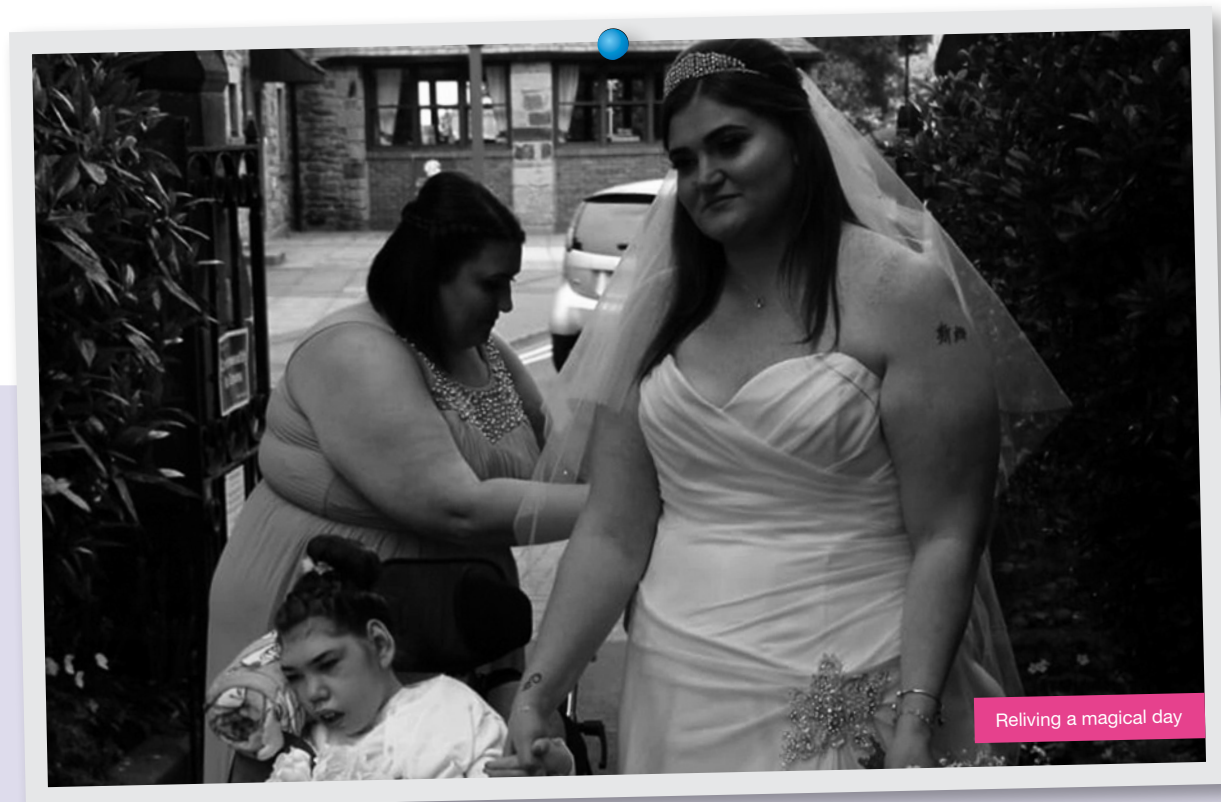


together for families

Issue 27
Summer 2019



Reliving a magical day

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



You can also access our free legal advice service by calling the helpline.

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

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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



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Win a Center Parcs family break

We have kindly been donated some short breaks for families. Register to become a Family Expert or Young Expert, as detailed on this page, to be in with a chance to win a family break to Center Parcs. Read our Terms and Conditions here:

<https://bit.ly/2Nysbli>

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

You're the Expert

No one knows what family life is like caring for a very ill child, better than you.

That's why we call the people who generously give their time to help us and those who work in the palliative care sector 'Family Experts' – reflecting all your knowledge and lived experience. And we need more experts!

If you're a parent, carer or family member of a child with a life-limiting condition please join our mailing list and become a Family Expert.

We will email you opportunities to shape our work, participate in research, and take part in consultations. There's no minimum time commitment and no obligation to take part in everything.

Take part in a family chat

We are hosting a series of online family chats this Autumn for parents and carers of children with a life-limiting condition – giving you the chance to tell us what you think and get support from other parents.

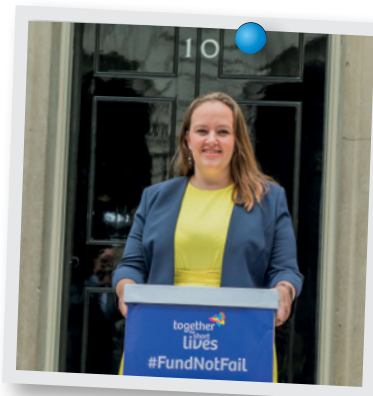
There will also be an expert on hand to answer any difficult questions. Topics we're going to cover are:

1) Making Memories: Guided by a play specialist, this will look at creative ways to make memories with your child. We have some special Hobbycraft goodies to give away as part of this session too!

2) Advance Care Planning: Making choices about your child's future care. This session will be delivered by a medical professional with plenty of opportunities to hear other parents' experiences.

3) Getting the right support for your family: Learn about the role of a social worker and share experiences about the highs and lows of securing support for your family.

Find out more and register: <https://www.surveymonkey.co.uk/r/DPZJZ23>



We'd love to hear from young people too – sharing experiences as a 'Young Expert'.

To get involved sign up to be a Family Expert at <https://bit.ly/2wFDinr> or get in touch with info@togetherforshortlives.org.uk if you would like more information.

A hop, skip and a jump to support us

Lots of families have been asking us what they can do to fundraise for Together for Short Lives recently.

The short answer is anything!... let your imagination be the guide. From the London Marathon to skydives, we have a range of challenges online to tickle your fancy, but if baking a banana bread or skipping to school is more your bag – we'll support you with that too. Just contact events@togetherforshortlives.org.uk to find out more.

And if you're looking for inspiration, look no further than marvellous mum, Sarah. Her little boy, Toby, has dystonic cerebral palsy and she wanted to get active to raise money in his honour. And so she found herself running the marathon!



"It was such an amazing experience to be able to run the London marathon for a charity that is very close to my heart."

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

Moments that matter

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

Children's Hospice Week is the only week in the year dedicated to raising awareness and funds for children's hospice and palliative care services across the UK, and the seriously ill children and young people they support.

2019 saw a bumper week of activity – building on the theme for this year's campaign 'Moments that matter', we teamed up with families and professionals to shine a light on services that help families create important moments in their lives together.



Her Royal Highness, The Duchess of Cambridge, as Royal Patron for EACH, sent a message of support to celebrate and mark Children's Hospice Week.



Mum, Gabriella, shared her story of how her family were supported by Forget Me Not Hospice and called on the public to sign her open letter to NHS England to ensure other families like hers can access vital support.

Peter Andre, Together for Short Lives and Chestnut Tree House Patron, joined families to create some very special memories together.



Shailza introduced us to nurse, Sarah, who helps her family create special moments.

"Sarah has become like part of our family. While I do sometimes use her three hour weekly visits to have some time to myself, on other occasions we plan to take the boys out. I can't manage to take both of them out on my own so we might plan a walk or a swimming trip. I am determined to give the boys as much quality of life as I can and they really enjoy these trips out and they absolutely adore Sarah."



Your questions answered

Tackling misconceptions has always been an important part of our work. It's our responsibility to ensure that families across the UK have a full picture of what children's palliative care is, and how it works.

We asked some experts from Children's Hospice South West as well as some experienced staff at Together for Short Lives some questions that you gave us. Here's what they said:

We are apprehensive about leaving our child when using the hospice, is this normal?

We encourage families to do what they want to do; the split is about 50/50, some parents like to go off and have some time out whereas others want to stay with their children all day.

What would we do all day on a respite visit?

We start by asking you what you want to do, you're welcome to use all the facilities including hydrotherapy pool, sensory room, and messy play areas. We also have a lounge where you can relax and enjoy some time together as a family.

Do the nurses cry?

Yes, sometimes nurses cry. We do feel sad and upset when a child dies, or a family is going through a particularly challenging time in their journey.

If my child dies in a hospice how long will I be allowed to stay with them afterwards?

Up to one week afterwards but this can vary between hospices.

What are your visiting hours?

Our hospice doesn't have visiting hours, we want to be your home from home, all the family are welcome to visit.

Any suggestions on how to encourage my child to see going to the hospice as a good thing to do?

The best thing to do would be to talk to your hospice team and ask them to meet with your child and find out what his interests are and what he would like to do when he is there. They may be able to arrange his stays so that other young people with similar interests are there at the same time or organise activities or outings with him.

Thank you to each and every one of you who helped to make Children's Hospice Week 2019 so special.

Holiday help

We take a look at three organisations providing specialist holiday support to families caring for a seriously ill child.

Donna's Dream House

Donna's Dream House Charity is based in Blackpool and provides free holiday experiences for children and teenagers with life-threatening illnesses and their families. Families can either refer themselves with a nomination form or they can be nominated by a professional supporting them.

Also part of Donna's Dream House is the Snowdrop Centre – offering free short breaks for bereaved families,

up to two years following the death of a child. Again, Families can either refer themselves with a nomination form or they can be nominated by a professional supporting them.

Families will also receive a selection of discount vouchers and passes for some of the local attractions when available, to use during their stay.

Contact len@donnasdreamhouse.co.uk for more information regarding eligibility criteria or visit the website: www.donnasdreamhouse.co.uk



Everything Ellie

Everything Ellie hopes to make every day a 'blue sky day' by providing a simple day at the seaside for seriously ill children and their family.

Their beach hut at Saunton Sands Beach, North Devon gives the chance to relax & take in the view. Ready equipped with windbreaks, deck chairs, picnic table, buckets, spades, ball games, blankets and body boards so all you need is you, your family, your dogs (if you have them) & a packed lunch to enjoy the day.

June 2019 also sees Ellie's Lodge – a six person self-contained Lodge with all home from home equipment – opening at Stowford Farm Meadows, providing short holidays for families from the South West. Referrals can be made through a consultant, school, hospice or social worker.

Find out more at www.everythingellie.co.uk

More details about other free short breaks, as well as grants, can be found on the Together for Short Lives Website: www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/short-breaks-holidays/



Jumbulance

The Jumbulance Trust was formed in December 2001 to provide specialist transport for people who are disabled or living with a life-limiting condition to give them the opportunity to travel on holidays throughout the UK and Europe.

The Trust provides vehicles and drivers at subsidised rates to regional groups, schools, disabled community groups, care homes, hospices and individuals around the UK and Ireland.

A Jumbulance is a luxury coach/ambulance which offers equipment for those who need extra safety, specialist medical attention, accessible facilities and comfort – who would find it difficult, if not impossible to travel by other means of transport.

While many trips are organised by groups and services who can take their own medical and care staff, it is possible for other groups or families to hire the Jumbulance too. Although there is a cost involved, it may be that there's an opportunity to join a group who use a Jumbulance near you. To find out more, email info@jumbulance.org.uk or call **01582 765423**.

Emma went on a Jumbulance holiday:

"Jumbulance offered me my first experience to have a holiday abroad. Austria was a beautiful place to explore, the week was full of fun and laughter. Everyone was supported as much as they needed and I was supported with all aspects of my conditions whilst having a fantastic time. It felt like a big family, ensuring no one ever felt left out, full of brilliant experiences and laughter. I would recommend a Jumbulance holiday to anyone, they are truly one of a kind."



Need to know

Victory for Children's Hospice funding campaign

Together for Short Lives has welcomed NHS England's decision to ring-fence £25 million of NHS funding to support children's hospices by 2023/24, increasing annually from this year's level of £12 million.

Great news, considering in June 2019, Together for Short Lives published new research on statutory funding for children's hospices in England which revealed that NHS and local council cuts are hitting lifeline hospice care for seriously ill children.

This pledge will take pressure off children's hospices and better enable them to plan and deliver vital care and support to some of England's most seriously ill children. The funding will come directly from NHS England and will no longer rely on match funding from clinical commissioning groups (CCGs), which is very good news for those delivering children's hospice care across England.

NHS England also says that it recognises that palliative care services provided by children's hospices are currently not universally available. It plans to carry out a needs assessment to understand whether additional investment nationally or from CCGs is required where children's palliative care is provided by other, non-hospice services.

NHS England's decision follows Together for Short Lives' long-term campaign which has been widely supported by children's hospice organisations, families caring for seriously ill children, bereaved families and thousands of the charity's supporters. **The All-Party Parliamentary Group for Children Who Need Palliative Care** has played a key role in raising this issue with ministers in Parliament.

Thanks to all who got involved. We did it!

Ask the government to #GiveItBack and increase funding for care for disabled children

The Disabled Children's Partnership (DCP), of which Together for Short Lives is a member, is asking you to add your signature to a letter calling on the chancellor to give back the £434 million of support owed to disabled children and families.

Every day, disabled children are missing out on £1.2 million of support from authorities. This is preventing disabled children from living their best lives and means families are incurring greater costs for health and social care in the long-term.

Vickey, a parent carer, has written to the chancellor asking him to take action to address the shortfall in funding for social care for disabled children and their families. You can add your name here: <https://secure.mencap.org.uk/en-gb/give-it-back>

Child Funeral Fund available now

The Child Funeral Fund, which Prime Minister Theresa May committed to in April 2018, was launched on 23 July.

The fund will relieve bereaved parents, guardians or carers of the costs of the burial or cremation of a child under the age of 18, in addition to certain expenses.

Fees and expenses will be met instead by government funding with providers (burial or cremation authorities and funeral

directors), claiming the fees and expenses they would have otherwise charged to families from the new fund.

We have been part of the campaign to introduce the fund and were one of several organisations to brief MPs ahead of a Parliamentary debate on the Child Funeral Fund on 1 May.

The Child Funeral Fund applies in England. Similar schemes are already in place in Wales, Scotland and Northern Ireland.

Disability living allowance update

At the beginning of July Motability announced that they would 'accelerate' their support for a new project to give vehicles to children under the age of three who rely on bulky medical equipment. An announcement on the details of the scheme, which follows a pilot project conducted by Motability and Family Fund last year, is expected soon.

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. Currently, children can only receive the higher rate mobility component of Disability Living Allowance (DLA) from three years of age.

We will share updates on the scheme when we have it on Together for Short Lives' website and social media pages.





Meet Laura, Jessica's mum and hear about her big day

This Children's Hospice Week we uncovered a really heart-warming story that's a little different from the family stories we usually share with you, but really shows what truly special moments can be created when family, community and services pull together and go above and beyond.

It's fair to say that many families will relate to mum, Laura's words – with the greatest will in the world from the people around you, mums and dads very often find themselves alone caring for their very ill child, because practically it is simply the only option.

Jessica Gray, aged 10 from Cramlington, Northumberland, has been supported by St Oswald's short break children's service since 2010. Jessica has complex health needs including cerebral palsy, epilepsy, scoliosis, respiratory needs and is registered blind. The support St Oswald's provides to Jessica and her family is an absolute lifeline – they do not have to feel alone all the time.

Talking about the support the family receives all year round from the Hospice, Jessica's mum, Laura, says:

"Jessica is cared for at the hospice for four nights a month. She absolutely loves her stays, her face lights up every time because she recognises the sound the doors make when they open. There's so much she enjoys – trips out, sensory activities, music therapy and the therapy pets that visit.

"Without St Oswald's support I don't think our wedding would have been possible."

And for me, I get time to relax. If Jessica is at St Oswald's over the weekend I sometimes go out with friends, which would be impossible without the hospice's support."

Last year, St Oswald's found out the exciting news that Jessica's mum, Laura, and her husband, Richard, were preparing to tie the knot in June. They knew that even the simplest of trips or plans could be a logistical nightmare for the family and so wanted to help to make their wedding day extra special.

Staff from St Oswald's helped to take care of Jessica in the run up to and at the wedding so that the couple could make the most of their special day – enjoying it together as a family.

Laura said: "Without St Oswald's support I don't think our wedding would have been possible. The day before the wedding I took Jessica to the hospice. This meant that I could do things like get my nails done and pick up my dress, like every other bride would do. On the day of the wedding, one of the members of staff even stayed late after her night shift so she could do Jessica's hair. Staff brought her to the wedding, and in the evening Jessica was brought back to the hospice to be cared for. The staff went over and above to help and I don't know where we'd be without them."

"My daughter needs a lot of support. I get a lot of emotional support from my family but physically, Jessica's needs means it is very difficult for anyone other than me to support her."



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