Making every moment count

OUR TEN YEAR STRATEGY

together for short lives

Imagine being told that your precious child will die before they reach adulthood. Imagine the heartbreak and the grief of facing that reality. Imagine how much you would want to fill every day with as much joy as possible, to make every moment count and to create special memories because you know that one day they will be all you have left to remember your time together as a family.

Now imagine not being able to because you don't have the right support. Instead of prioritising time together as a family, you are caring round the clock, often isolated at home, trying to make ends meet. Perhaps trying to balance caring 24/7 with the needs of your other children.

This is the reality for a growing number of families in the UK. There are three times as many children and young people living with life-limiting conditions as there were 20 years ago and that number could grow by a further 50% over the next decade. More seriously ill babies are surviving, and children and young people with complex conditions are living longer. There are more of these children and families living in poverty and a higher prevalence among already underrepresented groups, including Black, Asian and Minority Ethnic communities.

They are supported by some brilliant services and professionals providing children's palliative care – in hospitals, in children's hospices and at home, which offer a vital lifeline to families. High quality children's palliative care makes the world of difference. It begins when a child's illness is diagnosed and continues to their death, and beyond. It is holistic family support which enriches the health, psychosocial and spiritual needs of the child and family. It helps families care for their child and grieve their loss, but also to make the most of every moment they have and to create memories that last a lifetime.

But the reality is that many of these services are themselves under huge pressure, poorly planned and inconsistently funded by local and national commissioners.

Which means that, in 2023 in one of the most developed places in the world, the care that UK families receive depends significantly on where they live. And much of the care they rely on is funded by generous voluntary donations from the public.

Together for Short Lives is here to change this and our 10-year strategy sets out our roadmap to achieving this change.

Essie's story

A children's hospice became a beacon of hope for Essie's family after she was born with a life-limiting illness

When Lorna's daughter Essie was born, they were told that she would be blind, deaf and life-limited. "When your parenthood journey is different, you feel alone," says Lorna. "Time is your enemy because every day you wake up knowing it could be your last together."

Not knowing where to turn, the family found a lifeline in Chestnut Tree House Children's Hospice.

"Without them we would have been in a horrifically dark place," says Lorna. "I just felt relief: it felt like someone got it. There was going to be someone there to help us.

What Chestnut Tree House gave us, as a family, is memories that will last a lifetime. "When we arrived, there was a new nurse there called Mike – 'Magic Mike'! And he would sincerely do anything for anyone.

"Without something like Chestnut Tree House, you will genuinely feel like you don't know where to turn. But they saved us."

Mikey's story

For Mikey's parents, the demands of round-the-clock care left them unable to cope

Mikey lived in hospital for the first two years of his life, while experts tried to diagnose his condition. Today he has many care needs, including a tracheostomy, which he relies on for his breathing and a feeding tube directly into his veins.

Mikey's mum and dad, Chevonne and George, are exhausted. It has been recommended that Mikey needs two-to-one care with someone with him 24/7. They have been given a care package, which the family explain has never been fulfilled or met.

"There's no back-up if a nurse phones in sick in the evening," says Chevonne. "Last month for instance, no one turned up for the shift at 8pm, so I barely had half an hour's sleep. I was awake for nearly 48 hours caring for Mikey."

Mikey's parents have struggled to get the right care they need.

Chevonne explains: "A lot of Mikey's care needs are quite invasive and you have to be on the ball to do it, it was quite scary. We have had nothing but trouble trying to get the care we need."

Not having enough care, the family are under an extreme amount of pressure. "I rely on my two daughters to help me with a lot of Mikey's care – both before and after they return from school," says Chevonne

"They should be able to live a normal life and not constantly worry that Mikey is going to be OK. They should not have that worry on their shoulders.

"The whole system needs looking at. There are so many others that are in our boat too.

"It shouldn't be that way, you should be able to concentrate on being a family and not just the care side things."

Our purpose

Together for Short Lives' purpose is to ensure every child, and their family, has high quality children's palliative and end of life care, when and where they need it.

We are here to make sure families can access the right care and support and that those providing it have the skills and resources they need. 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. Because while we can't change the diagnosis, we can help children and families make the most of their time together.

How we create change

The challenges facing children and families and those who support them are complex. To help address them, Together for Short Lives works to have impact at three levels – with individual families, with services and professionals delivering care and with the wider health and care system.

System change	Policy decision makers	Working with leaders in governments, the health service, commissioning bodies and delivery organisations to constantly improve the funding, quality, consistency and coordination of children's palliative care.
	Regional co-ordination	Facilitating cooperation between different sectors and organisations to deliver a more integrated experience of palliative care for children and their families.
Improved delivery	Organisational development	Supporting providers of children's palliative care, to ensure they have the funding, resources and expertise needed to provide a sustainable, consistent, high-quality service.
	Workforce development	Working with the professional workforce delivering children's palliative care, to ensure they have the network, training, resources, confidence and skills they need to provide the best possible care.
Direct support	Children with life-limiting conditions and their families	Providing information and support directly to families of seriously ill children, particularly those who are unable to access that support elsewhere.

Our strategic approach

We are setting out a 10-year challenge because children, families and those who support them deserve a bold ambition and roadmap for change. For too long their needs have been overlooked by those planning and developing health and care policy which has led to this inconsistency. These are big challenges, and they need big and bold solutions.

It is also clear that the world is changing at a rapid rate, exacerbated by the COVID pandemic which will have significant long term impacts on wellbeing, the health and care system and the financial landscape for years to come.

To reflect this changing world, our strategy sets 10-year strategic ambitions, laying out our vision for how we want the world to look differently for children and families by 2033. We will prioritise our shorter-term objectives in a series of 2-3 year phases, evaluating and refining them annually to ensure we continue to progress towards our 10-year strategic ambitions.

This will enable us to be an agile organisation which can develop longer term impactful programmes, but adapt more flexibly to the changing environment.

Our strategic ambitions

To steer our work over the next decade, we have set three strategic ambitions to make sure more children and families are able to get the support they need.

1 **No family faces the journey alone:** Increase reach so that more children and families can ACCESS 24/7 palliative care

2 **The best care and support:** Improve the QUALITY of palliative care so families have the best support

3 **Support today, tomorrow and every day:** Strengthen the SUSTAINABILITY of children’s palliative care so families can rely on support

STRATEGIC AMBITION 1

Improving access

No family faces the journey alone

What is the problem we're trying to address?

- **There is a postcode lottery in support** which means not all families can access palliative care. Only one fifth of areas in England is able to provide 24/7 end of life care at home.

- **Caring for a seriously ill child compounds existing health inequality**. The highest prevalence is in already marginalised groups, including those from BAME communities and lower socio-economic areas.

- **There is growing demand**, as children live longer with greater complexity. This means more babies are born with life-limiting illness and more young adults are surviving into adulthood.

- **Services are poorly planned at local level**, leading to a disparity in what families can access locally.

Why is this a problem?

- **It can have a major impact on family health and wellbeing.** Shockingly, mothers of seriously ill children are 50% more likely to die prematurely themselves. Siblings are more vulnerable to mental health difficulties.

- **Families can feel isolated and exhausted caring 24/7**. 84% of families report feeling alone and isolated. Rates of family breakdown are higher.

- **Families often don't know what is available** and struggle to get support.

- **Families don't have choice** in how and where care is provided.

What is our role in addressing this problem?

- **Providing information and support** for children, young people and families to help them access care and raising the profile of what good children's palliative care looks like.

- **Supporting local commissioning and holding local areas to account** for providing 24/7 support in line with national standards.

- **Stimulating and supporting new models** of working to address gaps to ensure more consistency.

- **Encouraging and facilitating greater collaboration** between services to join up care and make the best use of resources.

- **Providing data and information** to support families, services and commissioners.

Our ten-year goals

1. More families know about, understand and are able to access care and support.

2. All areas are able to offer 24/7 support at the end of life.

3. All UK nations have a clear strategy and plan for children's palliative care.

4. There are integrated approaches to delivering care in all areas.

STRATEGIC AMBITION 2

Improving quality

The best care and support

What is the problem we're trying to address?

- **There is a lack of consistency** in what is provided and in the quality of care and support. This exacerbates the postcode lottery of support.

- **There are low levels of understanding** of children's palliative care among the wider health and care workforce.

- **There are not enough trained doctors, nurses and health and care professionals to provide children's palliative care**. This limits the capacity of the sector to meet the needs of children and families.

- **The definition of who needs palliative care is out of date**, with some conditions no longer considered to be life-shortening in childhood.

Why is this a problem?

- **Many families are referred to children's palliative care too late or not at all**. This means they are not able to benefit from services that could help them.

- **Families can receive different approaches and inconsistent quality** in provision.

- **There is more pressure on specialist sector professionals** to meet the needs of children and families.

- **Services don't have sufficient workforce to meet increasingly complex needs**. This limits capacity to deliver for children and families.

- **The broad categories make it challenging to plan services** that meet greatest need.

What is our role in addressing this problem?

- **Training and educating** generalist professionals in children's palliative care.

- **Lobbying for a workforce plan** to train more doctors and nurses.

- **Encouraging more nurses and professionals** into a career in children's palliative care.

- **Setting quality benchmarks and supporting services** to develop.

- **Leading consultation and review** on which children and young people need palliative care.

- **Identifying and sharing good practice** and new models of care.

- **Providing data and information** to support service development.

Our ten-year goals

1. **Services have the workforce to deliver with fewer vacancies.**
2. **Children's palliative care embedded in nursing programmes.**
3. **More generalist professionals trained in children's palliative care.**
4. **Quality benchmarks and common definitions in place and being met.**

STRATEGIC AMBITION 3

Improving sustainability

Support today, tomorrow and every day

What is the problem we're trying to address?

- **Funding for children's palliative care is too reliant on public donations.**
- **Statutory funding varies considerably from country to country and area to area.** 9% of hospices receive over half of their care costs from local commissioners, while 22% receive 5% or lower.
- **Costs of providing care are rising.** According to Hospice UK costs for adult and children's hospices have increased by £100 million in the last year.
- **There is no clear, consistent definition of what the state is responsible for** leading to variance in local funding.

Why is this a problem?

- **Services struggle to plan effectively or meet demand and need** when their funding is unpredictable.
- **Reductions in state contribution can lead to cuts in services.** Last year, 50% of children's hospices saw their local funding from the NHS fall.
- **The lack of stability stifles investment** in new approaches and services.
- **Any service reductions increase pressure on families** in hospital, hospice and community.

What is our role in addressing this problem?

- **Campaigning for more statutory funding** for children's palliative care.
- **Providing data/information to local services and commissioners** to improve local funding.
- **Facilitating greater collaboration and partnerships** between providers/networks.
- **Identifying collaborative approaches** to innovate and better use resources.
- **Raising money and profile** to support services.

Our ten-year goals

1. There is a national strategy in place in all four UK nations, with clear definition of what the state is responsible for funding.

2. The £300 million gap in funding in England has been closed.

3. Clear categories and definitions of children's palliative care.

4. Networked approaches in place for commissioning.

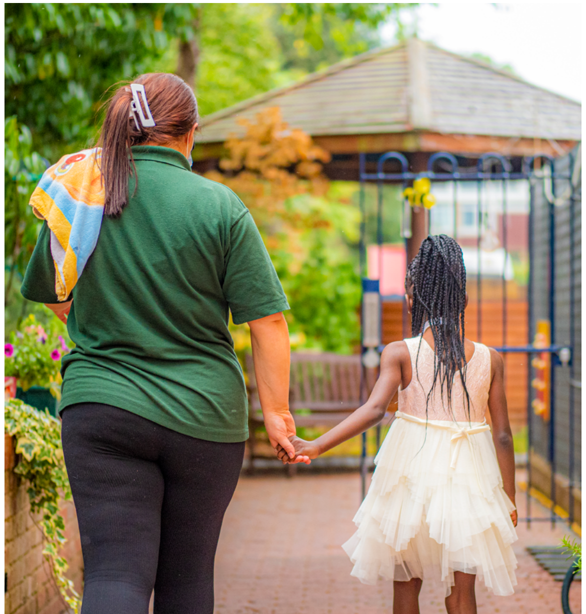
5. Growth in funding to support children's palliative care services in the form of grants and partnerships.

Our values

1. We put **children and families at the heart** of everything we do
2. We are **ambitious** about improving the lives of children and families and stand up for what we believe in
3. We are **collaborative** and bring people together to deliver the biggest impact
4. We are **inclusive and open** to new and different views, approaches and experiences

Our objectives 2023 – 2025

In order to achieve our three strategic ambitions, we have set out a number of objectives to be achieved between 2023 and 2025. This will be the first phase of our strategy and we will review these objectives as the external landscape changes to progress towards our 10 year strategic ambitions.



Strategic ambition 1 – Improving access

No family faces the journey alone

OBJECTIVES FOR 2023-25

1. We will lead an integrated campaign of advocacy to ensure every child and family can access 24/7 care and support.

This means:

- Pressing politicians and policy makers in all four nations to develop comprehensive funded strategies to deliver 24/7 children's palliative care.

- Supporting local commissioners to better plan, design and fund children's palliative care services in hospital, hospice and in the community.

- Proving data, information and insight to track progress and support commissioning and service development.

- Putting family experience at the centre, raising awareness of what they need.

2. We will extend the reach of our family hub so that all children who need palliative care can access it.

This means:

- Expanding what we offer to ensure we meet the changing needs of children and families, including advice, support and small grants.

- Engaging with diverse communities, to ensure that children and families from Black, Asian, and Minority Ethnic communities and those in disadvantaged areas can access the right support.

- Developing new approaches to reach families with information, harnessing the power of technology.

- Exploring how we provide information and support to young people with life-limiting conditions as they transition to adulthood.

3. We will stimulate and help develop new models of care to reach and support more children and families.

This means:

- Delivering the collaborative Kentown Programme pilot in Lancashire and South Cumbria, evaluating its impact and exploring the potential for further roll out.

- Delivering our collaborative outreach programme as part of our partnership with Morrisons, to pilot approaches to reaching families from diverse communities.

- Securing other significant grant making opportunities to support the sector to develop new models and approaches to reach more children and families.

- Sharing innovative local and regional models of care across the sector.

Strategic ambition 2 – Improving quality

The best care and support

OBJECTIVES FOR 2023-25

1. We will create a leading Centre of Excellence in children's palliative care with the very latest data, evidence and insight in one place.

This means:

- Bringing together the evidence base in one place, identifying gaps, commissioning and supporting research and data collection to address them.

- Harnessing the latest technology to share data, insight and evidence across the health and care sector and embedding it into a long-term physical centre to support education and development

- Developing links with academics and university partners to strengthen the evidence base and build capacity for research within the children's palliative care sector.

- Delivering training and education to non-specialist health and care professionals to improve knowledge and understanding.

- Identifying and sharing the latest in good practice, identifying and promoting innovations in children's palliative care.

2. We will develop a workforce strategy to help address the urgent gaps in the children's palliative care workforce.

This means:

- Mapping gaps in the existing workforce to understand what is needed and how to develop a workforce that can meet the needs of children and families in the long-term.

- Influencing agencies responsible for the health and care workforce to ensure we have sufficient skilled professionals to support children and families.

- Supporting education and training institutions to ensure children's palliative care is reflected in curricula.

- Identifying and developing career pathways for professionals and promoting children's palliative care as a career choice.

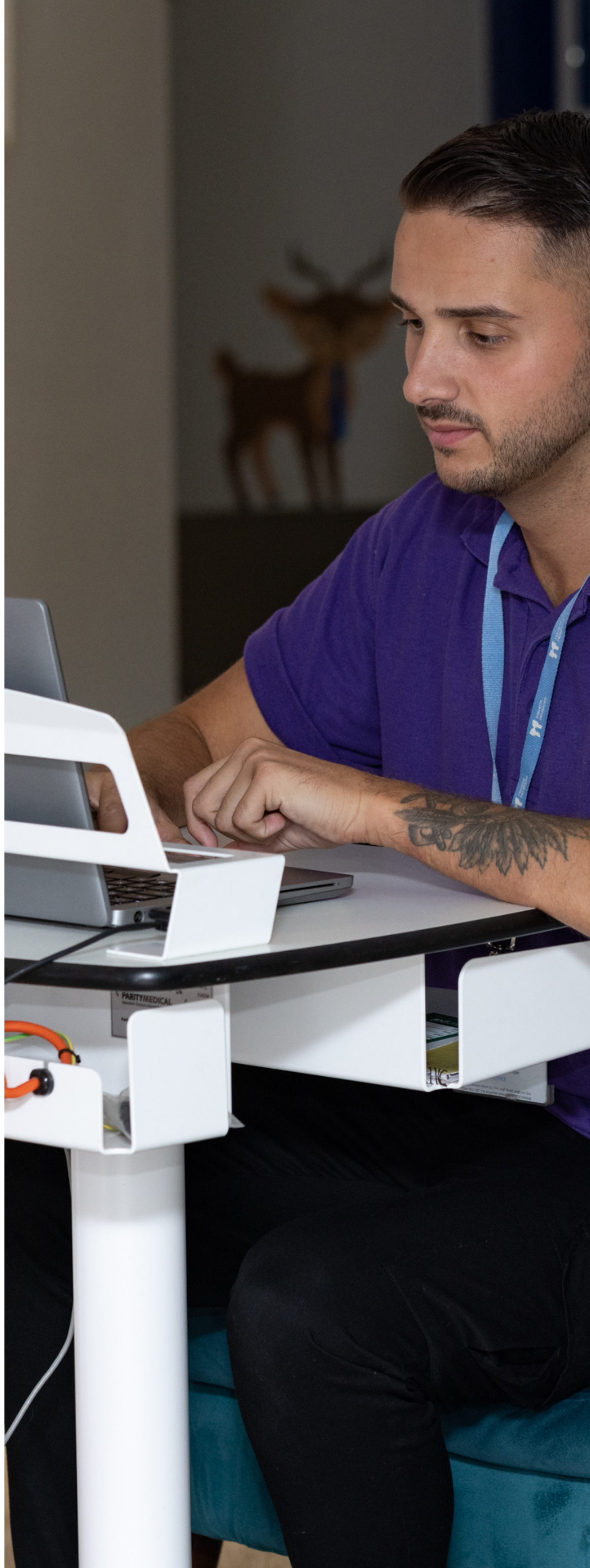
3. We will develop common definitions and quality standards in children's palliative care to ensure consistency across the UK.

This means:

- Reviewing the categories and definitions of who needs children's palliative care so services and commissioners can plan care effectively which meets the needs of children and families.

- Developing new quality standards for children's palliative care so that families can rely on consistent support wherever they live in the UK.

- Benchmarking progress to support services to develop and exploring potential for quality improvement programmes and support.



Strategic ambition 3 – Improving sustainability

Support today, tomorrow and every day

OBJECTIVES FOR 2023-25

1. We will advocate for better funding for children's palliative care in all four nations so that more money is going into children's palliative care.

This means:

- Developing a strong case for national government support based on evidence both of improved outcomes for children and wider savings and benefits for the health and care system.
- Campaigning for greater HM Treasury investment in children's palliative care to ensure services are more sustainable and clarity about what the state is responsible for funding.
- Securing an extension to the £25 million Children's Hospice Grant in England
- Working with services and networks in the devolved nations to ensure consistent funding for children's palliative care services.

2. We will support health and care commissioning of children's palliative care so care is better planned and resourced.

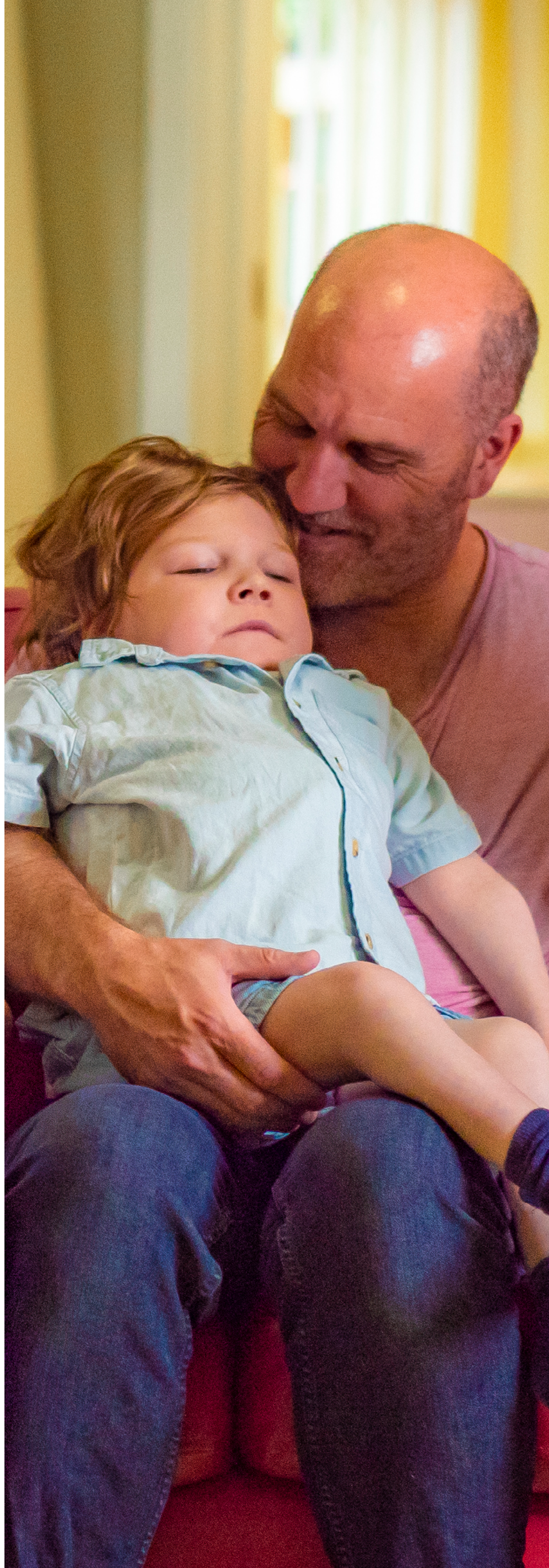
This means:

- Developing resources and support tools for commissioners on how to plan and commission children's palliative care.
- Supporting providers of children's palliative care to understand and influence their local health and care system.
- Encouraging and facilitating collaboration between networks, professionals and services to deliver more effective, efficient and co-ordianated support for children.

3. We will grow funding to support the sector to innovate and collaborate.

This means:

- Raising funds to support innovation and collaboration across the sector.
- Developing a sector leading approach to Environment, Governance and Social (ESG) priorities.
- Exploring strategic grant giving and other fundraising initiatives and platforms to stimulate new approaches and models across the sector.



Making it happen

The development of Together for Short Lives

To achieve this ambition, Together for Short Lives will need to continue to change to ensure we are in the best shape possible to deliver for children, families and the services that support them.

We have begun this process with investments in programmes and service development, fundraising and communications, along with a review of our purpose, theory of change and our values. But there is still work to do to ensure that our growth is sustainable and we have the resources and ways of working to deliver impact for children and families and the people who support them.

This means the development five enabling strategies and plans:

- **Our people and culture** – investing in making Together for Short Lives a great place to work, developing our people and a culture that delivers real impact.
- **The money and the mission** – raising more money to deliver our mission and building a great fundraising organisation. Reviewing our model of working to ensure we have the right systems and resources to deliver for the long-term.
- **Digital first** – to be led by data and insight in understanding need and our impact and exploring how we can better use digital tools and innovations to reach more people.
- **Telling our story** – elevating our brand so that we are better able to reach families, professionals and the public. Telling powerful stories and communicating the difference we make internally and externally.
- **An inclusive organisation where everyone belongs** – continuing to develop our work to make Together for Short Lives a diverse and inclusive organisation where everyone belongs and to ensure that we reach the high prevalence of families from different communities.

togetherforshortlives.org.uk

Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is a company limited by guarantee (7783702).

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