

Together for Short Lives  
Strategy 2018-2023



# Together

for the 49,000+





# Introduction

Together for Short Lives' strategy sets out a bold five-year ambition for children's palliative care across the UK. Our core focus is to achieve positive change for babies, children and young people with life-limiting conditions, their families, and the services that support them.

These services include children's hospices, palliative care charities, health and social care professionals and volunteers working in the NHS and in the community.

Together for Short Lives will achieve change by helping to:

- build a strong and sustainable children's palliative care sector
- ensure that children, young people and families are better supported, connected and empowered
- improve joined-up care and services
- build better understanding and support for quality children's palliative care.

Last year we asked a range of individuals and organisations: 'What does great children's palliative care look like?' In answering this, we listened to the views of families, young people, health and social care professionals, those working in children's hospices and in other charities across the UK, and those working overseas. We listened, and what we heard informed our strategy.

We heard that there are gaps in knowledge and understanding of children's palliative care, and although the sector is blessed with brilliant and dedicated people, they need support to develop their capability, knowledge and networks, and be able to help inform and shape good practice. We heard that the number of children and young people with life-limiting conditions is growing, but the policy and funding environment is not keeping up with growing demand. We heard that influencing the debate, informing policy and campaigning for change, and funding are key requirements of a membership organisation such as Together for Short Lives. And, that families and young people increasingly need help to navigate the maze of support they are entitled to – and that they want to play a role in speaking out so that their voices are heard.

Our ambition is that this is a shared strategy. Our work in meeting these challenges will require greater collaboration across the wider children's palliative care sector. It will require shared ownership and a collective drive to push this on to a busy public, policy and practice agenda. And it will require a

commitment from us all to share and learn together, to build on what works, to break down traditional barriers so that our shared work is centred on children, young people and their families. Together for Short Lives has a key role to lead by example in this respect. We are bound by a common cause to improve the quality of life and end of life care for babies, children and young people with life-limiting conditions, and for their families. This is what we are here for.

Our strategy is not a static document. We will keep it, and our priorities, under constant review. We will feed back to our members, and others, on our progress in meeting these priorities through our annual Impact Report.

We are one organisation, but one with a growing membership. Over 1,000 voices, partners and friends can help amplify and build our collective case and cause. Together, we can make a difference. In five years we can deliver the change we know is right and necessary so that children's palliative care services are adequately funded, understood and supported, so that no child or family is left behind.



**Barbara Gelb OBE**  
Chief Executive



**Dr Hilary Cass OBE**  
Chair

There are at least 49,000 babies, children and young people with life-limiting and life-threatening conditions across the UK and the number is rising. More seriously ill babies are surviving, and young people with complex conditions are living longer.

# Why we are here

Hearing the news that your child is going to die young is heart-breaking. Families often do not know who to turn to for help and struggle to get the care and support they need. This can be compounded by professionals being underprepared and not having confident and honest conversations with families about their child's prognosis, meaning that families either don't know they can use children's palliative care services or are poorly prepared and frightened of them. Families provide 24/7 care for their children at home, supported by hospices, palliative care charities, community nursing teams and specialist health professionals across the NHS. Yet they can often feel alone and isolated. These children and their families need our help nationally, and the support of services provided by our members locally more than ever.

Together for Short Lives is the UK-wide charity that, together with our members, speaks out for all children who are expected to have short lives. We provide support to the vital services across the charitable and statutory sectors who are providing lifeline care to this most vulnerable population.

Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life.



We can't change the diagnosis, but we can help children and families make the most of their time together.





Together for Short Lives' strategy for change sets out a bold five-year ambition for the future of children's palliative care.



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# Our strategy for change



We cannot achieve change for babies, children, young people, families and those that support them in isolation. By working in partnership across the children's palliative care sector with our members, patrons, stakeholders and supporters, together with the voices of children, young people and families at the heart of all we do, we can achieve so much more as a strong and powerful movement. Our national voice, data and evidence, resources, tools, networks and collective fundraising muscle can help us work together to provide a unified voice and drive for developing the best children's palliative care.

Our strategy for change seeks to:

- build a strong and sustainable children's palliative care sector
- ensure that children, young people and families are better supported, connected and empowered
- improve joined-up care and services
- build better understanding and support for quality children's palliative care.



# Our strategy at a glance

Together for Short Lives will lead:



Insight



Influence



Support



Voice

2018-2023

Together we will help:

1

Build a strong and sustainable children's palliative care sector for the 49,000+



2

Ensure children, young people and families are supported and empowered



3

Join up policy, services, care and support for children and families



4

Create greater understanding and support for children's palliative care

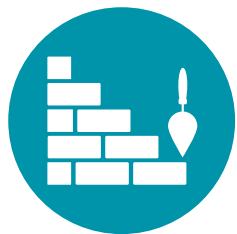






We cannot achieve change for children and families, and those that support them in isolation. By working in partnership across the children's palliative care sector, together with the voices of children, young people and families at the heart of all we do, we can achieve so much more as a strong and powerful movement.





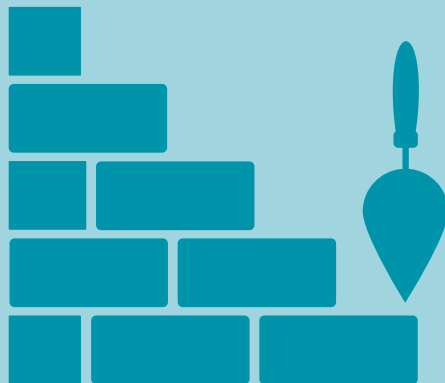
# 1. A strong and sustainable children's palliative care sector for the 49,000+

## Our challenge

There are serious risks to the long-term sustainability of the children's palliative care sector. The number of babies, children and young people with life-limiting and life-threatening conditions is growing, and they are living longer with complex conditions. Policy and funding is not keeping pace with their needs, and many individuals and vital charities struggle to develop new and sustainable fundraising income. As a result, services are overstretched, and family support is inadequate.

## Our ambition

Build a strong and sustainable children's palliative care sector



## What we will do

Together for Short Lives will:

1. Support and work with the sector to grow sustainable funding from statutory and other sources.
2. Play a leading role in developing data, knowledge and insight that will build an understanding of the number and the needs of children and their families. This will support increased investment in targeted services that make a real difference to children and their families.
3. Map service provision to identify gaps, stimulate the development of services and enable sharing of good practice.
4. Campaign for fair funding for children's palliative care across the children's palliative care 'journey' from diagnosis to bereavement.
5. Educate and build understanding amongst all funders of the social and economic benefits of investing in children's palliative care.
6. Support the implementation of The National Institute for Health and Care Excellence (NICE) guidance and standards.
7. Campaign with others to build investment in education, volunteering and workforce development to meet the growing demand for children's palliative care.

## Our outcomes

By 2023:

- We have the right data, knowledge and research that supports the sector to deliver more effectively.
- Governments, commissioners and funders better understand the value and benefits of funding children's palliative care and increase support in the areas that make the biggest difference.
- There is greater public support for improved state funding of children's palliative care.
- There are improved mechanisms for government funding of children's palliative care.
- Services are delivered more efficiently and effectively through increased collaboration and partnership.
- The children's palliative care workforce has the appropriate knowledge, skills and confidence.
- There are more care professionals working in children's palliative care to meet the demand for care.
- Government funding is available for the care workforce and its training needs.



Our ambition is for a strong and sustainable children's palliative care sector for the 49,000+ babies, children and young people with life-limiting or life-threatening conditions, and their families.





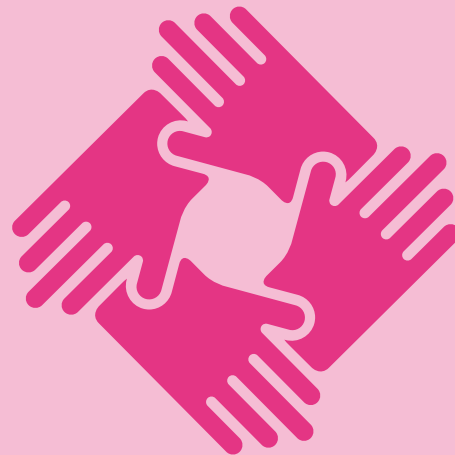
## 2. Supported and empowered children, young people and families

### Our challenge

The support children and families receive is patchy and variable. Choice remains a laudable public policy aim but is severely limited by the availability of funded services. Families face a postcode lottery of support, and many struggle to get access to the services and support they need. This can leave families feeling frustrated, isolated and alone while facing the challenge of providing 24/7 care for their child.

### Our ambition

Children, young people and families are better supported, connected and empowered



### What we will do

Together for Short Lives will:

1. Better understand the needs and requirements of children and their families, and work with the sector to support these more effectively.
2. Grow our family support work through our helpline, digital services and the resources we provide to address key areas of need.
3. Broaden and strengthen our network of children and families, giving them the skills to support each other and speak up.
4. Extend our legal advice service to assist families in getting the care and support they and their children are entitled to.
5. Grow our bank of family resources to help families and young people navigate the maze of support, providing guidance, vital information and signposting help.
6. Provide guidance and support for professionals to build and share good practice.
7. Explore digital technologies and applications as a means of improving family support and access to services.

### Our outcomes

By 2023:

- Professionals are better informed and can provide information to families on their care and support options and are more comfortable with having difficult conversations with families about their child's prognosis.
- Families are better able to find information about where to access the care and support they need at all stages of their journey.
- Families provide peer-to-peer support to one another.
- Families have access to advocacy support from a legal professional when needed.





Our ambition is for babies, children, young people and their families to be better supported, connected and empowered.





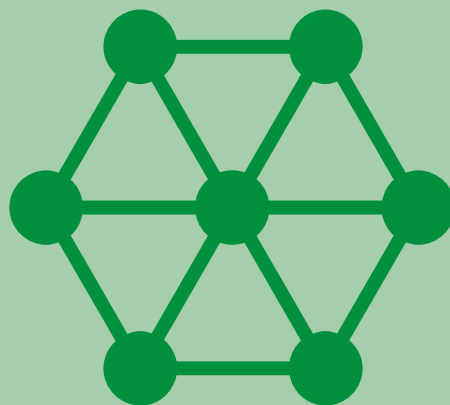
## 3. Joined-up policy, services, care and support for children and families

### Our challenge

Services are not adequately or consistently joined-up around the family and their needs. Policy makers, funders and commissioners too often operate in silos leading to inefficient or ineffective funding arrangements. Families and professionals continue to be frustrated by the lack of co-ordination across health and wider care services, which significantly increases the burden on those seeking care and those providing care.

### Our ambition

Improved joined-up care and services



### What we will do

#### Together for Short Lives will:

1. Develop an expert consultancy offer to work directly with our members to troubleshoot, explore and share new models of working.
2. Inform the work of funders and commissioners by sharing guidance and examples of good practice relating to improved joint funding and service delivery.
3. Support the implementation of Managed Clinical Networks and work with other countrywide and regional networks across the UK to help ensure that care is better planned and co-ordinated for children, young people and families.
4. Work for greater co-ordination and alignment of policy across key government departments so that policy thinking is more joined-up and centred on children, young people and families.
5. Distribute funding to support projects to improve the transition for young people between children's and adult services and share knowledge and learning from those projects to improve policy and practice.

### Our outcomes

#### By 2023:

- There is a national government strategy for children's palliative care in each nation.
- Improved co-ordination and sharing of information between service providers.
- Service providers and policy makers better understand the benefits of joined-up, person-centred care with services working better together to join up care.
- Families have better support in their engagement with the health system.



Our ambition is for policy, services, care and support to be joined-up and co-ordinated around the unique needs of babies, children, young people and their families.





## 4. Changing hearts and minds: Greater understanding and support for children's palliative care

### Our challenge

There is a low-level understanding of children's palliative care in both public and wider professional arenas. Too often knowledge of hospice and palliative care is focused on end of life, as opposed to also achieving a quality of life. This creates barriers to good policy making and to efficient and effective care and support. There is a cultural and societal fear of death and discomfort with talking about it – especially in relation to children. This compounds families' sense of isolation and loneliness.

### Our ambition

Build better understanding and support for quality children's palliative care



### What we will do

Together for Short Lives will:

1. Campaign for change through a proactive engagement programme across governments. The All-Party Parliamentary Group for Children Who Need Palliative Care will be an active body in furthering our collective voice across the UK Parliament.
2. Deliver national campaigns and strategic partnerships to raise awareness and champion change, together with our members, supporters and families.
3. Publish, in partnership with our members, guidance and pathways and deliver training to support best practice in understanding and delivering children's palliative care.
4. Represent our members on key government areas of policy and practice development and consultation across the UK.
5. Work in partnership with government departments to build awareness and understanding of children's palliative care.
6. Support our members in local campaigns with the public and local commissioners to improve understanding and support.

### Our outcomes

By 2023:

- Society and communities understand that children die, value those lives and those that care for them, and are more comfortable in talking about these issues.
- An understanding of children's palliative care is mainstreamed across health and social care systems and among professionals.
- Society and communities better understand what children's palliative care is and what hospices are. They recognise its value and are more vocal and active in its support for funding of better services.
- Individuals and communities are more active in supporting families and children's palliative care services.



Our ambition is to change hearts and minds, so there is greater awareness, understanding and support for the 49,000+ and children's palliative care.



# Children's palliative care voices



“As a children's hospice, our ability at Acorns to meet the growing complex needs of babies, children, young people and their families depends on our ability to secure funds and support to meet that need. The children's hospice grant is a vital element of this, and the children's hospice movement could not provide the services we do today without it. But planning to meet unmet need requires additional and sustainable sources of funding. Additional statutory funding means more qualified nurses and more support staff able to provide more of the high-quality care synonymous with children's hospices across the UK. If we weren't here, where would these children and families go?”

**Toby Porter, CEO Acorns Children's Hospice**



“Since working with Together for Short Lives and being a Young Avenger (I still LOVE the name!), I feel that what I have been raising as concerns or issues are finally being heard. People were so enthusiastic to listen to my story and how I coped through transitions etc.”

**Leah Booth, Young Avenger**

“Hallelujah! I have just had a call from the NHS and they have started the process of setting up the personal health budget. They have received your letter. Thank you so much. Wow, we were powerless without the voice of a lawyer.”

**Anonymous: Family supported by our advocacy service**



“Together for Short Lives is the glue that helps weave together the different health, social care and education services that families need, so in the future families won't have to fight and can focus on spending precious time together. James is now ten years old (he likes to prove the doctors wrong) and we know there will come a time when we will say goodbye to James. Knowing someone understands your situation is so comforting.”

**Mum, Amanda Harrison**



“As a GP with an interest in children's palliative care, it is great to know that I can call on Together for Short Lives for both practical written resources, and a source of expertise about developments in practice happening across the whole UK.”

**Dr Sarah Mitchell, GP – Birmingham**



“Campaigning with Together for Short Lives means we can change things for families in the future – a fitting legacy for our late son – priceless.”

**Sacha Langton-Gilks**

# Our Vision, Mission and Values

## Our Vision

For babies, children and young people with life-limiting conditions to have as fulfilling lives as possible, and the best care at the end of life.

## Our Mission

Our mission is to secure the best quality of life and the best end-of-life care for babies, children and young people who will have short lives.

## Our Values

### **We listen to families and our work is shaped by what they tell us**

Families are at the heart of everything we do. We listen to children, young people and families, and our work is shaped by their experiences and needs.

### **We are compassionate and responsive**

We are compassionate and caring about everything we do. We are open, honest and responsive to the needs of children, young people and families, and everyone we work with.

### **We will collaborate and bring people together**

We will bring the children's palliative care sector together so that we can achieve more for children, young people and families. We will work in partnership, collaborate, share expertise and bring a unifying spirit to children's palliative care.

### **We are innovative, creative and will act as a catalyst for change**

We are innovative and creative and unafraid to challenge the status quo. We will always go the extra mile and explore new ways of working to deliver the very best for children, young people and families.

### **We are passionate and determined**

We are passionate, determined, and ambitious about helping children, young people and families to live as full lives as possible. We will not stop until every family gets the care, support and services that they need.



49,000 babies, children and young people are living in the UK with conditions that are life-limiting or life-threatening, and the number is rising.

Hearing the news that your child has a life-limiting condition and is likely to die young is completely devastating. For tens of thousands of families in the UK this is the reality. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week.


Together for Short Lives is a UK-wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. We are here to help children and their families to access specialist children's palliative care services when and where they need it. We provide information, so families know where to go for support and have the help they need to make the right choices about their child's care. Together for Short Lives supports all the professionals, children's palliative care services and children's hospices that deliver lifeline care to children and families across the UK.

We can't change the diagnosis, but we can help children and families make the most of their time together.



**Together for the 49,000+**  
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