



together  
for short  
lives

TOGETHER FOR THE 49,000

**OUR VALUE**

**AND IMPACT**

2016-2017

**49,000 children and young people are living in the UK with conditions that are life-limiting or life-threatening.**

We are the leading UK charity that speaks out, together with our members, for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care.

We can't change the diagnosis, but we can help children and families make the most of their time together.

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# Foreword



Thank you for taking time to read Together for Short Lives' Impact Report – it's one of the ways we demonstrate the difference we have made with the money raised through our generous supporters. So, in part this is to say thank you for helping us make a difference to children and families.

Most importantly, though, this report is for the 49,000 children and young people with life-limiting conditions that we are here to speak up for. Improving their quality of life and end of life care is why we are here.

We don't work alone. Much of our impact has been delivered in partnership with our members across the UK. We know that by working together we have the best chance of delivering our ambition of positive change for children and families.

We are proud of the leadership that we have brought to bear in enabling some significant wins for children's palliative care in England. For example, our engagement with Ministers led directly to the explicit recognition of children in the Government's End of Life Care Commitment for England. Further, we were delighted to have secured the establishment of the first ever All Party Parliamentary Group for children who need palliative care, to bring the needs for this group of children and young people into relief in Westminster.

This year also saw the publication of the much-needed NICE Guideline on children's palliative care. We worked closely with NICE, families and our members to inform this work, and the resulting Guideline is a significant step forward in improving the planning and commissioning of children's palliative care.

We so often hear from families about how isolated they feel without adequate support or understanding. This year, we worked with services to pair families with volunteers in their communities, by piloting a Family Support Volunteer service. The volunteers gave families a helping hand at home with day-to-day practical tasks like cleaning, shopping and gardening – the kind of activities for

which there are not enough hours in the day to do if you are caring 24/7 for your child.

We have taken important steps forward in our work to transform young people's transition to adult services across the UK. With generous investment from funders, we have launched our new Transition Awards Programme – designed to fund innovative projects that will improve young people's lives.

Funding and a sustainable workforce remain key challenges for the children's palliative care sector. Together for Short Lives was asked by NHS England to lead a consultation with our members to inform the future of the Children's Hospice Grant. We continued to press for the overall value of this grant to be increased and were delighted with NHS England's decision to secure funding of the grant for a further two years.

An increasing number of seriously ill babies are surviving longer and need palliative care. In response, we have published a vital resource in our new *Perinatal Pathway* to help professionals deliver sensitive and timely support to families caring for them. We have also invested in a major review and consultation for the fourth edition of our *Guide to the Development of Children's Palliative Care Services* – a resource that has become the cornerstone of children's palliative care across the UK and internationally. We look forward to launching this in early 2018.

Finally, a special thank you to all those who ran, jumped, climbed, swam, baked and danced to raise money for Together for Short Lives. Be it funding from trusts or foundations, corporate partnerships or donations – your efforts, energy and enthusiasm are applauded daily.

We are both immensely proud of the work the charity has delivered and the impact it has had, but there is still much to do. The number of children with life-limiting conditions is growing, their needs and those of their families are increasing and so we continue to push for a system that meets that need. We have a strong foothold – we now need everyone's help so that we can start that climb to the summit.



*Barbara Gelb*

**Barbara Gelb OBE,**  
Chief Executive



*Terry Moran*

**Terry Moran CB,**  
Chair

# Our impact

When life changes forever,  
where do you turn?

**111 HOURS**

of support was given  
on our Together  
for Families  
Helpline



**100%**

reported the information they  
received was high quality

**99%**

would recommend  
it to a friend

**887 PEOPLE** are part  
of our family community.  
That's almost a third  
more than last year,  
and **THOUSANDS** of  
families are now part of  
our **42,000 STRONG**  
social media voice

Sometimes it can be too  
much to handle alone –

**66 FAMILIES**

were supported  
by our advocacy  
service in  
partnership with  
LawWorks this year



**ALMOST  
100,000  
PEOPLE**

visited our website  
as the children's  
palliative  
care hub



**42,000 GOT HELP**  
from our family pages

**7,000 FOUND  
SUPPORT** in their  
area using our directory

**ALMOST 6,500  
RESOURCES**  
downloaded to help  
families get the best care

Getting the right support  
makes a world of difference

**WE DISTRIBUTED**

**£720,000**

to children's hospice  
services to help them  
provide lifeline care



**WE SPOKE  
TO ALMOST**

**300**

**POLITICIANS**

ONE-ON-ONE  
ABOUT WHAT  
CHILDREN AND  
FAMILIES NEED  
MOST – THAT'S  
**25% MORE**  
THAN LAST  
YEAR



Once again, we helped ensure

**£11 MILLION**

in children's hospice grant funding  
in England from NHS England

**60 VOLUNTEERS**

recruited to help  
families at home

**62 FAMILIES** matched  
with volunteers, and  
**48** of these families have  
already started to receive  
regular volunteering to  
make life easier

**692 HOURS** of  
volunteering at home;  
that's the equivalent of  
**28 FULL DAYS**

Three pilot  
sites delivered a new  
**FAMILY SUPPORT  
VOLUNTEERING  
SERVICE**



## Growing up shouldn't mean growing out of support

**85 ADULT** hospices engaged in our Transition Taskforce – connecting children's and adult palliative care services

**46 ADULT** services are now working with children's services to develop services for young people



**£750,000**

raised to fund projects that make a difference for young people over the next three years as part of our new Transition Awards Programme

## Strengthening our collective voice for seriously ill children and their families

OUR MEMBERSHIP IS NOW  
**1,125 STRONG** –  
THAT'S MORE THAN  
**28% UP** ON  
LAST YEAR



**OVER 100 FAMILIES**

and young people in our reference groups



**679**

professionals attended 24 Together for Short Lives events over the year

A voice of  
**42,000**

on social media – made up of families, young people, care professionals and our supporters



WE SENT OUT  
**3,720** SOCIAL MEDIA MESSAGES – THAT'S  
**72 MESSAGES**  
**A WEEK**

## Changing perceptions



THIS YEAR'S  
**CHILDREN'S HOSPICE WEEK**  
WE TOLD EVERYONE IT WAS TIME TO PUT FAMILIES FIRST. THE UK TOOK NOTICE

OUR CAMPAIGN WAS SUPPORTED BY  
**HER ROYAL HIGHNESS, THE DUCHESS OF CAMBRIDGE**

WE REACHED **40 MILLION** PEOPLE ON TWITTER, MORE THAN DOUBLING LAST YEAR

WE HAD STORIES PUBLISHED IN THE MEDIA WITH A CIRCULATION OF ALMOST **30 MILLION**

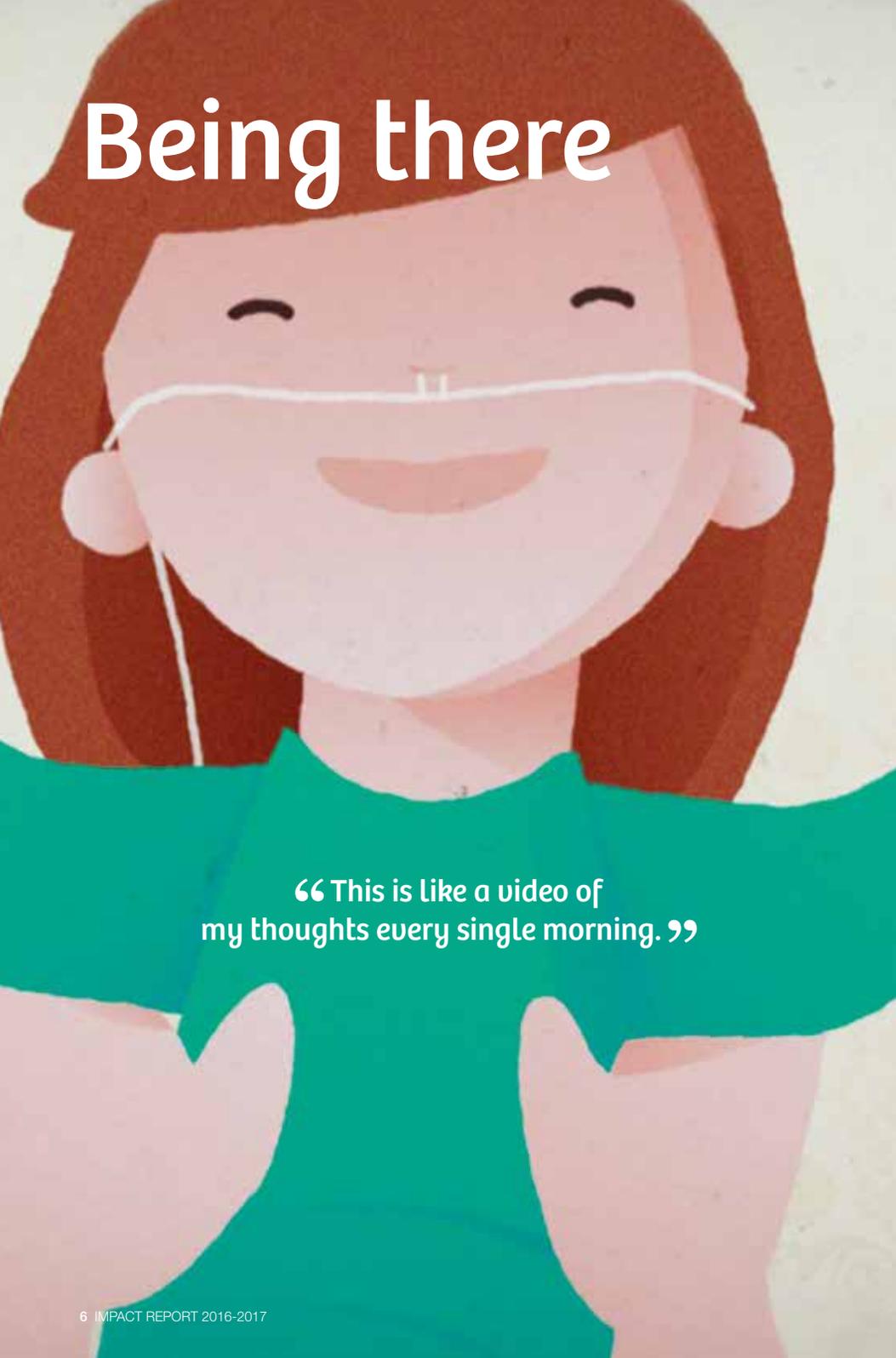
WE WERE  
**ONE OF 24 CHARITIES** campaigning to break the silence on baby loss



WE GOT THE SECTOR TALKING WITH OUR NEW BLOGS – SHARING  
**49 EXCLUSIVE STORIES**



# Being there



“This is like a video of my thoughts every single morning.”

## Through my eyes

Every family caring for a child with a life-limiting condition goes through many critical points throughout their journey together. From the second you get that life-changing news that your child is likely to die before you, family life changes forever...

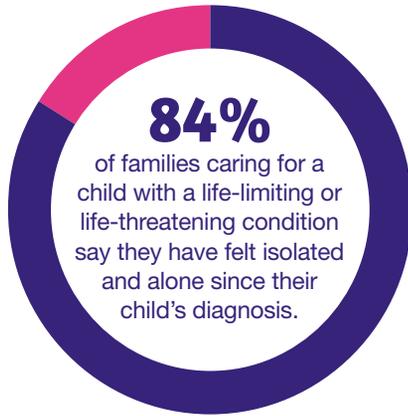
Who do you turn to for help? How can you possibly care for your child around the clock? What if something goes wrong? And if your child lives into adulthood – what does support look like for a young adult and how do you get it? Why is your voice not being heard? And what do you do when the worst happens – who will be there for you?

Together for Short Lives is committed to making life better for seriously ill children and their families. We work hard to be there for them and to make a difference through each of their defining moments, answering the questions that matter most along the way.

Being told that your child may not reach adulthood is something you hope will never happen to you and no one can be prepared for it. When it does happen, many parents don't know where to start, emotionally or practically. It's a critical time and one that will see families' lives turned upside down. Together for Short Lives is here to help families understand what is going to happen and what support is available, as well as connecting them with other families who can help them feel less alone and provide peer-to-peer support.

Through my eyes – our animation showing what it's like to hear your child will die young and how to find vital support was viewed almost

**30,000 TIMES**



“It’s hard to connect with anyone.”

## TOGETHER FOR FAMILIES HELPLINE

- We spent **111 hours** talking to families and professionals.
- **100%** of families reported that the information they were given was high quality.
- On average **99%** of families would recommend the helpline to other families.

“The help is out there but it can feel like a minefield and trying to make it all work can be impossible. That’s why getting help to find the care we needed has made such a difference.”

## A WHOLE WORLD OF SUPPORT

- Almost **100,000** people visited our website giving access to vital information and support.
- Our family resources were downloaded over **1,700** times.
- Our family community grew by almost a third to **887** members.
- **Thousands** of family voices are now part of our **42,000** strong social media community.

## FAMILIES TOGETHER FACEBOOK GROUP

- We responded to family calls to have a ‘safe place’ they can meet with other parents and carers by piloting this private group.
- **94** family members.
- **100%** want to remain part of the group for the foreseeable future.

“I feel like I can only share my true thoughts and feelings with parents who have had a child with a similar condition. I’m part of a Facebook group and the people there lend an empathetic ear and a shoulder to cry on.”

## A HELPING HAND WHEN YOU NEED IT MOST

- **66 families** were supported by LawWorks – providing free advocacy support to families who are having problems accessing the health and care system.

“Hallelujah. I have just had a call from the NHS and they have started the process of setting up the personal health budget. They have received your letter. Thank you so much. Wow, we are powerless without the voice of a lawyer.”



## Spotlight: A Happy Home

Three-year-old Maya has a complex multi-system disorder. Maya is not mobile, cannot speak and is fed through a tube. Together with mum and dad, Raj and Anita, she was living in a cramped two-bedroomed flat with two other adults and one other child. The family were at breaking point with no knowledge of how to apply for alternative accommodation.

Our advocacy drop-in clinic matched Raj and Anita to a lawyer who was able to advise the family on the legal issues they were facing, including welfare benefits. Happily, the family was able to move to a house outside the city and now has regular visits from physiotherapists, nurses and other health care professionals.

“We were at a loss at what to do but Claire was able to give us a clear picture of our options. She was amazing for us.” Raj

Our ‘Voices for Families’ service is generously supported by The Goldsmiths’ Company Charity and The Masonic Charitable Foundation.

## Joining up care

Thanks to funding from the Department of Education, we published an interactive and free guide to help families of children and young people with life-limiting conditions join-up their education, health and social care. We wanted to help families understand their rights and make the most of the special educational needs and disability (SEND) system. Our guide was written by our Trustee, Anna Gill OBE, a parent carer of a young person with a life-limiting condition, on behalf of the Council for Disabled Children (CDC).

Our digital SEND guide for families was downloaded nearly **400 times**.

# Supporting lifeline services



Many families have to fight to get the care and support they need whilst struggling to cope with the immense practical, financial and emotional pressures of caring for a child with a complex health condition. Cuts to funding and services put families in danger of missing out on vital help.

Together for Short Lives is playing a key role in ensuring that there are the right lifeline services available for children and families, today - and in the future. And shouting about them!

## Securing a sustainable workforce – You Can Be That Nurse

A specialist children's nurse with the right skills to provide palliative care and symptom management can make a huge difference to families – yet there just aren't enough nurses working in the sector, and it's getting worse. This year, Together for Short Lives has pressed government and health care planners to act to reduce nurse vacancies in the children's palliative care sector, and we made a powerful film to show the rewards of working with seriously ill children to bridge the nursing gap.

“To have nurses like Amanda means I'm not having to explain what Logan needs every time... It's someone you're handing over to that you can trust implicitly. And it's not easy to take on some of the roles we do every day at home unless you've got the experience to do it with the confidence at the same time.”

Liz Crooke, mum to Logan Chadbone

## WE OPENED PEOPLE'S EYES TO A CAREER AS A CHILDREN'S PALLIATIVE CARE NURSE



Our film was watched by over **34,000 people** and **500 people** shared our social media post about the campaign reaching over **95,000 people**.



We got people talking with **300** different contributors on social media and **700 tweets**.

We secured media coverage across nursing and specialist press including: *Huffington Post*, *Nursing Standard*, *Nursing Times*, *Nursing Children and Young People*, and *RCNi*.



“Working in children’s palliative care is the best thing I’ve done in my life.”

**Francis**, Children’s hospital palliative care nurse



“It’s an amazing job, what else can I say.”

**Amanda**, Team Leader, children’s hospice

## Helping families get the respite they need

We helped secure a two-year commitment from NHS England for vital funding for children’s hospice services in England of **£11 million each year**.

“If we no longer had the hospice grant, this would have a large impact on the funding we would have and therefore the services we could provide. End of Life Care would still be our priority and we would aim not to reduce this part of the service. However, other services would probably need to be reduced in accordance with the funding.”

A children’s hospice

We distributed **£720,000** to support local children’s hospices services all over the UK.

That’s the equivalent of **almost 30,000 hours of care** that we were able to fund.

## Reaching out

A key element of our work is about helping children and families get the very best care and support. This year we worked with some of the UK’s children’s palliative care charities to support service improvements and help them reach out to more children, including Martin House, Children’s Hospices Across Scotland (CHAS) and Eden Valley Hospice. Working with CHAS, we explored how they could extend their care offer of support to more children and families across Scotland, through their work with partner organisations and professionals. As a result of this work, CHAS is now leading a programme of work to address this issue and is working with the Scottish government to explore the best way forward for children’s palliative care in Scotland.

“CHAS has valued the support from Together for Short Lives in taking forward a hugely important piece of work to ensure more children and families in Scotland are able to access care that is right for them at the right time – supporting our ambition to reach every family in Scotland. The work we have undertaken together delivered a productive meeting for professionals from across health care in Scotland to explore what good children’s palliative care looks like in the future. The consensus from this meeting was that the time is right for a national paediatric palliative care network in Scotland.”

**Maria McGill**, CEO for CHAS – Children’s Hospices Across Scotland



## Family Support Volunteering

On top of caring for their child and juggling endless medical appointments, families can struggle with everyday tasks, like housework, shopping or spending time with their other children. Extra help from a volunteer at home can make a huge difference.

Funding from The Royal Foundation and The True Colours Trust over the last two years has enabled us to work with three sites to pilot an innovative way to support the families of children with life-limiting and life-threatening conditions. The Family Support Volunteer service engages volunteers to provide practical support in the homes of families. The pilot involved recruitment of volunteers to support families, to give families a break and help with practical jobs like washing up, cleaning out cupboards, gardening, picking up prescriptions or spending time with brothers and sisters who have a seriously ill sibling. Extra help at home can go a long way.

- **3 pilot sites** in London, Warwickshire and Bristol.
- **60 volunteers** recruited to help families at home.
- **62 families** matched with volunteers, and **48** of these families have already started to receive regular volunteering.
- **692 hours** of volunteering at home. That’s the equivalent of **28 full days**.

“It has made a huge difference to me. I was finding it frustrating that there were things I wanted to do but didn’t have the time to do. I feel less stressed.”

# Growing up



“We should be celebrating the fact that more young people with life-limiting conditions are living into adulthood, yet the lack of age-appropriate services for these young people mean that they are missing out on opportunities to live their life to the full. Urgent change is required.”

Barbara Gelb OBE, CEO

Advances in medical technology mean that the number of young people with life-limiting and life-threatening conditions is increasing, but a shocking number of young people are not getting the support and care they need. There is an urgent need for new initiatives to transform the experience of young people with life-limiting conditions as they move from children's to adult services. And we're taking the lead...

## Helping services to deliver lasting change

Together for Short Lives has launched a ground-breaking new Transition Awards Programme to help address the cliff edge in care experienced by young adults in their transition from children's to adult services.

We have secured **£750,000** to drive innovation and bring about real change for transition over the next three years.

We are working to fund partnerships between different services and different organisations who can work together to support young people. Awards will be in the range of **£40K-£150K** for **up to 30 months**.

## Collaborating for action

**Our national Transition Taskforce has developed regional action groups (RAGs)**

to foster engagement at regional and local level with young people themselves and their families as well as a variety of different professionals from the children's and the adult sector.

This year, we've gone one step further and developed **8 local action groups** within these regions to pinpoint and address the needs of young people locally.

**50% OF RAGs ARE NOW LED BY ADULT HOSPICE SERVICES** –

which shows a huge shift. Adult services are recognising the need for good transition and are actively involved in making it happen.

**85 ADULT** hospices are now involved in the Transition Taskforce – that's 85 hospices across the UK with young people on their radar – actively working to ensure that services are ready and equipped to help young people achieve the very best in care and support.

On top of this, **46 ADULT** hospices are working directly with children's hospices to develop their services for young people.

## Young People's Voices

Young people are always at the centre of our work – whether that's by speaking up as part of our **Young Avengers Group**, taking the lead in their region or helping us ensure our publications are meeting the needs of the people they are designed for.

“I'm thrilled to be co-chair of the Together for Short Lives Yorkshire and Humber transition regional action group. The group is really pleased to have someone with personal experience heading it up – after all, the whole reason why the people on the group are sitting around the table is for people like me. I've had personal experience and know how difficult the transition process can be. I've experienced many barriers to a smooth transition. I need to be involved to make sure this is improved for people in the future. I've seen first-hand in my work with social work students that talking to professionals improves their skills and their understanding of young adults with life-limiting conditions. In fact, my own social worker heard me speak while she was a student five years ago!”

Chris Edmonson

“Since working with Together for Short Lives and being a Young Avenger (I still LOVE the name!), I feel that what I have been raising as concerns or issues are finally being heard. People were so enthusiastic to listen to my story and how I coped through transitions etc.”

Leah Booth

“I'm so excited to be part of the group helping produce this document. I think it will be really useful in lots of different settings. I can imagine using it in hospital on a new ward I haven't been looked after on before as well as it being a document for new agency carers to familiarise themselves with, for example.”

Chelsea Corbett



Josh talks about moving to adult services in our new guide to transition for young people *Moving to Adult Services*:

**“LOVE LIFE AND LIVE IT – IT IS VERY PRECIOUS.”**

**Almost 1,000 people** have used this guide to prepare them for moving to adult services over the last year.

# Spotlight

## Our year at a glance



### The big conversation

Though it's never an easy conversation, Dying Matters 2016, run by The National Council for Palliative Care, was all about encouraging the public to talk to each other about dying, death and bereavement. Helping to break taboos in this area is so important and we were proud to do our bit to help.

“I want people to be able to get to know me, who I was and all about me as a person, even though I will no longer be living.” **Lucy Watts**



### Our Westminster Reception

Parents caring for seriously ill children, young people with life-limiting conditions and children's palliative care charities and professionals were joined by over **50 MPS AND PEERS** at a special Together for Short Lives Westminster Reception.



Amanda Harrison, mum to James, was told her little boy wouldn't live past five when he was diagnosed with Infantile Batten Disease. She shared her story at our ball:

“Families like ours shouldn't have to struggle to get the care and support they need. That's why I'm proud to be here tonight, sharing the important role Together for Short Lives plays as the vital national voice for all families like ours.”



Together for Short Lives is the glue that helps weave together the different health, social care and education services that families need, so in the future families won't have to fight and can focus on spending precious time together.

James is now 9 years old (he likes to prove the doctors wrong) and we know there will come a time when we will say goodbye to James. Knowing someone understands your situation is so comforting.” **Mum, Amanda Harrison**



### OUR MIDSUMMER BALL

helped us shine a light on the UK's **49,000** children and young people with life-limiting or life-threatening conditions.



## Time to put families first

This Children's Hospice Week we showed what life is really like for families, highlighting the challenges they face.

“It is a fantastic platform to promote family stories, fundraising activities, engaging with celebrities and improving our brand awareness.”

Tŷ Hafan, Children's Hospice

**OVER 40 MILLION** reached on Twitter

**OVER 600 PIECES OF MEDIA**

coverage – that's an average of 86 stories in the press per day

This year, Together for Short Lives was the chosen charity for *The Mirror's* Christmas Campaign. The campaign aimed to shine a light on the needs of children and families, sharing stories about their lives – including the challenges they face as well as profiling the amazing services and professionals that support them.

Reaching more than **6.5 MILLION** people



## Childhood Cancer Awareness Month

We want to reach out to more families when curative treatment has failed and they need specialist support and help.

**OVER 10,000 PEOPLE**

joined us in signing a petition to make cancer costs fairer for UK families



Great news for children's palliative care as The X Factor charity single was chosen to benefit Together for Short Lives and Shooting Star Chase Children's Hospice.

With an audience of **6.2 MILLION**

# End of life care and bereavement

A photograph showing a woman wearing a pink hijab looking down at a young girl lying in a hospital bed. The girl has an oxygen tube in her nose and is looking towards the camera. The woman has a gentle, caring expression. The background is slightly blurred, showing what appears to be a hospital room.

## Giving families choice in end of life care and time to grieve

Knowing that your child will die young is heart-breaking. It's too much for any parent to bear alone. Families need all the help and support they can get preparing for their child's end of life care – and it's vital that every family has time to grieve and is supported throughout their bereavement.

## Giving bereaved families a voice

We want to give bereaved families a voice with **30%** of our Family Reference Group being bereaved parents.

“When our son was at the end of his life our family was never connected to the amazing services available via Together for Short Lives, like the children’s hospice in our area, because the clinical networks to connect the services did not exist. Had we been connected we would have had hospice home care for our son, ongoing counselling and linked bereavement for ourselves and our other children – we had nothing. Campaigning with Together for Short Lives means we can change this for families in the future – a fitting legacy for our late son – priceless.”

**Sacha Langton-Gilks**, mum to David known affectionately as DD



Our resources on end of life care planning were **DOWNLOADED 512 TIMES**

Our end of life care support for families website pages were **VISITED 948** times and our bereavement support pages were **VISITED 5,137 TIMES**



“Having had such a positive experience of people supporting us to care for our baby at the end of his life, it felt so important to share what worked well in the hope that other families may experience something similar. It felt like such a constructive and positive thing to get involved in.”

**Sarah**, mum to Finlay

## Securing an end of life choice commitment

We believe that all families should be able to choose how and where they receive their child’s end of life care - at home, in hospital or in a children’s hospice. We were delighted when the government included children in its response to a review of choice in end of life care as a result of our lobbying efforts. The review initially only focused on adults; but following our work to press ministers on this issue, **the government’s final end of life commitment said those who plan and fund healthcare in England must prioritise palliative care for children.**

## Breaking the silence on baby loss

“In 2009 I lost my own baby boy who was stillborn at full term. Behind every stillbirth is a deep and lasting grief for each family affected. That is why this Baby Loss Awareness Week is so vital. These lost babies cannot be and will not ever be forgotten by the families who suffered such terrible tragedy.” **Patricia Gibson MP**, SNP

Together for Short Lives was one of 24 charities joining together for Baby Loss Awareness Week. The campaign aimed to make sure that parliamentarians and the public better understand the impact of losing a baby and why bereavement support is so vital. We briefed MPs ahead of a parliamentary debate on the issue, which resulted in former children’s minister Tim Loughton MP pressing ministers to address the gaps in support.

## Campaigning to end child burial fees

We’re part of the Funeral Poverty Alliance, and we’ve been pressing the UK’s governments to help provide more help to relieve families bereaved of a child with the costs of arranging a funeral. Following pressure from Carolyn Harris (Labour MP for Swansea East), **the Welsh Government announced that it would abolish burial fees for children.**

## Towards statutory leave for every bereaved family

We supported Will Quince MP’s campaign to make sure that parents across the UK bereaved of a child can take a fortnight’s statutory leave following their death. As a result, **the Conservatives committed to introducing this in their 2017 general election manifesto.**

# Speaking up

It is simply not fair that the most vulnerable families in our society, who often have the weakest voices, are not heard or understood by policy makers. Together for Short Lives has strived to get families heard over the last year on the issues that matter most.

## The hidden issues

We've been calling on the UK Government to lift the baby benefit bar. This would mean that families of young children under the age of three with life-limiting and life-threatening conditions would be able to access the mobility component of the Disability Living Allowance (DLA). This would help them to buy specially adapted vehicles to carry bulky life-supporting equipment. Currently the benefit is only available to children aged three and over, effectively trapping some families of young, seriously ill babies and children at home or in hospital, unable to make even the simplest of journeys.

Emma Murphy is mum to two-year-old Stanley who has Tay Sachs. He has no muscle tone and cannot move or support his head:

“The people who make these decisions haven't a clue what life is really like. To get this mobility element of the DLA, a child is supposed to be three years old. Stanley might not live until he is three years old. To be told he can't get this help is not right.”

We made the case for change at our Westminster reception in February, taking to heart Emma's words and showing the decision-makers what life is really like. We exhibited the astonishing amount of equipment that a family of a young child needs to pack when they leave the house. Ministers and other parliamentarians had the opportunity to see first-hand why this reform is so vital. We continue to work with officials at the Department of Work and Pensions to solve this pressing issue for families who do not have time to wait.



Stanley's family was given a **NATIONWIDE PLATFORM**, featured in *The Mirror* and on the BBC.



**150 GUESTS JOINED** us at Westminster to show their support.



Two organisations were so moved they **OFFERED TO PAY** for an adapted vehicle for Stanley's family themselves.

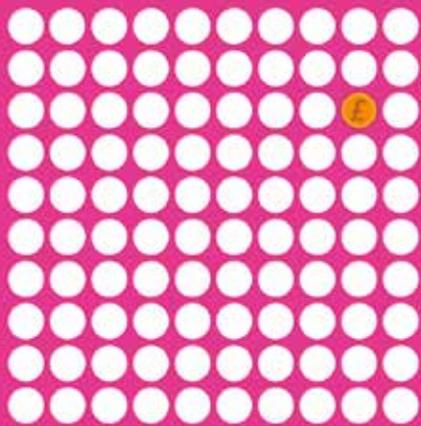
## Lifeline respite for families

For the first time, we published commissioning maps of children's palliative care which showed how well or how poorly local authorities and clinical commissioning groups plan and fund services for seriously ill children. **4 out of 5 (81%) local authorities were failing to plan and fund care for children with life-limiting conditions.**

Local authorities have a legal duty to provide short breaks for seriously ill children, yet around **1 in 7 (14%)** were failing to commission these services.

And our funding survey in November revealed that cuts and freezes in state funding for children's palliative care services means it's a bleak outlook for seriously ill children in England.

Local authorities are only contributing **1%** of the money charities need to deliver children's palliative care



## Recognising families' expertise

We recruited young people, parents and carers with first-hand experience of children's palliative care to join Care Quality Commission (CQC) inspections and become an 'Expert by

Experience'. Families do not choose to be a part of the children's palliative care world – they are thrust into it as soon as their child is diagnosed – but giving them the chance to choose to be part of its evolution and put the valuable knowledge they have built up over the years to good use is so important in making the sector the very best it can be.

“Being an Expert by Experience seemed like a constructive way to put to good use experience gained during years of contact with elements of the care system... helping to bring alive what might otherwise be a slightly sterile review by introducing supportive, or occasionally negative, comments from service users together with their families and carers.”

Howard Gill, dad to Jamie who has a degenerative metabolic condition affecting every organ except his heart.



## Making family voices count

Together for Short Lives welcomed the new NICE guidance – End of Life Care for Infants, Children and Young People, but we wanted to make sure the guidance was the best it could be for seriously ill children and their families.

It was vital to ensure it was about the whole of a child's life, no matter how short, and reflected the voices of families and children's palliative care experts.

Our response to the NICE guidance resulted in some important changes including: recognising the importance of managed clinical networks in delivering high quality co-ordinated children's palliative care and involving neonatal teams in care planning for babies when there's an antenatal diagnosis of a life-limiting condition.

Vicky Whyte, mum to Leah, shared her personal experiences to inform the NICE guidance:

“It really helps to know that part of 'Leah's legacy' is helping to make things better for others. Leah was very much a 'people person' and it's what she would have wanted.”



## Key connections

- We formed the first-ever All Party Parliamentary Group for Children Who Need Palliative Care.
- We made sure children and families were always on the agenda – responding to **26 consultations** in the last year.
- We talked to almost **300 MPs** one on one about how they could improve children's palliative care.
- Our voice was heard – Together for Short Lives was mentioned **8 times** in parliamentary debates. That's **166% up** on last year.

# Making it count

## Rising to the challenge



6,926 MILES HIKED  
BY 103 TREKKERS

£73,908



1,243 MILES RAN  
BY 67 RUNNERS

£52,246



20,166 MILES RIDDEN  
BY 63 RIDERS

£58,609



30,000 FEET SKYDIVED  
BY 33 DIVERS

£16,986



“We took advantage of two parents’ evenings at our school and sold cakes, snacks, books, squash, tea, coffee and biscuits!”

**Memoona and Noama** – Skydive



“I came across Together for Short Lives purely by accident – I’d googled ‘physical challenges for charity’! But it’s a great cause, and I’m really glad to have had the opportunity to support it. The trek was challenging, but extremely enjoyable – I realised I was more physically able than I had previously believed.”

**Meridula, RBS** – Together We Trek

A huge thank you to all our fantastic corporate supporters and the wonderful people who work for them. Thanks to their enthusiastic, creative and inspiring fundraising efforts, we were able to distribute over £745,000 to children's hospices and voluntary providers of children's palliative care across the UK. We have enjoyed the support of a wide range of hugely valued corporate partners over the last year, including Hobbycraft, Center Parcs, Hays, Clyde & Co and The Entertainer.

## Spotlight

In June 2016 Together for Short Lives and Center Parcs began a two-year partnership to help families make the most of their time together.

Each of the five Center Parcs Villages are twinned with their local children's hospice – staff have spent time getting to know their local service and understanding the lifeline support they offer to families in their community.

They help families make precious memories by donating 20 breaks a year in their specially-adapted woodland lodges.

“We had a wonderful time and we all felt that being given such a lovely break helped our family gain some strength whilst struggling with a really horrendous year. Center Parcs really do cater for wheelchair users very well and the lovely train drivers always made us smile. The accommodation was beautiful and quiet. A time to think and reflect. Thank you Center Parcs and Together for Short Lives for a holiday we desperately needed but couldn't afford. We have made some very happy memories.”

“This is a record-breaking amount we have raised for a charity partnership in one year. I am so proud of everyone involved.”

Martin Dalby, Center Parcs CEO



Across the Center Parcs Villages teams have gone above and beyond with their fundraising efforts:



Giving hospices barbecues, games consoles, space for meetings and days out



All this and more means that Center Parcs has raised over **£200,000** for the National Fundraising Scheme, supporting children's hospice services. That's more than double the original target for our first year.

# How you make a difference

We rely on charitable support to deliver our work for children and young people with life-limiting conditions and their families across the UK. All that we have achieved this year would simply not have been possible without the fantastic support, commitment and generosity of our supporters to whom we are truly grateful.

As well as raising funds to support our work, Together for Short Lives raises vital funds for children's hospices and other voluntary organisations so that they can continue to deliver the highest quality lifeline care to children, young people and families right across the UK.

Thank you.



## Summarised financial statements 2016-2017

### HOW MONEY WAS RAISED

**£1,580,169**

Fundraising income for Together for Short Lives' work



**£1,305,461**

Funds raised for member children's hospices and voluntary organisations



**£36,543**

Income from membership, conferences and training



**£78,771**

Income from investments and other sources



**£3,000,944**

Total raised



### WHERE YOUR MONEY GOES

**£218,938**

Support for families



**£345,177**

Quality of Life, Quality of Death



**£284,967**

Commissioning and sustainability



**£392,120**

Transition



**£431,771**

Community engagement and volunteering



**£745,799**

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



**£1,240,992**

Raising funds



**£3,659,764**

Total spent



# Thank you to each and every one of our supporters:

A D Power Will Trust  
Autoglass  
Bayer plc  
Bouygues UK  
CAF Grant Fund  
Center Parcs  
Christadelphian Samaritan Fund  
Clyde & Co  
CSS Investments  
Edith Murphy Foundation  
Frankie & Benny's  
Gareth Neame  
Hall and Woodhouse  
Hays  
Hobbycraft  
Interserve  
James Tudor Foundation  
Jimmy Knapp Cancer Fund  
John Ellerman Foundation

Leaders  
Lynn Foundation  
Mike & Cat Marshall  
Miss Teen Great Britain  
Mode Print Solutions  
Phoenix Trading  
Read for Good  
Riley Consulting  
Ritchie Charity Trust  
Scouloudi Foundation  
Scumrun  
Simon Cowell  
Simply Health  
Simpson Travel  
Syco Entertainment  
Sylvia Aitken's Charitable Trust  
Thales  
The Austin & Hope Pilkington Trust  
The Brian Mitchell Charitable Settlement

The Childwick Trust  
The Entertainer  
The Ernest Ingham Charitable Trust  
The Goldsmiths' Company Charity  
The Gurney Charitable Trust  
The Insolvency Service  
The Joyce Kathleen Stirrup Trust  
The Masonic Charitable Foundation  
The Michael & Anna Wix Charitable Trust  
The Royal Foundation of The Duke and Duchess of Cambridge and Prince Harry  
The Thomas J. Horne Memorial Trust  
The Thousandth Man – Richard Burns Charitable Trust  
The Worshipful Company of Needle-makers  
The True Colours Trust  
Tilney  
Wilko  
William Allen Young Charitable Trust

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And to all our anonymous supporters who give so generously

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# We are Together for Short Lives

We cannot achieve great change for children, young people and families in isolation. By working in partnership across the children's palliative care sector with our members, patrons, stakeholders and supporters, together with the voices of children, young people and families at the heart of all we do, we can achieve so much more as a strong and powerful movement.



“Our membership with Together for Short Lives gives us the opportunity to work together to help more children in real need. Together we are improving the quality of care and support available to children who just can't wait - and shouldn't have to wait – for the equipment they need.”

**Carrick Brown**, Senior Care Services Manager, Newlife – the Charity for Disabled Children

This year we have grown our membership and strengthened our family community, and enabled families and young people to share their experiences and needs through our policy, campaigning and awareness-raising activities.

We now have **1,125 MEMBERS** from all over the UK and beyond – that's a **GROWTH OF 28%**

Our family reference group has grown from **75** to **103 MEMBERS**, and we have **15 YOUNG AVENGERS**

Our family community has grown by nearly **30%** to **887 FAMILIES**, adding to the thousands of families that make up our social media following on Facebook and Twitter

## Together for the 49,000+

We've started a very important conversation with our community this year – with members, families, young people, professionals, service providers and all those with an interest in children's palliative care to help shape our strategy from 2018 onwards. We've asked everyone to share their vision for what great children's palliative care could look like in 2028 and what Together for Short Lives' role should be in achieving that vision. Thank you to everyone who has shared their thoughts, through our surveys, conversations, blogs and social media. We'll look forward to launching our new strategy for change next spring.

“As an extremely small charity with a team of four music therapists and a board of only seven trustees, it feels very important to forge links with larger organisations such as Together for Short Lives which has a much stronger voice to fight for the changes we believe are essential for the children and young people we work with... Having the information from Together for Short Lives at our fingertips has enabled us to pass on information and signpost our families to accessible, relevant resources and your helpline.

With Together for Short Lives we have a strong group fighting for the rights of the children and families.”

**Jan Hall**, Chair of Trustees and **Esther Mitchell**, Lead Music Therapist Thomas's Fund

## Together for Short Lives' members

Last year we had 878 members; this year membership has grown to 1,125. That's a growth of 28%.

### VOLUNTARY SECTOR ORGANISATION MEMBERS

A Child of Mine  
Acorns Children's Hospice  
Alexander Devine Children's Hospice Service  
Andy's at St Andrew's Hospice  
Batten Disease Family Association  
Bluebell Wood Children's Hospice  
Breathe On UK  
Brian House Children's Hospice  
Butterfly Children's Hospices  
Butterfly Project (Barnardo's Family Support Service)  
Butterwick House Children's Hospice  
Camp Simcha  
Centre of Children's Nurse Education (Crumlin)  
Charlie House  
Chestnut Tree House  
Child Bereavement UK  
Children's Hospice South West  
CHAS - Children's Hospices Across Scotland  
Chin Up  
Claire House Children's Hospice  
Contact a Family  
Demelza Hospice Care for Children  
Derian House Children's Hospice  
Digital Legacy Association  
Donna's Dream House  
Down's Heart Group  
Dreams Come True Charity  
East Anglia's Children's Hospices  
Ellenor  
Faculty of Health and Social Sciences (Bournemouth University)  
Family Nursing & Home Care  
Forget Me Not Children's Hospice  
Francis House Children's Hospice  
Friends and Families of Special Children Ltd  
Gully's Place Trust Fund  
Haven House Children's Hospice  
Havens Hospices  
Helen & Douglas House  
Hollybank Trust  
Hope House Children's Hospices  
Hospice Isle of Man - Rebecca House  
Jessie May  
Jigsaw, Cumbria's Children's Hospice  
Julia's House  
Keech Hospice Care

Kids Cancer Charity  
LauraLynn, Ireland's Children's Hospice  
Lifelites  
Martin House Children's Hospice  
MLD Support Association UK  
Naomi House & Jackspace  
National Association for Palliative Care Educators  
Newlife the Charity for Disabled Children  
Niemann – Pick UK  
Noah's Ark Children's Hospice  
Northern Ireland Children's Hospice  
Rainbow Trust Children's Charity  
Rainbows Hospice for Children and Young People  
React  
Rennie Grove Hospice Care  
Reuben's Retreat  
Richard House Children's Hospice  
RNIB Pears Centre for Specialist Learning  
Round Table Children's Wish  
Save Babies Through Screening Foundation UK  
Sebastian's Action Trust  
Shooting Star Chase  
SOFT UK  
Spinal Muscular Atrophy Support UK  
St Oswald's Hospice  
Sue Ryder Care Centre (The University of Nottingham)  
SWAN UK  
The Children's Trust  
The Cure & Action for Tay-Sachs (CATS) Foundation  
The Donna Louise Children's Hospice  
The Harvey Hext Trust – A Siblings Wish  
The James Hopkins Trust  
The J's Hospice  
The Muscle Help Foundation  
Thomas's Fund  
Tý Hafan  
Zoë's Place Baby Hospice

### STATUTORY SECTOR TEAM MEMBERS

Centre for Paediatric Spiritual Care (Birmingham Children's Hospital NHS Foundation Trust)  
Children and Families Division (Birmingham Community Healthcare NHS Trust)  
Children's Community Nursing Team (Central London Community Healthcare NHS Trust)  
Community Children's Nursing Services (NHS Lothian)  
Community Children's Nursing Team (South Warwickshire NHS Foundation Trust)  
Community Children's Nursing Team for Children with Life-Limiting Conditions (NHS Ayrshire & Arran)  
Diana Children's Nursing Service (Betsi Cadwaladr University Health Board)  
Essex Palliative Integrated Care Children's Respite Service  
Heywood, Middleton and Rochdale Children's Community Nursing Team (Pennine Care Foundation Trust)  
Paediatric Macmillan Team (Central Manchester University Hospitals NHS Foundation Trust)

Salford Diana Children's Community Nursing Service (Salford Royal NHS Foundation Trust)  
Small Heath Medical Practice  
Southbank Child Development Centre (NHS Greater Glasgow and Clyde)  
The Louis Dundas Centre, Paediatric Oncology Outreach & Palliative Care Team (Great Ormond Street Hospital for Children NHS Foundation Trust)  
The Royal Marsden Education and Conference Centre

### OUR PATRONS AND AMBASSADORS

Professor Sir Alan Craft – President  
Dr Ann Goldman – Vice President  
Simon Cowell  
Holly Willoughby  
Rosa Monckton MBE  
Professor Dame Elizabeth Fradd DBE, DL  
Rebecca Front  
John Overton  
Alex Corbisiero

### OUR CEO AND TRUSTEES

**Barbara Gelb OBE** – CEO for Together for Short Lives  
**Terry Moran CB (Chair)** – Chair of Hull and East Yorkshire Hospitals NHS Trust  
**Heather Wood (Vice Chair)** – former Chief Executive, Rainbow Trust Children's Charity  
**Rosalind Britton (Treasurer)** – former Finance Director, St Barnabas Hospices  
**Edward Belgeonne** – Founder and Chief Executive for a number of businesses in the mobile technology industry  
**David Butcher** – Chairman of Acorns Children's Hospice  
**Dr Hilary Cass OBE** – Consultant in Paediatric Disability  
**James Ellam** – Chief Executive, St Oswald's Hospice (resigned 16 May 2017)  
**Anna Gill OBE** – Parent, member of the Child Health Alliance and Health Education England's Patient Advisory Forum  
**Dr Richard Hain** – Consultant and Lead Clinician, Wales Network in Paediatric Palliative Care  
**Tina McCrossan** – former Director of Children and Young People's Services, Northern Ireland Children's Hospice (resigned 6 September 2016)  
**Maria McGill** – Chief Executive, Children's Hospices Across Scotland (CHAS)  
**Doug Morris** – Parent, South West Regional Representative for the National Network of Parent Carer Forums  
**Nuala O'Kane** – Director, Shropshire Community NHS Trust and former Chief Executive, Donna Louise Children's Hospice  
**Chris Roys** – Chief Executive, The Jessie May Trust  
**Richard Strawson** - Parent, Volunteer and Local Authority Senior Manager  
**David Widdas MBE** – Consultant Nurse for Children with Complex Care Needs, South Warwickshire Foundation Trust and Coventry and Warwickshire Partnership Trust

**Together for Short Lives is a UK wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives.**

Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life.

We can't change the diagnosis, but we can help children and families make the most of their time together.

**“Campaigning with Together for Short Lives means we can change things for families in the future – a fitting legacy for our late son – priceless.”**

Sacha Langton-Gilks

**“As a GP with an interest in children's palliative care, it is great to know that I can call on Together for Short Lives for both practical written resources, and a source of expertise about developments in practice happening across the whole UK.”**

Dr Sarah Mitchell, GP – Birmingham



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