



making a  
**lifetime** of  
**difference**

Our **value** and **impact** 2018-2019

# making a Lifetime of difference



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 the 49,000 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 stand alongside families, supporting them to make sure they get the vital care and help that they need.

Getting the right support can make a lifetime of difference. And that's what we're here for.



Effie



"Together for Short Lives was there for us when we felt lost. They were there to listen, to help find the care that was right for Effie and our family and they connected us with other families through their safe online forum. It helped us feel less isolated and alone. Having Together for Short Lives' support is priceless."

Carly Hadman, Effie's mum



# together for short LIVES



“The number of seriously ill children is growing, but government funding for services they rely on is not keeping pace. Many families face a postcode lottery of care – both for the support they receive throughout their child’s life, and the bereavement support available when their child dies. Families tell us they can feel alone and isolated as they struggle to get the care they need. That’s why we’ve grown our helpline and family support hub this year – it can be a lifeline to families in crisis.

By working together with the children’s palliative care sector, we’ve secured lasting policy change that will directly improve the lives of the children and families we’re here for. And we’ve redoubled our efforts to raise vital funds and to campaign for lifeline funding for children’s hospices. None of this is possible without the help of our wonderful corporate partners, supporters, funders and friends. There is still much to do but we know we can do even more with your continued support. On behalf of the 49,000+ children and families and the services and professionals that are there for them, I want to say a huge, huge thank you to each and every one of you.”

Andy Fletcher CEO, Together for Short Lives



We have had a fantastic year and made a real difference to children expected to have short lives. Here are a few highlights.

# the difference a year makes

# speaking out

Children's Hospice Week helped change perceptions and reached over

## 37 million people



We sent badges out to all

## 649 MPs,

asking them to wear them during Children's Hospice Week. **17** were seen wearing the badges, including Jeremy Corbyn MP and Caroline Dineage MP.



## 27

politicians engaged with the week's activities.



Over the year we reached

## 285 million

people through awareness-raising media work!



We were part of a

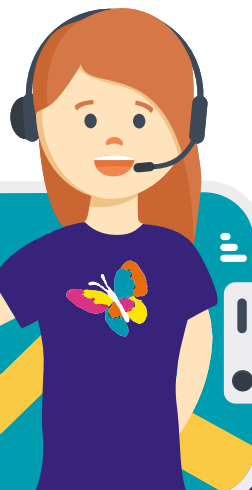
## 70-strong

coalition of charities speaking out for Baby Loss Awareness Week.



# the lifeline

Our helpline is a lifeline for families. This year we helped more families than ever.



We saw a **59%** increase in calls...



and provided **16,799** minutes of support.

## 114,000 people

visited our website, which offers vital support and resources for families and professionals.



## 75 families

were helped to access specialist legal support and advice to help them get the care and support they need.

# fighting for families



**6,670 people**

signed our #fundnotfail petition to increase government funding for children's hospices in England.

We had **541** one-to-one conversations with politicians and civil servants.

That's a huge increase of **72%** on last year!



# supporting professionals and lifeline services



Nearly **9,000** professionals and families downloaded our specialist publications.

**2,100** people accessed our new Guide to Children's Palliative Care.



Our helpline had nearly **350 calls** from professionals who care for seriously ill children and families.



We helped professionals develop their skills, with **577 people** joining our learning events and webinars.

**94%** said they would share the information they'd learned with colleagues.

# making a lasting difference

**£475,063**

has been raised and shared to fund lifeline care for children supported by children's hospices across the UK.

The funds raised at BGC Partners' Charity Day could help over

**18,000 families**

calling our helpline.



**20,000 feet** skydived by **2 skydivers**, raising

**£1,537**



**1,532 miles**

trekked by **62 trekkers** raising

**£80,415**

**1,661 miles**

ran by **40 runners** raising

**£78,451**



**1,031 miles**

cycled by **12 cyclists** raising

**£20,394**



Countless other bake sales, raffles, coffee mornings, paddleboard marathons, dance-a-thons, football matches, bucket collections, zipwires, skydives... raising an amazing

**£19,264**





This year, we've run campaigns and worked alongside our colleagues in the sector to amplify the voices of the families we work with.



# speaking out





## Pushing for change

Kirsty was the face of our campaign to increase the Children's Hospice Grant. She shared her story to show the value of the hospice care her family received when their daughter Ella was diagnosed with a rare genetic disorder.

"Working with Together for Short Lives and being invited to deliver the petition to Downing Street was a real honour. It gives me great comfort being able to share Ella's story and keep her memory alive whilst at the same time being able to help others in a similar situation. All children's hospices do a fantastic job and the thought of a parent not being able to access one for respite or end of life care is heartbreaking. That's why the work Together for Short Lives does is so important."

Kirsty



Kirsty outside Number 10



Sam and Lexi

"We had 19 days with our little girl. The six days we were at Keech were truly special. Our only regret is that we didn't go there sooner."

Sam, Lexi's mum

## Joining forces

We were part of a 70-strong coalition of charities that teamed up to raise awareness during Baby Loss Awareness Week.

We helped the hashtag trend in the UK's top 10, and 556 supporters emailed their MP demanding improved care for bereaved families.

We shared Danny and Sam's story as part of the week, focusing on the amazing care they and their daughter Lexi received from Keech Hospice Care when they discovered she would have a short life. The family were given the opportunity to stay at Keech to spend time together and make memories.



## Life's short

Our national campaign, Children's Hospice Week, shone a spotlight on the amazing children and families we're here for, and the services that support them. We asked the families we work with, and the public, to share the little things that make life wonderful. The campaign reached 37 million people.

CHILDREN'S  
HOSPICE WEEK  
21-27 MAY 2018



# fighting for families



“By sharing my experience of life with Lennon through Together for Short Lives, I can hopefully educate the people making decisions and improve the lives of other families facing the death of their child. It also means that I can keep Lennon’s memory alive, and know that he is still making a difference.”

Nikki, Lennon’s mum



**"I love the fact that Together for Short Lives is a voice for the disabled community, and for families whose children will have short lives. That's a big thing for me, because it's very difficult for individuals to have that voice, or the energy to have that voice. It's great that Together for Short Lives has that covered."**

**Mike Turner**, Iona's dad

Iona and family



## Nikki's story

Nikki's son Lennon died aged 10 as a result of an undiagnosed, life-limiting condition. Since his death, Nikki has worked with Together for Short Lives to campaign for vital services, so families like hers can access the support they need to keep going. She provided evidence to the All-Party Parliamentary Group inquiry which drew attention to the need for improved respite and out of hours care. She also contributed to our campaign to abolish child burial fees in England, speaking passionately on Radio 4's *Today* programme about the financial pressures families can face when a child dies.



Nikki and Lennon

## Exposing patchy care

We worked with a cross-party group of Westminster politicians, the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care, to investigate whether the government is meeting its end of life care commitment. Families, young people, doctors and experts provided evidence for the report, which found that the quality of palliative care children and families can access is patchy and depends on where they live in England.



Lucy and Junior at the APPG report reception

## Sustainable care

We teamed up with our members to secure additional funding for children's palliative care in the NHS Long Term Plan. As a result, NHS England has announced that up to £14million extra a year will be available for statutory and voluntary sector children's palliative care services by 2023/24.

**£14m**  
in extra  
funding

## Flexibility for bereaved parents

We know that everyone experiences grief differently: there isn't a timeline. That's why we campaigned as part of the National Bereavement Alliance to extend the window in which parents can take their two weeks of paid bereavement leave. Parents and kinship carers can now take their leave any time over a period of 56 weeks, rather than exclusively in the 56 days following the death of their child.

## Working together

We know from families that losing a child is not only the most heartbreaking time in their lives, but also the most expensive, with funeral fees and unexpected expenses pushing families into poverty. This year, we worked with families, other charities and Carolyn Harris MP to campaign for the government to abolish burial fees for children in England.

**"My heart goes out to the child hospice movement and my respect for it is ample, and what Together for Short Lives does to represent that movement is incredible."**

**Steven Brine MP**, while Health and Social Care Minister





# the lifeline



“My Care Transfer Plan is an important tool in our lives and has been used for an acute admission very successfully. What’s also invaluable is that nothing is lost in the emergency handover in hospital.”

**Margaret Jones,**  
Iwan’s mum



Iwan

## A winning case

Megan and her younger brother Harry both have rare and complex conditions, and until recently they didn't have a clear diagnosis. Although Megan had great care and support when she was young, things changed dramatically when she turned 18. The local clinical commissioning group said Megan's healthcare didn't meet their funding criteria. Megan's family was devastated and determined to fight. They called our family helpline and we offered them specialist legal support, guiding them through two long and complex appeal hearings. With our help, and a breakthrough on Megan's diagnosis, the family won, and Megan's funding continues.

**"[our legal advice specialist] has been amazing and provided a reassuring arm for us to lean on when we needed it. She was able to be impartial despite the challenging circumstances and methodically asked us to obtain all the evidence we needed for the appeal."**

Ian, Megan's dad



Ian and Megan

## A lifeline

Thousands of families live with the knowledge that their child will die young. They need our help more than ever. Our Family Support Hub gives families helpline support, connects them with other families like theirs, and helps them when things go wrong, giving specialist legal advice.

## Making life a little easier

Families often say that they struggle to communicate their child's care history, needs and wishes with the huge number of professionals involved in their care. So, this year, thanks to funding from the Bupa UK Foundation, we launched a special digital resource called My Care Transfer that can store valuable information about every child's unique needs and care. It's a flexible tool that works on tablets, mobiles and laptops and it's easy for families to share with care professionals. Mum, Margaret Jones, has found My Care Transfer invaluable for her son Iwan's care.

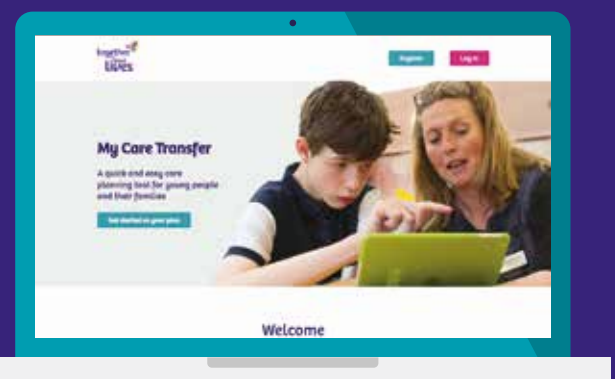
## Most common reasons for families calling our helpline:



This year we've helped more families than ever. Calls are getting tougher, with more families ringing us saying they can't cope, some at the end of their tether. Thanks to funding from the Department for Digital, Culture, Media and Sport and The National Lottery Community Fund, we have expanded our Family Support Hub so we can reach more families, helping them feel supported and less alone. Getting the right support can make a lifetime of difference.

**"Together for Short Lives has been a lifeline for my family. I first rang the helpline last year and the support I received was incredible. You invited me to join the Facebook group and I've made friends with loads of others in the same boat. You're an amazing charity and I really appreciate all that you offer."**

Mum contacting our Family Support Hub





# supporting lifeline services and professionals



**“Thank you to Together for Short Lives for all their support organising and delivering the regional workshops for the NHSE Service Specification pilot in Yorkshire. Their help in navigating the process was invaluable and they are on hand to support us with advice and guidance.”**

**Davina Hartley**, Regional Network Coordinator, Yorkshire and Humber Children’s Palliative Care Network



Chloe

## Living life to the full

The number of young people with life-limiting conditions is growing, so one of our priorities is to improve the transition from children's to adult services. This year we funded eight innovative projects through our Improving Transitions for Young People Fund that have the power to help young people like Chloe focus on what's important to them. Chloe is part of a project we funded that's led by and for young people with The Open University Sexuality Alliance and Hospice UK. It's designed to help disabled young people to talk about and explore their sexuality – an aspect of their lives which is often overlooked or dismissed.

**"I live with a number of conditions contributing to a life-limiting condition and disabilities. It's something I've dealt with since my early teens, the age where puberty hits and young people usually grow into relationships and their sexual identity. As a young person with a disability this was something very different for me to navigate, with very limited support and resources. I strongly believe that disabled young people could be supported in a much better way with regards to sexuality and relationships, and this project is absolutely a constructive answer to this."**

Chloe

## Working together

Thousands of professionals play a vital role in caring for the UK's 49,000 seriously ill children – and we're here to support them.

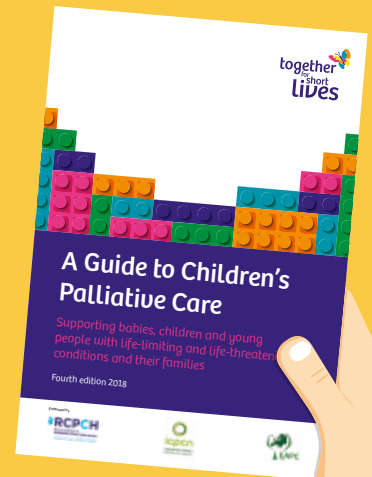
We took nearly 350 helpline calls from professionals needing support, information and resources for the children they care for. Our digital care forum connects professionals across the globe, creating a helpful pool of experience and good practice.

**350**  
calls from  
professionals

And we shared new resources to help professionals deliver specialist care: they downloaded nearly 9,000 specialist publications, with 2,100 professionals accessing our essential Guide to Children's Palliative Care.

**"The new edition of the Guide to Children's Palliative Care is so useful. It's particularly helpful when introducing children's palliative care to our new neuro-disability trainee doctors. The definitions and patterns of children's palliative care are useful to talk through with them with the diagrams in the booklet. I find the epidemiological data useful when I'm writing a business case for more resources. The research section has helped us focus our ideas and make a plan collaboratively."**

**Dr Antonia Wolfe,**  
Nottingham University  
Hospitals NHS Trust



## Sharing and learning

Over the year we've supported professionals to share practice and develop their skills, with 577 people joining our learning events and webinars.

**94%**  
said they would share some knowledge or information they'd gained at the events.





“It is such a relief to have the support of people who know what to do if there is an emergency and can stay calm. Before Julia’s House there was just a void. It feels so wonderful to have the help we so desperately needed; it feels like the beginning of everything.”

Hayley, Jack and Evie’s mum

Hayley with Jack and Evie



# making a lasting difference



## Supporting lifeline services

Every year we work with our corporate partners to raise money for children's hospices across the UK. This year, our National Fundraising Scheme raised an epic £475,063 for services like Julia's House, which has become a lifeline for Mum, Hayley, and her family.

**"Jack has cerebral palsy and has always had seizures every couple of weeks, but he started having one a week and the seizures were lasting longer and longer, it was so frightening. Sometimes things got so bad I needed to get Jack to hospital in the middle of the night. Evie would go downstairs and open the door ready for the ambulance. It felt awful to think that had become a normal part of life for her.**

**She doesn't make a fuss, but sometimes when things have been tough she will ask for a cuddle and you realise just how much this is impacting on her.**

**One day, a Julia's House nurse and carer came over to be with Jack so that I could take Evie to a theatre club. To be able to go somewhere with her mum seems such a little tiny everyday thing that other people take for granted, but it meant the world to Evie."**

**"I'm so happy to have got through the marathon in one piece. It was a fantastic day and the atmosphere was amazing. I'm quite achy today but it's definitely helped by the fact that I've been able to raise money for such a fantastic cause – it really was a privilege to run for Together for Short Lives."**

**Rachel Kendall**  
from Clyde and Co



## Reaching a milestone

This year our friends at Hobbycraft reached a very special milestone. They have baked, crafted and bucket shooed their way to reach a grand total of £1million fundraised since the start of our partnership with them in 2012.

**£1m**



Shalome, Emma-Jayne and Faith

## Time to recharge

This year, our partnership with Center Parcs raised more than ever before, but one of the most direct and special ways they supported families was by offering short breaks to families with a seriously ill child.

For Emma-Jayne's family, going on holiday had always felt like a scary prospect. Her daughter, Shalome, has a life-limiting condition and doesn't travel well, but armed with a new wheelchair-accessible vehicle, the family set off on their very own Center Parcs adventure. Here's the email they sent us after their break:

**"You have given us the confidence boost we needed! The lodge, accessibility and family focus at Center Parcs thrilled our souls. We were treated like royalty. Our five year old, Faith, knew she was gifted this holiday as she's an exceptional big sister. Your gift has blessed our whole family – more than you can comprehend.**

**We bonded like never before as the whole experience was inclusive, accessible and welcoming. The staff at Center Parcs deserve an incredibly special thank you: the lady who checked us in was genuinely interested in us; Richard at falconry dealt so incredibly well with Shalome and included her in everything; the pottery experience staff went above and beyond, even donating postage and items for memory making. We feel blessed beyond words."**

## Pedal power

Gaynor, who works for Simpson Travel in Greece, went from cycling novice to biking legend when she took on an epic 417km ride from Vietnam to Cambodia. She'd never cycled for longer than 30 minutes prior to her training, but that didn't stop her from completing her challenge and raising a jaw dropping £5,000!

**"Cycling from Vietnam to Cambodia was one of the most physically and emotionally challenging things I've ever done. I chose to raise money for Together for Short Lives because, as a Mum of two boys, my worst nightmare would be for something to happen to them."**



# your support is changing lives



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 seriously ill children and their families can make the most of every moment they have together, whether that's for years, months or only hours. We can only do this with your support.

Thank you to everyone who has supported and funded Together for Short Lives' vital work this year. Your generosity, passion and enthusiasm mean the world to seriously ill children and their families, and to the children's hospices, palliative care professionals and charities across the UK.

With your help we can guide families through the toughest of times and help change lives for the better. You can help us by funding our urgent "to do" list for children and families:



## Our urgent to do list for 2020



Launching a special bereavement fund for grieving families to help financial hardship following the death of a child



Researching families' experience of good children's palliative care



Reaching more families via our Family Support Hub



Developing a new online tool to share the latest research on the numbers of affected children within regions



Creating a specialist digital forum for care professionals



Publishing a new Safe Use of Medicines Toolkit



Sharing new data revealing the true picture of need nationally



Increasing lifeline funding for children's hospices

## How we raised the money



**Fundraising income for Together for Short Lives' work**

**£1,634,181**

**Funds raised for member children's hospices and voluntary organisations**

**£972,909**

**Income from membership, conferences and training**

**£34,174**

**Income from investments and other sources**

**£40,941**

**One-off income from a legacy to be invested in key strategic projects**

**£1,400,000**

**Total**

**£4,082,205**

## Thank you to all of our supporters

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## Where your money goes

**Our national work for children's palliative care**

**£1,163,330**

**Raising funds for our national work**

**£668,899**

**Funds shared with our member children's hospices and voluntary organisations**

**£475,063**

**Working with member children's hospices to raise funds**

**£448,658**



**Total**

**£2,755,950**



“Thank you so much for all your support. You listened and made me feel like I could cope with my daughter’s diagnosis of cancer. It was nice that you didn’t say it was all going to be ok when we know it won’t be. Your information about our choices on where she dies was an eye opener! You do amazing work for families and I can’t begin to say how much of a difference you have made to our family.”

Parent supported by our helpline



**Andy Fletcher**  
CEO for Together for Short Lives

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