dying, death and bereavement in co-designing local palliative and end of life care services.

In order to ensure access to mental health and wellbeing support at end of life:

- Governments across the UK must include the mental health and wellbeing support needs of people towards the end of life in mental health strategies and guidance.
- NICE and SIGN should produce and consult on new guidelines for mental health support for people approaching the end of their life at the earliest opportunity.

In order to deliver the needed improvements in bereavement support:

- NICE and SIGN must develop guidelines for the delivery of bereavement support, which seek to normalise help-seeking, and ensure easy-to-access information on grief support is provided.
- Governments across the UK should require all schools and other education settings to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement as part of life, including by ensuring that grief education is a mandatory part of the curriculum in each nation.

About this work

This work funded by was Marie Curie (Core Grant Ref 523838). Marie Curie commissioned the research team at the Marie Curie Research Centre at Cardiff University, School of Medicine, to develop the survey question set and Opinium, a UK-based commercial market research company, to administer the survey to a representative sample of the UK public and carry out the initial data analysis.

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