





Welcome to this year's Together for Short Lives Impact Report. The report describes the latest steps on our journey towards ensuring that all children and families have access to high quality, sustainable children's palliative care, when and where they need it.

We celebrate our achievements between 2022 and 2023, and also demonstrate where we've been able to change course to respond to the needs of the families we support facing the cost of living crisis.

For an overview of the year, please read the interview with our CEO Andy Fletcher on page 8.

I am absolutely delighted to have joined this year as the new Chair of the Board of Trustees. Following Dr Hilary Cass who was chair for ten years, and guided the organisation though a period of huge change, and the Covid pandemic, is a very tall order and a privilege. This impact report is dedicated to your legacy, Hilary.

Dr Lisa Kauffmann

### **Contents**

4	Priceless: Mother Helene on her son Dylan and their struggle with the cost of living	15	My day In Westminster: mother Sophie recalls speaking truth to power
8	CEO Andy Fletcher talks with renowned children's palliative care nurse Tracy Rennie	16	Reaching out: how Together for Short Lives is including isolated communities
10	Our impact in numbers	18	Together as Partners: the life-changing impact of our partner organisations
11	Pedal power: super-cyclist fundraiser Francesca Lennon shares her wisdom	20	My Hospice: healthcare technician Jen Plews on why she loves her workplace
12	Osian's story: how the Butterfly Fund will help his family to remember him	21	Star player and star supporter: inside Mason Mount's pop-up shop
14	Voices from the Support Hub: families express their thanks for the lifeline	23	Financial summary



### Priceless

Dylan was born with Scimitar Syndrome. His mum Helene discusses life with her special boy and how Together for Short Lives helped with the cost of living

At the 20-week scan, it was suspected, and then confirmed, that Dylan had Scimitar Syndrome, a rare heart and lung condition. "We were told there was a risk that Dylan's lungs wouldn't cope and he might not survive. But we wouldn't know until he was born. Nobody knew what the outcome would be. It was a very uncertain time."

To mum Helene's relief, baby Dylan was born a few weeks later. "Dylan was born with two black eyes and his fists up and he hasn't stopped fighting since!"

Dylan was born with only one functioning lung, but he hasn't let that stop him living a full life. "From day one, he has been the most loving, funny and intelligent little boy. And he's incredibly sassy! Every second spent with him has been a joy."

Hours, then days, passed and Dylan grew from strength to strength. Helene was reassured by the nursing team that Dylan would be able to live a normal life. Things were looking positive for the family.

But as Dylan grew, he took a turn for the worse. "It soon became clear that his better lung wasn't great either. Dylan was admitted back into hospital where he spent almost a whole year without leaving. He had open heart surgery and a tracheostomy fitted, and countless other interventions. We've been in and out ever since."

Dylan relies on 24/7 care to survive, much of which uses electricity to run. "We have so many pieces of medical equipment in our home just to keep him alive. We have ventilators, oxygen, suction machines, SATS monitors and a power assisted bed, all of which Dylan relies on."

As a single mother, Helene faces additional pressure caring for Dylan. "Being on my

own, I have had to make many sacrifices for Dylan's care. I don't have anyone to share the struggles with. But I would do absolutely anything for my boy. It's me and Dylan against the world."

On top of this, Helene was also facing spiralling energy costs, which made running Dylan's essential medical equipment even more challenging. Reducing their energy usage wasn't an option.

Helene was struggling to afford the essential electricity needed for Dylan's care. The family were desperate for help.

Through Dylan's nursing team at the local hospital, Helene was referred to receive the £250 Cost of Living Grant from Together for Short Lives – a financial gift to help families pay the running costs of essential medical equipment.

"The grant has helped us massively. As a single parent, I'm the only one bringing in income to support our little family. The grant made a huge difference in not having to worry where the money was going to come from for our energy bills. I am forever grateful."

### Our Cost of Living Grant: the families speak

"With my partner having to be off work because of our daughter's complex needs, money is extremely tight and we often have to go without heating. This will help pay for electricity and gas – plus we can provide healthy meals. We are very grateful."

"With the cost of living and energy bills rising and all the equipment my daughter has, I go through a lot of stress. With

this gift I've been able to get up to date and it has taken a huge weight from my shoulders."

"I have been able to go shopping for food without having to worry."

"I have two disabled children and have been struggling to keep the house warm for them. This month I can. I am so thankful."

### change change

Our Chief Executive **Andy Fletcher** talks to renowned children's palliative care nurse and former Director of Care at EACH **Tracy Rennie** about our achievements over the past year – and what's coming up in our ten-year vision

**Tracy:** It's great to see you again, Andy. I'm really excited to hear what's been happening over the past year.

Andy: It's great to see you too, Tracy.

**Tracy:** So, firstly, tell me about your new strategy? How was it developed and what excites you most about it?

Andy: About a year ago, we started thinking about how we could reshape our strategy, how we could help create a future that children and families would want to see. So we spent time talking to families and our advisory council, which, as you know as a former member, is a really important group, made up of people with lived experience and people working in children's palliative care.

We started the process by thinking about what the world might look like in ten years time. We looked at key areas including health, care and income generation, but we didn't want to set ourselves a rigid plan because we recognise that the world's changing at a rapid rate. So we've pulled our ten-

year vision into a two to three year plan, which will continually change and adapt.

At its heart are three things: improving access to children's palliative care, improving quality of care and ensuring its sustainability. So how do we make sure that every child and family who needs support can get it? There are huge challenges to access – so we need to ensure that families from different communities can access palliative care, understand what children's palliative care is and get families referred into services sooner.

We also want to improve the quality of care because there are some brilliant services and professionals out there doing great work, but there's no consistent approach to children's palliative care across the country.

It's a really challenging environment, trying to raise money to deliver this complex care, and it relies heavily on the voluntary sector and the generosity of the public to fund some of these services. So we want to see a more sustainable sector, one where the Government and NHS commissioners and stakeholders are clear about their own responsibilities and fund things accordingly. We're really excited about pushing forward towards this ambition.

**Tracy:** I feel really motivated just listening to you talking about it! You mentioned trying to reach more communities, but we know families don't always access children's palliative care when they need it. One of the key issues is a misconception about what children's palliative care is. How would you describe it?





"For me, children's palliative care is holistic. It's support for the whole family that starts at the point the child is diagnosed and goes on for their whole life – and into bereavement for their family too."

Andy: For me, children's palliative care is holistic care, something that is positive. It's care and support for children and families that starts at the point that the child is diagnosed and goes on for their whole life, and into bereavement for their family too.

Palliative care should also extend to the whole family, not just mum and dad, but brothers and sisters and grandparents and close friends. Of course, end of life care is a really critical part of that, but it's only one component of it.

It doesn't take away the pain of losing a child, but it does make sure that families feel they've created the very best possible life for their child or young person and for their whole family.

>>>





Tracy: I couldn't agree more. You mentioned the need to reach more diverse communities. How are you progressing work in this area?

Andy: Research has shown that you're more likely to have a child with a life-limiting illness if you live in an area of social and economic deprivation and if you're from a Black, Asian or Minority Ethnic community. We need to reach as many of those children and young people as we can, and also help the sector to.

So we started two programmes last year which we're really excited about. One is in Lancashire and Cumbria, which is a collaboration between Together for Short Lives, Rainbow Trust Children's Charity, and the Kentown Wizard Foundation, and is working with the NHS to help coordinate care and help families navigate their way through this complex world.

The other project is our three year partnership with Morrison's, which is fantastic, both in terms of raising money for local children's hospices and helping us to reach more families from different communities. We've got outreach workers in Birmingham, Manchester and Luton, working alongside services in those areas, to build relationships with different communities and help make children's palliative care more accessible to everyone who needs it.

**Tracy:** Can you tell me more about the work you've been doing to support the professionals working with children?

Andy: Absolutely. We've been looking at how we create change in the sector and a big part of that is about developing the professional workforce, developing services and working with policymakers and commissioners. This year, we really want to move that work forward.

We know that training, recruiting and retaining nurses and specialist doctors in children's palliative care is a real challenge. The Royal College of Nursing estimates that more than 5,000 Community

"I'm always struck by the number of people who want to make change happen. Our role is to encourage that energy"

Children's Nurses are needed to support disabled children and children with complex health needs, but at the last count, we had 713 nurses. We're miles off where we need to be, so there's a job here for us to ask 'how do we support people to understand palliative care and make more referrals?'

**Tracy:** So, there are two aspects to this work – influencing and lobbying to get more staff and services and highlighting how good it is to work in children's palliative care?

Andy: Yes. And one of the biggest joys of the year was bringing together more than 200 people at our national conference in Manchester in September to talk about the successes and challenges and share the latest data.

I'm always struck by the number of people who want to make change happen. As an organisation, our role is to encourage that energy and share learnings from it.

**Tracy:** How has the ongoing cost of living crisis affected the families you support?

Andy: It has had a huge impact. It's hard to imagine, unless you see it, the kind of energy-intensive equipment and technology that many children need at home to survive.

I was really pleased we were able to lobby and advocate for financial support for families in the run up to Christmas. We had an All-Party Parliamentary Group event in Westminster where we brought families together with parliamentarians and services to talk about this growing crisis and ask what relief might be available from the state. We also

launched a Cost of Living Grant which was supported by Morrisons and other generous funders.

**Tracy:** How do you manage to get politicians and health officials to find the time to listen to you?

"We've been running a really powerful campaign around extending the Children's Hospices Grant, which is a key part of funding for Children's Hospices."

**Andy:** It's not always easy. For us, it's about ongoing work to build a community of support

within Parliament and I think it's partly about how we share stories. We've been running a really powerful campaign around extending the Children's Hospices Grant, which is a key part of funding for Children's Hospices.

**Tracy**: What's been your proudest achievement in the last year?

Andy: Blimey, there are so many to choose from! I was incredibly proud of the work around our cost of living campaign. To have the team pull that campaign together so quickly, and to raise upwards of £200,000 and be able to share it with families in small grants was absolutely amazing.

**Tracy**: It's been great to find out what you've been up to – really motivating!

**Andy:** Thank you. Yes, reflecting on this has really energised me.



Andy explains what's exciting him about the near future of Together for Short Lives

"We've recently begun looking at the categories of children who need palliative care," says Andy. "In the '90s, four categories were developed which now need adapting for the 21st century."

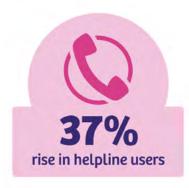
This work will form the foundation for ideas around access and quality standards.

"Ultimately, we want to develop a centre of excellence in children's palliative care, where all the insights, research and data can be shared with professionals."





# our impact in numbers



















Every £1 we invest in fundraising generates £5 for children's palliative care





### Pedal Power

Francesca Lennon cycled to every one of the UK's 54 children's hospices, clocking up an astonishing 3,200 miles and raising £87,000 for them via our National Fundraising Scheme. Here she remembers her epic trek...

Mum banned me from getting on a bike when I first shared my idea for the challenge – she just didn't trust me on one! Others thought it was an incredible idea but completely crazy, particularly considering I didn't have a bike and couldn't really cycle.

The most daunting part for me was preparing for the challenge whilst experiencing my own grief through child loss. My best friend's son, Henry, died from Acute Myeloid Leukaemia four months before I set off. I just never expected to be doing the challenge so soon after losing someone I loved so much.

The first day was completely overwhelming. I was preparing up until the last moment and had so much to think about – all that was ahead, saying my goodbyes – my head felt like it could explode. When it

was time to set off I dropped my bike and the chain fell off. My response was to call out: "Mum!"– I had a lot to learn!

Seeing, first-hand, what seriously ill children and their families go through every day inspired me to take on the challenge. Children's hospices offer incredible support but they rely on the public to be able to do their work. I wanted to raise awareness about what families go through and how we can join together as a society to ensure they have the support they need and deserve.

Front of mind, throughout the challenge, were the children and families I had looked after and all those seriously ill children out there that need our support. They carry on each day

They carry on each day through complete emotional and physical exhaustion and I wanted to make the biggest difference possible. Each week was dedicated to a different child and family that had kindly shared their story and the challenge was dedicated to Henry.

It was really important to me to be able to raise money for all the children's hospices in the UK. The Together for Short Lives National Fundraising Scheme gave me the perfect way of doing this, as well as raising awareness for the incredible work of the charity.

So many people got behind the challenge, helping with routes, making a website, coming up with ideas to make it the best it could be. Then, as it got closer, more and more people got in touch to offer support. It was a huge team effort from start to finish and it wouldn't have been possible without all the people willing me on.



# Osian's story

"Osian was full of joy and magic, and that is how we will always remember him," says Osian's mum George, remembering the boy who was born at 23 weeks and spent almost his whole life in hospital.

Baby Osian arrived into the world in November 2021 weighing just 507 grams. "I had an infection and so went into early labour at 23 weeks. We were told immediately that the chances of him surviving were very slim indeed. He had chronic lung disease and then later a narrow airway due to many months being ventilated. Every day was going to be a fight for him."

Osian was immediately moved to intensive care where he spent much of his life. He was placed on a ventilator and mum George was finally able to have a cuddle.

Months later, Osian was able to come off his ventilator and was moved onto high-flow oxygen and CPAP (Continuous Positive Airway Pressure) – a big step forward for the family.

After a successful operation to dilate his airway, Osian was moved out of intensive care and to a local hospital.

"There were so many times when we nearly lost him. In June 2022, he was fitted with a tracheostomy and it was the best thing to happen to him. He started to thrive as a baby. He was growing, sitting, laughing, smiling. But he was always silent." Due to Osian's condition he didn't have a speaking valve which meant that he couldn't make sounds. Finally, in January 2023, Osian was moved back home.

"I described Osian as 'showbiz' because that's what he was like when you met him. It was like he turned a light switch on, sometimes I think he was looking directly into your soul."

"Osian started to crawl and despite his illness he was living a truly full life. I made sure of it. That's what I want people to remember about him. He wasn't his illness or his condition. He suffered great hardship, but he was not sad."

In March 2023 everything changed. Osian suffered a blockage in his tracheostomy and quickly went into respiratory arrest, followed by cardiac arrest. "We quickly got his heart beating again and

got him to hospital. He spent five days in hospital where it was confirmed that Osian had suffered brain damage. It was such a shock. We were so unlucky."

Osian died on 25 March 2023. "Osian defeated so many odds, so when it came to his funeral, we truly wanted to celebrate his short life. We had music, and we wore bright clothes. We danced and we cried and we remembered all that Osian gave and shared with us. Grief is awful, it is cruel. Every day is different and unexpected. But we move forward because we have to."

After his death, Osian's family were referred to receive a **Butterfly Fund** grant from Together for Short Lives – a one-off £300 financial gift that the family can choose to spend however they want: "We have saved the money and will be spending it on our first holiday to Salou later this year. We have never all been on holiday together. We will spend time as a family and remember Osian. We want the kids to have fun."

"Life now is completely different. No parent should ever have to lose their child. It's tremendously sad and just so unfair. And so we spend every day talking about him and celebrating him – all that he brought into this world – and all that he left behind. He was magical."







Photos: Osian with his family, pictured (top) on holiday using money from the Butterfly Fund.

"I went to an online event for carers of siblings and, for the first time in a long time, I felt I could let my guard down. I actually felt really emotional. The event helped to normalise our family situation. It was so encouraging to feel that my family are 'normal' in the best way possible – to hear people suggest some of the things I'm already doing. It made me feel that I'm doing something right."

"Your grant ensured we could heat our home and meant we were able to bring my son home to have a beautiful, peaceful death, surrounded by his family."

"Your grant meant I could cook a hot meal for the first time in six months. It was my son's first Sunday dinner – and it's a memory we treasure, now he has passed away."

"Last year my life was turned upside down. Losing my youngest son, struggling with the cost of living... everything was crushing my soul. But the grant helped me pay my utility bills and settle some loans. You restored my faith in humanity."

### Voices from the Support Hub

Some of the families we've supported this year told us about their experience

"Knowing your child will die young is the hardest thing you could possibly carry around with you, but you have been there for us, taking some of the load. Knowing we can reach out at any time and someone will listen is so reassuring."

"You provide a safe place to talk about my fears – and my hopes – for what, I know, will be a very short life."

"Calling your helpline gave me
the confidence to ask my child's
consultant for an advance care plan.
I've been given the reassurance I
need for when the time comes, so
now we can get on with having as
much fun as possible."

"As a mum, not being able to cook hot dinners for my children for so long made me feel like such a failure. But receiving the slow cooker and oven from you has changed everything – and it's given me the confidence to try new recipes."





Like many families caring for a seriously ill child, Sophie relies on electrical equipment to keep her daughter Isabel alive, but faces rising energy bills. In November she gave a speech urging MPs to back our call for financial support for families. She remembers the day...

"I wasn't really sure what to expect when I arrived at Westminster but I was given a warm welcome, which put me as ease. It's not often that you get the opportunity to address the All-Party Parliamentary Group for Children Who Need Palliative Care so I was keen to make the most of it.

Rather than being nervous, I felt excited about being able to speak openly about a topic which I have become so deeply affected by.

It's never been easy, but it has felt financially impossible since the start of the cost of living crisis - especially the cost of energy, which has soared in recent years. It has heightened our anxiety and left us wondering if we can sustain caring for Isabel at home, where we want her to die, surrounded by those that love her. I felt really privileged to be able to speak on behalf of so many families who face similar challenges. I felt a sense, by the end, that my words had moved people in a way that I hadn't expected. So much of what we

experience has become normal that it's easy to forget just how devastating it is to outsiders. If nothing else, I felt proud for stepping outside of my comfort zone and I was reminded of how powerful my voice is.

"I was reminded of how powerful my voice is" – Sophie



Top: Sophie delivers her speech in Westminster. Above: with husband James telling Sophie's story

Isabel is a constant inspiration to me: I draw so much strength from her. She was at the forefront of my mind throughout my speech. I feel she deserves the right to die in the comfort of familiar surroundings, held by those who love and care for her. As her mum I will do anything – absolutely anything – in my power to make that happen.

It was a privilege to meet and chat with other parents in similar circumstances, who feel as passionately as I do about improving outcomes for families like ours. I was also grateful to chat briefly with Siobhan McDonagh, MP for Mitcham and Morden, who demonstrated such a great deal of compassion. We also met Peter Dowd, MP for Bootle, who was very understanding. He took us on a short tour of Westminster after the event and we sat and chatted further about the importance of supporting families of seriously ill children.

I will never forget this experience, and am grateful to Together For Short Lives for making it happen. It has encouraged me to speak up more: our story has power and hopefully, by sharing it, this will empower others to make changes that can impact positively on the lives of others."

## Together as partners

From volunteering and fundraising events, to transformative grant programmes and family events, our partners make a meaningful, tangible difference to the families we work with every day...



### **Breaking down barriers**

Since Walt Disney first brought animators and characters to visit hospitalised children in the 1930s, Disney stories have inspired a world of hope for seriously ill children.

Together for Short Lives developed and implemented a project in partnership with children's hospices, funded by **The Walt Disney Company**.

Throughout the summer of 2022, fun days were held at ten children's hospices across the UK. Families took part in fun activities and spoke to Together for Short Lives to help us to understand the reasons why sometimes families find it difficult to take up referrals to children's hospice services.

### **Crafting memories**

For the 99,000 children in the UK whose lives are expected to be short, art can be a magical outlet, and a special activity for families to make precious memories - something that shines through our partnership with **Hobbycraft**.

In November, we worked with crafting experts from Hobbycraft to host three memory-making workshops for 47 parents who have experienced caring for seriously ill children.

The online tutorials showed families how to create scrapbooks as a place to keep precious mementos. Not only did every parent want to sign up for another workshop, but many also valued the opportunity to meet others who









Left to right: mother Emma and daughter Logan-Ann crafting a Hobbycraft ceramic star; Christmas Skate Day hosted by BNP Paribas; Diwali gifts at Derian House Children's Hospice; Thea and her little sister at Center Parcs.

understood about caring for a child with a lifelimiting condition. "It's been so good to talk to others who really get it," said one parent.

This year, Hobbycraft colleagues raised a staggering £412,000 for children's hospice's services up and down the country – taking our partnership total to a whopping £2.5 million.

### Precious time together

Bringing families together sits at the heart of our partnership with **Center Parcs**. On top of their incredible fundraising, which has so far raised over £1.7m for the UK's children's hospices, they also gift 25 village breaks a year for families caring for a seriously ill child.

This year, the Harris family headed to Elveden Village with their five-year-old daughter Thea to spend quality time together and make precious memories. "Everyone was so accomodating" said mum Rachel, "and Thea's confidence soared."

Sadly Thea died shortly after the break, but her family continue to treasure the memories they made at Center Parcs. "We will hold those memories closely to our hearts," says Rachel.

### Reaching into the community

Our partnership with **Morrisons** is helping to reach families who are unaware of what services are available to them, particularly in non-white British communities. Our Outreach Support Workers, funded by the partnership, hold local events and days out for families to make precious

memories together, where we can link them to children's community palliative care services.

We held a Diwali event at Morrisons Chorlton store, handing out toys, chocolate elephants and information leaflets to 60 families, thanks to Morrisons supplier Surya Foods. One grandmother shared, "I hadn't heard about Together for Short Lives before, and I think my family could benefit from your support."

Our partnership has raised an amazing £4.3 million this year, helping us launch this important Outreach Project and distribute vital funds to the UK's 54 children's hospices. We have also launched the Making Memories Together grants, giving hospices up to £2,000 to create special moments for families to enjoy together.

#### Winter wonderland

In November, **BNP Paribas** held their annual Christmas Skate Day, raising an incredible £40,000 to support mums like Stacey through our Family Support Hub.

Stacey's daughter Tiffany spent most of her three years in hospital. During that time, Stacey reached out to our helpline for support. "It's because of events like these that Together for Short Lives can support families like mine," she said. "The charity means a lot to me as they offered a listening ear when I felt alone in hospital."

"Tiffany would have loved to see the Christmas lights here and take in the atmosphere of everyone laughing and coming together."



## This year we've been reaching isolated communities more than ever. Here are the day-in-the-life diaries of Ben, Kentown Support Family Service Coordinator and Lisa, Community Outreach Worker. funded by Morrisons

Ben: I press the snooze button on my alarm, after a late night studying for my counselling diploma. It's an excellent course which is equipping me with the understanding and skills that are vital in my role as a family service coordinator for South Cumbria and Lancashire.

I get my little one ready for his morning nursery session. The school is only a five-minute walk away, so I drop him off and return to begin my working day from home.

I check through my emails and see a message from a family I've nominated for a Center Parcs break. Mum had been desperate to provide them with something to look forward to this year and she's delighted that it's been booked. It reads: "Can't thank you enough for sorting this. I'm so grateful and know my children will have the best time together making memories. I can't wait. Thank you for giving us something to look forward to." It feels humbling to hear about the impact of the work I'm able to do in this role.

I also see a new family referral from The Kentown Children's Palliative Care Programme – a collaboration between Together for Short Lives, The Kentown Wizard Foundation and Rainbow Trust Children's Charity.

Each Tuesday, I have a caseload catch-up meeting with Kentown Support Nurses and Rainbow Trust Family Support Workers to ensure we can discuss the needs of every family within each of the five regions of the Kentown programme. I leave today's meeting feeling positive and keen to get on with the actions agreed. I message a mum, who missed out on a family event and mention the possibility of doing something similar elsewhere.

I ring another mum who needs support over the summer holidays. I've been researching short breaks for her family and I tell her about a canal barge break and offer to send her some National Trust day passes. I also catch up with the dad of a child in hospital who is trying to adapt his home.

I meet with a representative from the Butterfly Fund and we go through some new grant applications to help support bereaved local families. Then I check my 'to do' list and send out a final email of the day, ensuring a memory making event is confirmed for later this month.

Lisa: I wake up at 5:30am, excited to start the day. Every day is different for me, but it always starts with a proper cup of tea – Yorkshire brew only!

I manage the care for my uncle, who has a profound learning disability, so before the rest of my family wake up, I drive over to his house and make sure his care team are settled. Then I drive back to my house to make sure my husband and two sons are ready and out the door for school and work.

Once everyone else is set up for the day, my working day can begin. First on the agenda is a visit to Derian House Hospice to meet the family support team. It's nice to be able to put more faces to names. Today we are discussing the Butterfly Fund and how it can help the families I have been supporting in the local communities.

I then head back home for some lunch and to say hello to my dog, before spending the afternoon at my laptop.

In the afternoon, I reach out to local services who can help the families I support. I arrange for a family to have their daughter's picture taken with a memory photographer. I finalise arrangements for my visit to Angels Football Club United this weekend so I can connect fathers that I support with the club. I progress a couple of applications for families looking for financial assistance.

I check in with Amanda, my line manager at Together for Short Lives. I've been in post for five months now so it's a good opportunity to chat about the role and where we can take it.

Tomorrow morning I am visiting one of the families I support at their home to discuss a memory-making event for their one-year-old daughter. I love visiting families and feeling like I am providing the support they need. Their daughter likes to match the sticker holding her nasal tube to her outfit so I make a note to see what she has chosen tomorrow.

After work we sit down for tea as a family – this time is so important for me and I love to hear what everyone has been up to. After dinner and a dog walk, I go for a run – my favourite time of the day as I find it clears my head for tomorrow.





### My hospice

Healthcare technician **Jen Plews** tells us about the impact of Morrisons' Making Memories Together grants. Established as part of our partnership, the grants of up to £2,000 bring special experiences to children who receive hospice care, giving them and their families memories to last long into the future.

I've worked at the Butterwick House Children's Hospice in Stockton, County Durham for 24 years now and I can honestly say that no two days are the same!

I'm a healthcare technician, and I support our hospice nurses with every aspect of their role. This includes providing 24-hour care for the children, helping to check medications and planning and implementing play activities.

Today is admission day, so I've been preparing the bedrooms for our new arrivals. I've also been laminating posters for our Christmas pantomime. We're expecting our first child at 10am, so when she arrives for her first overnight stay with us, I'll help her unpack and find something fun to do.

For some people, the mere mention of the word 'hospice' can fill them with fear but Butterwick House is such a happy place where children and families make the most of every moment.

The partnership with
Morrisons is helping to show
people what we actually
do. It's important for people
to know what life is like for
our children and families, so
putting information up about
us in a supermarket, where
everybody goes, is a great idea.

I would describe Butterwick
House as bright, colourful
and noisy! You might find a
child watching Peppa Pig on
TV in one area of the room
while in another a child will be
playing the drums.

Some staff from our local Morrisons recently visited us to see the hospice for themselves. They were all so excited about doing a range of fundraising activities for us.

We've been lucky enough to receive money from Morrisons' Memory Making Fund and it has made a tremendous difference. Just being able to take the children and young people out again has been amazing.

Last Christmas, we arranged outings to our local garden centre so all the children could meet Santa. They loved having their photos taken, and watching the singing yeti, snowmen and penguins!

The fund has also enabled us to take some of our children out for meals. We have a local pub that we can walk to and it's just so nice to take them there, they love it!

Memory making is incredibly important for seriously ill children and their families, who often don't know how much time they have left together. Memories and photos of those trips are treasured. At a time when rising costs are making life hard for our families, our partnership with Morrisons is so valuable – because the joy of taking a seriously ill child out somewhere special is priceless.

### Star player and star supporter

Inside Mason Mount's pop-up shop...

In July 2022, a very special fundraiser launched in London to raise vital funds for our Family Support Hub.

Our Patron, Manchester United and England midfielder Mason Mount, held a unique pop-up shop selling a range of limited-edition 'MOUNTchandise' for one weekend only. The pop-up shop featured over 700 pieces of Nike items, complete with Mason Mount branding and was supported by Knight Frank, Nike, PB Leisurewear, Wagamama and many more.

Mason also generously donated a pair of match-worn boots, customised by artist Jordan Dawson, which were auctioned off to the highest bidder, and joined an exclusive Zoom call with fans who weren't able to attend.

The pop-up raised over £40,000, helping us make sure that the 99,000 seriously ill children and their families in the UK can make the most of every moment they have together – whether that's for years, months or only hours.





### Spotlight on young carers

At the Together for Short Lives Ball in March, sixteen-year old Lucy gave the audience an insight into life as a young carer for her sister Ellen. Our annual ball, kindly hosted by our Patron Simon Cowell, has so far raised £1.5 million for families of life-limited children.

## Thank you to all of our supporters

### **Major Donors**

Chantelle Rance
Claudia Restis
Gareth Neame
Jeremy Evans
Jonathan Shalit
Katia Restis
Kelly Hoppen
Kevin Smith
Lauren Silverman

Melanie Blake Mike and Catriona Marshall Muriel Jones Foundation

Paul Ashurst Reach Plc

Richard and Katie Brindle

Sarah Dodd

Toby & Jayne Ricketts
Tony & Debbie Mount
Tschuggen Collection

### Trusts, Foundations and Statutory Funders

Arnold Clark Community Fund
Baron Davenport's Charity
The Barratt Foundation
Health and Wellbeing Alliance
Doris Field Charitable Trust
Edith Murphy Foundation
Fowler Smith & Jones Trust
Hackney Giving
Lord Barnby's Foundation
MariaMarina Foundation
Moondance Foundation
Movement for Good Awards
Normanby Charitable Trust
Scottish Children's Lottery Trust

Scouloudi Foundation

Thales Charitable Trust
The Basil Death Trust
The Brian Mitchell Charitable

Settlement
The Crerar Trust
The Darkley Trust

The Edward and Dorothy Cadbury

**Trust** 

**Fairy Water Trust** 

The February Foundation
The Hospital Saturday Fund
The Hugh Fraser Foundation
The James Tudor Foundation
John James Bristol Foundation

The Light Fund

The Lillie Johnson Charitable Trust
The Mabel Harper Charitable Trust

The Masonic Charitable

**Foundation** 

The Michael and Anna Wix

**Foundation** 

The Morrisons Foundation Nancie Massie Charitable Trust The National Lottery Community

Fund

The Norman Family Trust

**Shanly Foundation** 

Thomas J Horne Memorial Trust

The True Colours Trust

W A Cargill Fund

**Warwickshire County Council** 

#### **Corporate Partners**

Amazon
Anglo Recycling Company Ltd
Autoglass

BGC Group

**BNP Paribas Leasing Solutions** 

**Britvic Soft Drinks** 

Center Parks UK

Cisco

Coca-Cola Europacific Partners

Colgate-Palmolive

**Dignity Plc** 

**Engineering Service Partnership** 

l td

**General Mills** 

Gravity Active Entertainment Hain Daniels Group of UK

Companies Hobbycraft

John Lewis & Partners

The Jordans and Ryvita Company

Lacka Foods

Life Health Foods Ltd

Making a Difference Locally

Marks and Spencer plc

Mars Food UK

Miss Teen Great Britain Mondelez International

Morrisons
Nestle Cereals

Next

PepsiCo UK

**Pinsent Masons LLP** 

**Pladis** 

Premier Foods

Procter and Gamble Reckitt Benckiser

Simpson Travel

Summers-Inman Construction &

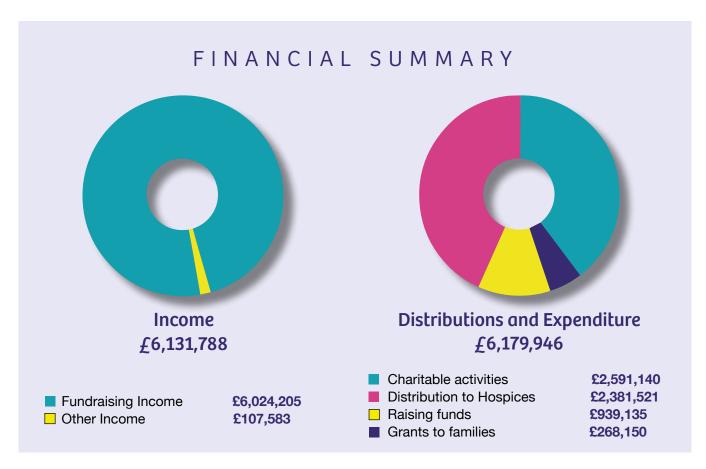
Property Consultants

**Tata Consumer Products** 

Terracycle UK Ltd

The Walt Disney Company Ltd

Walkers Snacks Ltd



### **Board of Trustees**

Dr Lisa Kauffmann, Chair (joined 30th March 2023)

Dr Hilary Cass OBE, Chair (term ended 30th March 2023)

Adam Smith Arlene Honeyman (term ends 17th November 2023) Emma Aspinall (joined 20th September 2023) Jo Laddie Mark Smith (joined 20th September

Paul Obey (term ends 17th November 2023)

Rob Lightfoot (joined 20th September 2023) Sarah Talbot-Williams, Vice Chair Bernie Watson, Treasurer Stephanie Nimmo Sue Hogg Tracy Tait

#### **Chief Executive**

Andy Fletcher

#### **President**

Professor Sir Alan Craft

#### **Vice Presidents**

Professor Dame Elizabeth Fradd DBE. DL Dr Ann Goldman

#### **Our Patrons and Ambassadors**

Holly Willoughby Jordan Banjo Lance Corporal Richard Jones Mason Mount Peter Andre Rebecca Front Rosa Monckton Simon Cowell

**Together for Short Lives,** Suite 1b, Whitefriars, Lewins Mead, **Bristol BS1 2NT** E: info@togetherforshortlives.org.uk T: 0117 989 7820



### 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).













Phone: 0808 8088 100

Email: helpline@togetherforshortlives.org.uk

Online chat: togetherforshortlives.org.uk/get-support

### Find your nearest Children's hospice

- 1. Acorns Children's Hospice
- 2. Acorns for the Three Counties
- 3. Acorns in the Black County
- 4. Alexander Devine Children's Hospice Service
- 5. Andy's at St Andrew's Hospice
- 6. Bluebell Wood Children's Hospice
- 7. Brian House Children's Hospice
- 8. Butterwick House Children's Hospice
- 9. Chestnut Tree House
- 10. CHAS: Rachel House Children's Hospice
- 11. CHAS: Robin House Children's Hospice
- 12. CHAS at Home teams, Aberdeen
- 13. CHAS at Home teams, Inverness
- 14. Children's Hospice South West
- (CHSW) Charlton Farm
- 15. Children's Hospice South West (CHSW) - Little Bridge House
- 16. Children's Hospice South West (CHSW) Little Harbour
- 17. Claire House Children's Hospice
- Demelza Hospice Care for Children - Kent
- 19. Demelza Hospice Care for Children South East London
- 20. Demelza Hospice Care for
- Children East Sussex
- 21. Derian House Children's Hospice
- 22. Dougle Mac Children's Hospice
- 23. East Anglia's Children's
- Hospices (EACH) The Nook
- 24. East Anglia's Children's Hospices (EACH)
- 25. East Anglia's Children's
- Hospices (EACH) The Treehouse
- 26. ellenor

Hospice

- 27. Forget Me Not Children's Hospice
- 28. Francis House Children's
- 29. Haven House Children's Hospice
- 30. Little Havens
- 31. Helen & Douglas House
- 32. Hope House Children's Hospices
- 33. Ty Gobaith
- 34. Jigsaw, Cumbria's Children's Hospice
- 35. Julia's House: Dorset Hospice
- 36. Julia's House: Wiltshire Hospice

- 35. Julia's House: Dorset Hospice
- 36. Julia's House: Wiltshire Hospice
- 37. Keech Hospice Care
- 38. Martin House Children's Hospice
- 39. Naomi House & Jacksplace
- 40. Noah's Ark Children's Hospice
- 41. Northern Ireland Children's Hospice
- 42. Rainbows Hospice for Children and Young People
- 43. Rebecca House Children's Hospice
- 44. Rennie Grove's Children's Hospice at Home
- 45. Richard House Children's Hospice
- 46. Shooting Star Children's Hospices:

- 47. Shooting Star Children's Hospices: Christopher's
- 48. St Oswald's Hospice
- 49. The James Hopkins Trust
- 50. The Jessie May Trust, Children's Hospice at Home
- 51. Ty Hafan
- 52. Zoë's Place Trust
- 53. Zoë's Place Baby Hospice
- 54. Zoë's Place Baby Hospice:
- Middlesborough
- 55. Hospice in the Weald for Children, Tunbridge Wells

