together for families

Issue 24
Summer 2018

Vivien and her family, Havens 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

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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).

Welcome to our Summer newsletter

Inside this issue...

CEO Barbara Gelb retires

We would like to say goodbye to our CEO Barbara Gelb OBE, who has retired after 16 years at Together for Short Lives and prior to that, Children's Hospices UK.

Barbara was instrumental in establishing Together for Short Lives and was awarded an OBE in in 2015 in recognition of her services to improving palliative care services for children. An example of her dedication was the Cliffhanger challenge, which involved climbing 175ft in the dark and then sleeping in a tent overhanging Snowdonia, to raise £30,000 for our work. Barbara will be replaced by Andy Fletcher, who has been CEO of Longfield Hospice since 2015 and was Director of External Affairs at Together for Short Lives, prior to this. We wish Barbara the best of luck on her retirement – she will be missed.

Complete our survey (**https://bit.ly/2Ncrdws**) to be entered into a prize draw to **win an off-peak* family break to Center Parcs**.

Nicola Parry Photography

New website

Have you seen our fantastic new website?

It is now quicker to find new resources and easier to keep on top of upcoming events. Have a look and let us know your thoughts! **www.togetherforshortlives.org.uk**

Talented Magician named Ambassador

We are very excited that world-class celebrity Magician, Mind Reader and winner of ITV's Britain's Got Talent, Richard Jones, joins our team as ambassador. Read the news story here: **www.togetherforshortlives.org.uk/richardjones**

Keep in touch

Call the Helpline
0808 8088 100

Email us
info@togetherforshortlives.org.uk

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

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*The off-peak family break will be outside of school holidays. T&C's apply on our website **www.togetherforshortlives.org.uk/cp18**

On going care

Teaming up to tackle transition

Together for Short Lives has joined forces with the Bupa UK Foundation to create a body of digitally responsive and easy to use resources, designed to guide young people and their families through the move to adult services, a process known as transition.

Our ***Transition factsheet***, available online and in print, provides an insight into what a good transition to adult services looks like, and how you can achieve it. To ensure the best person-centered care is possible throughout the process, there are informative sections on health, education, housing and employment showing what plans must be in place. The factsheet also covers planning, national variations on care provision, and benefits.

Our second resource, ***A checklist to a good transition***, is designed to help seriously ill young people to assess how well agencies involved in their education and care are working together, to enable a smooth transition. The checklist focuses on empowering young people to play an active role in planning and decision-making, whilst acknowledging the ongoing role parents and carers are likely to play in their care.

Our third resource, the completely digital ***My care transfer***, focuses on ensuring good communication with care professionals. We often hear from families that admission to hospital can be made more stressful when key information is lost, so we've created a resource where families can keep everything from personal care preferences, to daily routines and emergency care plans, right at their fingertips. The resource is accessible through our website, and families can print, send, save or update their information whenever they need to.

We couldn't create these resources without the valuable insight and time provided by the families who guide, critique and test our resources. Thank you for all your help and to the Bupa UK Foundation for their fantastic and generous support!

Multisensory Toys for children

National charity SMA Support UK have free multisensory toy packs available for babies newly diagnosed with SMA Type 1 or SMARD (Spinal Muscular Atrophy with Respiratory Distress).

The packs include items that provide visual, tactile and auditory stimulation designed to offer entertainment during the day, fun at bathtime and comfort at bedtime. The packs can be delivered by an Outreach Worker in conjunction with a home visit.

To request a pack or to get in touch with SMA Support UK, contact their Support Services team by phoning **01789 267 520** or email **supportservices@smasupportuk.org.uk**

Legal advice and support

Voices for Families is an advocacy service where families needing advice or support can be introduced to volunteer lawyers by phone or at a growing number of children's hospices.

We work with LawWorks, the charity arm of the Law Society, who provide a dedicated member of staff to match families with legally trained advocate volunteers to provide dedicated support to help families with specific problems they may be facing.

What is advocacy?
Advocacy is simply helping to get your voice heard. An advocate can ensure you get the support you're eligible for and represent you to ensure your views are genuinely considered.

Voices for Families will match you with an advocate who has legal training. They can act on your behalf, give you information and tell you about your rights to ensure you get the help and support your family needs. They can also help you explore your options if you want to challenge a decision made about your family – issues such as housing, adaptations or care packages – and will help you to express your wishes and concerns.

How can advocacy help my family?
The Voices for Families advocates can help you understand the law and your rights, as well as helping to ..helping to make complaints and draft letters.

Families have told us that having the support of a legal advocate often gets their issues heard and resolved faster. Read the Williams' family story on page 6 on how Voices for Families have helped them when their care package was stopped.

To access Voice for Families, call our Helpline on **0808 8088 100***

*The service is free to those with children under 25yrs. It is not able to assist on immigration or medical care issues.

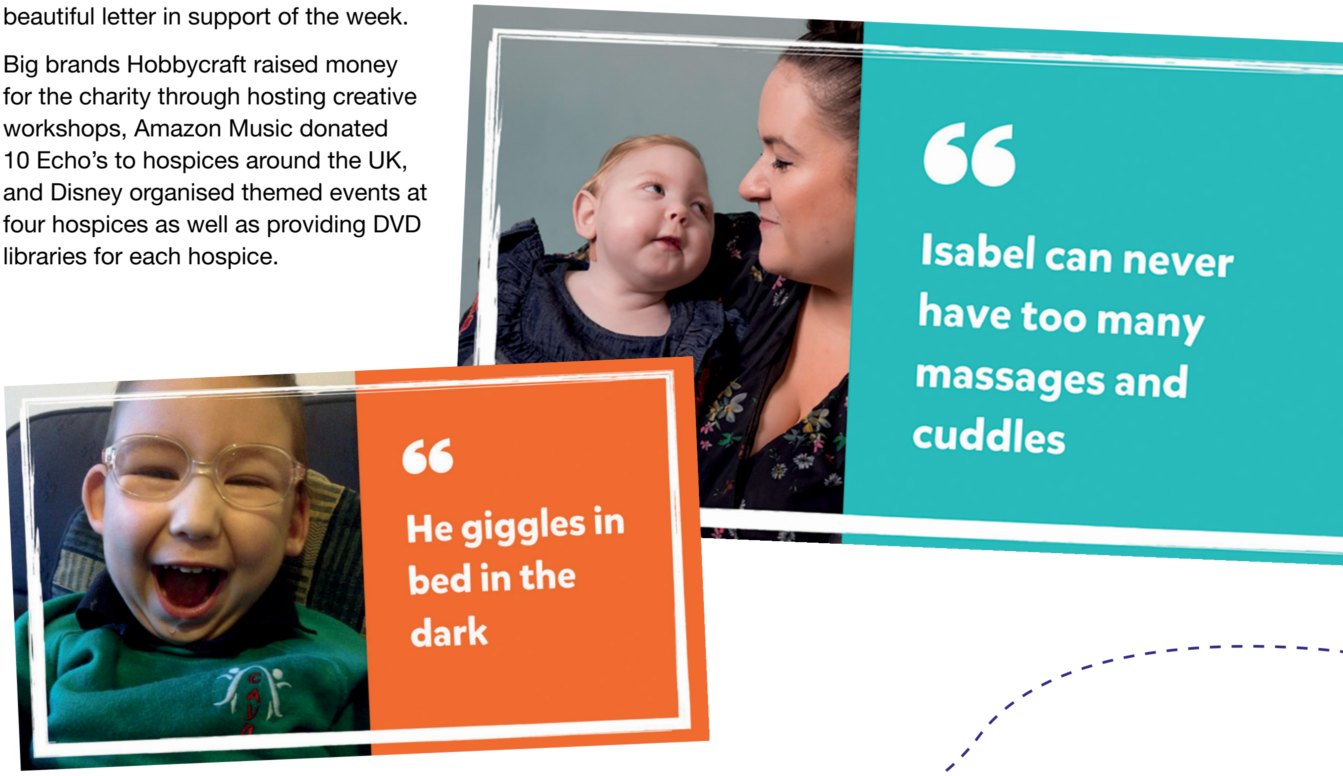
Children's Hospice Week 2018

Our focus for Children's Hospice Week this year was to raise awareness through the theme of 'Life's short' by sharing moments that matter to families and young people. Thank you to all families who shared moments – we loved seeing what makes you happy!

We were so pleased that our celebrity patrons got involved with the campaign. Our patron Simon Cowell appeared on Loose Women, talking about how visiting a children's hospice for the first time was truly life-changing.

Holly Willoughby shared a video of the moments that matter to her, and HRH The Duchess of Cambridge wrote a beautiful letter in support of the week.

Big brands Hobbycraft raised money for the charity through hosting creative workshops, Amazon Music donated 10 Echo's to hospices around the UK, and Disney organised themed events at four hospices as well as providing DVD libraries for each hospice.



Do you have a Superhero in your family?

We've got the perfect family challenge for you! There are two annual events to choose from: Superhero Tri on 18 August, and npower Winter Wonderwheels on 2 December. Find out more: **http://superheroseries.co.uk**

Policy news around the UK

Child burial fees scrapped

In May, the Scottish Government announced that bereaved parents will no longer be charged by local authorities to bury their children.

They have committed £500million to pay for the fees, helping to mitigate some of the financial pressures that hundreds of Scottish families face at such a difficult time.

This announcement follows similar changes in England and Wales. During a speech in the Welsh Labour conference in 2017, Welsh Government First Minister Carwyn Jones AM announced Wales would be scrapping burial and cremation fees. The Prime Minister similarly intervened to establish a Funeral Fund in 2018, meaning all fees will be met by the government funding.

The Northern Ireland government is now the only UK government yet to scrap fees for child burials.

Campaigning for short breaks funding

Together for Short Lives is a member of the Disabled Children's Partnership (DCP), a major coalition of more than 60 organisations campaigning for improved health and social care for disabled children, young people, and their families in England.

On 19 April, parents and members of the DCP delivered a petition to 10 Downing Street calling on the government to increase funding for vital short breaks services, receiving over 3,780 signatures.

Our call came as more and more short breaks services up and down the country are closing or being threatened with closure. Parents are having to take drastic measures such as fighting through the courts or organising protests locally to stop the closures.

On 10 May, NHS Hertfordshire Valley Clinical Commissioning Group (CCG) voted to close the Nascot Lawn Centre for severely disabled children. On 21 May, we issued statements as the DCP calling on Worcestershire County Council and North Yorkshire County Council to protect overnight short breaks services under threat of closure.

If you would like to join the fight for better short breaks funding, or campaign on any of the other vital issues affecting disabled children, sign-up to join the DCP mailing list at **https://support.disabledchildrenspartnership.org.uk**

DCP Quality of Survey results

This year, the DCP asked family members of disabled children to share their views on the quality of health and social care services over the last few years. The results are saddening:

- **64.9%** of family members thought the quality of social care services has gotten worse
- **75.3%** of family members thought the quality of health services has gotten worse
- **45.3%** of family members are aware of specific plans to reduce social care of health services in their area

Research opportunities

We are often approached by researchers and academics looking for children, young people and families, to take part in vital research to improve the level and quality of care that is provided to seriously ill children and their families, in the UK and around the world. Research is usually carried out through telephone or face-to-face interviews with a qualified researcher, or through completing a survey.

Parent's Experience of Transition for Young People with Cystic Fibrosis
Study lead: Joanne Kelly, Coventry University

We are looking for parents to share their experiences of the transition process whilst living with a young person (12-29 years) with Cystic Fibrosis, to understand their role and responsibilities.

Contact us at **info@togetherforshortlives.org.uk** if you can help.

Family story

No one is more aware of the consequences of reduced local funding and cuts to UK services than families caring for children with complex health needs. The Williams' family share their story of how Voices for Families, our advocacy project running in partnership with LawWorks, has helped them.

Macsen is a 6-year-old boy who, according to his father Matthew, is obsessed with Pokémon, Cartoon Network and loves listening to the music of Little Mix. At 6 months old, he was diagnosed with cerebral palsy with limited control of his arms and legs, and he has to be moved regularly to avoid developing bed sores.

Since his first birthday he has suffered from severe epilepsy and can have up to 22 seizures a day. He needed an operation to relax his hamstrings when he was 4 as he pulls his legs up towards his stomach when he is in pain but, because of complications during the operation, he caught a superbug, meaning he is on constant antibiotics. When Macsen was 5 he was also diagnosed with a rare genetic mutation and so now experiences high levels of constant pain, vomiting almost continuously between 2pm and 9pm each day, needing an adult with him constantly to prevent him from choking.

Macsen's parents, Matthew and Lisa, do a wonderful job of caring for Macsen and his older brother Ioan, though both parents have health problems of their own. Matthew has an inherited degenerative condition where his muscles are gradually wasting whilst Lisa suffers from migraines, amongst other medical conditions. Lisa's health issues meant that Matthew had to take increasing amounts of time off work to care for Macsen. Up to a couple of years ago, the family had been assigned nurses from 7pm every evening to look after Macsen and help administer his medication during the night, but this level of care was abruptly stopped, and the family became desperate for help. They tried for months to persuade the relevant authorities to increase the support they were receiving, but without success.

> "There is no way that they would have offered the extra support without the intervention from Claire and we wouldn't have even considered a family holiday without it," says Matthew, "We have a huge amount to thank her for – she has been brilliant."

Thankfully, the Williams' family contacted Together for Short Lives and were referred to the legal clinic run by LawWorks at a local hospice in South Wales. There, the family met Claire Curtis, a lawyer from Clyde & Co, who had been trained by LawWorks to provide free legal advice on the issues the family were facing. After hearing about the full extent of the problems, Claire was able to draft a lengthy letter to both the Continuing Care Team and the Social Workers involved to set out clearly the needs that the family had, and the enormous pressures they were under.

As a direct result of the letter, a revised care package was agreed, specifically designed to meet Macsen's health, social and education needs. The family now has a healthcare support worker every night and 10 additional hours of care from healthcare workers who can administer some of Macsen's medication at other times of the week, according to the needs of the family.

As a result, both Matthew and Lisa can now spend time with Ioan and with each other in the evenings. Matthew can fit in more exercise which helps to delay the progress of his condition and Lisa has time to recharge her batteries.

Even more significantly, Macsen now has the chance to interact socially with staff who have special training to encourage him to play with all the sensory toys, lights and musical instruments that he enjoys. His parents say this has made a huge difference to his life. The family are also planning a holiday to Disneyland, Paris with one of their healthcare workers, something that wouldn't have happened if not for the help and dedication of the LawWorks team.

Voices for Families clinics are now operating from Ty Hafan, Richard House, Haven House and St. Oswalds. If your child is supported by one of these children's hospices, ask a member of the Care Team for details of the next clinic. We are currently working to find funding to expand the service to other UK nations.

Families in England and Wales may also access support through Voices for Families by calling our Helpline on **0808 8088 100**

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