

Transforming hospice care

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



Children's hospices strategy

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**

Keep up to date with our work on social media:

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Introducing our new direction

June 2017

Dear colleagues

We are delighted to share with you our new direction for the children's hospice movement across the UK.

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

This version of the strategy highlights how our new strategy is relevant to the 38 children's hospices in the UK that together make up 17 per cent of our membership. It also seeks to tackle the challenges raised by children's hospices across the UK, by partner organisations, and in 'The Future of Hospice Care: implications for the children's hospice and palliative care sector', produced by Together for Short Lives in 2013.

Together we will open up hospice care for everyone.



Tracey Bleakley
Chief Executive



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

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."



Unmet need

A report by Fraser and colleagues¹ in 2011 found that for every 100,000 children who attended hospital, 400 had potentially life-limiting conditions. Today we estimate that 49,000 children are living with a life-shortening condition with the variety and complexity of their conditions varying enormously along with the levels and intensity of care they need at different times.

However the paediatric palliative care workforce has not increased to meet demand. In 2013, there were only 15 paediatric palliative care consultants in comparison with 434 adult palliative care consultants. This disparity is partially explained by the fact that general paediatricians provide a level of specialisation in palliative care, and the fact that many of these children and young people have long periods where they are relatively stable. It is also the case that children are less likely to receive GP support, as many GPs do not have a significant input into the care of these children.

On average, children spend five times as long under the care of a specialist palliative care consultant as adults. Children also have more unpredictable end of life episodes and often have several incidences where they appear to be approaching end of life. The same level of support needs to be available for each of these episodes whether or not the child actually dies.

1. Fraser et al. Life-limiting and life-threatening health conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity. Final report for Children's Hospices UK 2001. Division of Epidemiology, University of Leeds, 2011.

Our 4 strategic goals

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

The children's hospice sector has constantly evolved to meet the changing needs of children and young people for over the last 20 years. However on its own it cannot meet all the additional and growing demands for care and support for those families living with life-shortening conditions. It is therefore vital that we help to increase capacity and the style of care beyond hospices into a range of settings. In this way we can ensure that many more young people live well, achieve their goals and dreams and die in the place of their choice, and have the best experience possible for themselves, their carers, family, friends and community.

Strong and sustainable networks and partnerships between hospice care and acute hospitals, NHS community teams, district nurses, GPs, social care, housing, education and other partners and charities will enable this to happen. Trained and supported carers, families and communities play an active role as co-deliverers and coordinators of care, and supporting and empowering them in a whole community approach will bring strength and resilience to everyone working in the sector.

The change that is needed:

All children and young people with life-shortening conditions and their families, wherever they are:

- will receive the same expert holistic hospice care
- are aware as much as possible about how the condition will progress and are supported to prepare and plan as needed
- are cared for by the wider 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 so they can enjoy their life, achieve their goals and dreams, manage symptoms and pain and receive relevant psychological and spiritual support.

High level indicators of success:

- An increase in the number of strong and sustainable networks and partnerships between hospices and other care providers and charities.
- Strong local and national relationships are established between hospices, care providers and GPs to access the children not currently benefitting from hospice quality care.
- Mechanisms are in place to promote person-centred care whatever the setting.
- Less unnecessary time in hospital and more time at home or in community settings enjoying childhood and young adulthood.
- 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. Children's hospice care is often a post-code lottery and many children are not 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 families feel they are disadvantaged towards the end of life and do not have easy access to appropriate hospice services. These groups include certain faith and ethnic 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:

All children and young people with life-shortening conditions and their families, wherever they are will:

- have access to hospice quality care and support
- 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
- benefit from greater understanding and knowledge within hospices of the unmet need in their catchment populations
- receive more joined up and expert support, thanks to better collaboration between hospices, primary care, and other relevant clinical and social care teams and more systematic sharing of expertise.

High level indicators of success:

- A greater number of children and young people and their families in previously under-served groups using hospice services.
- Increased formal links between hospices and different social groups within their communities.
- More and better data on unmet needs through the development and use of local population datasets.
- More partnerships at national and local level between Hospice UK, hospices and other clinical specialty and national leaders (eg child care and cardiologists).
- There is a shift in social attitudes about the value of hospice care for all groups in society.

Goal 3. Work with communities to build capacity and resilience to care for children and young people with life-shortening conditions

Family members and carers play a critical role in caring for children and young people with life-shortening conditions. They usually provide the vast majority of care 24 hours a day, seven days a week, for many years at the same time as looking after the whole family and often balancing work commitments.

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:

Carers will:

- be recognised as an integral part of the care being delivered and experts in their child
- receive the training and assistance they need to support the child or adult they are caring for, recognising that these needs will change as the child grows up and / or the condition progresses
- have access to support that can help them cope, including bereavement care
- benefit from a more compassionate, flexible employment culture and practice that recognises and supports employees who have caring responsibilities
- be part of strong and resilient community networks.

High level indicators of success:

- Increased use of bereavement and counselling support for families and carers.
- Easier access to appropriate information for carers and those around them, including employers.
- New technological solutions available to support those providing care.
- The adoption of new employment practices related to supporting carers.
- Engagement by policy makers on employment practices related to caring for those with terminal and life-shortening conditions.
- New pilots of volunteering initiatives to fill the gaps in informal community networks.

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

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

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



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