



We are here to make sure that no child or family is left behind when it comes to getting vital care and support

49,000 babies, children and young people are living in the UK with conditions that are life limiting or life threatening, and the number is rising. Parents, carers, brothers, sisters, relatives and friends are all affected – we estimate at least 400,000 people.

Hearing the news that your child is going to die young is heartbreaking. From the second you get that life-changing news, everything you know changes forever. It's an incredibly distressing and confusing time, and families say they can feel isolated and lonely. Families coming to terms with this devastating news simply don't know where to turn for help, and too many

families struggle to get the care they need. These families simply don't have time to wait.

No family should face this heartbreak alone. Getting the right support can make all the difference. Together for Short Lives is the UK charity that's making life better for seriously ill children and their families. We're here to ensure that no child or family is left behind when it comes to getting vital care and support.

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

Andy Fletcher

CEO for Together for Short Lives (appointed 25 June 2018)

Barbara Gelb OBE

CEO for Together for Short Lives (retired 15 June 2018)

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Foreword

This year Together for Short Lives has reached some important milestones in our mission to make sure that every single seriously ill child and their families get the help and care they need. Together, with the support of the children's palliative care sector, we have secured policy change that will directly improve the lives of these children and families, and we raised over £1,000,000 to pay for the lifeline care they need in children's hospices and palliative care services. Our helpline, advocacy and family support services are reaching and supporting more families than ever. And we have secured funding for new research, so we can identify the most up-to-date number of seriously ill children right across the UK.

We are helping to transform care and support for young people with our new Improving Transitions for Young People Fund, and we've pioneered new ways of supporting families through our volunteer programme, including launching our digital Together We Can volunteer hub. Importantly, we've helped families, young people and our members to shout louder, helping the public to better understand children's palliative care and the vital role it plays in children's lives.

But it's not been a year without challenge, and Together for Short Lives has needed to take some tough decisions to make sure we are fit for the future and in good shape to deliver our new strategy for change. We are living in challenging times, where financial pressures can directly impact families and the dedicated services and professionals that care for them. It's shocking that families facing the heartbreak of knowing their child will die young still struggle to get the right support and face a postcode lottery of care. Spending precious time fighting for their child's care compounds the sense of loneliness shared by many of the families we are here for. We must change this.

And we know that the number of seriously ill babies, children, and young people is growing. Medical advancements and high-quality healthcare mean that more babies are surviving and young people are living longer, but the funding and services supporting them haven't kept apace with the increased demand. These families and the lifeline services that are there for them need our help more than ever. There is much to do to ensure that children, young people and their families are empowered and get the right support and that services are sustainable and co-ordinated.

We cannot address these challenges or change lives without your help. Thank you to everyone who has supported Together for Short Lives – by adding your voice, by sharing your story, by funding our charity, by running, climbing or baking cakes – your help means the world to the families we support. By working together, we can achieve much more. Over the coming year we look forward to working with families, our supporters, members and partners, and all those involved in children's palliative care, to deliver lasting change – so no child or family is ever left behind.



Andy Fletcher, Chief Executive



Hilay Cas

Dr Hilary Cass, OBE – Chair





Together we support



We supported more families than ever via our family helpline.



We gave quality one-to-one support to professionals.



151,500+

people visited our website hub to get vital support.

100%

of the families supported by our advocacy service said that our help was good or very good.

+33%

Increase

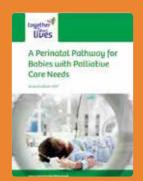








Together we empower



Our new pathway to improve care for seriously ill babies was downloaded by

1200+

We shared vital information to support children and families.

5214+
specialist
resources
downloaded



Our series of six learning webinars about improving support for young people reached at least

150 PEOPLE 100% enjoyed the events.

91% would change an aspect of their work as a result.



Together we change



Children's Hospice Week helped change perceptions. It trended on Twitter for

6 HOURS!

During Children's Hospice Week we shared powerful stories in the media – reaching over

61 MILLION PEOPLE

Our social media stories reached over

30 MILLION



In one week in October we were mentioned on 4 separate occasions in Parliament.

325

one-to-one conversations with politicians and civil servants,

about what children and families need most.

Together we amplify

+ +4000

45,600 people now engaged across Facebook and Twitter.

1231

charity and professional members make us a powerful collective voice for children and families.

We were one of 44 charities calling for bereavement support for families grieving the loss of a baby.

In Baby Loss Awareness Week 99 MPs acted to support our joint calls and 71 buildings across the UK turned blue and pink to remember babies who have died.



We are changing perceptions of what it's like to care for a seriously ill child.

In July we gave over 30 media interviews and reached an





Our campaign for 24/7 out-of-hours care for seriously ill children reached an audience of 39M over one weekend in November 2017.

Together we can do even more

Over £1M

has been raised and shared to fund lifeline support for children, young people and families in children's hospices and specialist charities.

THAT'S 37,800 EXTRA HOURS OF VITAL CARE.



790 miles
41 runners
raising
£82,033



1,755 miles 101 trekkersraising **£74,592**



2,620 miles 37 cyclists raising £62,681



1/1/1

190,000 ft 19 skydivers raising £4,453

1000 Miles 2000 Miles 3000 Miles

Our awesome supporters took part in bake sales, raffles, coffee mornings, paddleboard marathons, dance-a-thons, football matches, bucket collections, zipwires and more, raising an amazing

£82,760





The Lifeline

Our Together for Families helpline has continued to grow from strength to strength this year, signposting families and professionals to the right support for them and providing a listening ear to families who need to talk. The overall number of calls received by families has increased by 31%, evidence that more families than ever are turning to us for support.



"Reading your booklets has made me feel like I'm not mad. Your support has been incredible and just knowing I can pick up the phone gives me the strength to get through this horrendous time."

A mum who has a four-year-old daughter with **Niemann-Pick Disease**





Helping the helpers, so no child or family is left behind

We've supported thousands of professionals who deliver lifeline care to children and families, and we've developed new tools and innovative learning events to inspire and improve practice.

Over 700 professionals joined our learning events and webinars, and 90,000 people visited our information hub for children's palliative care professionals. Our new

pathway to improve care for seriously ill babies was downloaded by over

Our new series of learning webinars about improving care for young people reached at least 150 people, with 100% of attendees saying they found the sessions enjoyable, and 91% saying they would change their practice as a result.

1200 individuals.

"We were asked to get a garden and patio area ready for a child's party – he was in hospital at the time. When the little boy came home for his birthday party in the garden the parents were so pleased."

A volunteer from the Warwickshire site

Team. Demelza House

Children's Hospice

Fighting your corner

With more families than ever seeking our support, the advocacy service we offer in collaboration with LawWorks. Voices for Families, continues to plug gaps left by changes to the legal aid system. Pro-bono lawyers have worked alongside families to secure the care packages and living arrangements they are entitled to. This year, the scheme was extended to operate in three new settings.

John Roden and his family were supported through our Advocacy Project via Richard House, and were rehoused as a result.

"I had been battling with the local council for years – and we'd got nowhere. Then we found out about Together for Short Lives' Advocacy drop-in service. They listened to our story and wrote to the council. Almost immediately, I got a call saying they'd found a brilliant new flat for us. On the day we went to visit, I walked through the front door and said "YES"- there was so much space for Hope to explore. It's made a tremendous difference to us as a family. It's our palace."

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We know that families value any practical support that gives them time to spend together. That's why we created Together We Can, with support from True Colours Trust and The Royal Foundation, a complete guide to setting up a family support volunteering service. Trained volunteers can provide practical support to families caring for a seriously ill child. The resource has been downloaded 706 times since its launch, and 88 families have been matched to volunteers.



Helping families feel valued

We want children, young people and families to have as fulfilling lives as possible. Through our involvement in the Care Quality Commission's Expert by Experience programme, we've helped parents like Sue put their first-hand experience to good use, informing the work of services and commissioners.

"Together for Short Lives has been incredibly supportive of my journey with Simone, including giving me a better understanding of end of life plans and "transition processes from children's to adult services. In short, they are always there working hard for a better deal for our children. And if that's not amazing enough they even helped me to get a brilliant job working for the Care Quality Commission."

Sue, Simone's Mum

Let's get digital

This year we've focused more than ever on digital support for families, starting with a new mobile-optimised website.

We've also moved our secret family Facebook group from the pilot stage into part of our official family offer. Moderated by parents with experience of caring for a life-limited child, the group provides a safe space for families to share their highs and lows with people "who just get it".

"I'm very grateful for the group and it has been a lifeline at times for me."

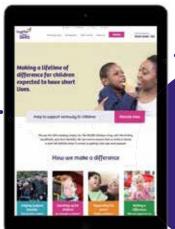
Bringing families together

Carly was one of many parents who took part in our research, which revealed that 84% of families feel isolated following their child's diagnosis. With her help, we are reaching out to more families via our family community.

"Isolation can happen gradually, as we stopped being able to go out and do the things we used to do. Being around normal, healthy children made us realise just how different we had become."

Carly Hadman, Effie's mum





"The new website looks awesome, really neat and device responsive, I could get 'round it better on my phone".

Chelsea Corbett



Young Avengers take the stage

Our Young Avengers – a group of young people with life-limiting conditions, had an amazing year: speaking at events, giving media interviews, sharing stories, having their say at Westminster and sharing their experiences.

Young Avenger Chelsea and bereaved Mum Josie headed up our BBC Lifeline Appeal. They both loved the experience and were so keen to help others in need of support.

Emma was one of many Young

Avengers who helped us develop

a special new checklist tool, generously supported by the Bupa UK Foundation.
The checklist enables young people to assess the quality and coordination of their care as they make the transition to adult services.

"It has been a pleasure to be part of developing the checklist...an important tool that I believe will help many young people and their families through the transition journey. Like all the work I do with Together for Short Lives it has been an exciting and fulfilling opportunity."

Emma Roberts, Young Avenger









Changing lives

At Westminster, we've fought alongside families to close a legal loophole barring children under three from accessing the mobility component of Disability Living Allowance. The change has opened a world of opportunities for families with seriously ill children, who can now access the specialist vehicles they need to travel.

"We are looking to make changes to Motability, and I am pleased to say that many in this House have supported the campaign led by Together for Short Lives to extend the Motability scheme to under-threes"

Penny Mordaunt, MP



"If we didn't have a wheelchair accessible vehicle for Stanley we'd be extremely limited in terms of what we could do. The vehicle helps us get out and about, giving Stanley the quality of life he deserves and helping us make amazing memories."

Emma Murphy, Stanley's Mum

We've also been working behind the scenes by supporting the All-Party Parliamentary Group for Children Who Need Palliative Care. We've helped the group to educate and inform politicians about the value of children's palliative care, motivating them to take action. We've also helped the group to launch its first inquiry, examining the extent to which children and families can make palliative care choices in England. This will report in Autumn 2018.

"I pay tribute at the outset to Together for Short Lives for both the work it does in supporting the APPG (for Children Who Need Palliative Care) and the voice it provides for babies, children, young people and their parents when a short life is expected."

Paul Masterton, MP

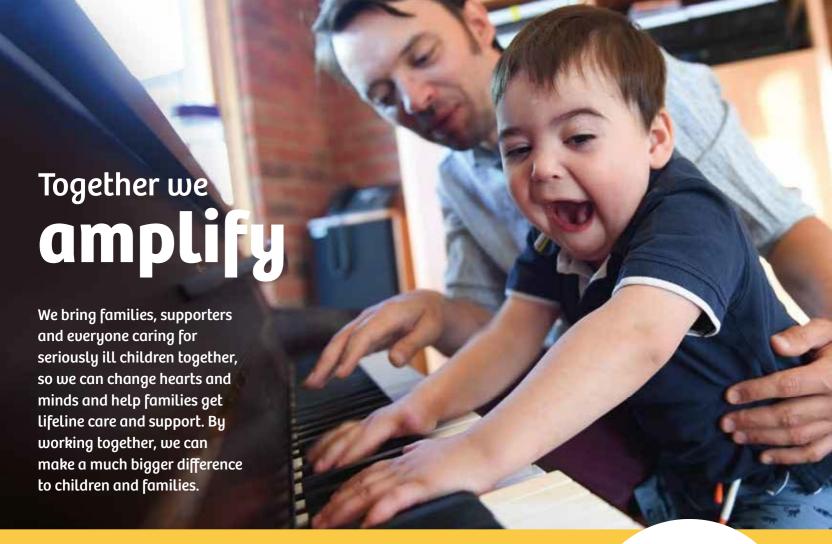


Teaming up with families and professionals

We've come together with professionals and families to shape important guidance that sets out how children's palliative care should be planned and provided, consulting our members on NICE's new guideline on 'End of Life Care for Infants, Children and Young People' and running a series of focus groups with young people. Our feedback to NICE was informed by parents and professionals and ensured that the standard now reflects the vital role of community nurses and the importance of helping families plan for the future when their child's life-limiting condition is recognised during pregnancy.

Reducing the burden for families

Many families facing their child's death have the added financial burden of paying to bury their child, with costs often amounting to hundreds of pounds. This year, we got behind a call led by Carolyn Harris MP to abolish these fees. As a result of the campaign, the prime minister announced that the government would create a funeral fund, enabling local authorities across England to waive these charges. This followed the Welsh Government's decision to abolish child burial fees in 2017. These much-needed changes will have a huge impact on the families of the 4,000 children who die every year in England and Wales, many of whom are forced to face significant financial costs at such a difficult time.



Children's Hospice Week

Our Children's Hospice Week campaign raised vital funds for children's hospices and helped reassure families that lifeline care is available to them. The week was supported by Her Royal Highness, The Duchess of Cambridge, 18 special celebrity friends and 50 hospices and palliative care services. We put seriously ill children and children's hospices in the spotlight – Children's Hospice Week trended on Twitter for six hours. We reached over 61 million people by sharing powerful stories about children, families and hospices in the media – our social media stories reached over 30 million.





A good death is priceless

When families face the heartbreak of their child's death, we want to make sure that every child has the end of life care they need, and a good death. This year we've been working hard, in partnership with bereaved parents and five national

charities, to end a cruel postcode lottery and help families facing the unimaginable to have the best possible end of life care. We shared our ambitions to help every child have a good death at a special Westminster event called Follow the Child.



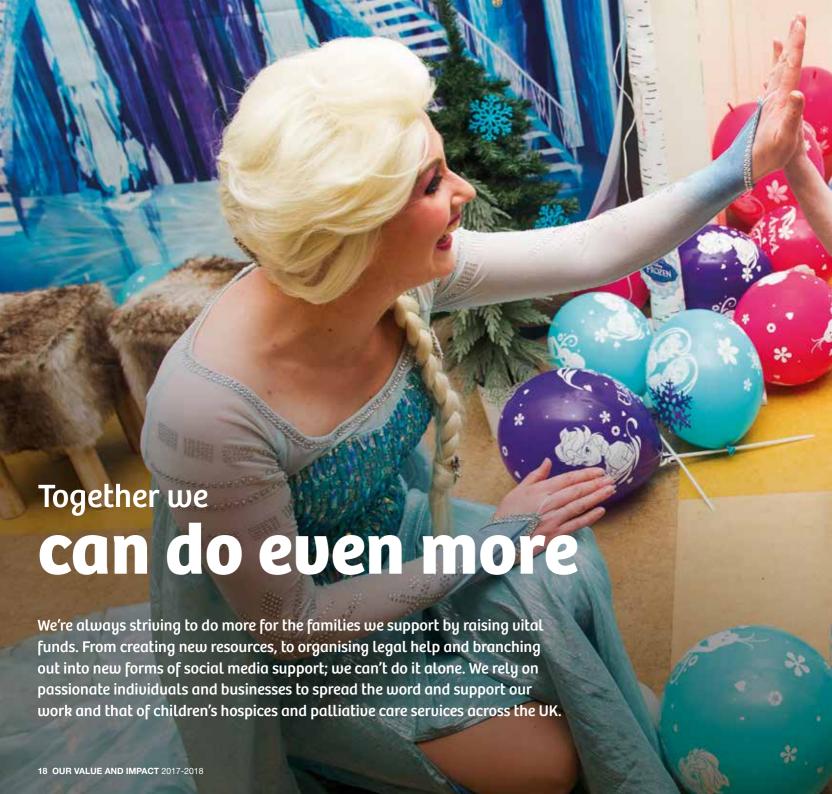
No child or family should ever be left behind

Caring for a child with a life-limiting condition is a 24-hour, seven-day-a-week job, but too many families can't access the out of hours support they need. Our new research exposed that a third of NHS funding bodies in England do not plan and fund community children's nurses to give the specialist care seriously ill children need outside of normal working hours. We worked with BBC Radio 5 Live's team on an exclusive 5 Live Investigates feature, calling for an urgent government review of children's palliative care – generating a media reach of over 39 million.

Hayley, mum to Holly who has a complex life-limiting condition, shared her story to help us campaign for 24/7 care. When it comes to out-of-hours and weekend care, Hayley is left without any support.

"We don't have anyone through the night, we don't really have anyone at the weekend. I'm dealing with lifethreatening situations, and if I make the wrong decision that could have a serious impact on Holly. I feel like I'm trying to do a job, but I'm not given the right tools to do the job, and I feel quite isolated and alone and scared sometimes. I'm not a clinician, I'm a mum. To have that support, it's like when somebody gives you that hug and says, it's going to be ok."

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Making magical moments with Disney

In November, Disney UK and Together for Short Lives launched a festive campaign to raise funds and awareness, creating magical memories for children supported by local children's hospices.

The campaign focussed on activities around two new releases - Olaf's Frozen Adventure and Star Wars: The Last Jedi. Disney leveraged the enormous popularity of the Star Wars franchise and the anticipated new release as a 'force for good', selling official commemorative notes through online marketplace, eBay, to support the charity.

£325,000 was raised across the entire campaign and gifts in kind with a value of over £36,000 were donated to children's hospices across the UK, allowing them to hold a magical 'Olaf's Frozen Adventure' themed party for the families they support.

The collaboration paved the way for a long-term relationship between the brands, and we are enormously proud to have been named as one of Disney UK's strategic partners.

positive shared social experiences." Sara Hanson, Director - Charitable

Programmes at Disney UK

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Pedal power

"I'd reached a milestone birthday (my 50th) and wanted to take on a physical challenge. I had visited the local children's hospice that our Village supports, Charlton Farm, and was extremely touched by both the people using the facilities and the people who worked there."

Andy De'Ath, General Manager at Center Parcs Longleat Forest, who took on a 575km cycle challenge through Route 66 in America.

Picture: Andy De'Ath

Teaming up with legal eagles

Since 2012, legal firm Clyde & Co has raised over £360,000 for local children's hospices and supported hundreds of seriously ill children and their families.

One of the most impactful ways Clyde & Co's lawyers have shown their support is through their pro bono work as part of LawWorks and Together for Short Lives' Advocacy Service: Voices for Families. The project matches Clyde & Co lawyers with families caring for a seriously ill child, offering free legal advice to help them deal with complex issues such as housing, benefits and care packages.

More than a marathon

Loz Braiden and his friends set themselves the ultimate physical endurance challenge to support our work with children and families. Loz, Matt and Ben set off from Paris to cycle the 251 miles to Buckingham Palace in under 24 hours. Arriving with only 9 minutes to spare, they got up the next morning to successfully run the London Marathon.

"Being passionate about the bond I have with Together for Short Lives pulled me across a finish line that I doubted I would reach.

I am so honoured to be part of the Together for Short Lives family and ask anyone that reads this to reach beyond your daily routine and be inspired to give that extra piece of your heart to this very worthy charity."

Loz Braiden





A view from the top

We practise what we preach when it comes to creative fundraising! Our former CEO Barbara Gelb OBE teamed up with Hobbycraft's then-CEO, Catriona Marshall, to tackle an epic cliffhanger challenge.

The intrepid duo made their way to Snowdonia, where they completed a 175ft night climb & spent

the night in a tent suspended from the rock face.

The nail-biting challenge raised over £30,000 for Together for Short Lives.

Sharing the love

We know that practical support is invaluable to families looking after a child with a life-limiting condition – that's why we raised and shared

over £1m

with children's hospices and specialist charities across the UK, the equivalent of

37,800 HOURS

of care for seriously ill children and their families.



We've got the X Factor

Now in its 7th year, our partnership with the X Factor gives us valuable exposure, beaming our work into the living rooms of millions every year.

This time, we were thrilled when our Patron Simon Cowell generously pledged £250,000 to Together for Short Lives and a local children's hospice live on air!



"The James Tudor Foundation was delighted to support Together for Short Lives' series of webinars supporting health professionals and carers of life-limited young people moving through transition into adult services. This is a very difficult time for these young people and their families and anything that helps in making information accessible is a great advantage."



Your support is Life changing

Together for Short Lives wants to make sure that every single seriously ill baby, child and young person and their families gets lifeline care and support. We cannot achieve change for these children and families without your help.

Your support is changing lives. We want to say a huge thank you to each and every one of our generous supporters and funders for helping us do more for children and families. Your generosity, passion and enthusiasm mean the world to seriously ill children and families and the tremendous children's hospices and palliative care charities right across the UK.



How we raised the money



Total

£3,132,244

Fundraising income for Together for Short Lives' work

£1,310,922

Funds raised for member children's hospices and voluntary organisations

£1,640,957

Income from membership, conferences and training

£91,463

Income from investments and other sources

£88,902

Where your money goes

Our national work for children's palliative care

£1,367,945

Raising funds for our national work

£762,316

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

£1,005,252

Working with member children's hospices to raise funds

£448,742



Total

£3,584,255

Thank you to all of our supporters

A D Power Will Trust Anne & Tony Murtagh Arbonne Charitable Foundation Autoglass Baron Davenport's Charity Bayer UK and Ireland **BUPA UK Foundation Burdett Trust for Nursing** Clara E. Burgess Charity Claudia & Evan Breibart Center Parcs Clvde & Co eBay De La Rue Dribuild Edith Murphy Foundation Gareth Neame GREAT Britain Campaign Hall and Woodhouse Hays Hobbvcraft Hoover Foundation Hospital Saturday Fund James Tudor Foundation Jenny Holt Jimmy Knapp Cancer Fund John Ellerman Foundation Leaders MariaMarina Foundation

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"The John Ellerman Foundation are delighted to be supporting the development of Together for Short Lives' new website, which is integral to their work supporting families through difficult times as effectively as possible."

John Ellerman

Charitable Trust



Together for Short Lives

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Thanks to all the families. children's 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).

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Our members

Voluntary Sector Organisation Members

A Child of Mine Acorns Children's Hospice After Umbrage Alexander Devine

Children's Hospice Service

Andy's at St Andrew's Hospice

Annabelle's Challenge 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 Charlie House

CHAS - Children's Hospices Across

Scotland

Chestnut Tree House

Child Bereavement UK Children's Hospice South West

Chin Up

Claire House Children's Hospice

Contact

Demelza Hospice Care for Children

Derian House Children's Hospice

Digital Legacy Association

Donna's Dream House Down's Heart Group

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

Northern Ireland Children's Charity

Hospice Isle of Man -Rebecca House Jack Tizard School

Jessie May

Jigsaw, Cumbria's Children's Hospice

Julia's House JUMP Childrens Charity Keech Hospice Care

Kids Cancer Charity Krabbe UK

Lifelites

Martin House Children's Hospice

MLD Support Association UK Naomi House & Jacksplace

National Association for Palliative Care

Educators Niemann-Pick UK

Noah's Ark Children's Hospice

Children's Hospice Rainbow Trust

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

Sebastian's Action Trust Shooting Star Chase

SOFT UK

Spinal Muscular Atrophy Support UK

St Oswald's Hospice

SWAN UK

Taylor-Made Dreams 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 Muscle Help

Foundation Thomas's Fund Tv Hafan

Zoë's Place Baby

Hospice

Statutory Sector Team Members

Centre for Paediatric Spiritual Care (Birmingham Children's Hospital)

Children and Families Division (Birmingham Community Healthcare NHS Foundation 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

Paediatric Macmillan Team (Manchester University NHS Foundation Trust) Paediatric Palliative Care & Bereavement Support (University Hospitals Bristol NHS Foundation Trust) Salford Diana

Children's Community Nursing Service (Salford Royal NHS Foundation Trust)

Southbank Child **Development Centre** (NHS Greater Glasgow and Clyde)

The Louis Dundas Centre, Oncology Outreach & Palliative Care Team (Great Ormond Street Hospital for Children NHS Foundation Trust) The Royal Marsden

Education and Conference Centre