

Briefing: November 2024

End of life care services in England and Wales: considerations for the Terminally Ill Adults (End of Life Bill)

The Nuffield Trust is an impartial think tank which tries to improve health through policy analysis and research.

Introducing assisted dying has major implications for health systems – and the way our health service works today will influence how it could happen.

Some have argued that the state of end of life care is so weak that it might be unable to support assisted dying, or pressure people wrongly to take it up. Others have suggested that problems in end of life care make choice more important. This briefing draws on research over a number of years to shed light on how end of life care is really working and what recent trends have been. It then explores five key questions for the implementation of assisted dying, which we believe will determine the impact its introduction would have on the NHS.

The Nuffield Trust is neutral regarding legalisation of assisted dying

We hold a neutral position on whether or not assisted dying should be legalised, for whom, and in what circumstances. We are committed to identifying evidence to support decision-makers in understanding the implications of legislation for health and care services, in line with our remit to improve the quality of UK health and care through evidence-based policy analysis.

Key facts about deaths and end of life care in England and Wales

- In 2023, [there were 544,000 deaths in England](#), of which 43% occurred in hospital, 28% at home, 20% in care homes, and the remainder in hospices or elsewhere.
- There has been a trend for the last two decades towards more people dying at home, and this trend accelerated at the start of the pandemic.
- A large proportion of health and care is delivered for people in their last year of life (on average 30% of hospital beds are occupied by someone who is in the last year of life).

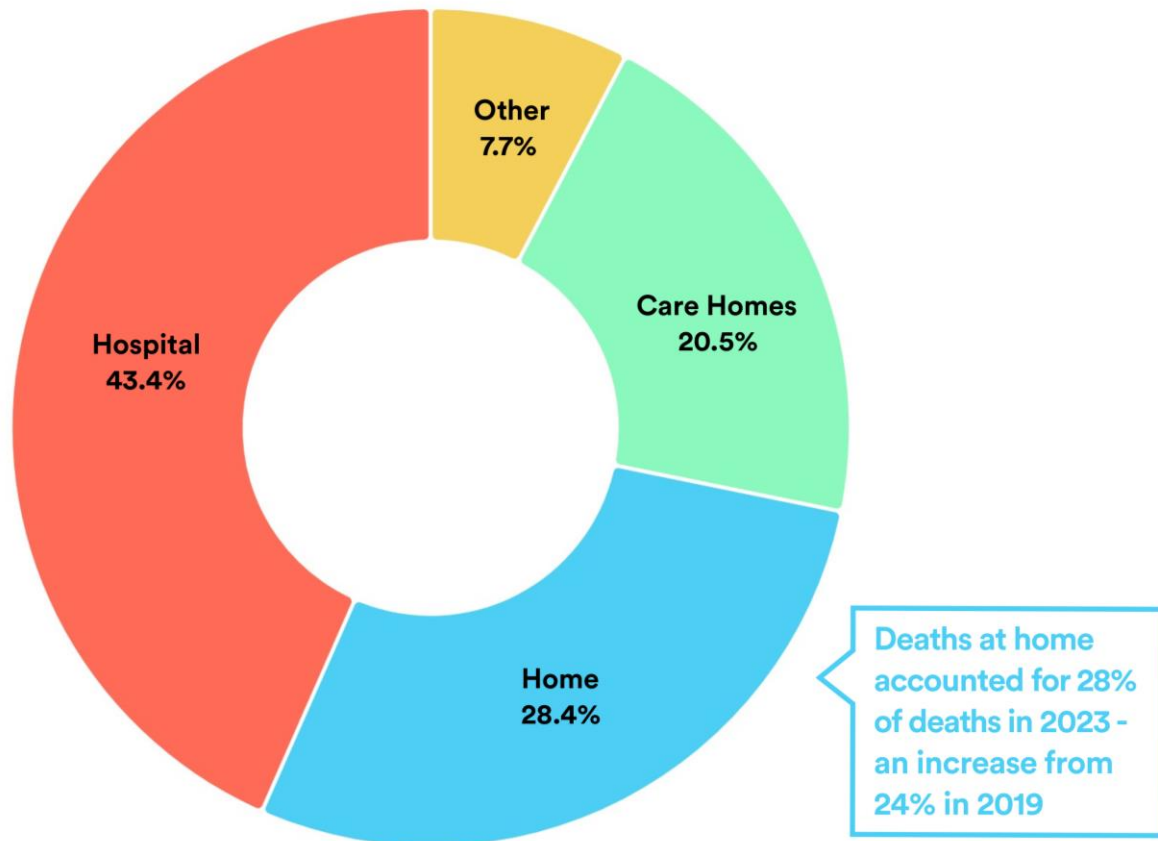
- Almost everyone needs health care at the end of life, and many people also need social care, but these services are in a poor state. For both NHS and specialist hospice services, there are funding pressures and staffing shortages, and access is patchy.
- Many people have symptom control needs at the end of life - for example with pain, breathlessness or nausea. Too few have their wishes met about how they are cared for, with over half of people not having advance care plans.
- Access to good quality end of life care is not equal. Our research shows that 47% of people in the most deprived areas died in hospital in the first year of the pandemic, compared to 41% people in the least deprived. People from Asian, Black or mixed ethnic groups who die at home are less likely to be prescribed medicines to manage their symptoms, with Asian people being prescribed an average of 1.06 medications and Black people 0.98, compared to 1.6 for White people.
- Many key considerations for how assisted dying would really work in or alongside the NHS and social care are yet to be addressed. In particular how standards would be upheld, and whether people will need to pay privately or rely on support funded through charity, as is the case for much social care and end-of-life palliative care currently.

How are people cared for at the end of their lives?

[End of life care](#) is usually defined as care for people likely to die within a year. This happens across many parts of the NHS and social care.

[Palliative care](#) is a special type of care for people at the end of life, to make them as comfortable as possible, relieve pain and other distressing symptoms, provide psychological, social and spiritual care and give support to families, carers and those close to the person. It is estimated that [75% of people who die in the UK could benefit from palliative care, but only around 50% actually receive it](#). Most people at the end of life will receive **most of their care from general health and care services** including from hospitals, GPs, community nurses, and social care providers.

Place of death, England and Wales, 2023



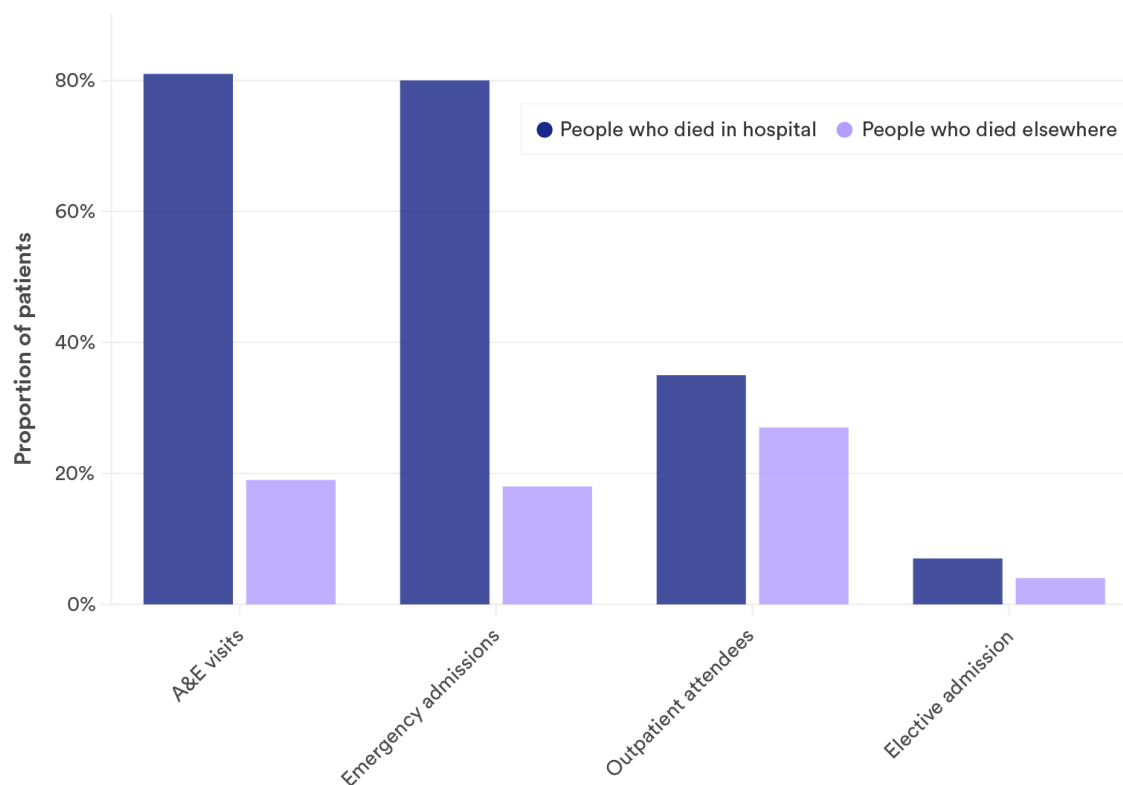
Source: Nuffield Trust analysis of Office for National Statistics data.

(<https://www.nuffieldtrust.org.uk/news-item/what-primary-and-community-services-do-people-who-die-at-home-receive>)

Emergency NHS services play a very important role for people at the end of life. As the chart above shows, hospitals are still the most common place to die, even though this may not always be what patients wish for and even though deaths at home have risen. Around 80% of people who die in hospital have an emergency admission in the month prior to their death. The proportion of people having an A&E visit in the last month of life is similarly high (81%). A fifth of people who died in other locations also attended A&E or had an emergency admission in the last month of life.

For the 43% of people who die in hospital, there is **insufficient specialist care**: **only 60% of hospitals met the current standard** to have face-to-face specialist palliative care advice available for eight hours a day, seven days a week.

Proportion of people using hospital services in the last month of life (September 2022 to August 2023)

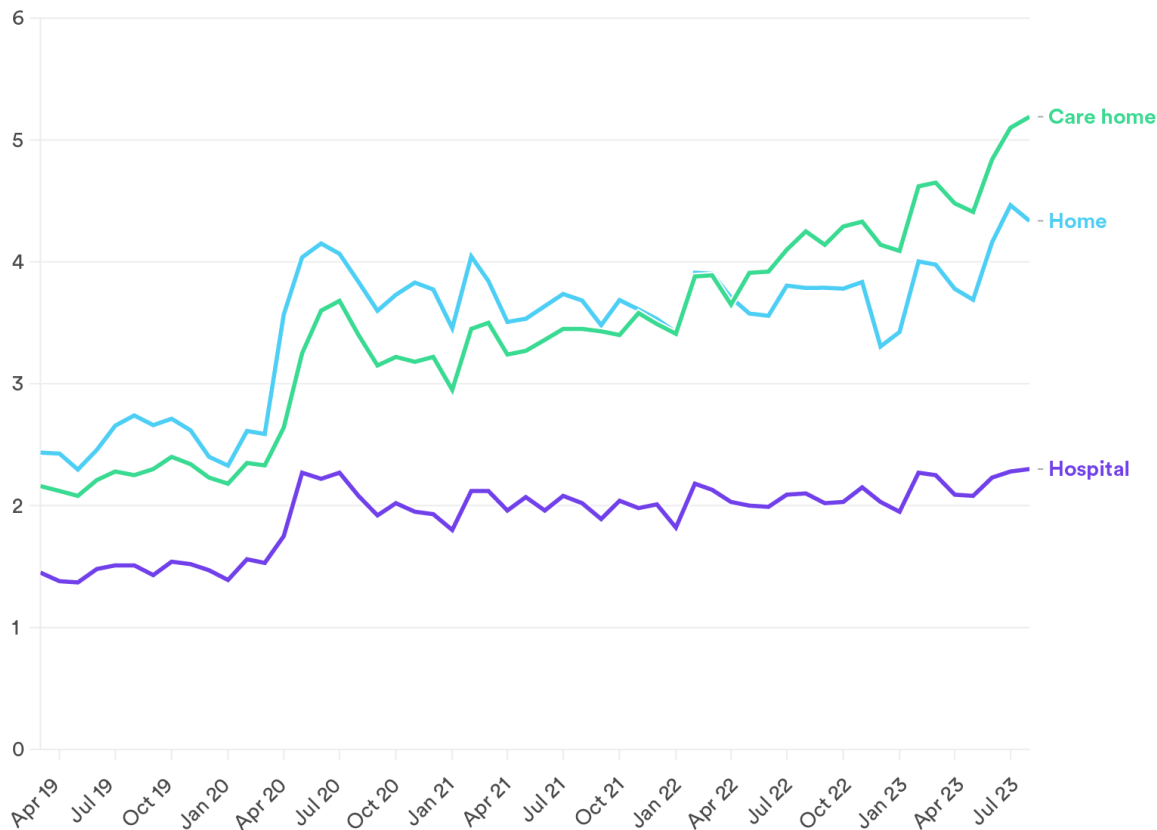


Source: <https://www.nuffieldtrust.org.uk/news-item/how-are-hospital-services-used-at-the-end-of-life-0>

The care people receive from [GPs and primary care teams](#) at the end of life is changing significantly. For people dying at home, the number of contacts from their GP/primary care team more than doubled between March and August 2019 and the same period in 2023. Meanwhile, the [decline in patients always seeing the same GP](#) risks increasing unplanned [hospital admissions](#). **Recognising someone is likely to die can help them access better care.** However, among [people who die at home](#) only 40% are identified in their GP record as being at the end of life.

For people [who died in care homes](#), over 90% had a contact with a GP/practice in the last month of life (a 44% increase since 2019), which in part reflects a [programme](#) designed to enhance the provision of primary care to care home residents.

Contacts with the GP/practice team in the last month of life, by place of death



Source: <https://www.nuffieldtrust.org.uk/comment-series/using-health-and-care-services-at-the-end-of-life> (NB this chart is drawn from data in two separate blogs)

While the NHS is as stretched as it is now – including these hospital and primary care services most people need when they are dying – **it is questionable whether high-quality care for people at the end of life can be delivered consistently.**

What issues are specialist hospice services facing?

Provision of specialist palliative care services is fragmented, with access to care variable and funding insecure.

Independent hospices are important providers of specialist palliative care. Although only about 5% of people die in a hospice bed, hospices are estimated to provide support in [approximately half of deaths in the UK](#), for example, providing care at home or specialist advice. Hospices receive the majority of their funding from [charitable](#) sources. **Increases in**

costs for hospices, combined with a challenging funding environment across the charitable sector, have heightened [concerns about the stability](#) of the hospice provider sector.

Access to specialist hospice care is variable, with more deprived and [diverse](#) areas being less well served.

What social care is provided to people at the end of life?

As well as the almost [one in five people who die in a care home](#), many more people rely on home care at the end of life – for support with personal care, preparing and eating meals, and taking medication. There is very **limited visibility of provision of home care** for people at the end of life, so it is difficult to be certain whether people are getting what they need: [a study from 2012](#) found that 15% of people received local authority-funded care in the last year of life.

Which services are people missing out on and what inequalities are there?

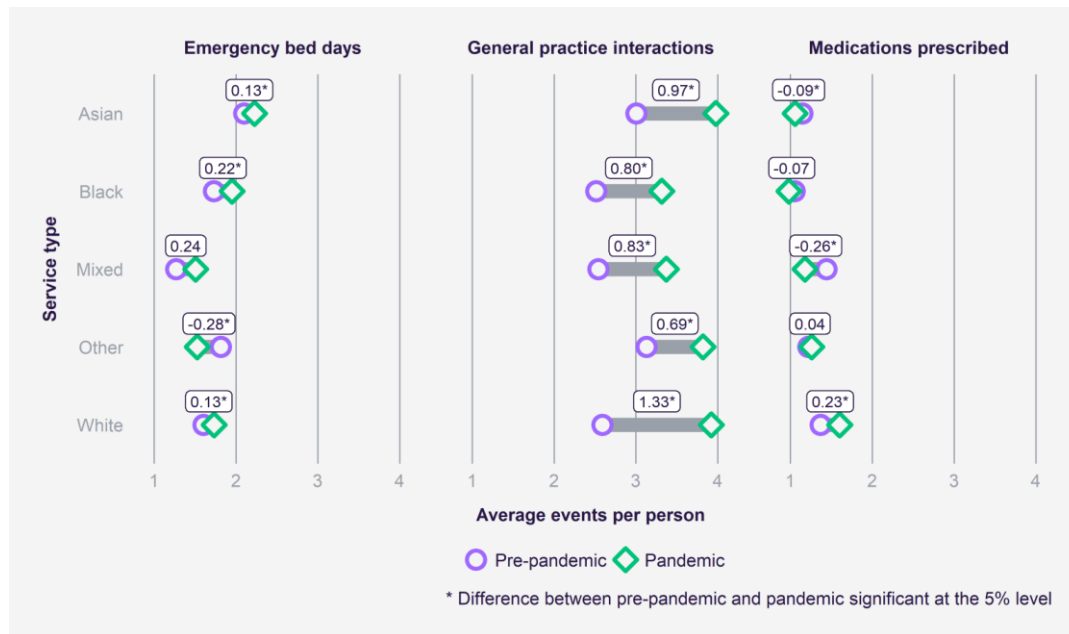
Many people who die do not receive the care they need, which impacts on both them and the unpaid carers who support them. A recent post-bereavement [survey of experience](#) at the end of life in England and Wales found **a third of people were reported to be severely or overwhelmingly affected by pain in their final week of life.** It is common to find poorly coordinated care, difficulty accessing services out of hours, and insufficient support for unpaid caregivers.

Only a quarter of people who die at home have an advance care plan recorded in their GP record, and only 12% of people who die in hospital. Even among people with an advance care plan, the proportion for whom this plan was actively used to shape their care is unclear.

There are also **inequalities in end of life care.** People from more deprived areas are more likely to die in hospital, and to be [admitted to hospital](#) at the end of life even if they then die at home. Our research shows that 47% of people in the most deprived areas died in hospital in the first year of the pandemic, compared to 41% people in the least deprived.

People from Asian, Black or mixed ethnic groups who die at home are prescribed [fewer medications](#) for symptom control at the end of life, and these differences increased during the pandemic.

Average events per person in the last month of life by ethnic group for selected service types in the pre-pandemic and pandemic cohorts



Source: <https://www.nuffieldtrust.org.uk/research/deaths-at-home-during-the-covid-19-pandemic-and-implications-for-patients-and-services>

How can end of life care be improved?

End of life care should be included in the government's ambition to shift more care from hospital to home and places close to home, especially given that the number of people dying in their own place of residence is increasing.

Efforts to improve end of life services need to consider care provided across all settings, such as from GPs, as well as improving access to specialist services like hospices.

Better end of life care training could [enhance confidence](#) among the GP teams, community nursing and social care staff who provide care for people who are dying.

Despite their critical role in provision of end of life care for [people in the community](#), [district nurse numbers are declining](#). More should be done to bolster this workforce.

Key questions on introducing assisted dying: how will it work with or alongside the NHS?

As the Assisted Dying for Terminally Ill Adults Bill is a private members bill rather than coming from government, it is **not accompanied by a specific plan for how it would be implemented** and how public services are meant to respond. The Bill is consistent with a range of quite different approaches, depending on the use of the powers set out in Clause 32, and in other key clauses, for the Secretary of State. This leaves some important questions for MPs to carefully consider on how assisted dying could work in or alongside our health and care services.


If assisted dying is to be publicly funded, it will sit alongside services which are largely not. Social care at the end of life is often paid for by its users themselves. Hospice care is free at the point of use, but more than half of hospice care is funded through charity in combination with government grants and local NHS funding. This could create a financial imbalance in the different options that an individual near the end of life will be considering, unless other services are changed.

On the other hand, **if assisted dying is not publicly funded, it may be difficult for the Bill to achieve its aims of improving choice for all patients.** Access to assisted dying would be dependent on the ability to pay, or on certainty that charitable funds could and will be used in this way.

A separate but related question is **whether NHS trusts will be able or expected to provide this service** – an option left open under Clause 32. Will professionals involved who are also NHS doctors be working in a private capacity or as part of their NHS contract? It is also yet to be settled **which organisations will regulate the service for quality of care, what standards are expected, and what kind of data might be gathered** to monitor this. These are important considerations for all parts of care, with many standards for access, quality and outcomes applied in different ways to NHS trusts and social care providers, services and treatment decisions, and individual clinicians.

Lastly, the Bill also does not stipulate how people might find out which clinicians are willing to discuss assisted dying, an architecture which would need to be built by the NHS or privately.

Nuffield Trust is an independent health and social care think tank. We aim to improve the quality of health and social care in the UK by providing evidence-based research and policy analysis and informing and generating debate.

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