



Meeting current and future need for hospice and end of life care

Five priorities for the next UK Government



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Summary

Over the course of the next Parliament more than 3 million people will die in the UK. Of these, around three-quarters will have an 'expected' death, that is, they were known to be unwell or their death was not sudden.

The UK has proud tradition of good hospice and end of life care, delivered through charitable hospices, the NHS and social care, and is rightly ranked best in the world.¹ But that does not mean everyone who needs expert palliative and end of life care receives it, or that their carers are adequately supported. Experts estimate that across the UK 118,000 people every year do not receive the care they need when facing end of life.²

There is much that the UK Government can do to ensure hospice and end of life care in the UK is accessible to all, sustainable and ready for the changing needs of our communities. We call on the next UK Government to make changes across five priority areas in support of these ambitions:

- 1. Make charitable hospice care sustainable through a robust statutory funding model**
- 2. Reduce inequalities and meet need for palliative and end of life care by making the system intelligence-led**
- 3. Mitigate negative impacts of caring on carers through a right to return to their job**
- 4. Meet current and future need for palliative and end of life care by investment in skills and workforce for primary and community care**
- 5. Resolve the gap between social and health care for adults and children at end of life or with life-limiting conditions by delivering a social care settlement that addresses their unique needs**

What is hospice care?

Hospice care aims to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal condition. It helps people live as fully and as well as they can to the end of their lives, however long that may be. Hospice and palliative care can benefit anyone approaching the end of life or living with an incurable illness. It can be delivered in many different ways and settings, in GP surgeries, in hospitals, in the home or community, or in hospice inpatient units.

Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support. There is equal emphasis on a person's clinical, physical, emotional, social and spiritual needs. Most hospice care is delivered by local charities, and funded primarily through charitable donations.

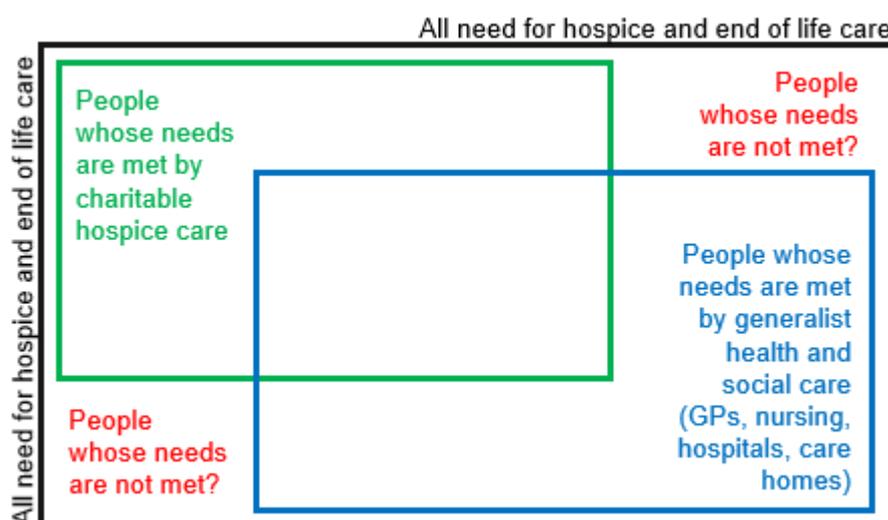
More than 200,000 people a year receive some form of care from a charitable hospice, be that through home-based care, outpatient clinics, day hospice or inpatient hospice.³

What is unmet need for hospice and end of life care?

Despite the inevitability of our lives ending, experts estimate that annually 118,000 people at end of life across the UK do not receive the care they need. They will not have their end of life or palliative needs addressed in a joined up, holistic way.

At an individual level, unmet need for hospice and end of life care takes many forms, but most simply it is a failure to recognise a person is approaching end of life and ensure their physical, emotional and spiritual needs are met. Unmet need can mean that a person has complex pain issues that could benefit from the specialist skills of a consultant but no referral is made. It can mean that without being supported to understand the processes of end of life, a family calls an ambulance for a person experiencing restlessness, leading to them then dying in a busy accident and emergency department instead of peacefully at home. It could mean a person dies sooner than they might because support around nutrition and mobility were not given the right priority.

At a population level, while there is some understanding of who does not receive good end of life care, such as people with non-cancer diagnoses or the very old, there is a lack of robust analysis to identify who is missing out on the right care and why this is the case.



Over the next 25 years, demographic change will increase the level of need for end of life care, as more people die each year with more complex needs. There is a need to address current unmet need and prepare for the future.

How is charitable hospice care funded?

Hospice care is provided at no charge to the people who use it. In total adult and children's hospices spent £1.47 billion in 2017-18, of which £354million, or 32 per cent, came from statutory sources. The majority of charitable hospice revenue is realised through fundraising. Adult hospices in the UK receive, on average, one third of their costs from the NHS. Children's hospices are supported at a much lower level, receiving 17 per cent of the cost of providing care from statutory sources.⁴ As such, charitable hospice providers are major funders and commissioners of care for people at end of life or with life limiting conditions

Our priorities for the next UK Government

1. Make charitable hospice care sustainable through a robust statutory funding model

Charitable hospices are an essential and significant part of palliative and end of life care delivery in the UK, providing support to an estimated 200,000 people every year. The majority of this care is funded by charitable donations from local communities. A contribution to the cost of hospice care comes from statutory sources, predominantly the NHS. There is no agreed mechanism or model for the funding of charitable hospices, which leads to different levels of funding across the UK and from provider to provider. This creates uncertainty and undermines the ability of charitable hospices to plan for the future and secure financial stability.

We call for the next UK Government to deliver a funding compact with charitable hospices that delivers stability, reflects population need and supports transformation and innovation.

2. Reduce inequalities and meet need for palliative and end of life care by making the system intelligence-led

Across the UK some 600,000 people will die in the next year, and around three-quarters of these will have an 'expected death' in that they are known to be ill and/or approaching end of life. Over the next 20 years the number of people dying each year is set to increase as those born in the post-war baby-boom reach end of life.

Despite these certainties, we know very little about their needs, and how or whether these needs are met.

We call on the next UK Government to address this by undertaking:

- *detailed needs assessment for the adult population at end of life*
- *detailed needs assessment for babies, children and young people with life limiting conditions*
- *robust evaluation of palliative and end of life care, including impact on individuals and economic assessment*

3. Mitigate the long-term negative impacts of caring on carers through a right to return to their job

Well-supported carers are essential to good palliative and end of life care, but frequently experience long-term negative financial and labour market effects as a result of their caring.

We call on the next UK Government to mitigate these negative impacts and prepare for the future needs of dying people by implementing a statutory entitlement for carers to return to work following a fixed absence period of up to two years to care for a loved one.

4. Meeting current and future need for palliative and end of life care means investment in skills and workforce for the front line

Primary care, community and district nursing and social care (including care homes and care at home) are essential to good end of life care and are the main point of care for most people at end of life.

The workforce is already under great strain, with high vacancy levels and limited investment. Changing demographics, the growing population of older people with multiple conditions, and more

complex needs of people living in the community will increase these pressures. If our community workforce is to meet current and future need for care we must invest in their skills development and plan for the workforce of tomorrow.

We call on the next UK Government to commit to:

- *investment in skills development in palliative and end of life care across primary care, community and district nursing, and social care*
- *planning and investment in the primary care, community and district nursing and social care workforce to be based on robust population needs assessment, particularly the needs of people in the last years of life*

5. Resolve the gap between social and health care for adults and children at end of life or with life-limiting conditions by delivering a social care settlement that addresses their unique needs

It is imperative that the next UK Government delivers a workable social care settlement.

We call on the next UK Government to ensure that the social care settlement provides a seamless relationship between health and social care services regardless of funding model, and directly addresses the unique needs of:

- *people in the final years of life (fast access and responsive to rapidly changing needs)*
- *children with life limiting conditions and their families (supports the child and family to live well)*

About Hospice UK

Hospice UK is the national charity for hospice and palliative care. We work to ensure all adults and children living with a terminal or life-shortening illness receive the care and support they need, when they need it.

For more information

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¹ The Economist Intelligence Unit (2015) The 2015 Quality of Death Index, see <https://www.eiu.com/industry/article/1413563125/white-paper-quality-of-death-index-2015/2015-10-07>

² Hughes-Hallett T et al. Funding the right care and support for everyone – Creating a fair and transparent funding system: the final report of the Palliative Care Funding Review' An independent review for the Secretary of State for Health. London: Department of Health, 2011. We have drawn on the methodology set out in 'this paper to quantify levels of need/unmet need.

³ Hospice UK (2017) Hospice care in the UK 2017. London: Hospice UK, 2017

⁴ Hospice UK (2019) Hospice Accounts 2018 London: Hospice UK and haysmacintyre, 2019



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