

together for families

Issue 25
Winter 2018



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

Copyright Together for Short Lives, 2018. The views expressed in Together for Families are not necessarily those of Together for Short Lives.

We are the UK's leading charity for the 49,000 children living with life-limiting conditions, and their families. We are here to ensure that no child or family is ever left behind when it comes to getting vital care and support.

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 Winter newsletter

Inside this issue...

2 Together for Short Lives news

Highlights from the charity

3-4 Families in Action

Hear from some families and the work that they have been involved in

5 Policy news from around the UK

6 Family story

Read Emma's story

Welcome

I am delighted to introduce myself as the new Chief Executive of Together for Short Lives. I took over from Barbara in June, having previously worked closely with her for five years at the charity as Director of External Affairs. In 2015 I left to become CEO of an adult community hospice in Gloucestershire. It's great to be back.

I have been meeting staff and volunteers and touring the UK meeting children's hospices, hospitals, community services and the amazing families they support. We are working on our plans for the coming three years – at the heart of this is making sure we are there for families, through our information and advocacy. We will also continue to press to make sure that there are sustainable local services available to support you, throughout your journey.

Andy Fletcher, Chief Executive



Making Impact

We've got lots to celebrate this year. From family support and empowerment, to big policy breakthroughs and incredible fundraisers, we're so pleased to show you how we've grown in our latest impact report.

This year, we've been working hard to grow support networks for families, answering 31% more calls from families in need and raising over £1,000,000 to fund lifeline support for families in children's hospices and specialist charities.

If you'd like to learn more about how our little team is making a big difference for children & families across the UK, head to <http://togetherforshortlives.ouryear.org>



Remembering Baby Loss

For the annual Baby Loss Awareness Week, we joined up with over 60 different charities and organisations, including Bliss and Sands, to raise awareness and celebrate the memories of babies who have died, and their families. During the week, which runs from the 9th-15th October every year, over 100 buildings are lit up pink and blue to highlight baby loss. Danny and Sam, who only had 19 days with their daughter Lexi, shared their story on our social media channels. On the final night social media was alight with photos of candles and lights for 'The Wave of Light', in remembrance of all the babies lost.



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

Families in Action

In this edition we want to celebrate families who are using their voice and experiences to make a difference and stand alongside others in similar situations.

Bereaved mother's campaign to raise profile of Neonatal HSV

Mum Chezelle lost her baby at 19 days old when he contracted the Neonatal Herpes virus shortly after he was born.

The virus can be transmitted by a person with an active cold sore virus kissing a newborn, or if the mother, with no history of the virus, becomes infected in the last trimester of her pregnancy. Mothers who have a history of the virus are at lower risk of passing this onto their babies due to protective antibodies.

The virus is so rare in babies that doctors failed to notice the seriousness of her son's condition until it was too late.

Since 2012, Chezelle has worked with NHS England to raise awareness of the illness and encourage early detection and management of the virus. Her campaign 'What's In A Kiss?' has had significant achievements, including being the first UK campaign to distribute awareness posters and leaflets to London hospitals and deliver workshop training to Neonatal doctors and midwives. Chezelle has also been a parent advocate supporting NHS



England with the development of new guidelines and frameworks for supporting bereaved parents in UK hospitals. Chezelle has worked hard to ensure that parents are well informed, so they can protect their babies from this deadly virus.

To learn more about Chezelle's campaign visit: www.whatsinakiss.com and watch her powerful film: <https://bit.ly/2AnC42X>



Vicky, volunteer Facebook moderator

We caught up with Vicky, to ask her a few questions about the volunteer role.

Why did you get involved in volunteering?

In 2013, during my teenage daughter's year long battle with an illness which sadly led to her death, I unfortunately was not aware of the support available through online support groups. Leah and I spent 20 weeks away from home, often very far away, receiving treatment for her bone marrow failure. She was usually nursed in isolation. After Leah died I heard about Together for Short Lives and the excellent work that they do in supporting families who have children and young people with life-limiting conditions. In 2016 I started volunteering with them, via the Family Reference Group, I also put myself forward to be a volunteer parent moderator for their Facebook support group for parents/carers of children with life limiting conditions.

What have you got out of the role?

Although this support group was not available when Leah was ill, it's important to me to ensure that this support is available to other parents who are in a similar heart-breaking situation. Being involved has also enabled me to contribute to the future of good quality end of life care: my recommendations, based on my experience, were included in the 2016 NICE Guidance for End of Life Care for Infants, Children and Young People.

Join our Families Together Facebook Group by emailing info@togetherforshortlives.org.uk



Voicing family experiences

Mum Carly Hadman, shared her family's journey at The Nutcracker Ball in November. Her beautiful daughter, Effie, sadly died in early 2017.

Carly says: "When Effie was three, we found out that she had Late Infantile Batten Disease. We had already accepted that Effie's life may be different, but with her diagnosis we knew that Effie's future was stark. Together for Short Lives was there for us, when we felt lost. They were there to listen, to help find the care that was right for Effie and our family and connecting us with other families through their safe online forum."

"Sharing our story at The Nutcracker Ball is really important to us as a family as it is a lasting legacy to Effie. Together for Short Lives was there for us when we felt lost and so I want to help raise awareness of the vital work they do."



Families in Action

Blogging mums

Nikki Lancaster, mum to Lennon Ruffles who died last year from complicated health disorders, blogs about her experience as a mother of a child with a life-limiting illness.



She uses this platform to encourage other families in the same position as her, as well as sharing her own thoughts and feelings. Nikki is an ordinary mum with two lovely children and a busy life; but blogging is her escape, where she can take five minutes a day to give her thoughts and feelings an outlet. Read her powerful blog, titled 'Living with Lennon' here: <https://livingwithlennon.com/blog/> and follow her on Twitter: @LivingwithLen5.

Rosie's Rainbow Pantry

Louise is a mother of four to Sam, Megan, Rosie and Ellis. Rosie sadly passed away aged forever 15 in 2017. Louise set up Rosie's Rainbow Pantry to help parents at the most difficult of times, when their child is coming to the end of their life and when families become bereaved.

The charity provides food delivered by a supermarket to help families through this difficult time.

Rosie had a battle with cancer lasting many years and as part of her wish to give back and to help people, she raised thousands of pounds for charities, for which she was recognised with several prestigious awards. Rosie's Rainbow Pantry very much embodies the spirit of Rosie.

"In the last few weeks of Rosie's life we were lucky to have a fantastic group of friends who would bring us shopping and meals. At the time our attentions were on Rosie and our other children and food shopping was just not a priority. It wasn't till after Rosie passed away we really appreciated what our friends had done for us and wondered about families who didn't have a support network. This is what gave me the



concept for the charity, which helps us continue Rosie's legacy."

The charity is run by Louise and a group of Rosie's family and friends.

A weeks' worth of food shopping is delivered to your house or available to collect from your local Click and Collect Tesco store. The food the families receive enables them to spend less time in the kitchen and can be tailored to the family. Sweets and chocolate spread are also included, which were Rosie's favourites.

If you would like to access this service, please contact: info@togetherforshortlives.org.uk or call our helpline on **0808 8088 100**.

You can read more about Rosie's Rainbow Pantry here: <https://rosierainbowpantry.org>

New programme launched for parent carers

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. This programme has received a lot of support from parent carers, with one parent saying:

"Taking a moment to notice something else, something beautiful, helps you switch off from the things you worry about".

If you care for a child or young person aged up to 25 with special educational needs and/or a disability, and would like to take part in this programme to look to improve your health and wellbeing, then please head over to <http://sites.exeter.ac.uk/healthyparentcarers/taking-part/> for more information or email healthyparentcarers@exeter.ac.uk or ring the programme organisers on **01392 722 968**.

This programme is only available for parent carers who live in Devon, Cornwall or Somerset.

Healthy
PARENT CARERS

Policy around the UK

Over 6,500 call on the Prime Minister to #FundNotFail seriously ill children

On 12 September, we delivered a petition to 10 Downing Street.

The petition, signed by 6,670 people, called on the government to use some of the £20billion NHS funding boost announced in June to increase the NHS England Children's Hospice Grant to £25million, provide parity of funding between children's and adult hospices, and put in place a funded children's palliative care strategy. If you were one of the 6,500 – thank you! The petition is having a big impact in helping us to secure meetings with MPs and motivate them to take action on your behalf.

Kirsty Murray, whose daughter Ella was just three months old when she was

diagnosed with a rare genetic disorder called Miller-Dieker Syndrome – helped launch the campaign to recognise the care she received from West Midlands charity Acorns Children's Hospice.

Kirsty said, "I am delighted that thousands of others have joined me in calling on Theresa May to increase statutory funding for children's palliative care services. Acorns were amazing and helped us to give Ella the best quality of life, whilst supporting us as parents.

But the funding that services like Acorns receive has been falling in real terms. If this continues, I am deeply concerned that other families like



ours will not receive the vital care and support that will keep them going and will not have the choices available to them for their child's end of life care."

Kirsty delivered the petition, alongside the CEO of Together for Short Lives, representatives from the children's palliative care sector, MP Catherine McKinnell and Baroness Brinton. Since then, MPs at Westminster have also joined the campaign, with many signing Early Day Motion (EDM) 1564, which asks the government to take the action we set out in our petition, and asking questions in Parliament.

Cross-party report calls for choices for children at end of life

The All-Party Parliamentary Group for Children Who Need Palliative Care, a cross-party group of MPs and peers at Westminster, has published a report following its inquiry into the government's end of life care choice commitment for babies, children and young people in England with life-limiting conditions.

Through their commitment, ministers have outlined six ways in which people of all ages who need palliative care should be supported. The government is very clear about the care and support that children with life-limiting conditions should receive.

Despite this, evidence gathered by MPs and peers from young people, families, services and professionals has shown that children are being let down by a patchy system that varies from area to area. Their report has highlighted five areas of concern, including access to out of hours support, specialist medical care and short breaks for respite. The APPG

calls for action on children's palliative care funding and the workforce available to deliver care – and for the commitment to be included as a priority in the NHS's new 10-year plan. Without this action, ministers run the risk of failing to meet their commitment by 2020.

Nikki Lancaster, (see Nikki's story on page 3) a parent who helped to advise the inquiry after caring for her son Lennon, says:

"To give Lennon the quality of life we wanted him to have, we depended on a network of services. For families like mine, high quality children's palliative care is essential. Without it, we just

couldn't have survived. We need the Government to fulfil its commitment and help children and families make the most of every minute".

We're now inviting the public to ask their MP to take action in parliament. Visit www.togetherforshortlives.org.uk/appg to find out more.

There are lots of ways for families to get involved in our campaigning for children's palliative care. It could be as simple as writing to your local MP, or arranging to visit them at a constituency surgery. Visit www.togetherforshortlives.org.uk/campaign to find out how to get involved.

NICE are looking for lay people to join their committee that will be looking at babies, children and young people's experience of health care. To qualify you must have used the NHS services sometime in the last two years. To find out more information, please visit: <https://bit.ly/2zWUTJ0>. Closing date is 5pm, Wednesday 12th December 2018.



Family story



Children's hospices provide care for all the family. Emma Harwood shares her story of finding out about her daughter Shalome's disorder, and how Forget Me Not Children's Hospice were there for them as they faced the unimaginable.

"It all began at the 20-week scan. We went to the scan hand in hand, excited to hear the baby's heartbeat and maybe find out the gender. Our first pregnancy had been normal, and it didn't really occur to us that this was actually an anomaly scan.

During the scan, the sonographer told us they couldn't find part of the baby's brain, and from the silence, it was obvious that something was up. After a day of being passed between professionals we were referred to a specialist women's foetal medicine unit, to go for a more detailed ultrasound. The scan confirmed our worst nightmare. Our child's brain hadn't formed properly: she had Holoprosencephaly and was, according to the doctors, "incompatible with life".

We were given a number of options to consider. Our faith cemented our decision to continue with the pregnancy.

Following even more scans we were told she might make it to term, and may even survive birth, but we were told we wouldn't have long with her. She'd be vegetative, and completely paralysed.

We couldn't get our heads around that, and we were particularly concerned about our daughter Faith, our eldest, who would be 18 months if the baby

was born at full term. Were we going to introduce her to her sister, knowing she would probably die very soon after birth? That was the biggest pull on our hearts, because for us we were choosing our journey, we were deciding what would happen. But for Faith, she had no choice. We were imposing our choice on her. As parents, we wanted to protect her and shelter her from everything.

At 38 weeks, we were referred to Forget Me Not Children's Hospice by a screening nurse who chased us down the corridor to tell us about the charity. We went for a first visit while I was still pregnant, and fell in love with the place and its amazing staff. It was great just to have a telephone number to ring anytime we wanted.

"We spent Shalome's first week of life at Forget Me Not Children's Hospice making memories and they are an ongoing part of our lives."

Against all odds, Shalome survived birth and has defied all expectations. She's spastic quadriplegic, and has locked-in syndrome, but on her good days – she's happier than my healthy four year old! Although there are challenges, Shalome is one of the longest surviving children with her condition and there's certainly quality of life there that we'd never expected. So much joy has come out of Shalome's life, especially for her big sister, Faith. It's given her life a depth of meaning that very few four-year-olds would have.

We are blessed in getting support from lots of great organisations. We've also found lots of useful information from Together for Short Lives.

"Their family newsletter, Together for Families, showed me that our family isn't alone, and opened up a network of families in a similar position."

This is invaluable, and it gives me the time I need to get my head around everything.

Looking to the future, we're hoping to grow our family. We know that Shalome won't be with us forever, and we're not oblivious to that, but our faith gives us hope and a comfort for the future."



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

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