

# Transforming hospice care

## A five-year strategy for the hospice movement **2017 to 2022**



“Hospice care in the UK is at a **pivotal moment...**  
**Radical change** is needed.”

# About Hospice UK

## **We are the national charity for hospice care.**

We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

Visit our website to find out how our work supports people living with terminal and life-shortening conditions and their families: **[www.hospiceuk.org](http://www.hospiceuk.org)**

Keep up to date with our work on social media:

Twitter: **@hospiceuk**

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# Introducing our new direction

March 2017

Dear colleagues

We are delighted to share with you the new direction for the hospice movement across the UK. This over-arching strategy will be complemented by the local strategy of each hospice and shaped by the communities they serve in England, Wales, Scotland and Northern Ireland. Here we outline the challenges and opportunities ahead of us and what needs to be done to achieve our vision of ensuring that everyone who needs hospice care receives it.

The most significant shift in our strategy is a sharpened focus on the beneficiaries of hospice care. Everything we do centres on the adults and children who need hospice care and their carers. In this, we move beyond a focus on Hospice UK's members and the care they provide. We are committed to opening up hospice care: widening access to new communities and extending our reach to new settings.

Our strategy is the product of a great deal of consultation and discussion with our members, supporters, partners and other stakeholders. This collaboration enabled us to create the first ever plan for the hospice movement as a whole. The support we have mobilised for this bold new direction will be vital as we work to translate our goals into action.

**Together we will open up hospice care for everyone.**



Tracey Bleakley  
Chief Executive



The Rt Hon Lord Howard  
of Lympne, CH, QC  
Chairman

# 5 years, 4 goals, 1 big ambition... to open up hospice care

In 2017, the modern hospice movement founded by Dame Cicely Saunders turns 50. We believe our ambitious new direction carries forward Dame Cicely's original focus on the ill, the dying and the bereaved.

Our strategy also enables us to look to the future and ensure that we continue to anticipate and respond to the needs of society in caring for adults and children with terminal and life-shortening conditions.



## Our 4 strategic goals:

1. **Extend our reach** and enable hospice quality care to be delivered in any setting.
2. **Tackle inequality** and widen access to hospice care.
3. **Work with communities** to build capacity and resilience to care for those at the end of life.
4. **Empower** a strong, dynamic and responsive hospice sector.

## How we created the strategy

This new five-year strategy draws on the extensive findings of the Commission into the Future of Hospice Care (2012 to 2013) and reflects perspectives from across the hospice movement.

To create our strategy:

- **Hospice UK's trustee board** shaped the strategic planning process and, alongside the **Advisory Council**, provided detailed feedback at key stages along the way; the board agreed the final strategy in December 2016
- chief executive Tracey Bleakley and senior staff sought members' views in more than a **dozen roadshows**, which took place from Bristol to Ballyclare, Cardiff to Glasgow in 2016
- we **engaged partner organisations and stakeholders** across the voluntary, public and private sectors, as well as staff and volunteers in dozens of face-to-face and online meetings and conversations.





# Our vision and mission

## **Our vision is hospice care for every person in need.**

We want to bring about the wide-reaching social and cultural transformation that is needed in how adults and children in the UK are cared for at the end of their life. We are committed to empowering individuals and communities to embrace the ethos of hospice care and extend its breadth and reach to improve everyone's experience of death, dying and bereavement.

## **Our mission is to enable hospice care to transform the way society cares for the dying and those around them.**

Around one in three of us has a friend or family member who has benefitted from hospice care, and more than 80 per cent of the public believe that everyone with a terminal illness should have a right to hospice care. As the hospice movement, we must retain everything we have achieved to date but grow and evolve to meet the needs of those at the end of their life today and those in the future, whatever their needs might be.

## **Our definition of hospice care**

Every hospice across the UK was founded to respond to the needs of the community it serves, and continues to develop in order to meet these changing needs. As a result of its history and geography, each hospice will offer a unique range of services. This wonderful variety gives the hospice movement vibrancy and strength.

As we go forward, it is vital for us to understand and articulate why we believe hospice care is so special, how it differs from any other end of life care and why it should be sustained and developed so that it reaches everyone who needs it.

In offering our definition of hospice care, we are aware that there are multiple definitions of the term, as there are for the related concepts of 'palliative care', 'end of life care' and 'supportive care'. For the hospice movement it means the following:

**"Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different."**



# Death and dying in the UK

"You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

**Dame Cicely Saunders**

Anyone with a condition that is terminal or life-shortening could benefit from hospice care and support. In 2015, just over 600,000<sup>1</sup> people died in the UK. Of these, experts estimate 75.5 per cent of all deaths, or 455,000 people, will have had a 'predictable death' in that their death was not sudden and their health was known to be poor.

In 2015-16 charitable hospices in the UK provided expert end of life care to an estimated 200,000 people; this potentially represents around 44 per cent of all people likely to need expert end of life care. In addition, hospices also provided bereavement support for 41,000 people and reached many more people indirectly or informally through support for families and carers.

People with a diagnosis other than cancer are under-represented in hospice care referrals. Charitable hospices estimated that the vast majority of the referrals they received in 2015-16 were for people with cancer. Hospices report that referrals for people with a non-cancer diagnosis are slowly increasing, but cancer remains the primary diagnosis in most people they see.

## Children's hospice care

Care for babies, children and young people is a significant and distinct type of hospice care. There are around 49,000 children estimated to be living with a life-shortening or terminal condition. These babies, children and young people require specialist support, both medical and social. The needs of these children and their families can be highly complex and long-term – hospice care might support a family over a number of years, and across many settings. As more and more young people with complex health needs are able to live well for longer, there is also growing need for services which support transition into adulthood.

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1. Hospice UK. Hospice care in the UK 2016: Scope, scale and opportunities. London: Hospice UK, 2016.

## Unmet need

Experts estimate that there are potentially 100,000 people who have an unmet need for expert end of life care across the UK.<sup>2</sup> While much end of life care is successfully delivered by generalists, such as GPs and nurses, there are times when specialist care is needed.

‘Unmet need’ means many things. It can mean that a person has complex pain issues which might 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 breathlessness, 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 needs like nutrition and mobility were not given the priority required.

## Changing communities and demographics

Over the next 25 years, the number of people dying each year is projected to rise and the number of people with a need for expert end of life care is also likely to increase. Changing demographics mean that there will be more people living and dying with multiple conditions with less local family support. All this will change the end of life journey for large numbers of people, and presents a clinical challenge too, as it becomes increasingly difficult to identify the ‘dying phase’ at end of life.

This has consequences for adults and children with terminal and life-shortening conditions, but also those around them. According to Carers UK, around 2.3 million adults have given up work to care for an elderly, disabled or seriously ill relative and almost three million have reduced their working hours.<sup>3</sup> As well as taking a toll socially and emotionally, caring can affect family finances, and have a knock-on impact on tax revenues and benefit payments.

As our communities and needs change, there is no doubt that families, carers and informal care networks will be expected to do more to care for people approaching the end of their lives. We need to go further in supporting families, carers and local communities in playing this important role.

**Hospice care in the UK is at a pivotal moment, driven by significant social and demographic change. Radical change is needed to ensure expert care is available for every adult or child towards the end of their life.**

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2. Hughes-Hallett T, et al. The final report of the Palliative Care Funding Review. London: Department of Health, 2011. The report identifies a significant proportion of people facing a predictable death will have their needs met by hospices and other expert end of life services, and through generalist support such as GPs, but some 100,000 people will have neither.

3. ‘Research reveals over two million quit work to care’, Carers UK.

# Our 4 strategic goals

## Goal 1. Extend our reach and enable hospice quality care to be delivered in any setting

The hospice sector alone cannot meet all the additional and growing demands for end of life care. It is therefore vital that we help to increase capacity and the style of care beyond the walls of hospices in a range of settings. In this way we can ensure that many more people live well towards the end of their life, die in the place of their choice, and have the best experience possible for themselves, their carers, family, friends and community.

Strong and sustainable partnerships between hospice care and care homes, social care, sheltered accommodation, housing associations, acute hospitals and other charities will enable this to happen. Trained and supported carers and families playing an active role as co-deliverers of care will ensure that more people are able to achieve what matters to them as life draws to a close.

### The change that is needed:

- People at the end of their life, wherever they are:
- will receive the same expert holistic care as in a hospice
  - are aware that they may be approaching the last days of their life and are encouraged, along with those around them, to discuss, prepare and plan as needed
  - are cared for by their friends, family and community who are recognised for the integral role they play and receive the training and support they need
  - will benefit from the expertise of a highly skilled and well supported workforce that is equipped with the latest research and knowledge of best practices to be able to control pain, manage symptoms and offer relevant psychological and spiritual support.

### High level indicators of success:

- A reduction in the number of unnecessary admissions to hospital at end of life.
- An increase in the number of strong and sustainable partnerships between hospices, care homes, hospitals and other care providers.
- Strong local and national relationships are established between hospices and GPs.
- Mechanisms are in place to promote person-centred care whatever the setting.
- Experience, research and innovation are shared between all providers to ensure the development and replication of good practice.



## Goal 2. Tackle inequality and widen access to hospice care

Access to hospice care is currently inequitable. People with conditions such as dementia, heart and liver failure, lung disease and frailty would benefit greatly from hospice care but are not widely being referred. At the same time, some children with life-shortening conditions are living longer and need support to transition into adult services.

In addition, many groups feel they are disadvantaged towards the end of life and do not have easy access to appropriate hospice services. These groups include certain faith groups, the LGBT (lesbian, gay, bisexual and transgender) community, homeless people, prisoners and the traveller community.

To address this, we need to understand better who is not receiving hospice care and to help local hospices to better understand the needs of the community in their catchment area. Also needed is research into the most appropriate services and approaches, plus education, support and shared best practice to help focus scarce resources and respond to unmet needs.

The change that is needed:	High level indicators of success:
<p>People towards the end of life, whoever they are, will:</p> <ul style="list-style-type: none"><li>• have timely access to hospice care if they have a life-shortening condition other than cancer</li><li>• receive the support that is appropriate for their needs; this includes more support for children who are living longer with life-shortening conditions as they make the transition to adult services</li><li>• benefit from greater understanding and knowledge within hospices of the unmet need in their catchment populations</li><li>• receive more joined up and expert support, thanks to better collaboration between hospices, primary care, elderly care and other relevant clinical and social care teams and more systematic sharing of expertise.</li></ul>	<ul style="list-style-type: none"><li>• A greater number of people in previously under-served groups using hospice services.</li><li>• Increased formal links between hospices and different social groups within their communities.</li><li>• Improved intelligence on unmet need through the development and use of hospice care and local population data sets.</li><li>• More partnerships at national and local level between Hospice UK and hospices and other clinical specialty leaders (eg elderly care, child care and cardiologists).</li><li>• There is a shift in social attitudes about the value of hospice care for all groups in society.</li></ul>

### Goal 3. Work with communities to build capacity and resilience to care for those at the end of life

Carers play a critical role in caring for someone towards the end of life so they can be supported to live well and to die at home if this is their wish.

For the carers themselves, this can be very demanding indeed. Many have to take a break from work or even give up working entirely. Yet many employers do not recognise their needs, for example for greater flexibility or more support. We also know that informal networks and the wider community play a vital support role. Too often, however, the health and social care sector is ill-equipped to support such networks and to adapt to situations where traditional family structures are not in place. This must change. Hospice care cannot be delivered without well-supported carers and resilient communities.

The change that is needed:	High level indicators of success:
<p>Carers will:</p> <ul style="list-style-type: none"><li>• be recognised as an integral part of the care being delivered</li><li>• receive the training and assistance they need to support the child or adult they are caring for</li><li>• have access to support that can help them cope, including bereavement care</li><li>• benefit from a more compassionate, flexible employment culture and practice that recognises and supports employees who have caring responsibilities</li><li>• be part of strong and resilient community networks.</li></ul>	<ul style="list-style-type: none"><li>• Increased use of bereavement support for families and carers.</li><li>• Easier access to appropriate information for carers and those around them, including employers.</li><li>• New technological solutions available to support those providing care.</li><li>• The adoption of new employment practices related to supporting carers.</li><li>• Engagement by policy makers on employment practices related to caring for those with terminal and life-shortening conditions.</li><li>• New pilots of volunteering initiatives to fill the gaps in informal community networks.</li></ul>

## Goal 4. Empower a strong, dynamic and responsive hospice sector

A strong hospice sector is essential if we are to achieve our ambitious vision for hospice care for everyone in need. We must continue to push boundaries, to challenge and provoke and constantly develop and evolve services, partnerships and networks in order to reach and support more people.

The change that is needed:	High level indicators of success:
<p>The hospice sector will:</p> <ul style="list-style-type: none"><li>• demonstrate strong governance and leadership</li><li>• be financially sustainable and resilient</li><li>• keep developing a skilled and committed workforce of staff and volunteers, and plan for its future workforce</li><li>• benefit from economies of scale through greater collaboration and new partnership models</li><li>• consistently collect and share high quality data and use this to adapt and learn</li><li>• value sharing best practice, expertise, business intelligence and experience.</li></ul>	<ul style="list-style-type: none"><li>• Hospices adopt new approaches to respond to and prepare for the future.</li><li>• New and diverse income sources, including government funding, are developed and sustained.</li><li>• Innovative and sustainable models of care are launched, replicated and scaled up.</li><li>• More and better quality data sets are available, eg on population needs and outcomes data.</li><li>• National leadership across the four nations stimulates new ways of working, approaches and partnerships.</li><li>• Greater public awareness of the value of hospice care and more public engagement on related issues such as death and dying, caring and bereavement.</li></ul>

**5 years, 4 goals, 1 big ambition... to open up hospice care.**



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