

together
for short
lives

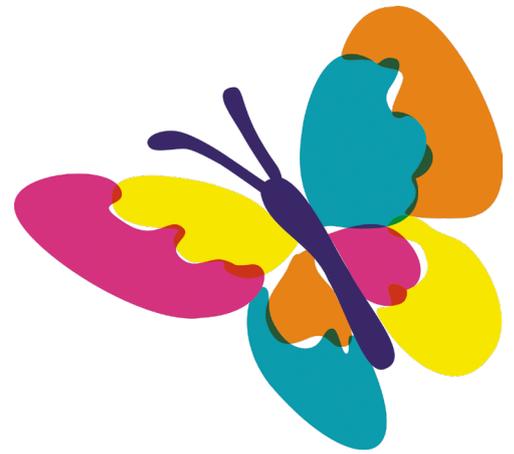


Our
impact
2023 - 2024

High quality palliative care is a lifeline to children like Alessi, her brother Lakelyn and her mum Reagan



Welcome



At Together for Short Lives, we believe in a future where every seriously ill child and their family has access to high quality children's palliative care, when and where they need it.

This is a future that all of us at Together for Short Lives are working towards. This is a future we can only make possible with the incredible support of people like you.

While the challenges facing children, families and services are complex, there are clear solutions. We're working to help seriously ill children and their families **access** the palliative care they need. We're striving to get more expert healthcare professionals on the ground, and better support for them, to increase the **quality** of care. And we're campaigning for **more sustainable** funding to strengthen these crucial services long into the future.

This year, we've reached more families than ever before through our Family Support Hub. We've brought together thousands of healthcare professionals to improve the way care is delivered. And we've campaigned to influence policy to give long-lasting support to seriously ill children and their families.

This year's impact report is a testament to the extraordinary work you've made possible and I hope you enjoy reading about it. On behalf of seriously ill children and their families across the UK, thank you so much for your continued support.

Andy Fletcher
CEO, Together for Short Lives

P.4 Together we support

Through emotional, practical and financial help, our Family Support Hub exists to make sure no family faces the journey alone.

P.7 Together we unite

Through resources, training and networking, we bring healthcare professionals together to improve the care they provide.

P.10 Together we're strong

Through networks and fundraising, we build partnerships so that families get the support they need, long into the future.

P.13 Together we campaign

Through campaigning, we make sure the voices of seriously ill children and their families are heard by those in power.

Together we support

Always there

At Together for Short Lives, we believe that no family should face their journey alone. That's why, this year, we have supported more families than ever before.

How did we support families?

Through our Family Support Hub we've supported families financially, practically and emotionally. From free food shops to making wishes come true, we've been there when families needed us the most.

517 financial grants and food shops provided, to a value of over £200,000

438 families supported through our Helpline service

1,415 families given information at community events

Get support:
togetherforshortlives.org.uk/get-support

The Butterfly Fund

When a child dies of a life-limiting condition, we can support their family with our Butterfly Fund: a one-off £300 financial gift that families can spend however they want. This year, we supported 245 families with a Butterfly Fund grant in the toughest of times.

George (pictured below) was diagnosed with Cerebral Palsy at birth. When he was eight years old, a brain scan revealed fluid in his brain. Tragically, George was not strong enough to undergo the surgery needed to remove the fluid. He died twelve days later.

After his death, George's family were referred for a Butterfly Fund grant. They used the money to pay for the food shop the week of his death. His mum Carrie told us: "The grant didn't just help me, it helped eight other children. It helped a whole family when it mattered most."



The Cost of Living Support Fund

This year, we also provided 86 payments of £150 to families facing increased living costs.

One mum who received the grant told us: "A gift like this has just made my life easier and less stressful. It means I can enjoy time with my daughter without worrying how I am going to afford everyday costs for a short while."

Center Parcs gifted breaks

Thanks to our partnership with Center Parcs, we gifted a further 25 village breaks to families caring for a seriously ill child. These breaks give families the opportunity to spend quality time together, create memories and enjoy a holiday without the financial burden.

This year, Orla's family headed to Center Parcs Woburn Forest with the goal of making as many precious memories as they could.

Thirteen-year-old Orla was diagnosed with a brain tumour as a baby. Ever since, her family have tried to enjoy every day together.

"Most families take a bike ride together for granted," says Orla's mum Susan, "but it's something we've never been able to do.

"At Center Parcs, Orla and I were able to cycle around together using a wheelchair bike, with her brothers Eddie and Simon on their own bikes. For the first time since Orla's diagnosis, we could all cycle together! It's something we will remember forever."



Orla and her mum Susan (above). Ted at Demelza children's hospice (right).



Energy support

Thanks to our partnership with SGN, we launched a new energy advice service, supporting families to lower their bills and sign up to the Priority Services Register.

In the first couple of months, 49 families received energy support. This included support to change tariffs, vouchers for pre-payment meters and support to pay off energy debts.

Ted is registered blind and was born with spina bifida. His mum Annie had an appointment with our Energy Adviser, she told us: "She was very helpful and informative – a pleasure to speak to."

Making a difference locally

Through two groundbreaking projects we've been supporting families close to home, thanks to funding from Morrisons and the Kentown Wizard Foundation.

Our Morrisons Community Outreach Workers support families in Birmingham, Greater Manchester, Bedford, Milton Keynes and Luton, ensuring they can access care where and when they need it. This support included:

98

Crisis Pantry
food deliveries
arranged

76

Butterfly
Fund grants
provided
after a child
died

142

families referred
to our Family
Support Hub for
extra help

One family supported by Lisa, a Community Outreach Worker, told us: "Lisa has changed our family. Being able to go out, and having the courage to go out, with all of the children together... it's amazing. She has made such a difference to us all."

With Lisa's help, the family has been able to spend quality time together and meet other families through activity days and coffee mornings. Lisa was also able to arrange for the family to receive a Cost of Living grant and Crisis Pantry food shop, easing the financial pressure of caring for a child with a life-limiting condition.

The Kentown Children's Palliative Care programme brings together three services: nursing care, social care and information and awareness. Together, our Family Service Coordinators, Rainbow Trust Children's Charity Family Support Workers and Specialist Children's Palliative Care Nurses from five NHS Trusts support families in Lancashire and South Cumbria.

122 new children were referred
to the Kentown Programme
for support this year



Rafferty's story

When Rafferty was unexpectedly born severely disabled, his family were referred to the Kentown Programme for support.

Our Family Service Coordinators were able to arrange a free holiday, a financial grant to support them after he was discharged from hospital and a free food shop.

Rainbow Trust's Family Support Workers visited Rafferty's siblings to support them at home and a Kentown Nurse was there to answer questions and help them navigate appointments and meetings.

Picture, top: Rafferty with his mum Harvie

Together we unite

As the leading UK charity for children's palliative care, we unite the sector and increase the knowledge and skills of the professionals who support and care for seriously ill children and their families. Through resources, training, specialist programmes, and peer-to-peer networking, we improve the care provided by professionals.

1,244

professionals spoke to us about how we can support the families they're caring for

80,000

individuals visited the professional section of our website this year

33,000

professionals downloaded our resources on children's palliative care



Mya with Heather,
Community Carer (above)
Lucy Maxwell (right)



Supporting the sector

"I would like to say a huge thank you for all the support that Together for Short Lives has given the families that I have referred to the Family Support Hub.

"The financial assistance with the Cost of Living grant and the free food shops have proved invaluable to families who are struggling with a whole host of issues as well as caring for their child. Knowing I can refer families to Together for Short Lives and they will follow up with a really special service adds another dimension to the care I can offer the people we support. The advice regarding energy providers too has proved to be so helpful."

**Lucy Maxwell, Family Support,
Derian House Children's Hospice**

Who is children's palliative care for?

A categorising workshop, 2023



We've been working with colleagues from across the sector to bring our understanding of who needs children's palliative care up to date

The framework for categorising life-limiting and life-threatening conditions in children, first established in 1997, is outdated. It no longer reflects the significant advances in medicine, society, technology, or the changing demographics of affected children.

Those responsible for commissioning children's palliative care urgently need an updated framework to make better-informed decisions about funding.

Nearly three decades later, we've spent the year engaging with the sector to update our current understanding of how to identify and support children who need palliative care.

This is crucial work that will help develop children's palliative care services and ensure we reach the right children at the right time.

This vital work would not have been possible without support from The True Colours Trust, whose deep understanding of children's palliative care and commitment to our mission of ensuring seriously ill children and their families get the care they need, is immeasurable.

Learning to communicate well with families

Effective communication is central to families' experiences of healthcare. When parents are told their child may not reach adulthood, life is suddenly turned upside down – and the impact of this news is difficult to soften.

We often hear from families that early conversations about their child's prognosis are handled poorly and that they regret not being given the opportunity to ask questions and let the information really sink in. A poor experience of being given bad news can impact families forever.

That's why we're developing a communication training package for NHS professionals working at universal and generalist level, who aren't specialists in children's palliative care.

We will be launching this new initiative at our May 2025 Conference, 'Built to last: Towards a strong, sustainable future'.

Building a Legacy Together

Since February 2022, Morrisons and Together for Short Lives' partnership has been raising vital funds for children's hospices across the country and helping families make precious memories together.

With this incredible fundraising, we have launched a new Building a Legacy Together grant, to help children's hospices pay for things like renovations, new outdoor spaces and therapy equipment to ensure families caring for a child with a life-limiting condition can be supported in a comforting, joyful environment.

In our first round of funding, we awarded eleven grants worth a total of £476,000 to hospices across the UK, from CHAS in Scotland to the James Hopkins Trust in Gloucester.

Zoe's Place in Middlesbrough used the grant to create a new playground featuring wheelchair-accessible amenities like slides, trampolines, and roundabouts, as well as sensory elements such as music chimes and bells.

Beth Hill, from Zoe's Place said: "We're immensely thankful to Morrisons for their generous support in funding this project. The new playground not only enhances the quality of life for the children and families, but also symbolises our commitment to providing inclusive, accessible environments."

Our aim is to raise £10 million in partnership with Morrisons by the end of 2024. This will enable another two rounds of Building a Legacy Together grants and we can't wait to see what projects are supported next. Thank you to Morrisons colleagues, suppliers, and customers for making these grants possible.



Children at Zoe's Place Middlesbrough enjoy the accessible playground funded by Morrisons' Building a Legacy Together grant

Together we're strong

Right now, rising costs, falling NHS and council funding and inconsistent approaches to planning are stopping seriously ill children accessing the palliative care they need.

With the help of our supporters, we're paving the way for long-lasting change so that families can get the support they rely on, long into the future.

Helping local NHS bodies get it right for seriously ill children

42 separate local NHS bodies in England, known as integrated care boards (ICBs), have a legal duty to plan and fund – a process known as commissioning – children's palliative care. Yet our research has shown that less than half (41%) of ICBs fully specify the 24/7 end of life care at home

that children and young people should be able to access.

ICB funding for local children's hospices in England varied by as much as £366 per child in 2023/24.

To bring about a more consistent approach, we have created a dedicated website to act as a one stop-shop for ICBs that need help to meet their legal duty of care. Informed by commissioners and experts within children's palliative care, our site gives local officials a deeper understanding of how children's palliative care can be commissioned effectively through guidance and best-practice case studies. The site has been over a year in the making, and we're excited to see the difference it will make.

Since 2021/22, children's hospices in England have received:



Building a national movement with local action

This year, over half (51%) of children's hospices in England reported a financial deficit – a number set to grow to nearly three quarters (69%) in 2024/25, should statutory funding continue to fall.

Thanks to the wonderful support of national businesses, we're able to reduce the pressure on children's hospices through our National Fundraising Scheme.

We twin locations with their local children's hospices, with fundraising being ringfenced to support seriously ill children and their families in local communities.

This year we celebrated the 20th anniversary of fundraising through these partnerships and we're proud to have raised over £34 million so far – funding that has helped keep hospices' doors open, purchased life-enhancing equipment, and built new, state-of-the-art facilities.



Fundraisers completing the Global Adventure Challenge

This year's highlights

Our friends at Hobbycraft smashed their previous fundraising records by raising over £475,000 in just one year. This record total is an incredible achievement in our 12th year of partnership.

We also launched a new three-year £1 million partnership with the Peninsula Group, which will raise more vital funds for children's hospices.

"Thank you so much on behalf of all the children and families served by Julia's House, for the National Fundraising Scheme. It's a triumph in the current climate to have raised so much, and we're really grateful to all involved."

Martin Edwards, CEO, Julia's House

"Children's hospices are places full of life and joy, and they help families make precious memories – something that sits at the very heart of our partnership. Our store teams have created really special connections with their local children's hospices and we are so proud to play our part in supporting their lifeline work."

Dominic Jordan, CEO, Hobbycraft



Top: Hobbycraft colleagues at their annual Superhero Saturday; Middle: Martin Edwards, CEO of Julia's House; Bottom: Dominic Jordan with Hobbycraft's Magnificent Seven Trek team

Together we campaign

Save the Children's Hospice Grant

In July 2019, NHS England (NHSE) pledged to increase the Children's Hospice Grant to £25 million by 2023/24. This crucial and welcome contribution to the cost of providing lifeline hospice care meant that by 2023/24, the grant represented approximately 15% of children's hospices' charitable expenditure.

Given the importance of the grant, in Spring 2023, we surveyed children's hospices to find out how they are funded. From this, not only did we find children's hospices across England to be providing more and more complex care, but we also found that they would struggle financially if the Government and NHSE failed to renew the grant for 2024/25. If this were to be the case, we found that:

- 38% would cut end of life care.
- 79% would cut respite for short breaks.
- 66% would cut hospice at home services.

Our campaign focused on what children's hospices would have to cut if the grant was not renewed. We took it to Westminster and thanks to the combined efforts of children's hospices and the public, the Minister of State for Social Care, Helen Whately, committed to renewing the grant for 2024/25 during Children's Hospice Week.

Exposing local NHS funding

Integrated care boards (ICBs) are responsible for allocating NHS funding to children's hospices. In May 2023 we issued a series of freedom of information (FOI) requests to all 42 ICBs to learn how much money they had spent on children's hospice care in 2022/23.

On average, ICBs spent £151.03 for every case of a life-limiting or life-threatening condition among children and young people in their local area. However, the amounts spent by each ICB varied by as much as £483 per child in 2022/23.

Off the back of this report, we secured media coverage with The Times and achieved 54 supportive actions from politicians, which included tabling written questions, signing early day motions or writing to local ICBs. We even secured a meeting with the Special Adviser to the Prime Minister on Health and Social Care.



Supporters campaign outside Westminster



Our campaigning led to the Minister of State for Social Care, Helen Whately, committing to renewing the grant for 2024/25 during Children's Hospice Week in June 2023

Short lives can't wait

We believe that no family should face their journey alone. Being able to access 24/7 end of life care at home is vital. However, there is a postcode lottery for families looking to access this support.

To examine the extent to which children, young people and their families can access 24/7 end of life care at home, we conducted a mapping exercise among paediatric palliative care networks to identify geographical areas across the UK where services meeting quality standards around 24/7 end of life care are being provided.

We also issued a series of freedom of information requests to all 42 ICBs to understand the extent to which children's palliative care service specifications are aligning with national quality standards in this area.

From our mapping exercise, we found that only a third of local areas in England are meeting the required standard for 24/7 end of life care at home for children and young people. We also found that this standard is not met at all in Northern Ireland, and only in a minority of areas in Scotland and Wales.

These findings formed the basis for our Short Lives Can't Wait campaign that subsequently secured national media coverage on ITV News. The findings also became the focal point of the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care's annual general meeting, which 17 parliamentarians attended including the Minister of State for Social Care, Helen Whately.

Following the campaign launch, approximately 3,500 people signed our open letter to the new Prime Minister. We also achieved a total of 74 supportive actions from politicians across the UK. These actions included letters to relevant ministers, ICBs, or health boards, written questions, and commitments to meet for further discussions.

Making it happen

It's only thanks to the support of inspiring individuals, generous groups and committed corporate partners that we can be there for seriously ill children and their families through diagnosis, treatment, bereavement and beyond.



Making miles matter at the London Marathon

Fifteen runners took on the iconic event in support of Together for Short Lives this year, raising a whopping £55,682. Alongside can-do colleagues from our partners at Center Parcs, Hobbycraft and Morrisons, the team included incredible individuals like Hollie, whose nephew Oliver was cared for at a children's hospice. "Knowing that Oliver has an inner strength and determination to battle through things that most adults won't ever have to experience got me through those 26.2 miles!"



Putting for good

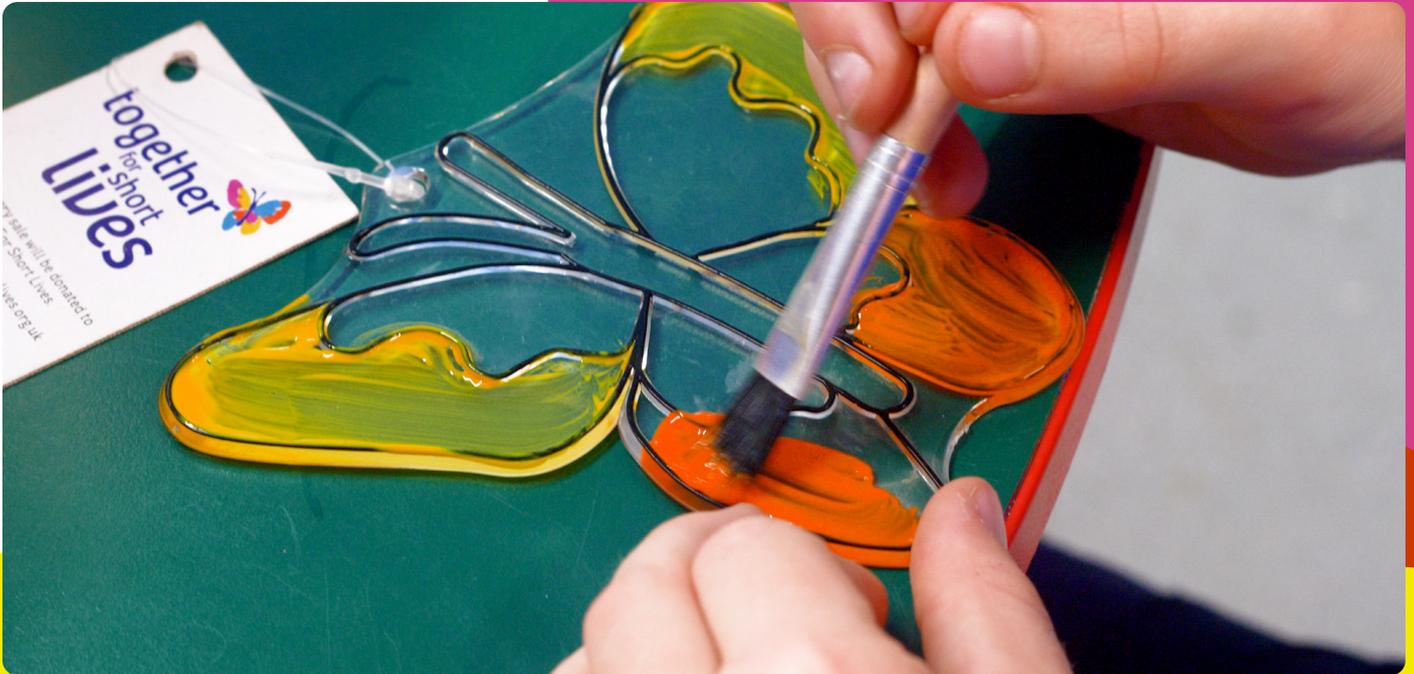
The Belton Woods Golf Club raised over £2,900 through a Men's Captains Golf Charity Day with this year's captain Grant Beck reflecting that their fundraising made them "so aware that every child has the right to live their best life."



Diolch, Harriet!

Harriet Evans took on the Rotary Across Wales Walk, which exceeded her fundraising target and raised nearly £600. As a trainee Clinical Psychologist, Harriet was inspired by the support we give to families through our Family Support Hub. Harriet prepared by going on numerous training walks, building up distance each time – and getting her feet used to the blisters!

Thank you to these amazing supporters and to everyone else who has fundraised for our work this year.



Hobbycraft takes fundraising to new heights

12 years into our partnership with Hobbycraft, we continue to be amazed by the new, creative ways its teams find to fundraise for seriously ill children and their families.

This year, the new 'Shine Together' Butterfly Suncatcher winged its way online and into stores with 50p from every sale raising funds for the UK's 54 children's hospices.

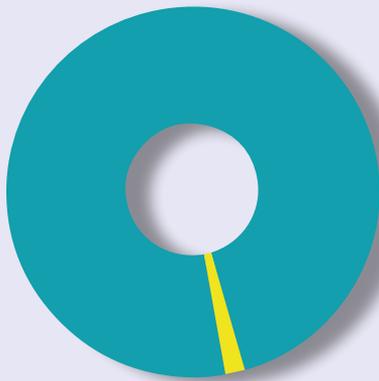
For us, butterflies are a particularly poignant reminder that while some lives are short, they can be beautiful, unique and full of precious moments.

Kids and adults alike have loved creating their very own design on the blank canvas, brightening their day through arts and crafts and creating precious memories whilst doing so with loved ones.

Clockwise from left: Steve took fundraising to new heights with his wing walk; Hobbycraft colleagues got tough and muddy; Colleagues from Gravity stepped up during Children's Hospice Week; Our Patron Holly took to the trading floor at BGC's annual Charity Day; Mum Manraj spoke about her son Arjun at our annual ball; Chris made his miles matter at the London Marathon

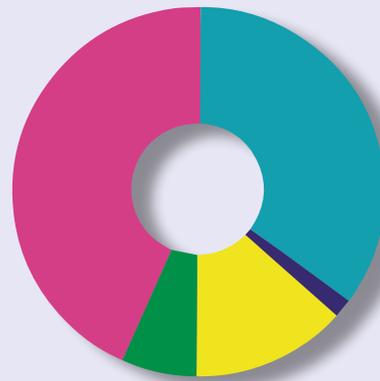


Financial summary



Income
£6,901,670

■ Fundraising income	£6,733,221
■ Other Income	£168,449



Distributions and Expenditure
£7,629,175

■ Charitable activities	£2,576,902
■ Distribution to hospices	£3,212,257
■ Distribution to partners	£727,548
■ Raising funds	£1,017,218
■ Grants to families	£95,250

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Thanks to everyone who granted permission to share their images in this publication

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Get in touch with our confidential helpline by phone or email, or just scan the QR code with your phone's camera.



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