

together
for short
lives

Our
impact
2024 - 2025



Welcome



Seriously ill children and their families deserve the chance to live a full life, supported by care that enables them to thrive.

But for many, it's a lonely and isolating experience. Parents and siblings struggle in a system that doesn't meet their uniquely challenging needs.

That's why we're here – to make sure they can access high quality children's palliative care, when and where they need it. 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.

Your support is making all this possible.

Together, we've supported families through difficult times, offering lifeline practical, emotional and financial help. We've connected them to our incredible community – people who really get what they're going through. This year our Family Support Hub has been there for more than 1,200 families – more than at any time during our history.

Together, we've united our sector. We've helped professionals and services to pool their knowledge and expertise, to deliver outstanding children's palliative care. We've been

collaborative and inclusive, pushing boundaries and leading the conversation to find new and better ways of doing things. This year, we hosted our national conference, 'Built to Last: Towards a strong, sustainable future', bringing together over 400 delegates from across the children's palliative care sector to explore how we can create a more resilient, connected sector.

Together, we've campaigned to make sure that seriously ill children and their families get the care and support they need. We've rallied our community and given people a voice. And where the system has fallen short, we've demanded change. 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.

I hope this report, which covers April 2024 to March 2025, gives you a sense of the positive impact you have had on seriously ill children and their families across the UK. On behalf of them, and from all of us at Together for Short Lives, thank you so much for your continued support.

Nick Carroll
Chief Executive,
Together for Short Lives

Together we support



When time is short and challenges seem overwhelming, we're right there with families, so they don't need to face things alone.

Whether that's directly providing practical, emotional or financial support, or simple, clear information they can trust. Together, we help families to:

- feel heard when they just need someone to listen
- understand what's going on, what might happen and the choices they have
- get support with the practical, emotional and financial challenges they face
- find out which palliative care services are available – and how to access them
- connect with other families who are going through similar things.

And because we know time is short, we've made it easy for them to get in touch:

 **0808 8088 100**

 **helpline@togetherforshortlives.org.uk**

 **Family Support Hub:**
togetherforshortlives.org.uk/get-support

“ Together for Short Lives are the best charity I have ever received help from. They are kind caring and most importantly, understanding.

At the coffee morning I attended, they had an amazing approach at making everyone feel comfortable and seen and heard. I felt like I was in a room full of people leading the same life as me, which I have never felt before.”

- A parent who has accessed our Family Support Hub

In 2024-25:

1217
families were supported through our helpline

27,000
people visited our website for support and advice

The number of families using our Facebook group grew by
20%



We arranged
£68K
 worth of food shops to
 families in 2024/25,
 including one for Sarah's
 family (left).

Providing a lifeline to families and professionals

We have been a go-to place for professionals caring for seriously ill children, in the NHS and voluntary sector, across hospitals, the community and in children's hospices. We've helped them to put families in touch with the lifeline support we can provide.

Professionals have told us they have directed families to our Family Support Hub, seeking financial support and access to grants – and that we are a kind, attentive, motivated and compassionate team.

Rising cost of living

When a child is seriously ill, we provide practical support to help families make the most of their time together. We arranged for nearly 550 families to receive a free food shop or vouchers thanks to our partnerships with M&S Food, Morrisons and Rosie's Rainbow Pantry.

"I have found the support of the Together for Short Lives Family Support Hub invaluable in my everyday work. I see the professionals (there), that both the families and I communicate with and seek support from, like extended members of the team and wouldn't be able to do my job, as well as I do, without them."

– An NHS professional who works directly with seriously ill children and their families

Shortly after Layla arrived into the world she had a cardiac arrest which then resulted in a prolonged resuscitation. As a result, Layla has cerebral palsy and extremely complex needs.

We supported her family with a free food shop, a voucher to use at her local supermarket and a financial grant, to help when times were tough.

Her mum Clara said: "I cannot even put into words how grateful and how much you have helped me. From the food shop at times when we have been struggling, to be able to buy a new bed thanks to the help of the grant. I am so, so grateful."



Keeping the lights on

Too many families of seriously ill children experience energy poverty because of the higher costs they face in powering life-saving equipment – and heating and lighting their homes to care for their child.

Our energy service has continued to support families struggling with their energy bills and energy debt. More than 450 families have had a bespoke 1:1

appointment with our energy advisor, and more than 200 families have benefited from an energy voucher to help make their bills more manageable. For example, our energy advisor was able to work with one family's energy company to wipe over £20,000 worth of energy debt.

We are grateful to SGN and Cadent who have made all of this work possible.

“ Thanks so much to your energy advisor and for this voucher – we wouldn't have heating otherwise. Honestly, we'd be freezing without it. Thank you.”

– Family quote

Our energy impact in 2024/25

Our energy
advisor supported
451
families of seriously
ill children

We distributed over
£31K
in energy vouchers to
help families power
their homes



**Talitha and Holly
Willoughby at
BGC Charity Day**

The Butterfly Fund

After their child dies, parents with a seriously ill child are faced with bills and expenses, as well as the immediate loss of benefits, which causes stress and worry, taking up the time they should have to grieve. Over the last year 635 families received £300 from our Butterfly Fund after the death of their child. This one-off financial grant is there to ease the financial burden after a child dies.

We're grateful to BGC Partners and Cantor Fitzgerald for choosing us as one of their beneficiaries for 'BGC charity day'. Funds raised on the day, along with money raised from Trusts and Foundations throughout the year, go directly towards our Butterfly Fund. Thank you to our celebrity ambassadors, including Holly Willoughby, whose support at the charity days has shone a light on our work.



A dream is a wish your heart makes

When time is short, families need the right support to spend precious moments together and create memories that will last forever.

Thanks to our partnership with Make a Wish UK, 275 families had their extraordinary wishes granted this year. Jack met his favourite Disney characters, Spiderman and the Hulk, at 'A Disney Wish UK' - a special three-day immersive experience for families.

"I'd always thought meeting Disney characters meant going on a plane, which is almost impossible with Jack's needs," said his mum. "This was a chance for us to make special memories together in a place where nothing was off limits for him."

Making it possible

Our partnership with the Caretech Foundation has enabled us to support more families through our Family Support Hub this year, reaching regions where there are a high prevalence of life-limited children, but low service provision.

Together, we've supported families through difficult times, connecting them to an incredible community who really get what they're going through.

Tariq Raja, Executive Director of the foundation shared: "We are delighted to partner with Together for Short Lives to build on the Family Hub model and ensure more people receive the support they need at a crucial, and very difficult time, of their lives."

"I cannot describe the positive impact of knowing that strangers are going the extra mile in funding and reaching out to support families in their time of need. I witness it every week and advise all the families I support to be in touch with the Family Support Hub at Together for Short Lives."

– An NHS professional who works directly with seriously ill children and their families



Dame Rachel de Souza, the Children's Commissioner for England, opens our conference

Supporting seriously ill children and their families can be tough, and it can be challenging for professionals and services to find time to connect, share their experience and learn from each other.

In 2025, we hosted our national conference, 'Built to Last: towards a strong, sustainable future', bringing together over 400 delegates, including researchers, professionals and students, alongside families with lived experiences, who all came together to share learning, showcase new models of care, and champion bold ideas for the future.

Delegates told us that we:

- inspired professionals to share insights into strengths, weaknesses, and opportunities in the children's palliative care sector, challenging

them to be bold and innovative, with children and families at the heart of care

- presented new approaches to delivering services for various age groups and diverse populations, ensuring they could be applied locally
- focussed discussions on improving access to high-quality palliative care for underserved and marginalised communities to ensure equity across the sector.

With sessions spanning practice, policy, education and research, 'Built to Last' celebrated fresh voices and diverse perspectives. The event reaffirmed our leadership role in shaping a strong, sustainable children's palliative care sector that puts children and families at its heart.

"This was my first time attending the conference and I found it inspiring, educational and amazing."

"The conference reignited a flame within my own career path to ensure better and do better."

"The Parent speakers were powerful in reminding me to be sensitive: the little things make a big difference."

"I gained a lot of information which will introduce new ideas to my team."



Top: Mums Emily, George and Kate feature in our online training course. Bottom: our new booklet, 'Caring for your baby when the future is uncertain,' available now from our website.

Communicating with families

A poor experience of communication can live with families of seriously ill children forever, and when communication breaks down, misunderstandings and conflict situations can occur. Building on this focus of communication and connection, we launched our new online course, 'Children's Palliative Care: Learning to Communicate with Families'.

Developed in collaboration with experienced practitioners and families, the course helps professionals develop confidence and compassion when navigating difficult conversations. Early feedback shows that 95% of participants felt better equipped to support families after the training.

Our work to support medical

professionals is an area where we are keen to encourage collaboration and partnership. For this course, we were grateful to JP Morgan and the Southampton Hospitals Charity for their generous funding, which enabled us to consult with medical professionals across different areas of the NHS and pilot the learning platform.

Perinatal Resource

Hearing the news that your baby's future is uncertain is a worrying and upsetting time for families. We joined up with the charity, Bliss, to produce a new resource to help parents understand the choices and support available when their baby is diagnosed with a life-limiting condition or when the prognosis is unknown.

Already adopted by several neonatal units, it is improving

consistency and empathy in how families are supported across the UK. Several Trusts and Foundations generously awarded funding to support the creation of the guide including the Hospital Saturday Fund.

Uniting the sector

Over the past year, we have hosted a range of professional development events, including our Educators' Forum, Leaders of Care and Networks Forum, and the 'Together, We Learn' webinar series. These sessions bring together hundreds of professionals from across the UK to share expertise, discuss challenges, and learn from best practice. Through these platforms, more than 1,000 professionals have engaged in training and shared learning opportunities, including new modules on communication and energy poverty awareness.



The Kentown Programme

The pioneering Kentown Children's Palliative Care Programme has filled a critical gap in care and support for seriously ill children and their families.

The pilot, a collaboration between Together for Short Lives, Rainbow Trust Children's Charity and NHS Lancashire and South Cumbria Integrated Care Board, has brought Nurses, Rainbow Trust Family Support Workers and Family Service Co-ordinators together to offer a new, innovative and complementary package of clinical, social, emotional and practical support. The care has been delivered in the home and in the community and adapted to meet the needs of each child and family.

This model, the first of its kind across the UK, was funded by The Kentown Wizard Foundation. The three-year pilot ran from 2022 until 2025 in response to families experiencing fragmented care, inconsistent access, and a lack of clear pathways to support.

These challenges were particularly prominent in the North West of England, which has one of the highest populations of children with life-limiting conditions in England. Access to

support is something of a postcode lottery, varying according to families' ethnic and socio-economic background.

The evaluation, conducted by Edge Hill University and led by Dr. Kate Knighting, found:

- **Holistic impact:** over 250 families were referred to the programme, with a third benefiting from integrated nursing, family support, and coordination.
- **Deep emotional connection:** Families felt genuinely seen and heard through relationship-based care, describing the support as having transformed their ability to navigate complex systems.
- **Inclusive and accessible:** The programme reached families who hadn't previously accessed specialist children's palliative care, offering a vital alternative route that embraced the whole family.

The programme bridged critical gaps in care by fostering collaboration across services, enabling earlier, family-led advance care planning, and introducing a coordinated, family-focused approach that complements existing NHS, children's hospice, and voluntary sector support.



Families from the Kentown Programme enjoy a visit to Cockfields farm for peer support and family fun, including an accessible tractor ride.

Together we campaign

Throughout 2024/25, we continued to campaign to ensure seriously ill children, and their families get the care and support they need. With the system falling short, we have gathered new data about families experiences, mobilised the support of politicians and rallied our community to demand change.

Short Lives Can't Wait

Thousands of families caring for seriously ill children face a postcode lottery when accessing high-quality children's palliative care. This is particularly stark in children and families' access to 24/7 end of life care at home, provided by nurses and supported by advice from specialist consultants. Our Short Lives Can't Wait campaign aimed to change this.

Phase one (March-July 2024) highlighted our mapping of the extent to which care is being planned, funded and provided in line with national UK quality standards.

Using these new findings, we gave oral evidence to the House of Commons Health and Social Care Select committee, and co-developed joint manifesto asks with other palliative care charities, which we then launched at a parliamentary event in Westminster.

Phase two, launched during Children's Hospice Week (June 2024). We urged parties contesting the General Election to commit to overcoming barriers families face in accessing sustainable, high-quality palliative care.



Built to Last?

To maintain the pressure, in March 2025, we launched our campaign and report: **Built to Last? Securing the future of children's palliative care**, revealing that:

- Only 19% of integrated care boards (ICBs) in England formally commission 24/7 end of life care at home in line with national quality standards.
- There is an estimated £310 million funding gap for children's palliative care services in England.
- There are significant workforce shortages and inconsistencies in the way support is planned and funded by local NHS and council bodies across the UK, which are not being held to account by the UK's governments.

Alongside new research we commissioned showing that families are feeling abandoned and overwhelmed by a system that is not meeting their needs, we launched the campaign at a parliamentary reception hosted by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care and attended by 32 parliamentarians.

Our campaign enabled us to achieve coverage across the Daily Mail, Independent, LBC, Times Radio and ITV Granada as well as regional papers and radio stations.



As a result of our
influencing work, over

200

actions were taken by politicians to press
the UK's governments to improve access
to high quality, sustainable palliative care
for seriously ill children



Mother Clare addresses politicians, advocating for better funding for children's hospices in March 2025

Securing ringfenced NHS funding for children's hospices

Throughout 2024/25, we also continued to campaign for an equitable and sustainable funding solution for children's hospices. Our annual funding report revealed that:

- Crucial services would be cut if the new UK Government failed to maintain the £25 million NHS England (NHSE) funding for children's hospices.
- Local NHS and council funding for children's hospices—which was already patchy and unsustainable—continued to fall during 2023/24.
- Amid a year of high inflation and rising costs, children's hospices were relying more on their charitable expenditure and reserves to provide vital care and support.

Our report generated 193 items of online and print coverage, including ITV News, MailOnline and The Independent, reaching a potential audience of 656 million people across the world.

Following the election, we met with the new Care Minister, Stephen Kinnock, alongside the APPG co-chairs, and briefed MPs ahead of a Westminster Hall debate where 17 MPs highlighted the urgent need for sustainable funding. We also highlighted the impact of increased employer national insurance contributions, estimating a £4.9 million rise in charitable expenditure and securing front page coverage from the Daily Express.

We then relaunched the APPG for Children Who Need Palliative Care with a drop-in event and roundtable meeting attended by 40 MPs, including a parliamentary aide to Health Secretary, Wes Streeting. In December, Streeting confirmed the Children's Hospice Grant would continue and increase to £26 million in 2025/26.

Progress made

While significant challenges remain, progress has been made in some of the outcomes we sought to improve during 2024/25:

19%
of ICBs in England now commission 24/7 end of life care at home

973
community children's nurses are employed by the NHS in England

Andy (right) has so far climbed three mountains and raised nearly £4000 in memory of son Charlie.

**Making a
difference,
together**

Short lives can't wait. That's why, together, we'll always be there for seriously ill children and those who love them. Each day, families face enormous challenges, but they can also experience the magic of special times together. Your support makes all this possible.

Thank you.

Celebrating 20 Years of Partnership

We are proud to celebrate a 20-year funding partnership with the Scouloudi Foundation, whose curiosity and engagement have enriched every aspect of our work. Their longstanding commitment, which reached an incredible £108,000 this year, has given us the confidence to plan vital services for children and families. This year alone, their

generous award of £20,000 could provide over 600 hours of vital respite hospice care for families.

Alpine Andy

In memory of his beloved son Charlie, Andy took on an incredible challenge to climb five mountains in his memory: "Charlie's Mum and I don't ever want Charlie to be forgotten, so this is my way of keeping his memory alive." So far, despite being thwarted by serious weather conditions, he has completed three summits and raised nearly £4,000. Thank you Andy for your incredible grit and determination!

Pedal Power

Catriona and Mike Marshall, who founded the charitable foundation Transforming Lives,

inspired and motivated cyclists to join them on their annual fundraising event 'The Cheshire Dash'. Covering over 100 miles in one day the team crossed the finishing line having raised over £33,000 for families and children's palliative care. What an achievement – thank you!

Thank you Simon

A special thank you to Simon Cowell for 15 glorious years as our Patron.

He has built an incredible legacy for seriously ill children and their families across the UK, visiting multiple hospices, hosting seven fundraising balls and backing numerous campaigns.

By inspiring and motivating others along the way, he's done so much, for so many.



Left: The Cheshire Dash raised £33,000 for seriously ill children. Right: Simon Cowell has been a patron for 15 years



Lifeline funding for children's hospices

Local children's hospices provide vital services for families caring for a child with a life-limiting or life-threatening condition. From diagnosis, through treatment, and beyond bereavement, hospices provide expert care, compassion, and hope when families need it most.

Together for Short Lives is proud to champion and support the UK's 53 children's hospices.

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 vital care to seriously ill children and their families across the UK.



Top of page: 27 colleagues from Center Parcs take on the Three Peaks Challenge along with our CEO, Nick Carroll.
This picture: Jack with mum, Tina



Jack has a rare neurological condition called Aicardi-Goutières Syndrome. His family have been supported by Francis House Children's Hospice in Greater Manchester since he was one year old.

Recalling their first visit, mum Tina said: "I just remember the neurologist saying the word 'hospice' and you immediately think, 'oh my goodness, are we there already?' But then you arrive and it's just nothing like you'd imagined.

"I was struck by how unlike a hospital it was. There were settees and a full Sunday roast all set out, and everyone was so friendly and chatty. They invited us in like it was home and made us feel really welcome. Especially Jack's sister Sophie, who was only eight and still coming to terms with everything. It was clear they were here for all of us."

Partner spotlight: Center Parcs

For over a decade, Center Parcs has been an extraordinary partner, standing alongside Together for Short Lives and children's hospices nationwide. Colleagues and guests have raised over £2 million, enabling families to cherish every moment they have together at their local children's hospice.

In 2024, a team of 27 dedicated employees took on the National Three Peaks Challenge, conquering Ben Nevis, Scafell Pike and Snowdon in just 24 hours. Their incredible effort

– and having all their fellow colleagues behind them – raised £50,000 for children's hospices.

Center Parcs colleagues and guests have also donated their skills by volunteering at their local children's hospices, including renovating sensory gardens and using their specialist skills to help fix and maintain hydrotherapy pools, as well as treating parents to their award-winning spa treatments at the hospice.

For families caring for a seriously ill child, time is precious and every moment counts. Through our Family Support Hub, we were so delighted to provide 25 complimentary breaks to families in 2024/25. A total of 141 children, family members, friends and carers enjoyed a three-night stay at a woodland lodge at one of the five parcs.

Making every moment special

Frankie, who has a rare form of mitochondrial disease, went on a gifted break to Center Parcs Longleat Forest in February last year.

A full-time wheelchair user, he requires access to a range of essential medical equipment throughout the day, including suction machines and feeding pumps.

Mum, Hannah, said: "The adapted lodge was amazing, very spacious for our family of five and met all of Frankie's needs. Center Parcs is adapted for wheelchair users, so we found everything really accessible.

"We are just truly grateful for this trip you have gifted us. We can't thank you enough. As a family, it's given us a chance to make magical memories that we'll treasure for a lifetime.

"You never know how much time you have together as a family. You have to make every moment extra special."





Partner spotlight: Hobbycraft

Every family deserves magical memories - especially at times like Christmas and Easter. Thanks to our wonderful partners at Hobbycraft, children's hospices across the UK have been transformed into even more joyful and creative spaces during the festive seasons.

In addition, Hobbycraft store teams across the UK have fundraised through in-store events and community activities, turning creativity into care

for children who need it most.

Our partnership with Hobbycraft matched its largest annual fundraising total to date - £473,000. With 100 stores around the country, Hobbycraft colleagues regularly take part in coordinated themed activities throughout the year, arranging bake sales, fancy dress, crafting sessions and raffles in support of their local hospices.



Watch Hobbycraft turn children's hospices into winter wonderlands for Christmas

The new garden counselling room at Forget Me Not Children's Hospice, thanks to funding from Morrison's.



The Morrison's legacy

Creating spaces of support

2024-25 saw the final months of our partnership with Morrison's, which raised £10.7million for children's hospice and palliative care services across the UK. Highlights this year included our 54 Challenge, a month-long relay in August 2024, which raised £543,000, our biggest fundraising campaign with Morrison's.

Every Pack Gives Back continued to go from strength to strength - in total we featured products from 33 suppliers including Nestle, Kellogg's, Unilever and Mondelez, raising £726,000 during the year. 14 own-brand products, including a Together for Short Lives butterfly bag and teddy, were sold in stores raising a further £342,000.

We were also awarded Best Short-Term Partnership (Third Sector Business Charity Awards) and Corporate National Partnership of the Year with a Retailer (Charity Times Awards).

While the partnership is officially over, the impact it has had will continue for years to come. Thanks to the Morrison's colleagues, customers, and suppliers, together we:

- Raised £6.5 million for children's hospices, which could provide 215,685 hours of vital care.
- Created precious memories through events and activities for 6,223 family members.
- Reached 1,415 new families through our community outreach work, enabling more families to access the support they need.
- Provided 756 families with emergency support, including Cost-of-Living support grants, Crisis pantry food deliveries, and Bereavement grants to fund funeral costs.

In 2023 we proudly launched our Building a Legacy Together Grant, funded by Morrison's. Since its launch, it has helped 30 children's hospices improve their spaces or build new renovations, outdoor spaces, therapy equipment and more – to ensure that children's hospices can continue to provide the best quality care for seriously ill children and their families.

Forget Me Not Children's Hospice used their grant to create a new garden counselling room. This calming, peaceful space offers a private and comforting environment for families to receive emotional support. Stacey John, Family Support Team Leader and Counsellor, said:

"It's an exciting addition for the counselling team, as it allows us to see even more families at hospice due to restricted space in the main building."

Thank you

to our
supporters

Major Donors

Simon Cowell
Lord & Lady Davies
Sarah Dodd
Jeremy Evans
Mike and Catriona Marshall
Gareth Neame

Trusts

Basil Death Trust
Doris Field Charitable Trust
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Dr Lisa Kauffmann

This year's report is dedicated to our former Chair of Trustees, Dr Lisa Kauffmann, who sadly passed away in October 2025.

Lisa was a widely respected figure in the children's palliative care sector, dedicating so much of her professional life and her retirement to improving quality of life for seriously ill babies, children and young people and their families.

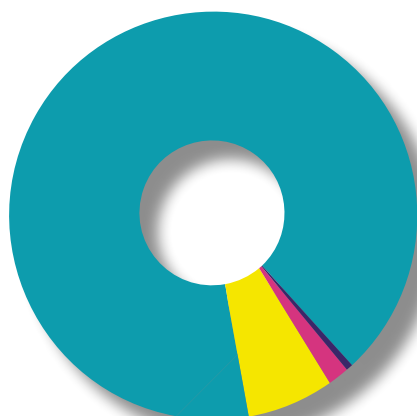
Her career spanned over 25 years, during which she worked as a consultant in community paediatrics with children with complex disabilities and later specialised in children's palliative care.

Dr Kauffmann joined Together for Short Lives as Chair in March 2023 and served until 2024, playing a huge role in shaping our work. She will be greatly missed.



**Nurse Suman from ellenor
Hospice Care, with Isla**

Financial summary



Income
£6,027,895

Donations and Legacies	£5,259,241
Other Trading Activities	£620,497
Investments	£106,850
Charitable activities	£30,872
Other income	£10,435



Distributions and Expenditure
£6,595,638

Distribution to hospices	£2,730,436
Charitable activities	£3,212,257
Distribution to partners	£726,858
Raising funds	£607,227
Grants to families	£197,400

Board of Trustees

Andrew Heywood Hughes, Chair (from 1 April 2025)
 Adam Smith (resigned 1 September 2024)
 Bernie Watson (Resigned 30 November 2024)
 Jo Laddie
 Jeremy Evans
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 Mark Smith
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 Sarah Lorking, Treasurer
 Sarah Talbot-Williams, (Chair, resigned 31 March 2025)
 Stephanie Nimmo
 Sue Hogg
 Tracy Tait

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Chief Executive Officer

Nick Carroll (from 7 November 2024)
 Andy Fletcher (to 18 October 2024)

Executive team

Nick Carroll
 Martin Cordy (from 1 April 2025)
 Jo Killip (from 27 January to 4 April 2025)
 Dr Helena Dunbar (to 28 February 2025)
 Mala Langdon (to 31 January 2025)
 Andy Fletcher (to 18 October 2024)
 Kate McSweeney (to 29 April 2024)



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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