HospiceUK



Hospice UK Strategy
2024-2029

Hospice care for all, for now and forever

Hospice care for all, for now and forever

2024 - 2029

HospiceUK

Hospice care eases the physical and emotional pain of death and dying, letting people focus on living right until the end.

But too many people miss out on this essential care.

Hospice UK fights for hospice care for all who need it, for now and forever.

This is our strategy.

Our vision

Hospice care for all, for now, forever

Our mission

To promote and protect hospice care for all

The UK faces a turning point, with demand for children's and adult palliative and end of life care set to surge in the coming years.

Our ageing population means that many more people are going to die each year – and we're determined that they and their loved ones get the care they need and deserve.

Hospice UK's strategy shows how, with the right support, the hospice sector can step up to this challenge.

- Toby Porter
CEO of Hospice UK

For all, for now, forever

Hospice UK is the national champion for hospice care. We represent a community of more than 200 hospices from across the UK, delivering services to adults and children.

Our membership includes the UK's independent charitable hospices, two national palliative care charities (Sue Ryder and Marie Curie) and charities supporting NHS hospice services.

Every year, our hospices care for 300,000 people living with life-limiting conditions or facing the end of their life. They provide bereavement, counselling and practical support to 60,000 of those dear to them.[1] By 2040, around 130,000 more people will die each year in the UK than today.[2] More children with complex needs are surviving beyond infancy and into young adulthood, and medical and social complexity is increasing with age.

Hospices provide care which is free at the point of use. But, unlike in the NHS, it is not fully state funded. While hospices receive some government funding, more than £1 billion of the £1.6 billion they need each year comes from generous donors.[3]

The cost of providing hospice services is going up, while ever more people need palliative care. The financial situation for hospices is likely to deteriorate even further, and it is local communities who will pick up the cost.

Already, we know that some groups and communities are missing out on hospice care and there is a pressing need to do more to reach them.

A severe national shortfall of staff for adult and especially children's services also presents additional challenges for many hospices.

By working collaboratively with hospices and other partners, our aim with this five-year strategy is to secure hospice care for all who need it.



300,000

People received palliative and end of life care from hospices

600,000

Hospices provided 600,000 days of inpatient care for people nearing the end of life





910,000

Generalist palliative care nurses, healthcare assistants, social workers and carers from hospices made 910,000 home visits

880,000

Specialist palliative care doctors and nurses from hospices made 880,000 home visits





820,000

Outpatient visits were made by patients to hospices for services such as physiotherapy and counselling

1 data from Hospice UK: Hospice Activity and Demographic Survey, 2022-2023
2 based on data from ONS National population projections: 2020-based interim, released 12th January 2022 and ONS Dataset: Vital statistics in the UK: births, deaths and marriages, released 24th February 2023
3 data from Hospice UK Hospice Accounts Report, 2021-22

Hospice UK Hospice Activity Data Survey, UK, 2022-23

The context: a turning point for the UK

The UK is at a turning point when it comes to the numbers of people dying and those living with life-limiting conditions.

The death rate is expected to increase for at least the next 20 years. That means around 130,000 more people will die each year than do now, and more people will struggle with grief and bereavement. The care and support these people will need will put a huge strain on the country's resources.

Whether and how we prepare for this monumental shift will reveal a huge amount about who we are and what we value as a nation.

Currently too many people are dying in places and ways that do not meet their wishes. End of life care is sporadic and inadequate for both children and adults.

Already there is considerable unmet need and inequity in who receives hospice and palliative care. We should not accept the lack of dignity and justice for those who are currently missing out.

The UK's hospice sector has the services and the expertise to lead the way. Hospices across the UK are ready and willing to help governments plan for more and better end of life care, and to work with health and care partners to deliver it. But they cannot do this under the current set up.

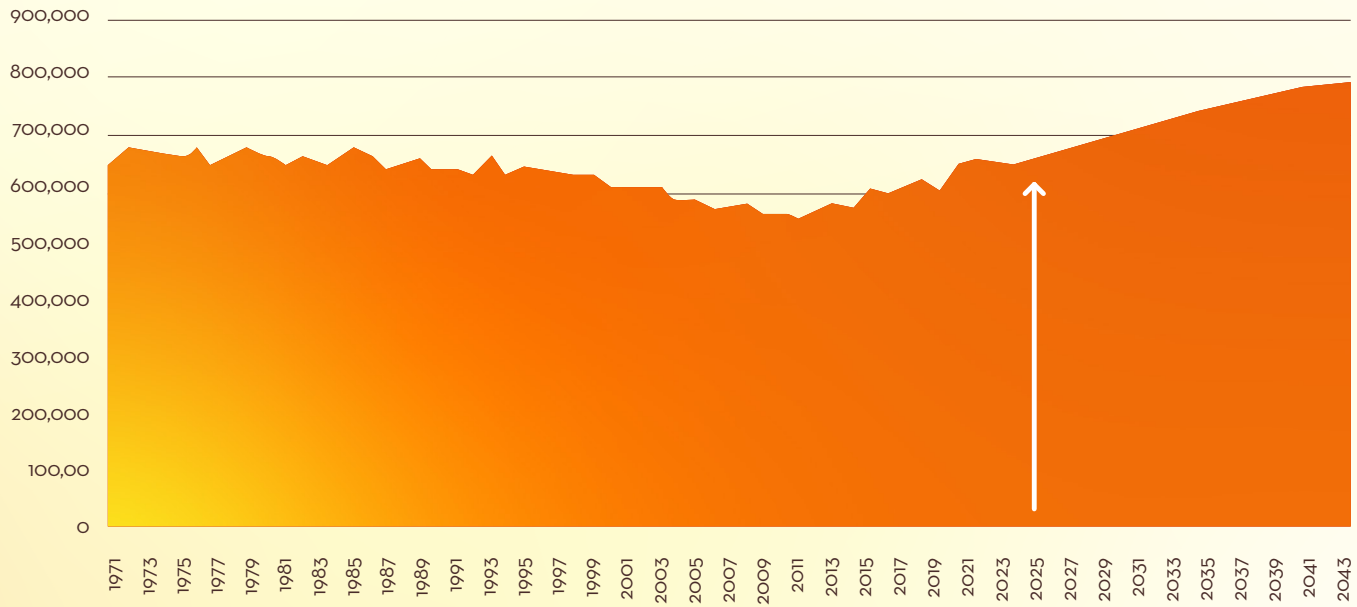
Hospices are a vital part of the health and care system. Their expertise in supporting people with frailty and complex needs is critical. But they cannot be asked to do even more, with even less.

With more people dying every year, we must put a new approach in place. We must find new ways for hospices to use their strengths to the full and overcome the challenges they face.

If we are successful, we can reach more adults and children who need vital hospice care and meet the growing needs of the UK population.

> Approaches to death and dying reveal much of the attitude of society as a whole to the individuals who compose it."
>
> **- Dame Cicely Saunders**
> Founder of the hospice movement

Deaths in United Kingdom
1971 - 2022 actual, 2023 - 2043 projected



Based on data from ONS National population projections: 2020-based interim, released 12th January 2022 and ONS Dataset: Vital statistics in the UK: births, deaths and marriages, released 24th February 2023

Why is demand for hospice care increasing?

More people are dying in the UK. After decades of a stable, slightly declining death rate, demographic trends mean that the annual number of deaths - currently approximately 650,000 - is steadily increasing. It will reach 780,000 in 2040.

- Our ageing population means that more and more people are living with complex, long-term conditions such as frailty and dementia, which require specialist management.
- Medical advances mean that more children are being born and living longer with life-limiting conditions.
- There is greater demand for services such as counselling and bereavement care, as the importance of these interventions is increasingly understood.
- There is growth in demand for hospice care services to be delivered in different locations including hospices, homes, hospitals, care homes, and virtually.
- There is pressing need to reach currently underserved communities and people who are missing out.
- There is greater demand being created by pressures on other health and care services, which threatens to leave hospices to fill the gaps.



HospiceUK

Our strategic priorities

HospiceUK

The hospice sector is well placed to help meet the challenging context faced by the UK in the coming years. Hospice UK is the voice and champion of the sector. Working in collaboration we have identified three priorities that together will enable the hospices to give more people the dignified death they deserve.

Priority 1

To improve equity of access:

We will work so people get the end of life care they need, and support hospices to reach those we know are missing out.

Priority 2

To enhance quality care:

We will support hospices to deliver individualised quality care amid rapidly changing demands.

Priority 3

To achieve sustainability:

We will fight for hospice services, making sure they are well funded, governed and well staffed long into the future.

Priority 1. To improve equity of access

Making sure everyone gets the care they need

We know that whether you get high quality palliative and end of life care depends on who you are, where you are, and why you are ill. Too many people are missing out on this essential care.

We estimate that one in four people do not receive the specialist care they need at the end of their lives. Patients living with frailty, dementia, respiratory conditions and neurological diagnoses are less likely to receive hospice care.

Evidence also shows that it's the same communities who are most likely to miss out on healthcare during their lifetime who are the least likely to get the best possible care at the end of life. The lack of diversity in the sector both in the workforce and in patients using hospice services is not acceptable.

This is an issue of social justice. More must be done to reach minoritised and underserved communities. Our ambition is for the hospice sector to lead the way.

What we want to achieve

- More people receive hospice care earlier to live well, right until the end.
- Improved experience of hospice care for underserved communities.
- Increased reach of palliative care expertise for people whatever their clinical need and wherever they live.
- Enhanced hospice staff confidence and competence to meet the needs of their communities.

To achieve this, we will

- Work with healthcare services to understand local population need for palliative care, and support hospices to identify gaps in their services.
- Explore the social and geographic issues and solutions to secure equitable access to end of life care.
- Be vocal in calling for the changes needed to improve equity of access and increased reach by hospices across healthcare.
- Provide grant funding for hospices to pilot new ways of inclusive working with underserved communities.
- Work with experts to support patients with a clinical need but who are less likely to access hospice care.
- Share training, support and resources for hospice staff to improve access to and reach of their services.

How we will measure our success

- The numbers of people benefiting from hospice care increases.
- The gap closes between what local populations need and what services deliver.
- Following grant funding from Hospice UK, projects to improve equity of access for underserved communities are rolled out permanently.
- Hospice staff report more confidence in their skills and partnerships to serve the needs of diverse communities.



Priority 2. To enhance quality care

Supporting hospices to deliver individualised quality care

Since its foundation, hospice care has represented an excellent standard of quality care in the UK. Today it is a fundamental part of our health and care system, but one that often feels undervalued.

Hospice care puts the patients and their family at its heart, both before and after someone's death. It is there at the most difficult time of someone's life, providing expert clinical care and holistic support. Hospices can lead the way in delivering expert end of life care, sharing their knowledge and working with other health and care professionals.

There is a need to better evidence the value of the individualised care, for both a patient and their family, that children's and adult hospices provide. As the national champion of hospice care, Hospice UK will use our voice to highlight the quality and value of hospice care.

What we want to achieve

- Enhanced capability and skills for all hospice professionals to maintain quality standards in a changing clinical, social and digital environment.
- Continual improvement in the quality of care, informed by patient reported experience.
- Good leadership and collaboration that supports professionals across the wider health and care system.
- Better evidence of the value of the hospice sector as partners in the wider health and care system.

To achieve this, we will

- Provide tools for hospices to measure, compare and continually improve the quality and safety of their services.
- Share good practice and facilitate learning between and across hospices and the wider health and care system.
- Share information on approaches to implementing national guidance and regulatory frameworks.
- Focus on closing the gaps in quality provision for children moving into adult palliative services and for people who are ageing with frailty.
- Collect hospice service, workforce and finance data to demonstrate the outcomes and impact of hospice care at a national level.

How we will measure our success

- Hospices report appropriate staff skills for the communities they serve.
- Hospices take a quality improvement approach to service development.
- Patient reported experience is used consistently to evidence and improve care.
- Collaboratives are sharing knowledge and good practice across health and care systems.
- Hospices meet evolving regulatory requirements.



Priority 3. To achieve sustainability

Making sure hospices thrive into the future

Hospices are a vital part of the wider health and care system across the UK. Given the scale of demand facing the end of life care sector it is critical that hospices can not only survive but thrive into the future.

And yet, even at current levels of demand, hospices are finding it increasingly difficult to fully fund and staff their services.

The financial situation for many hospices is precarious. On average, they must fundraise for around two-thirds of their costs. This model is not sustainable, particularly given rising prices and staff salaries.

Like the health and care sector at large, hospices are finding it hard to recruit and retain staff, struggling to match the pay and benefits of hospital services.

All organisations are required to evolve with changing times, and we need hospices that are adapting to digital transformation, which are well governed and able to work collaboratively in a complex environment.

What we want to achieve

- Sufficient and sustainable funding for hospices to deliver care for everyone who needs it, including fair and consistent funding from national governments.
- A long-term and adequate supply of appropriately trained staff and volunteers delivering care to those at the end of life and those with limiting conditions.
- Well governed organisations that are vital partners in wider healthcare systems.
- Digital technology that underpins the efficient and effective use of resources.



Data from Hospice UK Hospice Accounts Report, 2021-22

To achieve this, we will

- Mobilise members, supporters and the public to lobby governments to provide fairer funding so everyone who needs end of life care receives it.
- Work with decision makers in the four nations to secure sustainable, long-term, statutory funding solutions. These will be built on the value and contribution made by hospices to the wider health and care system.
- Support hospices to integrate fully into their local health and care system and secure fair commissioning deals to meet the needs of patients and families.
- Deliver a national legacy campaign to help build a long-term funding stream for hospices.
- Work with education organisations to design training and attract professionals into the palliative care workforce.
- Support hospice boards to lead their organisations through the challenges of governing and financing hospice services.
- Encourage discussion amongst hospice staff about assisted dying in preparation for the impact of any change in laws across the UK.
- Support hospices to access digital technologies and skills to streamline and strengthen their ways of working.

Priority 3. To achieve sustainability

Making sure hospices thrive into the future

How we will measure our success

- Fairer funding is supported in national parliaments and publicly.
- Clear and consistent hospice funding frameworks are agreed.
- Hospices receive robust, multi-year contracts with funding uplifts equal to local hospital services.
- Attractive career pathways and support enable hospices to increase staffing numbers.
- Hospices have policies and procedures that support well-led organisations.
- Hospices and their staff report confidence in using digital technology in their work.



The hospice workforce

16,000 Total hospice clinical workforce

12,200 Nurses & healthcare assistants

950 Doctors*

2,850 Health and care professionals

95,000 Volunteers helping hospices deliver care & support services





Data from Hospice UK Hospice Clinical Workforce Survey, 2022-23. Volunteer statistic from Charity Commission and Companies House for Scotland.
*Additional doctors are employed within the NHS to work across sites.

Delivering our strategy

Hospice UK unites a national community of dedicated professionals and volunteers and strives to provide a space where our members can collaborate.

To deliver our three priorities, this strategy is underpinned by two ways of working.



Firstly, we can only achieve our goals if we pull together as a **community**, drawing on the best of who we are and what we do to learn, advocate and deliver better end of life care for all in the UK. We will generate support and knowledge from the wider palliative care community, national charities, volunteers, patients, families and all those who want to see equitable end of life care in this country.

We will use the collective strength of the thousands of amazing people who work and volunteer in hospices to be a strong, campaigning voice at a national level. We won't be afraid to challenge governments, health bodies such as the NHS, local commissioners and others to do better when it comes to the planning and delivery of end of life care.

Our community is built on stories and experiences of people, patients, families and volunteers so we will continue to share openly about death, dying and grief, reducing stigma and taboo, including through our Compassionate Employers programme and Dying Matters Awareness Week.



Secondly, Hospice UK needs to be an **outstanding organisation** to ensure that the best and most skilled staff can contribute to us being a great membership body. Hospice UK needs to be a super place to work to attract diverse talent and we are determined to foster a positive culture and employee experience.

To deliver our ambitious strategy, we also need to be a great fundraising organisation, in which all staff, volunteers and trustees can play their part in securing the funds we need to achieve our goals. Our strategy will also succeed by deploying the right technology and we will continue to develop robust monitoring and evaluation systems to track our performance, with data analytics driving our decision-making.

This strategy was produced in consultation with our members, supporters and other partners. Thank you to all those who gave their time.

We can't achieve the ambitious goals in our strategy without your support. To find out how you or your organisation can help us reach our vision of hospice care for all, for now and forever, please visit **hospiceuk.org/support-us**

HospiceUK

www.hospiceuk.org
t: 020 7520 8200
@hospiceuk

Hospice UK,
Hospice House,
34 – 44 Britannia Street,
London WC1X 9JG

©Hospice UK 2024.
Company limited by guarantee.
Registered in England and Wales No. 2751549.
Charity registered in England and Wales No. 1014851
and in Scotland No. SC041112. VAT No 731 304476.