Time to Care: Better End of Life Report 2024
Briefing for Parliamentarians

Summary

- New research published as part of the Better End of Life research programme highlights that whilst the number of people who need palliative and end-of-life care is increasing steeply, our health and care system is already struggling to meet that demand.
- The largest nationally representative survey of people affected by dying, death and bereavement since 2015 has found that:
    - Too many people are dying in pain and without the support they need for their symptoms;
    - Gaps in 24/7 community care are preventing people from dying in comfort at home;
    - Patients and unpaid carers are suffering due to poor communication and coordination;
    - Current workforce capacity is insufficient to meet demand for end of life care;
    - Unpaid carers are taking on significant caregiving roles with little support.
- People are not getting the care and support they need at the end of life, but these factors are also likely to be heaping additional pressures on our health and care systems – through avoidable hospital admissions, complaints about poor experiences, and an unacceptable burden on unpaid carers.
- Without urgent action, gaps in access to palliative and end of life care will only grow. There is currently no realistic national or local plan to address the scale of this challenge.
- As the new government states its ambition "to shift more healthcare out of hospitals and into the community, to ensure patients and their families receive personalised care in the most appropriate setting" these findings demonstrate the scale and urgency of policy change required to ensure that all patients with a terminal illness receive the best possible palliative and end of life care in their communities.

Context

There is currently significant unmet need for palliative and end of life care. This is due to both a postcode lottery for accessing services and inequalities in the end of life experiences for some marginalised communities. **Marie Curie estimates that 1 in 4 people currently don't get the end of life care and support they need. That's 150,000 people every year.**

This is a critical time to improve palliative and end of life care. Too many people are dying without the care and support they and their unpaid carers need. The number of people in

England who need palliative and end of life care is increasing as our population ages and people live longer, often with multiple and complex conditions. Up to 90% of deaths would benefit from palliative care, the need for which is expected to increase by 26.5% by 2048.

More people now die at home, but hospital emergency service use in the final months of life is increasing. With around a third of NHS costs accrued in the last year of life, the design and delivery of end of life care has huge implications for public spending. Both the NHS and charitable hospices are facing extreme financial pressures, and long-term investment in the primary and community care workforce has been insufficient to meet the rising demand.

Integrated Care Boards now have a legal duty under the Health and Care Act 2022 to commission palliative care services that meet the needs of their local populations. The statutory guidance requires them to address inequity of access and provide safe, personalised, high-quality palliative and end of life care with sufficient workforce in all settings. This includes 24/7 access to services.

However, previous *research by Marie Curie* has found that significant improvements are required to ensure that ICBs fully understand population health needs and to enable the commissioning of palliative and end of life care services which address those needs. *Previous research published as part of the Better End of Life programme* has also highlighted significant gaps in 24/7 service provision, with many areas not having a single point of contact, overnight nursing services, or the ability to facilitate access to medicines out-of-hours for patients with palliative and end of life care needs.

About the Better End of Life research

The Better End of Life programme is a collaboration between Marie Curie and King's College London's Cicely Saunders Institute, Hull York Medical School at the University of Hull, and the University of Cambridge. The programme examines evidence on the current state of dying, death and bereavement across the United Kingdom and proposes policy changes to ensure that everyone has the best possible end of life experience. This year's report '*Time to care: findings from a nationally representative survey of experiences at the end of life in England and Wales'* is based on findings from the largest nationally representative survey of people affected by dying, death and bereavement since 2015.

Key findings in England

Too many people are dying in pain and without the support they need for their symptoms.

- More than one in three people were severely or overwhelmingly affected by pain (34%) or breathlessness (40%) in their final week of life.
- Almost two thirds (64%) of unpaid carers felt anxious most or all of the time about the person's illness or treatment and more than a third (38%) reported that the person who died felt depressed most or all of the time during their final week of life.
- Barriers to accessing palliative care medicines were common, particularly 'out-of-hours'.
- People who were financially worse off were more likely to be affected by severe and overwhelming symptoms.

- Inequalities in access to palliative care persist, particularly for older people and those with a non-cancer diagnosis.

Gaps in 24/7 community care prevent people from dying in comfort at home

- Most end of life care occurs in the community: 64% of people spent most of their last three months of life in a private home; 24% in a care home and 7% in hospital.
- Difficulty accessing health and care professionals in the community was common.
- Emergency service use in the final three months of life was high, with 61% of people who died using an ambulance and 53% visiting A&E at least once.
- One in seven people (15%) who died in hospital had been there less than 24 hours.
- Over a third (37%) of people who died in hospital had no friends or family present.

Patients and unpaid carers suffer when communication and coordination are poor

- Half of respondents (50%) were unhappy with at least one aspect of the care the person who died received. One in nine people (11%) made a formal complaint.
- Fewer than half of the respondents (42%) said they'd had a key contact person to co-ordinate care. The lack of coordination created challenges in knowing who to contact for help or what was available.
- Recognition of palliative care needs was often considered too late. Healthcare professionals had discussed death and dying with just one in three (37%) of the people who died, though these conversations were more likely to have happened with the person's family (66%).
- One in four people who died (25%) either probably or definitely did not know they might die because of their illness.

Workforce capacity is insufficient to meet demand for end of life care

- Staff across health and social care settings often did not have enough time to provide adequate care for dying people.
- Most people who died had contact with health and care professionals in the community, most often from GPs or district or community nurses. Despite this, nearly one in five people (19%) who died had no contact with a GP in the last three months of life.
- Almost half of respondents felt health care professionals mostly listened or provided sufficient help.
- Lack of communication was a common source of frustration.

Unpaid carers take on significant caregiving roles with little support

- Most respondents undertook essential caregiving roles but many felt unprepared, lacking the knowledge, skills, and access to professional support needed.
- Of respondents still in work, 12% took between 31 and 90 days paid or unpaid leave, while 5% quit or changed their jobs (including retiring early), to care for their loved one.
- One in six respondents (15%) met the criteria for 'disturbed grief' – with bereaved people who are younger, female, or the spouse of the person who died, as well as those who had a poor experience of care, most at risk.
- Most (71%) of those who met the criteria for disturbed grief had not accessed bereavement support.

Recommendations for policy change

Theme	Recommendation	For action by:
Making a good end of life experience possible for all	Develop a national strategy for palliative and end of life care to support delivery of local plans.	UK Government; NHS England
Better symptom management support	Improve access to medicines through more pharmacies stocking palliative medicines and more professionals trained to prescribe and administer them.	NHS England; Integrated Care Boards
	Produce and consult on new guidelines for mental health support for all people approaching the end of their life.	National Institute for Health and Care Excellence
Delivering 24/7 community care	Strengthen equitable access to palliative care through increased investment in primary care and community nursing services.	UK Government
	Ensure 24/7 access to palliative and end of life care including through a single point of access offering advice, guidance and support.	Integrated Care Boards
Better integrated services and timely co-ordination of care	Commission services that offer everyone the opportunity to set out their wishes for the end of life and ensure these plans are shared and followed by health and care providers.	Integrated Care Boards
	All health and care professionals should be funded to receive training in and have time to follow clear national guidance on advance care planning.	UK Government
	Electronic care coordination systems should be resourced in ways that incentivise their sustained use and sharing with progress on the use and availability of shared records, including advance care planning, being audited regularly.	Integrated Care Boards
A workforce that is fit for purpose	Publish, at least every two years, independently verified projections of future demand for the palliative and end of life care workforce (including specialist palliative care) and ensure a properly resourced plan is in place for meeting this demand.	UK Government
	Make palliative and end of life care training a compulsory part of training and continuing professional development for	UK Government

	all health and care workers, not just those in regulated professions.	
Improve support for unpaid carers	Increase support for carers of people at the end of life through better identification, needs assessment, financial and bereavement support.	Local Authorities
	Extend statutory bereavement leave and pay entitlement of two weeks to all people with a close relationship to a person who has died.	UK Government

Questions for the Secretary of State for Health and Social Care

- Too many people with a terminal illness are currently dying without the care and support they and their unpaid carers need. Will the Secretary of State commit to developing a national strategy for palliative and end of life care, and backing it with long-term and sustainable funding, to ensure that everyone has the best possible end of life experience?
- Marie Curie's research has found that too many people are dying in pain and without the support they need for their symptoms - more than one in three people were severely or overwhelmingly affected by pain (34%) or breathlessness (40%) in their final week of life. What plans does your government have to improve 24/7 access to medicines for those in need of palliative and end of life care?
- Patients with a terminal illness and their unpaid carers suffer when communication and coordination are poor. What steps does this government intend to take to ensure that people at the end of life benefit from better integrated services and timely co-ordination of care?
- Labour's election manifesto committed to the publication of regular, independent workforce planning, across health and social care. Given that much of our palliative and end of life care services are provided by charitable non-NHS providers like Marie Curie, will the Secretary of State confirm that this future workforce planning will consider the specific needs of and challenges for this sector?
- Marie Curie's research has found that emergency service use in the final three months of life was high, with 61% of people who died using an ambulance and 53% visiting A&E at least once. What plans does your government have to improve 24/7 community palliative and end of life care to reduce avoidable pressures on our NHS?

About Marie Curie

Marie Curie is the UK's leading end of life charity. We are here for anyone with an illness they're likely to die from, and those close to them. We bring 75 years of experience and leading research to the care we give at home, in our hospices and over the phone. And we push for a better end of life for all by campaigning and sharing research to change the system.

For more information or to arrange a meeting to discuss the contents of this briefing, please contact: parliament@mariecurie.org.uk