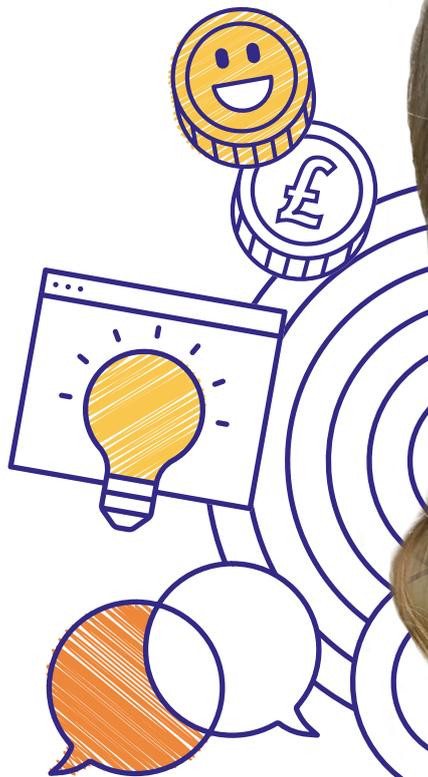


bringing colour to families' lives

Our value and impact
2019-2020





welcome

93%
of families felt isolated
during the pandemic



This has been an extraordinary year for all of us. For Together for Short Lives, as the UK-wide charity supporting some of our most vulnerable and seriously ill children and families, and the professionals and lifeline services they rely on, these have been our most testing times.

We have had some great successes in 2019-20. We invested in growing our helpline and family support services, reaching more families than ever. In 2019 we launched our Butterfly Fund, which helps to relieve some of the financial burden families face when coping with the death of a child. We won our children's hospice funding campaign, after years of tireless campaigning, which will more than double the NHS's Children's Hospice Grant in England to £25 million. And we have won some exciting new partnerships with M&S Food and Premier Foods, raising lifeline funds to directly support children's hospices across the UK.

I'm pleased to share that the projects we funded through our Improving Transition for Young People Programme have made good progress in improving the experience of transition into adulthood. The projects are wide-ranging, from exploring how to support young adults to have relationships, to looking at how to effectively extend adult hospice provision for young people. We are indebted to the three funders of the programme, and we'll look forward to sharing all the learning next year.

But the coronavirus pandemic changed everything for everyone. Sadly, we could not deliver all we'd hoped to. With coronavirus gathering pace across Europe, some of our plans had to be put on hold. Instead, during February and March we focused our energies on helping vulnerable families to deal with the cruel cocktail of isolation and fear for what the virus meant for their child. Many shielded long before lockdown, while others struggled with medical supplies, PPE, food deliveries and financial hardship. Through the support of some generous funders we launched a Covid-19 Emergency Relief Fund, helping struggling families to make ends meet. And the wonderful company Foodbuddy responded to our call for help, stepping up to give families caring for seriously ill children emergency food parcels.



“Just wanted to let you know that our girl was born sleeping. Thank you for listening and for telling me what I can ask for including the footprints that I can't stop looking at. We were so scared of this virus and how it was going to disrupt her birth but the midwives were fantastic and because of you I felt strong going into the hospital. Thank you a hundred times, for being there and for working when all the suggested support was closed.”

Parent supported by our helpline

When a child's life is expected to be short, there's no time to waste.

Together for Short Lives is here to make sure that the 99,000 seriously ill children and their families across the UK can make the most of every moment they have together, whether that's for years, months or only hours.

We are a lifeline for families who care for vulnerable and seriously ill children. Getting the right support can make a lifetime of difference. And that's what we're here for.



Meanwhile professionals and services working on the frontline also needed support, with charity shop closures and a halt to community fundraising hitting the sector hard. Working with a coalition of charities, we stepped up our lobbying for funding on behalf of palliative care charities, children's hospices and social care charities, helping to secure emergency funding for the sector direct from the Treasury.

And there is so much more to do. The demand for our work has never been greater. The number of children living with life-limiting illnesses is growing and many are living with greater medical complexity. Families often do not know where to turn for help and struggle to get the care and support they need – it's an unjust system based on where you happen to live. Many talk of being trapped at home, isolated and alone, providing round the clock care.

Getting the right support for families is vital, but it will be made more challenging by the Covid-19 pandemic – its impact on families, professionals, local services and ourselves will be significant and lasting. We are determined to meet this challenge, adapting the way we work to build a strong and effective charity that can continue to improve the quality and sustainability of children's palliative care for years to come. And we will not rest until children and families get consistent and sustainably funded support, wherever they live and for as long as they need it.

We cannot do this without the generosity of our supporters. Your support has been wonderful and has helped us to bring a bit of colour to the lives of the families we are here for. Huge thanks for your continued support, your help means the world to seriously ill children and families.

Andy Fletcher
CEO for Together for Short Lives



the Lifeline



The Virtual Cuppas have been invaluable especially while shielding. The weekly sessions have given me something to look forward to. I have been able share my fears with people who understand, and also share the precious moments too. It made me feel less isolated.

Mum Donna and daughter Mary

Support during the pandemic

Isolation has been tough for everyone, but for families caring for a vulnerable child with a serious illness, life has been nearly impossible. To support families most in need we acted quickly by:

- Introducing a Covid-19 Emergency Relief Fund for families in financial hardship – we helped 500 families.
- Launching an online Covid-19 FAQs for families and professionals.
- Setting up online 'Virtual Cuppas' for families feeling isolated during the pandemic.
- Arranging a Zoom interview with three NHS Doctors who answered burning questions from families.



Lottie and Freddie

A helping hand

The impact of Covid-19 meant that many families were forced to shield early, impacting heavily on their finances. When Covid-19 locked families down, we opened up a special Emergency Relief Fund – a one-off £200 cash grant that they could spend on whatever they chose.

Lottie and Ed live in East Sussex with their son, six year old Freddie, who has a rare genetic condition. The family live in a flat with a small balcony and have been shielding for many months.

☺☺ Thank you so much for the funding you have given Freddie. He has been without school since early March and has ADHD alongside many other complex medical conditions. We plan to spend this on stimulating new books and toys and, perhaps even a bike if we have enough. ☺☺

Just a call away

In January a Mum called our helpline in serious debt following her young son's funeral. As a single parent and full-time carer she had no savings. She had only 9p in her bank account when she reached out to us.

We were able to apply for a financial grant on her behalf, and her debts were immediately cleared within two days with the £3,000 she was awarded. She said:

☺☺ I really don't know what to say, thank you doesn't seem enough... you've no idea how much of a weight this has lifted after losing my boy. ☺☺



Kristi's children

Coming together online

☺☺ I've attended a number of the Virtual Cuppa sessions during lockdown. We have not left the house at all since February, other than a couple of emergency hospital admissions with our youngest daughter. Isolation though is nothing new but the forced stop on the hectic nature of our lives has been really difficult. Like most other parents, one of the ways we cope is by organising and constantly fulfilling all the different roles that we all play: nurse, physio, speech and language etc, and rarely a day goes by without phone calls, meetings, appointments and the endless jobs that need to be done to keep our children safe, well and happy.

Lockdown though brought a sudden halt to this and it left me feeling like I'd been hit by a train. The Virtual Cuppa events have given me the opportunity to chat to others and discover that I wasn't the only one to feel like this. The sessions and your Family Support Facebook group offer opportunities for us to remember that we aren't alone. ☺☺

Kristi, Mum to Adrian, Abigail, Donna and Chloe

This year calls to our helpline have more than **doubled.**

We've provided 250 hours of support to families – that's **15,000 minutes.**

Our Covid-19 FAQs page for families has been viewed nearly **10,000 times.**

500 families have been helped by our Covid-19 Relief Fund, with most grants being spent on living costs.

Fighting for families

Doubling funding for lifeline children's hospices

We stepped up our campaign to more than double NHS England funding for children's hospices – and we won.

News that some children's hospices were struggling to keep their services open strengthened our resolve, helping us secure blanket media coverage, and put pressure on the government. In July 2019, ministers responded and promised a huge increase in the NHS Children's Hospice Grant from £12 million to £25 million by 2023. Taking the pressure off children's hospices helps them to focus on what really matters, providing vital care to children and families who would have been lost without their hospice's support.



44 MPs signed our Early Day Motion to increase the Children's Hospice Grant.



We won our long-standing campaign to increase the lifeline Children's Hospice Grant (England) to **£25m a year.**



450 one to one conversations were held by us with politicians and policy makers.



63 MPs joined our parliamentary drop-in event during Children's Hospice Week 2019.

Joining the fight

Our funding campaign made a huge difference to Acorns Children's Hospice and the families they support like Mark and his daughter Isabella. Mark joined Together for Short Lives' campaign to fight for children's hospice funding, fighting hard to save Acorns, his local children's hospice in Walsall.

Mark's daughter Isabella was diagnosed with neuroblastoma, a rare childhood cancer, when she was three. Isabella and her family were supported by Acorns children's hospices, and sadly, in April 2019, Isabella passed away, aged just 11.

Our beautiful, courageous and fearless little girl always had a smile on her face, despite what she went through. A big part of the reason for that smile was Acorns in Walsall. It was a place that Isabella loved to visit when she was well enough to be out of hospital. It became just like home because of the wonderful building and what's inside, but more importantly, because of the incredible staff and volunteers that make Acorns what it is: a safe haven, full of joy, laughter and love. The support Acorns has given to Isabella and to us as parents over the years has just been incredible and without them we just don't know what we'd have done. Many times we were taken by the hand and led out of the dark and the fog we were in. We've had so many good times, and we've had some really tough times too, but all the way through, Acorns is the reason I'm still standing right now.



Mark and Isabella



Caroline Dinenage MP, former Care Minister at the Department of Health and Social Care, joins our Children's Hospice Week drop-in

Taking the pressure off grieving families



Working with a coalition of charities, we've been fighting to relieve the financial burden families face when a child dies. In 2019, we were part of a winning campaign to secure paid time off for parents bereaved of a child. A new funeral fund that waives fees charged for a cremation or burial of a child, which we campaigned for, has also been introduced. In 2019 we launched our new Butterfly Fund for grieving families, giving families a special no strings attached gift to help families when they need it most.

Through the Butterfly Fund we've helped families like Emma's, whose daughter Neriah sadly died this year. Neriah was only three years old.

Thank you so much for the Butterfly Fund gift. It is much appreciated and has helped us feel less alone. The hard financial pressures and lack of support for bereaved families of a child with long-term health needs or life limiting conditions is really challenging. Your gift has been of great help to us to do a few meaningful things to honour Neriah.

Neriah's parents, Emma and Dwayne



force for good

Rising numbers

In April we helped to launch new research that shows that the number of children in England with life-limiting or life-threatening conditions has continued to rise over the last 17 years. *The Make Every Child Count* study, conducted by the University of York, has revealed that the number of children in England with life-limiting or life-threatening conditions increased to 86,625 in 2017/2018 compared to 32,975 in 2001/2002.

The publication is the culmination of a nearly two-year research project, led by Professor Lorna Fraser and steered by Together for Short Lives, with funding from the True Colours Trust. That more seriously ill children are living longer is cause for celebration, however there is an urgent need to make sure that children's palliative care services are properly planned, funded and delivered and we will use this data to lobby government, the NHS, and children's palliative care providers to do this.

“Amazing, just amazing. We didn't know what to expect anyway, but never in a million dreams would we have expected this – absolutely amazing.”

Mum Louise, attending Disney's Festive Celebration in December



£1.5m

fundraised for children's hospices by our partner Hobbycraft.



£58,154

raised by 60 runners running 1,114 miles.



100 families

supported by children's hospices attending our partner Disney's Festive Celebration.



£400,000

raised at our Frozen 2 fundraising ball supported by Disney and M&S Food.

Memories to last a lifetime

We work with some amazing charity partners to support the UK's 54 children's hospices through our national fundraising scheme. Our longstanding partner, Center Parcs, has raised a massive £1 million since the partnership began in 2016. It's a perfect example of how our partners can make a difference nationally and locally. As well as fundraising through staff challenges and guest donations, each village and Head Office is twinned with their local children's hospice, directly supporting families in their local communities. This year staff at Center Parcs Elveden Forest achieved their goal of funding a soft play room for East Anglia's Children's Hospices; making a real difference for children and families there. Across their other UK villages, staff have also donated their time to help out at children's hospices, creating beautiful garden spaces and taking the Center Parcs experience straight to their local hospice's door. We are thrilled that this partnership has been extended to 2022.

“Together for Short Lives really is the perfect charity partner for Center Parcs – like us, they are dedicated to making sure families have quality time together. I know from speaking to my colleagues that this is a charity that has really touched the hearts of our employees and guests and I'm thrilled we will be supporting such a worthy cause for another year.”

Center Parcs CEO, Martin Dalby



Team from Center Parcs visiting East Anglia's Children's Hospices

Sewing and stitching to success

It was another great year for our partnership with national retailer Hobbycraft. In the last year they:

- Raised £325,000 – its highest yearly fundraising total to date
- Supplied a Christmas hamper of craft supplies to every hospice in the UK
- Held five in-store themed fundraisers to support Together for Short Lives

- Created a Christmas film about hospices which was watched one million times

And its CEO Dominic Jordan, alongside senior staff and our own CEO Andy Fletcher, trekked 100 miles across Hadrian's Wall to raise £30,000.

In all the partnership has raised over £1.5 million for children's hospices since the partnership began in 2012.



Together creating Moments that Matter with Disney

We were honoured to be chosen by Disney UK as charity partner for the long awaited Frozen 2 movie. As families flocked to cinemas to experience the highest-grossing animated film of all time, we worked in partnership with Disney UK to create hundreds of Moments that Matter across the UK to help build emotional resilience for seriously ill children and those closest to them. These events, which also raised vital awareness and funds for our work, included Disney UK's Festive Celebration in Birmingham, where hundreds of seriously ill children and their families experienced a fully immersive and sensory journey into the Frozen 2 Arendelle world. Families also enjoyed a magical day in Manchester with Disney's Frozen 2 characters Elsa, Anna and Olaf to mark the launch of Marks and Spencer's limited edition tote

bag collaboration with Frozen 2 and Together for Short Lives. Twenty children's hospice Moment Makers, who change the lives of these children every day, were invited to attend the film's Premiere in London with their families, where they also met our Patron Holly Willoughby. In total Disney provided over £250,000 of in-kind support to bring these transformative Moments to life. Disney were also the headline sponsor alongside M&S for our Frozen 2 Ball in November, with our Patron Simon Cowell. The evening was full of Disney magic, joy and togetherness and was a spectacular night for the ball's special guests – raising over £400,000 to support our work.

thank you for making a lifetime of difference

Coronavirus has left families feeling more isolated and alone than ever. Our urgent 'to do' list is growing daily.

More than ever, we want to thank you for your incredible generosity. The impact of the pandemic has left families feeling exhausted and alone but thanks to your support, we have been there when they needed us most. You can help us to reach even more families.

Based on new research this year we estimate that 99,000 children are living with a serious illness, and this number is predicted to grow. There are still areas we are desperate to reach, including families in the poorest parts of the UK and communities where prevalence is very high. Our ambition is to reach every family who needs our help, but we cannot support them without your help.



Emma, Mum to Lily and Harry, who has a life-limiting condition, received a much-needed emergency food parcel from Foodbuy during the peak of the pandemic. She said:

“I felt totally overwhelmed that we were being offered a lifeline and “thank you” didn’t seem to go far enough. We really appreciated the support. Many, many thanks again.”

Our urgent to do list

We have one bold ambition:

To reach every family caring for a seriously ill child who needs help – especially those who are isolated and hidden.

We'll support families by:



Giving grieving families financial support through our Butterfly Fund



Growing our information hub



the money

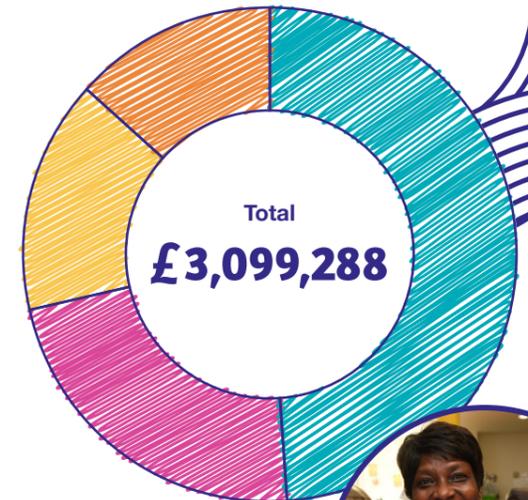
How we raised it

- £2,041,521** Fundraising income for Together for Short Lives' work
- £962,831** Funds raised for member children's hospices and voluntary organisations
- £34,944** Income from membership, conferences and training
- £79,767** Income from investments and other sources
- £1,272,000** One-off income from a legacy to be invested in key strategic projects



Where we spent it

- £1,517,162** Our national work for children's palliative care
- £703,559** Raising funds for our national work
- £465,734** Funds shared with our member children's hospices and voluntary organisations
- £412,833** Working with member children's hospices to raise funds



Thank you to all of our supporters

We are so grateful to all our wonderful supporters for making our work possible. Thank you to everyone who supported us in 2019-20 and throughout the Coronavirus pandemic.

- | | | | | |
|--|------------------------------|------------------------------------|---|-------------------------------------|
| A D Power Will Trust | Faltrego Films | John Ellerman Foundation | Scouloudi Foundation | The National Lottery Community Fund |
| Autoglass | Foodbuy UK | John Lewis & Partners | Shanly Foundation | The Roger & Douglas Turner Trust |
| Baron Davenport's Charity | FSJ Trust | John Swire 1989 Charitable Trust | Simpson Travel | The Russell Trust |
| BLM Solicitors | Flourish Arbonne Foundation | Kevin Smith | St. James's Place Charitable Foundation | The Souter Charitable Trust |
| BNP Paribas Leasing Solutions | Gareth Neame | Lord and Lady Davies | Stuart Machin | The Thomas J. Horne Memorial Trust |
| Bob & Nicola Parker | Glenn & Sarah Thomas | MariaMarina Foundation | Summers-Inman Construction & Property Consultants | The True Colours Trust |
| Bridgepoint Charitable Trust | Gravity Active Entertainment | Marks & Spencer | Syco Entertainment | The Walt Disney Company Ltd |
| Center Parcs UK | Ground Control | Mason Mount | Thales | TK Maxx & Homesense Foundation |
| Childbase Partnership | Hadrian Trust | Matt Fiddes | The Astor Foundation | Toby & Jayne Ricketts |
| Children with Cancer UK | Harvester South Coast | Mike & Cat Marshall | The Entertainer | Transport for London - Legal Dept |
| Claudia & Evan Breibart | Highfields Trust | Miss Teen Great Britain | The February Foundation | Travers Smith Foundation |
| Crerar Trust | Hobbycraft | Peter and Emily Andre | The James Tudor Foundation | Unum |
| Daksh Gupta | Hospital Saturday Fund | QBE Foundation | The James Weir Foundation | Webhelp |
| Department for Digital, Culture, Media & Sport | Hugh Fraser Foundation | Royal Mail | The Lawson Trust | |
| Dignity plc | Jeremy Evans | Simon Cowell & Lauren Silverman | The Light Fund | |
| DM Thomas Foundation for Young People | Jimmy Knapp Cancer Fund | Scottish Government Wellbeing Fund | | |



Your support is a lifeline at the moment, other parents have been so good at suggesting ways to relax and keep calm about everything that's going on (Corona!). I'm feeling less anxious because they've been sharing where I can get help with the practical things too.

Family accessing our safe online support forum

I can't put into words the difference the money made to our family. We were able to get extra electric, gas and food which has made a huge difference and we are so thankful and grateful. We cannot thank you enough.

Family supported by our Covid-19 Emergency Relief Fund

Board of Trustees

Dr Hilary Cass OBE, Chair

Sarah Talbot-Williams, Vice Chair
from 13 December 2019

David Butcher, Vice Chair
to 12 December 2019 (retired 12 December 2019)

Bernie Watson, Treasurer
from 1 October 2019

Rosalind Britton, Treasurer
to 30 September 2019 (retired 30 September 2019)

Alaana Linney
(appointed 16 May 2018)

Arlene Honeyman
(reappointed 20 November 2019)

Paul Obey
(reappointed 20 November 2019)

Sue Hogg
(appointed 31 July 2019)

Tracy Tait
(appointed 31 July 2019)

Toby Porter
(appointed 4 November 2019)

Jo Laddie
(appointed 4 November 2019)

Adam Smith
(appointed 4 November 2019)

Stephanie Nimmo
(appointed 19 February 2020)

Chris Roys
(retired 8 April 2019)

Richard Strawson
(retired 9 December 2019)

Maria McGill
(retired 30 September 2019)

David Widdas MBE
(retired 30 September 2019)

President

Professor Sir Alan Craft

Vice Presidents

Professor Dame Elizabeth Fradd DBE, DL

Dr Ann Goldman

Our Patrons and Ambassadors

Simon Cowell

Holly Willoughby

Rosa Monckton

Rebecca Front

Lance Corporal Richard Jones

Peter Andre

Jordan Banjo

Together for Families Helpline:
0808 8088 100

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

Together for Short Lives
2nd Floor, New Bond House
Bond Street, Bristol, BS2 9AG

0117 989 7820
info@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk

Editor: Marcella Pinto

Design: Adept Design Print: Swallowtail Print

Photography: Thanks to all the families, children's hospice and palliative care services and supporters who granted permission to share their images.

Registered charity in England and Wales (1144022) and Scotland (SC044139) and is a company limited by guarantee (7783702).

© Together for Short Lives, September 2020