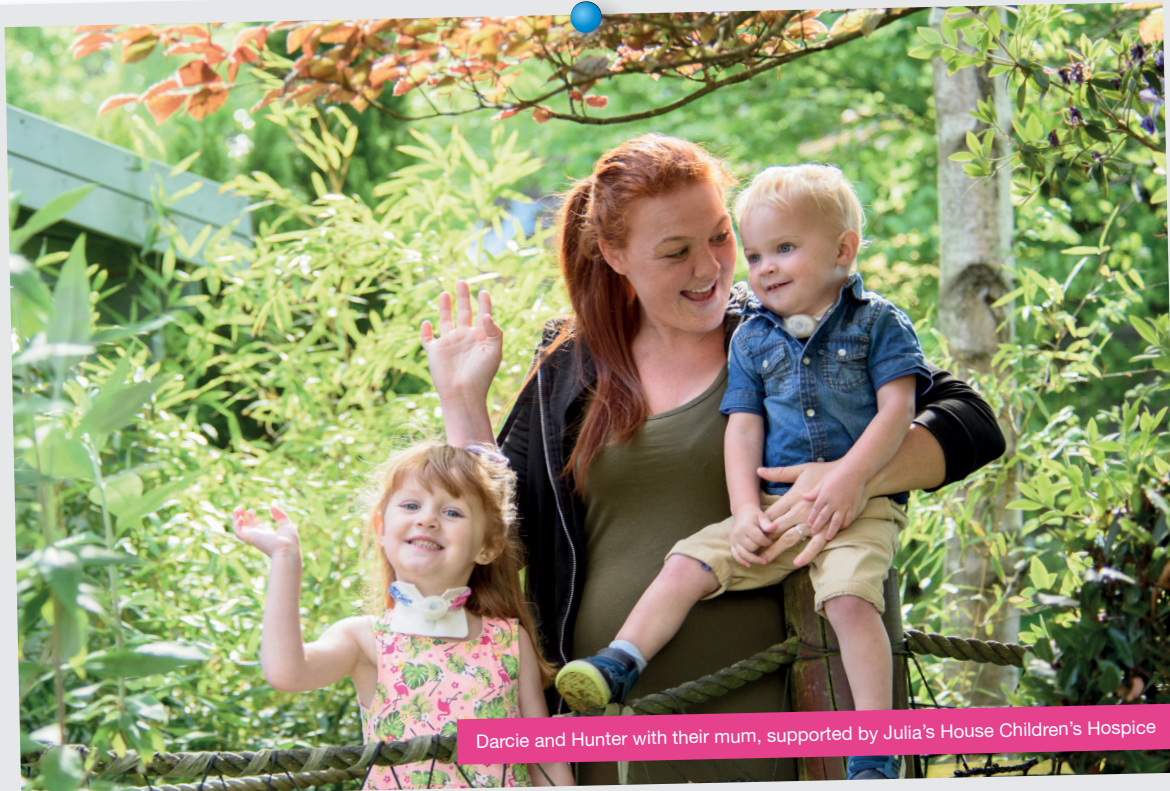


together for families

Issue 26
Spring 2019



Darcie and Hunter with their mum, supported by Julia's House Children's Hospice

Our free Helpline is for any parent, carer or professional who looks after or knows a child or young person who is expected to have a short life.

Open Monday – Friday, 10am-4pm

Outside of these hours, please leave a message and we will respond as soon as we can.

Together for
Families Helpline

0808 8088 100

info@togetherforshortlives.org.uk



If you would like to receive our newsletter by post or email, please contact info@togetherforshortlives.org.uk

Editors: Sara Detzler, Annie Dahl & Clare Cox

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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.

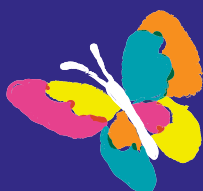
Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is incorporated as a company limited by guarantee (7783702).

together
for
short
lives



Welcome to our Spring newsletter Inside this issue...

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Keep in touch

Call the Helpline
0808 8088 100

Email us
info@togetherforshortlives.org.uk

Visit us
www.togetherforshortlives.org.uk

Follow us

 @Tog4ShortLives

 togetherforshortlives

Peter Andre named Patron

We are thrilled that Peter has become a Patron of Together for Short Lives, as well as Chestnut Tree House.

Peter said "I'm really blown away by the work of Chestnut Tree House and Together for Short Lives. What they do is incredible and I am honoured to become a Patron of both charities." Read the news story here:

www.togetherforshortlives.org.uk/peter-andre-is-our-new-patron



Greatest Dancer presenter named Ambassador

In other celebrity news, Jordan Banjo, member of the world-famous dance troupe Diversity is our new charity ambassador.

Read the news story here:

www.togetherforshortlives.org.uk/jordan-banjo-is-our-new-ambassador



Family Support Hub funding

We're excited to have been awarded funding by Her Majesty's Government (HMG) and National Lottery Players to grow our Family Support Hub and to help reduce the isolation that many feel when looking after a seriously ill child.

The funding will help us reach out to more families through our new online support, helpline and website. Look out for more information coming soon!



HM Government



COMMUNITY FUND



Welcome Hannah

Hannah Davenport has joined our team as Information and Support Assistant, providing information and support to families who call our helpline or email us. Look out for Hannah at Disabled Living's 'Kidz to Adultz' events across the country this year.

Email **info@togetherforshortlives.org.uk** to receive our newsletter via email or if you would like to contribute to future editions.

Sibling support

In this issue we want to shine a spotlight on sibling support, looking at services and helpful resources available.

Over the Wall free camps



The charity, Over the Wall, provides a variety of free camps for children and young people living with serious health challenges, as well as for their siblings and families.

The camps run across the UK and work with Anthony Nolan, Crohn's and Colitis UK and Children's Heart Surgery Fund, as well as many others. If you're interested in this camp, or if you would like to help out, please visit: www.otw.org.uk

Understanding Siblings' Needs

Our factsheet, written with help from Sibs, is for parents or carers with a child who has been diagnosed with a life-limiting or life-threatening condition.

It can be difficult to know how to talk to siblings of a brother or sister about their diagnosis, and this resource is designed to help you start the conversation. It will guide you through how siblings may respond, and how to find the right time, words and approach. The factsheet also provides information about other charities who may be able to help you.

Visit: <https://bit.ly/2UvRxZQ>



Sibs charity for brothers and sisters of disabled children and adults

Sibs is a UK charity for children and adults who are growing up with, or have grown up with, a disabled brother or sister.

Sibs supports younger and older siblings, as well as health professionals – providing information, support and training. Their offer for young siblings, aged 7-17, includes a moderated forum, help from the Sibs team and a variety of support – from help with how to deal with certain feelings to information about disabilities and conditions. If you would like to find out more about Sibs and get in contact with their team, visit: www.sibs.org.uk



Rosie's Rainbow Pantry

Rosie's Rainbow Pantry was set up in remembrance of Rosie, who was 15 years old when she sadly died from cancer.

Her mum and family friends set up the charity for recently bereaved families to receive a weeks' free shopping, delivered straight to their front door. The food can be tailored to each family and is carefully selected so bereaved families can spend less time in the kitchen and more time with each other. If you would like to access this service, please call our Helpline on **0808 8088 100**.

You can read more about Rosie's Rainbow Pantry by visiting: www.rainbowspantry.org

Policy news around the UK

NHS England makes children's palliative care a priority

Together for Short Lives has welcomed NHS England's decision to highlight children's palliative care as an important priority in the new NHS Long Term Plan (LTP).

In the LTP, NHS England pledged to provide a further £7million per year to children's palliative care services, if this is matched by local NHS clinical commissioning groups (CCGs). NHS England currently provides an annual £11million grant just for children's

hospices, but ministers have not yet confirmed whether other children's palliative care services will be able to access this too. While we welcome NHS England's intention to allocate funding for both statutory and voluntary sector children's palliative care services in the LTP, we are concerned that opening the grant out to other services could potentially dilute and reduce children's hospice funding. This could threaten a number of services that families currently rely on.



We would still like the government to increase the Children's Hospice Grant to £25million, bring about parity of funding between children's and adult hospices – and develop a funded children's palliative care strategy. At the very least, we are calling on ministers to protect the £11million grant for children's hospices – and make the additional £14million available to statutory and voluntary sector palliative care services so that they're able to meet the government's end of life care choice commitment for children.

New mobility scheme for children under three expected soon

For several years, we have been campaigning for children under the age of three who rely on bulky medical equipment to be given financial support equal in value to the mobility component of the disability living allowance (DLA) benefit.

Following a pilot project conducted by Motability and Family Fund last year, ministers have stated that they expect plans for a scheme to "significantly increase the scale of this project" will be published in the "near future". We will share news about the scheme when we have it on Together for Short Lives' website and social media pages.

Disability living allowance (DLA) is available to all families who incur extra costs as a result of meeting the additional care and/or mobility needs of a disabled child. However, children can only receive the higher rate mobility component of DLA from three years of age.

Key benefits set to change in Scotland

In April 2018, the Scottish Parliament voted to establish a devolved Scottish social security system. This means the Scottish Government now has the opportunity to decide what benefits are available in Scotland, and how much they should be worth.

In a recent debate in the Scottish Parliament, Cabinet Secretary for Social Security and Older People, Shirley-Anne Somerville MSP, outlined some of the changes that will take place:

- Eligibility for disability assistance will be extended from age 16 to 18 to "allow continuity for families during those crucial transition years."
- Entitlement to winter heating assistance (a £200 lump sum) will be available to the 16,000 children and their families who receive the highest care component of disability assistance.
- An additional payment will be made to the estimated 1,800 Scottish carers who look after more than one disabled child, "recognising the higher costs that they face."

Social security in Scotland is expected to be completely devolved by the end of 2021.

According to The University of Exeter, parent carers are at an increased risk of health problems and often prioritise their children's own wellbeing and health, sometimes to the detriment of their own. The university, in partnership with NHS England and parent carers, have created a programme called 'Healthy Parent Carers' which provides information about simple steps that parents can take daily to improve their health and wellbeing. If you care for a child or young person aged up to 25 with special educational needs and/or a disability, live in Devon, Cornwall or Somerset, and are interested in taking part in this programme, then please head over to <https://bit.ly/2TVCS5N>

Policy news around the UK

Children's Funeral Fund expected in summer 2019

The Prime Minister has announced that the new Children's Funeral Fund will be introduced in July. This will enable local authorities in England to waive the fees they currently charge bereaved families for children's burials and cremations.

Theresa May announced the fund in April last year. However, it is still to be implemented, and we have supported a campaign led by Carolyn Harris, Labour MP for Swansea East, to press the Prime Minister to make good on her commitment. Carolyn, whose son Martin died aged eight in 1989, had already been successful in campaigning for this vital reform in Wales and the Welsh Government began to provide funding for local authorities to waive child burial fees in 2017.

Funding support available from Charities

The Child Funeral Charity (CFC) provides financial assistance to parents who have lost a child aged 16 and under and who need help paying for the essential elements of a funeral.

Referrals are only accepted from a range of professionals who are working with the family and the Trustees judge each referral on its own merit. The CFC funds funerals for pre-term babies up to their 17th birthday and the family must reside in England or Wales. They decide within 48 hours of receiving a referral form. Contributions have ranged from £20.00 to £250.00.

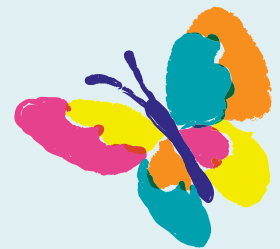
To check your eligibility and to read about the help available: www.childfuneralcharity.org.uk



CHILDREN'S HOSPICE WEEK 17-23 JUNE 2019 MOMENTS THAT MATTER

Children's Hospice Week is our flagship annual fundraising and awareness campaign.

The theme for 2019 is 'Making moments that matter.' Please get involved during the week by sharing moments that mean the world to your family on Twitter by using our hashtag #childrenshospiceweek and tagging in @tog4shortlives. Visit our website to find out more: <https://bit.ly/2wP20Vu>



This year we have two fantastic treks for you or your friends and families to take part in, all whilst raising money to allow Together for Short Lives to continue to support families across the country. Together we Trek London travels 26 miles through beautiful woodland, thriving nature reserves and quieter spaces. Enjoy the unexpected views and chance encounters with local wildlife, such as green woodpeckers and muntjac deer. Together we Trek Cotswolds travels 21 miles through the rolling hills and gorgeous market towns of the Cotswolds area of outstanding natural beauty. Bourton-on-the Water also known as "Venice of the Cotswolds" is the location for the start of our journey before heading through picture postcard villages.

To find out more and to sign up see www.togetherforshortlives.org.uk/trekking



Ethan's story



We had been trying for Ethan, and we were so excited to become parents.

At our 20 week scan we were given the news that Ethan's heart wasn't growing properly, and that doctors could see some worrying abnormalities. Ethan was diagnosed with hypoplastic left heart – the left side wasn't growing as it should be. The doctors laid out our options: we could have a termination, which I didn't want, or we could wait and see what happened. For me, that never translated into, "your son could die". I hadn't even thought about that, and I was still hopeful that everything would be okay. Matt was definitely more realistic about it, he had to tell me, "Anna, this is how it is". In my head I was never losing my child, I was having this baby no matter what.

The hospital arranged for me to be induced. It was quite a traumatic labour, and I ended up being rushed into theatre where they gave me a spinal block. As soon as Ethan came out, there was a team waiting for him. They held him up, to show him to me, then he was rushed off to be examined.

By the evening we knew the situation was worse than we thought. It was so hard for us, and the nurses too, because he looked so healthy – like he didn't belong in intensive care. We were told we might not have much time together, and the hospital staff gave us the option to stay there, or to look into Bluebell Wood, our local children's hospice. I was determined to go there whatever the cost: I wanted for us to spend the short time we'd have together as a family, making memories.

Bluebell Wood was amazing, and surprisingly, it was free. Even though arriving there is a complete blur in my mind, I still remember that everyone

was waiting at the door for us. We were welcomed with open arms and taken to Ethan's room, where they'd built a double bed for Matt and I, so I never had to leave his side.

The biggest thing I remember about Bluebell Wood is that even though we were going through the hardest time in our lives, I have so many lovely, funny, happy memories there. That was down to them. Like, I remember Ethan's first bath. We wanted a few photos, so one of the care team stood on the toilet with the camera! We spent lots of lovely time in the sensory room listening to music and walking around the place with the pram. They're things I would never have been able to do at the hospital.

"I wanted for us to spend the short time we'd have together as a family, making memories."

We spent a lot of time reading to him too, and that's what we were doing when he passed away. The last book I read to him was Peter Pan, and it was fitting really, the boy that never grew up. I could see he was turning blue so we rushed back to his room, where he died in my arms.

The care we've been given since Ethan's passing has been fantastic. The staff at Bluebell Wood have gone above and beyond for us. Angie, the hospice's counsellor, has been a great support and an equally wonderful friend to us. She also runs a bereavement group where we went as a couple to meet other couples who had lost a child. I've made some long-lasting friendships through that, and it's so good to just have other people who understand what you're going through as a mum and dad.

Finding those people is important, because you do lose some people when you go through something like that. Some people just don't know how to behave around you or don't know what to say. I suffered anxiety and panic attacks, and some days I struggled to even leave the house – I was scared of what people would think of me.

Whilst the months following Ethan's death were some of the hardest I've faced, having maternity leave was a blessing for me. It meant I had time to grieve for Ethan and that we didn't have the pressure of needing money. I had the time to think and remember and heal. I'm in a pretty good place now, and I can cope with my grief. Of course, there are days when it gets on top of me and all I want to do is cry, but more often than not I'm okay.

Since Ethan's passing, we've had another baby, Robyn. We named her that because ever since Ethan left us, robins have appeared to us everywhere. They've been a real symbol of comfort for us, and we thought it'd be a lovely connection between Ethan and his baby sister.

I sometimes worry about how I'll explain all this to her – that she has an older brother who can't be with us. She's only three at the moment, but his photos are all over the house and I show them to her telling her, "this is Ethan". We've also got a little memory bear made of his baby grows, called Ethan bear, so I know the questions will start to come soon. That's OK though, because I want him to be part of our lives forever. Whether he's here or not, he's my son, and he'll always be a massive part of my life.

If you would like to share your family story, please email us at info@togetherforshortlives.org.uk

Pass it on! When you have finished reading this, please share it with your family and friends