

# Making every moment count

The next phase of our  
10-year strategy:  
2026-2028

together  
for  
short  
lives



## Our purpose

Every child deserves many moments of happiness together with their loved ones. But for many families accessing palliative care, it's hard to thrive when services don't fully meet their needs — leaving parents and siblings feeling isolated and alone, and children missing out on life-changing support.

Our strategy refresh for 2026–2028, shaped by the voices of families and professionals, means that Together for Short Lives is focussed on what matters most: achieving our purpose to ensure every child, and their family, has high quality children's palliative and end of life care, when and where they need it. With your support, we can make sure every family can thrive as they navigate their child's life, death and bereavement.

Just because you have a child living with a serious illness, life doesn't slow down or make things easier for you. I still work — I work hard. I'm a professional, but I'm Tilly's mother too.

"And she depends on me for her life.

"It could be a lonely life, it could be an isolating life. I think for some parents with children living with serious illness, it can be that.

"If things get tough or I need to ask questions I know I can call Together for Short Lives.

"But the support is there. When I need them, it feels like **we're together.**"

**Dee Cowburn**  
**mother to Tilly, who has**  
**Rett Syndrome**



## Who we are and what we do

Together for Short Lives is the leading UK-wide charity for children living with serious illness, their families and the services that provide them with palliative care.

**Together we support** families to live their lives, through the ups and downs, offering practical, emotional and financial help.

**Together we unite** our sector by prioritising and sharing crucial research, leading guidance and standards, connecting professionals and raising vital funds for children's hospice and palliative care services.

**Together we campaign** to make sure that children with serious illness and their families get the care and support they need, when and where they need it.

Supporting, uniting, campaigning, together.

**We are Together for Short Lives.**

"Being a children's hospice nurse, you're always aware that families deserve the best.

That's where Together for Short Lives comes in: every children's hospice professional can count on them to help us be our best.

"Whether that's supporting us with advice, lobbying on our behalf in Parliament or raising vital money for us through their own fundraising.

"Children's hospice professionals don't have to go it alone. Thanks to Together for Short Lives, **we're in it together.**

**Cathy, Children's Hospice Nurse at Charlton Farm**



## Our strategic priorities

We published our current 10-year strategy in 2023. Our new, refreshed strategy reflects the work we have done to adapt and shape Together for Short Lives for our next strategic cycle, the period 2026 to 2028.

In doing so, we have listened to families of children living with serious illness and the professionals and services who provide them with palliative care, so we can focus on what matters most to them.

Our strategic ambitions are:

- 1. Increase equitable access to children's palliative care.**
- 2. Improve the quality of care, ensuring the best support for families.**
- 3. Strengthen sustainability so families can rely on care where and when they need it.**

These are big challenges, and they need big and bold solutions.

"I remember feeling nervous that day, visiting Downing St. I mean who wouldn't?"

"I was there to call for 24/7 palliative care for children living with serious illness to be available at home, in children's hospices and in hospitals, in memory of my son Oliver.

"I honestly thought that when your child is dying, you would have 24/7 care at home. But it turns out, that often isn't the case.

"There is an amazing network of children's hospices, NHS teams and charities around the UK providing children's palliative care. It's incredible to think that, through Together for Short Lives, we can speak with one voice.

In Westminster it felt like **we were together.**

**Clare Buchanan, mother to Oliver, who died in 2023.**



## What we have achieved already

Thanks to our amazing supporters, we have made much progress in our first strategic cycle to make sure more families get the support they need.

Across our programmes, we have worked to strengthen support for families of children living with serious illness by improving access to children's palliative care and equipping professionals, and influencing national policy:

- Our Morrisons-funded community outreach project focused on areas of highest need, connecting 1,415 families to services
- To improve understanding of children's palliative care among non-specialist professionals, our Learning to Communicate with Families initiative engaged 199 professionals across

health, education, social care, faith groups and the voluntary sector.

- Our 2025 Conference brought together over 400 attendees to explore best practice and innovation in children's palliative care, inspiring and reinvigorating professionals.
- Through our energy support work with SGN and Cadent, we advised more than 125,000 families on heating and safety and provided in-depth assistance to 4,500 families, helping to reduce debt, improve safety and ease financial pressures.
- We secured £80 million in ringfenced NHS funding for children's hospices for 2026–2029 – described by Derian House as “a huge campaign win... for children living with serious illness and their families.”
- Thanks to our campaigning, 19% of local NHS bodies in England now formally commission 24/7 end of life care at home in line with national quality standards, up from 14% in 2024.
- Through the Kentown Wizard-funded Community Palliative Care Programme, we coordinated nursing, social care and hospice support for families who often struggled to navigate fragmented systems.
- We have generated vital income to sustain children's palliative care in the UK. In 2024-25, our supporters helped us to raise and distribute over £2.7 million to support children's hospices, ensuring they could continue to provide crucial care to children living with serious illness and their families.

## The context we are working in

A greater number of politicians and policymakers across the UK are recognising the amazing impact that palliative care can have for families of children living with serious illness. More understand why it is vital that families can access it, and why it is unacceptable that too many are left isolated and alone by a system that is not meeting their needs.

- In England, a House of Commons Health and Social Care Committee Expert Panel evaluated the state of palliative care during 2025. It found that inconsistent and poorly informed commissioning is a major barrier preventing children living with serious illness and their families from accessing high-quality palliative care, when and where they need it.
- A 2025 report by the Commission on Palliative and End of Life Care, of which our Chief Executive, Nick Carroll, was a commissioner, found similar challenges.

- In 2026, the Children's Commissioner for England published a report revealing that thousands of children in England spend prolonged periods in hospital – sometimes months or years – not because of medical necessity but because the support required for safe discharge is unavailable.
- A Northern Ireland Assembly Health Committee inquiry report has found that children's palliative care in Northern Ireland is significantly underfunded, creating major barriers to delivering the care children and families need.
- Public debates on proposed assisted dying laws in England, Scotland and Wales have put unprecedented focus on how, as a society, we care for people of all ages at the end of their lives.

The UK Government has acknowledged the challenges facing children and families in England and ministers across the UK have already committed to act, including by developing an all-age modern service framework (MSF) for palliative care for

England. They plan to shift access to health and care as close to home as possible.

The Scottish Government's palliative care strategy and a Welsh Government national service specification include ambitions that children will have more equitable access to well-coordinated, timely and high-quality palliative care.

These commitments are welcome and provide important context to our refreshed strategy.



## The challenges we still face

NHS and voluntary sector children's palliative care professionals in hospitals, children's hospices and the community go above and beyond to meet the needs of children living with serious illness and their families. Yet families continue to face a series of challenges in accessing high quality, sustainable support when and where they need it because the system does not work for them.

We have listened to families of children living with serious illness and those who support them, hearing their stories and gathering data to build our insight of the state of children's palliative care across the UK.

We have grouped these insights by our three strategy priority areas of access, quality and sustainability. Across each one, we are clear about the challenges, why they are important, and what statements we will be able to make if we are successful in achieving our three strategic priorities:



# 1. Access

## Key challenge

Less than half of families feel well supported: too many feel isolated and abandoned after their child is diagnosed, lack emotional, practical and financial support, and cannot easily access information and guidance.

There is a postcode lottery in planning which means that not all families can access palliative care that meets standards for each part of the UK.

Access varies according to families' ethnic and socio-economic background, and transition: we have qualitative evidence to support this, but do not know enough about the full scale of the challenge.



## This is a problem because:

Without access to palliative care, children living with serious illness and their families are less likely to have an opportunity to live a full life in which they can thrive.

widening health inequality and increasing numbers of families will be unable to benefit from the best care and support

Too many families will continue to experience poor health and wellbeing outcomes.

Without better evidence and action there will be a

## If we are successful over the course of our next strategic cycle, we will be able to say:



A majority of families feel well supported with access to care, emotional, practical and financial support and help to connect with other families.

All local NHS bodies across the UK plan children's palliative care that meets standards.

We have worked across palliative care to develop better outcomes for transition patients.

We know the full scale of inequalities of access to children's palliative care and have worked with those impacted to reduce them, to receive equitable care.

## 2. Quality

### Key challenge

Vacancy rates among the groups of all health and care professionals needed to provide palliative care to children living with serious illness are too high (including social care and allied health professionals)

Too few health and care professionals who could provide palliative care to children living with serious illness have the skills to do so due to inconsistent education and training.

The existing children's palliative care workforce is not organised effectively across the UK. There is no nationally agreed framework for workforce standards and service models, leading to inconsistency in care quality.

There is inconsistent use of data and evaluation of outcomes, and a comparatively low evidence base (compared to adult palliative care).



### This is a problem because:

Workforce challenges mean too many children and families cannot access the palliative care they need, when and where they need it.

If professionals lack the right skills and knowledge, the quality and safety of care for seriously ill children is compromised, and providers face higher costs to recruit and retain from a limited pool.

A lack of standardisation in service provision, models and frameworks causes many professionals to feel disempowered and lack confidence in caring for seriously ill children.

It prevents the ability to replicate and fund the most effective work.



### If we are successful over the course of our next strategic cycle, we will be able to say:

Vacancy rates are lower among the groups of health and care professionals needed to provide palliative care to children living with serious illness (and encompass retention plans, service resilience and digital innovation in use of workforce).

All health and care professionals who could provide palliative care to children living with serious illness have the skills and knowledge to do so, underpinned by the right evidence, national frameworks and standardised education and training.

The children's palliative care workforce is organised into regional and national delivery networks across the UK. Sector-wide standards for workforce and service models are defined and embedded through regional and national networks.

Nationally agreed quality benchmarks and outcome measures in place, monitored through a shared data and improvement framework and a framework of research priorities and digital tools.

### 3.Sustainability

#### Key challenge

The NHS does not provide enough funding to sustain services across the voluntary or statutory sector, or to enable children's palliative care standards to be met across hospitals, communities and children's hospices: in England, the funding gap is £310 million.

NHS bodies do not have the data they need to show them how many children could benefit from palliative care, or what the complexity of their

needs are, in part because there is no clear definition of the population.

There is no consistent way for children's palliative care providers to record and report the volume and complexity of the support they are providing.

Funding for children's hospices from UK-wide charitable sources is not enough to meet growing demand and complexity or deliver non-specialist services.



#### This is a problem because:

If children's palliative care services are not financially sustainable, they will be unable to provide the support that families need, leaving them without access.

As the costs incurred by children's palliative care providers grow, they will be forced to cut the services they provide or restrict families' access.

Local NHS bodies are unable to plan and fund children's palliative care services effectively because they do not know what the demand for this care is.

NHS funding for children's palliative care providers does not match the volume or complexity of the support they are delivering and also does not facilitate the delivery of non-specialist support / services.



#### If we are successful over the course of our next strategic cycle, we will be able to say:

The gap in NHS funding for children's palliative care is filled.

NHS bodies have access to data about the volume and complexity of the population of children living with serious illness who could benefit from palliative care, underpinned by a clear definition.

Children's palliative care providers are funded according to the

volume and complexity of the support they provide, based on activity data recorded and reported using consistent approaches.

Children's hospices receive more money from UK-wide charitable sources.

Nationally agreed quality benchmarks and outcome measures

## How we will deliver the next stage of our strategy

We will achieve our goals by focussing our work on three priority areas: direct support, system change and income generation:

Focus area	Who we will reach	What we will do
<b>Direct support</b>	Children living with serious illness and their families	Providing information and support directly to families of children living with serious illness (signposting and referring into existing services and working to fill gaps in provision).
<b>System change</b>	Policy and decision makers; regional co-ordination	A renowned <b>Centre for Evidence and Practice</b> , collaborating, commissioning and sharing significant research and evidence to drive clinical excellence and policy design.  Working with leaders in governments, the health service, commissioning bodies and delivery organisations to improve the funding, quality, and consistency of children's palliative care.
<b>Income generation</b>	Children's hospice member organisations	The <b>children's hospice partnership fund</b> : a leading fundraising scheme, working together with children's hospices to secure national corporate partnerships.

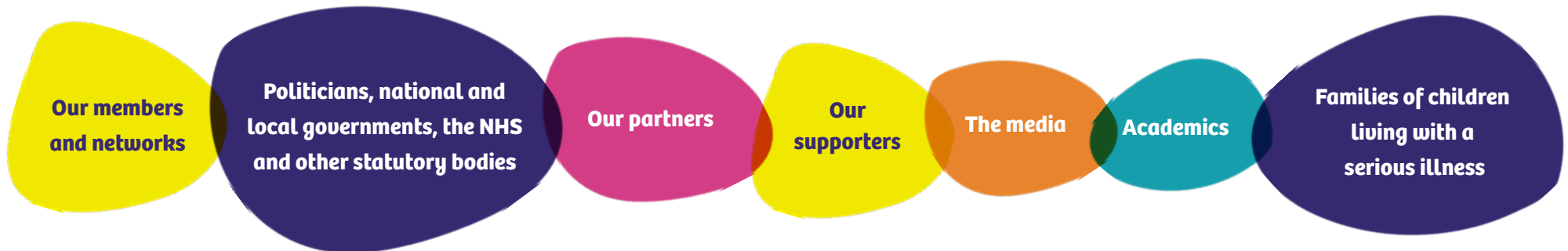
# Our values

As we work to achieve our goals, our values will be at the core of everything we do:



# Who we work with

Because collaboration is at the heart of how we work, we will partner with our members and stakeholders across the whole system to achieve our purpose for children and families



## What our strategy means for you

### **For families of children living with serious illness and professionals who we will reach through our direct support**

We will:

- 1. Map the resources and support available to families of children living with serious illness across the whole system**, then develop support tools for families where we can add value and signpost and refer to others where support is already available.
- 2. Consult families to assess what they need and want, including the support they need with the cost of living and the additional costs of caring for their child.**
- 3. Provide equitable access to our Family Support Hub**, making sure those with the greatest need can receive our direct service offer, which will include support with energy costs.
- 4. Pilot artificial intelligence tools** (alongside the skills, knowledge and experience of our sector) to develop new guidance and resources for families, professionals and services.
- 5. Improve the way we involve families in co-creating our services, our resources and our projects.**

### **For families – and the professionals and services who support them – who we will reach with our work to change the system**

We will:

- 1. Lead the sector to set shared research priorities** (and establish a Centre for Evidence and Practice that improves the sector's evidence base)
- 2. Complete and roll out the new Categories of Care** (with the Association of Paediatric Palliative Medicine (APPM). Defining which children may benefit from palliative care, what services should be provided, and what standards professionals should be educated to.
- 3. Lead the sector to develop a whole-system vision for the future of UK children's palliative care.**
- 4. Develop and implement an effective membership offer that provides clear value across the whole sector**
- 5. Ensure balanced and equitable representation for children, families, professionals, and service providers through sector wide consultation (and a strengthened Advisory Council)** so that our policy positions and campaigns reflect their views and bring about the change they need.
- 6. Lead the development of guidance on service models and workforce standards;** sharing best practice in planning, funding and providing children's palliative care across hospitals, community and children's hospice settings.
- 7. Develop and implement the most effective way for our sector to meet, learn and share through UK-wide events, both online and in-person.**



## **Developing impactful ways for our supporters to connect with our cause**

We will:

- 1. Conduct a review to reframe our National Fundraising Scheme as a strategic programme** that generates income for children's hospices. We will identify ways of diversifying our sources of income for the programme and explore opportunities to utilise social impact finance and volunteering to enhance the programme.
- 2. Develop a strategy to recruit and retain an active community of patrons and ambassadors** to help us deliver our income generation aspirations.
- 3. Explore UK-wide opportunities to raise funds for our non-children's hospice member organisations and teams.**
- 4. Develop a new income generation strategy** and case for support that recognises and prioritises funding needs across the breadth of Together for Short Lives

We will inspire you to support us. And we will show you the amazing impact you are having on families.

Step by step, hand in hand, day by day, so that no one has to face living through their child's short life – and death – alone.

## **For politicians and policymakers**

We will help you make sure the families you serve receive high quality, sustainable children's palliative care they need, when and where they need it – in ways which reduce pressure on the NHS and deliver the best possible value for taxpayers' money.

## **Working together as staff and trustees**

Delivering this strategy well depends on how we work. We will:

- Produce a plan for improving and maintaining the wellbeing of our staff, making sure they have the skills they need and develop continuously.
- Revise the way our Board of Trustees governs the charity.
- Implement a new process for approving projects and campaigns that ensures they achieve impact, are sustainable and are co-created with families.

## Call to action

Contact us, join us and support us. Together we will make sure that children living with serious illness and their families get the care and support they need, when and where they need it.

Because the number of children living with serious illness is so small compared to adults, we need your help so we can shout louder with them. With your support, our refreshed strategy will mean that they can access high quality children's palliative care, when and where they need it.

"This is a challenge that, for me, is personal.

I've done it a few times now – getting on my bike to raise money for Together for Short Lives.

"I was inspired after the loss of my close friend's son, Henry, who died from leukaemia at the age of nine.

"It's a long ride sometimes! The going can be tough.

"But the money goes into supporting families, supporting children's hospices – those people are the real heroes.

"Together for Short Lives are an amazing organisation and I'm proud to think that **we can make a difference together.**

**Francesca Lennon, children's nurse and fundraiser**

