together for families

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September 2016

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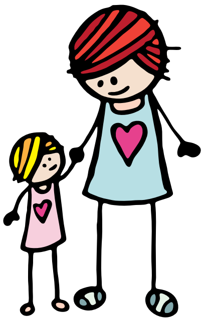
In this issue:



Together for Families helpline

0808 8088 100

info@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk

The Together for Families helpline provides information for families, carers and professionals; and for those calling on behalf of a friend or relative. The free helpline is for parents and carers who look after or know a child or young person who is expected to have a short life.

The helpline is open Monday to Friday between 10am and 4pm. Outside of these hours, you can leave a message and we will get back to you as soon as possible.

Email **families@togetherforshortlives.org.uk** to subscribe to *Together for Families*, or if you would like to contribute to a future edition – we'd love to hear from you.

Follow us and join the conversation!

twitter.com/Tog4ShortLives

facebook.com/togetherforshortlives

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Together for Short Lives is a UK wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

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 the September edition of *Together for Families.*

Who said summer was a quiet time? You can see from the articles in this edition that things seem to have been as busy as ever!

We have listened to what our readers told us through our annual survey, and articles on page 4 remind you of the different ways we provide information and support to help families. Although we feature some new services and resources in this newsletter, there isn't room for them all so do visit our website regularly for updates.

While the scrapping of the 84-day rule concerning DLA is to be celebrated, as the article on page 5 reports, there is still a considerable long way to go before every family is able to get the care and support they need.

We are thrilled to share our new Impact Report 2015/2016 with you. Our report, called *Making an Impact: Moments that Count* shows the work that we have done, together with our members, and the difference we've made in supporting families and speaking out on their behalf. This year we have produced our first ever digital version, which you can view here: **www.togetherforshortlives.org.uk/impact2016**. Please do take a look – there are some amazing quotes and photos of children, young people and families – you might even see a picture of you!

This summer we were excited to share our new resource for young people making the transition to adult services and have been really pleased with the feedback we've received. Do take a look and share it with others who may be interested.

We are also really grateful to Aimee for sharing her family's experience of how they were supported by Rainbow Trust. If you would like to share how a service has supported you, we would love to hear from you. Do email us at **families@togetherforshortlives.org.uk**.

Julia, Helen and Charlotte

New resource for young people making the transition to adult services

We are delighted to share our new resource, *Moving to Adult Services: What to Expect*. The electronic guide was created with, and for, young people with life-threatening conditions who are making the transition to adult services.

The guide was funded by the Department of Health and provides information to support young people to make decisions for themselves, and plan their lives as they want to.

The first section of the guide outlines what young people can expect at different stages of the process of transition to adult services, highlighting useful resources and signposting to further information.

The second section of the guide sets out the multi-agency approach needed to enable young people to live their lives as they would wish. This covers health, social care, education, employment and housing, outlining the key issues that need to be considered as young people reach adulthood, and the opportunities that may be available to them.

Leah Booth, one of the young people involved in developing the guide, said, "Going though change can be scary and confusing at any time but add in a lack of information and support and it can be overwhelming. The *Moving to Adult Services* guide changes all that. It provides all the information I, or anybody else, needs to make informed decisions and shows that it's okay to want things in life and have dreams. It's simple, easy to understand and is a really useful guide created by the very people who will use it the most".

Moving to Adult Services: What to Expect can be downloaded for free from our website: **www.togetherforshortlives.org.uk/movingon**.

Research shows seriously ill children face a postcode lottery of support across England

We carried out a series of Freedom of Information requests to all clinical commissioning groups (CCGs) and local authorities (LAs) in England to ask them about their spending on children's palliative care. The results showed that 4 out of 5 local authorities are failing to plan and fund children's palliative care services.

Local authorities have a legal duty to provide short breaks for disabled children, including those with life-limiting or life-threatening conditions, yet around 1 in 7 (14%) are failing to commission these services. Our new interactive map and rating system allows the public to see how their local authority and clinical commissioning group is performing.

Overall CCGs performed better than LAs. 120 (65%) of CCGs received a four or five-star rating with the majority 127 (93%) of CCGs stating that they commission children's palliative care. However, too few were able to identify exactly how much funding was spent on children and young people with life-limiting or life-threatening conditions. Despite evidence of some good practice, the overall picture is inconsistent.

Barbara Gelb, our Chief Executive said: "These findings show that, despite some good examples, the overall approach to children's palliative care is at best inconsistent and at worst typified by ignorance. It's a postcode lottery, with many children and young people being denied the support they need."

If you aren't satisfied with how your local authority is commissioning children's palliative care, then please write to your MP, the head of your local authority and the head of your local CCG. Go to our website to view the map and download template letters and emails. **www.togetherforshortlives.org.uk/datamap**

Experts by Experience recruited

In March's edition of Together for Families we invited readers to apply to become an Expert by Experience (ExE) for the Care Quality Commission (CQC).

An ExE is someone who uses health, mental health and/or social care services or who is a family carer of someone who uses these services. They work alongside CQC inspectors to carry out inspections. ExEs have the important role of capturing the views of people who are using the service that may inform the rating given to that particular service.

We were delighted by the response to this invitation and have now recruited 17 new experts who can bring their experience of children's palliative care services to the inspection regime. They will play an important role in the inspection of children's hospices and other health and social care settings in central England. We are particularly thrilled to have four young people involved in this activity. Supported by their carers, we know that their first-hand experience will enrich any inspection team.

Being an Expert by Experience offers an opportunity to work on a casual basis – a factor that is attractive to those with caring or other commitments. Individuals can choose how active they will be and are offered training and support to fulfil the role throughout their involvement. For the young adults, the programme provides them access to meaningful employment with an income.

We will be focusing our next round of recruitment in the Autumn to enrol more young adults. Do look out for details on our website or social media pages. Meanwhile, if you are interested in finding out more on becoming an Expert by Experience, please contact **charlotte.barry@togetherforshortlives.org.uk**.

Tired Out: New online information hub supports families raising disabled children to find help about sleep

The 2013 report, *Tired All the Time*, confirmed what many parents of disabled or seriously ill children already knew: sleep difficulties are a major concern.

Parents, carers and siblings told us that the effects are not only physical: they had also experienced financial, emotional and social challenges as a result of sleep deprivation. 93% of the families surveyed reported being awake during the night with their children, 49% reported health issues as a result, while almost a third had not sought professional support. Even when professional support was accessed, some parents felt that this lacked any practical advice, and many felt that the extent of their lack of sleep was not taken seriously.

Following *Tired All the Time*, Family Fund made a commitment to better support families with their sleep, and their first step towards this is the launch of **www.tiredout.org.uk**. 'Tired Out' is a hub for families, carers and practitioners where they can find information, resources and support for sleep issues all in one place. By working with a number of partner organisations including Sense, Cerebra and The Children's Sleep Charity, they aim to provide a comprehensive and accessible resource for sleep support, where advice, information and details of local support are readily available.

Families told Family Fund that they wanted to find services and events in their local area, have access to information and research into sleep issues for disabled children, and perhaps most importantly, have the opportunity to share experiences and talk to other families who understand just how dramatic an effect sleep deprivation can have. Tired Out will make it easier for families who are struggling to find help easily.

For further information on Tired Out, to share your experiences or to tell them about a related service or event in your area, email **tiredout@familyfund.org.uk**
Web: **www.tiredout.org.uk**
Facebook: **www.facebook.com/TiredOutFF**

Family Fund
Helping disabled children

Tired Out

Watch our new animation

This summer we launched a compelling new animation that shows the daily challenges families face caring for a child with a life-threatening condition, and the impact on family life.

Through My Eyes raises awareness of the pressures facing families providing round the clock care, and highlights the range of services providing vital support.

The moving film is told from the point of view of a mother looking after her daughter and focuses on the difficulty coping with the 'everyday' pressures of family life on top of caring for a child with complex and unpredictable medical needs.

The script was developed using the words of real families, and was created and produced for Together for Short Lives by creative animation studio, The Like Minded.

Watch and share the video on the Together for Short Lives YouTube channel: **www.youtube.com/Together4ShortLives**.

Feedback from our family survey

Many thanks to those of you who took the time to complete our survey that was sent out with the March edition of *Together for Families*. We know how busy you are, so your feedback is much appreciated and will help us develop and improve our support to families.

Our survey showed that while most families found our resources and services helpful and informative, many were not aware of the different ways that they could access our support:

- Only half of *Together for Families* readers have visited our website
- Very few have asked us questions via the Helpline or email service
- Many weren't aware of how their experiences can be used to support our work and help other families.

This page shares some information about how we can help.

Freephone Helpline

Our helpline is for any parent or carer who looks after or knows a child or young person who is expected to have a short life. Whatever your query, our trained staff are on hand to help.

Over the last 12 months we have received calls to the helpline asking for:

- Requests for our family resources
- Information about what children's hospice and palliative care services are available to families locally
- Information regarding the new SEND reforms
- Information about children's disability charities, grant-making organisations, bereavement support, emotional support and benefits information.

If you have a question or want to find a particular service, do call us on 0808 8088 100 or email **info@togetherforshortlives.org.uk**.

Advocacy Service

We work in partnership with LawWorks (a charity for legal professionals willing to offer free support) to provide an Advocacy Support Service. If you are a parent of a child with a life-limiting or life-threatening condition, or an affected young person, and are looking for free support for any of the following issues, then do get in touch:

- Welfare benefits or personal budgets
- Assessments and care plans for your child
- Housing and adaptations, including suitability of your accommodation
- Employment disputes, including flexible working
- Transition to adult services

Please contact the helpline on 0808 8088 100 to speak with someone about how to access advocacy support. An advocate can assist you and your family through some of the problems you're facing, acting on your behalf to help you get the support you need.

Online support

Our website **www.togetherforshortlives.org.uk** contains a host of information and resources that can help support you. From the homepage of our site just click on the 'Help for Families' tab.

Here you'll find a section on the 'Family Journey', which breaks down the experience of a family caring for a child with a life-threatening condition into four distinct stages (diagnosis, ongoing care, end-of-life and bereavement) and gives information and advice on each stage, as well as signposting you to further helpful resources.

There is also a 'Family Resources' section which contains all the factsheets and guides we've produced. These cover a variety of different issues, ranging from advice on practical issues such as equipment or legal support, to finding support for more emotional needs, such as bereavement support or understanding siblings' needs. We also have a range of more in-depth guides and articles – all of which are available to download for free.

If you need help finding a specific service, the 'Support in your area' section is a searchable online directory of children's palliative care services and organisations, ranging from children's hospices and condition specific organisations, to information and advice services and providers of equipment. You can search either by 'all services' close to your post code, by region, or by the type of service you're interested in, and results are either displayed on an interactive map, or in a list.

The 'Your Questions Answered' section contains a number of very common FAQs, while the 'Family Stories' shares the experiences of families who are caring, or have cared, for seriously ill children.

A pilot family Facebook forum

In response to the interest expressed through our survey in establishing an online forum, we are piloting *Families Together*, a private Facebook group.

Families calling our Helpline have told us that it can help them to feel supported and less isolated when they can share experiences with others who are in a similar situation. Social media provides a great way to enable this kind of peer support and can be accessed at a time and place that suits each family.

If you regularly use social media, then do apply to be a member of the *Families Together* pilot.

Membership of this group is limited during the pilot phase so do apply to join this group soon by emailing **families@togetherforshortlives.org.uk**. Members will be asked to complete a simple application form and agree to the terms and conditions of membership. If the pilot proves successful, *Families Together* will become another strand of our offer of support for families.

Also, make sure you are following us on Twitter **@Tog4ShortLives** and like us on Facebook: **@togetherforshortlives**. We always try to respond quickly to any questions or comments, and it's a great way to share and support other families too.

DLA: 84-day rule is scrapped

We are delighted that the government has scrapped the unfair rules which removed benefits for families whose child is in hospital for long stays.

Previously, families in receipt of Disability Living Allowance (DLA) or Personal Independence Payments (PIP) had their benefit payments stopped if their child was in hospital for more than 84 days. This affected approximately 500 families each year.

The change, which has now already come into force, was the result of a legal challenge by Craig and Lynette Mathieson, whose son Cameron spent most of his life in hospital until his death in 2012. The Supreme Court judged that the existing rules were a breach of human rights, which prompted the change in law.

Welcoming the news, the Mathieson family said "we are proud to now have this wonderful legacy for our beautiful boy".

Contact a Family, who led the campaign, have developed a new factsheet 'Disability Living Allowance when your child is in hospital' which explains what the new rules mean for parents.

Visit their website to download it: **www.cafamily.org.uk**.

contact a family
for families with disabled children

Center Parcs prize draw

We are delighted to announce that for the fourth year running Center Parcs has donated 10 short breaks to be used by Together for Short Lives family members.

The breaks can be taken at any of the five UK Center Parcs village locations: Whinfell Forest in Cumbria, Sherwood Forest in Nottinghamshire, Elveden Forest in Suffolk, Woburn Forest in Bedfordshire and Longleat Forest in Wiltshire. Accommodation will be in a three-bedroom Woodland Lodge. The breaks can be taken for a long weekend (Friday-Monday) or midweek (Monday-Friday) but excludes school and public holiday periods.

We are inviting members of Together for Short Lives' family community to enter into a draw to win one of these breaks. To enter the draw, please email your contact details to **families@togetherforshortlives.org.uk** by 12pm on the 14 October 2016. Please include details of your child's condition, age and access requirements. We will contact the lucky families and organise the holiday for a convenient time. All holidays need to be taken by April 2017. We wish you the very best of luck!

Tracy and her family were one of the lucky winners from our 2015 Centre Parcs draw. Tracy said: "We had a fantastic trip to Center Parcs. Harrison especially loved the rabbits, ducks, deer and squirrels but his most favourite thing was the lazy river. My parents loved spending some quality time with us all and we made the most of every minute. Thank you for the chance to make some beautiful memories together."

CenterParcs

Government Response to the Review of Choice in End of Life Care

The government formally responded to the 'Review of Choice in End of Life Care', which was published in February 2015.

The document, 'Our Commitment to you for end of life care' was written by Ben Gummer, the former Minister for Care Quality at the Department of Health, and sets out how England will improve palliative care during the course of this parliament (to 2020).

While the original review did not include children and young people, the government's response does as they "felt it was important to recognise the importance of end of life and bereavement care for children and young people and to highlight some of the particular needs of children and young people with life-threatening or life-limiting conditions, as well as some of the challenges faced by children's palliative care services."

The government has committed to six ambitions for end of life care:

- honest discussions between care professionals and dying people
- dying people making informed choices about their care
- personalised care plans for all
- the discussion of personalised care plans with care professionals
- the involvement of family and carers in dying people's care
- a main contact so dying people know who to contact at any time of day

The response recognises the differences between children's and adult palliative care, that an increasing number of young people are living into adulthood, and that those planning and funding children's palliative care face additional challenges due to the relatively small numbers of children, young people and families who need it.

The statement acknowledges that palliative care for children involves more than just end of life care and stresses that they can "benefit immensely from access to expert care and support including respite care, delivered in a children's hospice setting, by community palliative care services, or 'hospice at home' services".

Head to the Government website to read the response in full: **www.gov.uk/government/policies/end-of-life-care**.

Phoebe’s story

When Phoebe was 14 months old, Aimee, her mum, noticed a rash on the back of her legs. Aimee did the glass test on it, checking for meningitis, and when the rash didn’t disappear, she called 111. She was told to take Phoebe to the hospital. Despite the doctors finding nothing wrong with her, this was just the start of more complications to come.

Aimee said “Over the next few weeks Phoebe was admitted to hospital for various infections but nobody took any blood tests. At one visit I was told she had a common cold. On another visit to the hospital she seemed fine but within an hour, her temperature rose and she went limp. She had blood tests done which, doctors told us, would take three days for results but within hours of them taking her blood, I was told her tests were being rushed.

An oncology doctor came in and asked me questions about Phoebe’s swollen stomach, her bruises which were now in her groin too. My husband arrived at the hospital early in the evening and at 6:30pm, the consultant sat us down and told us that Phoebe had leukaemia. Our whole world came crashing down.

The following day she was sent to the oncology ward where she spent the next two months because she was so poorly. My husband couldn’t go back to work as we had our then three-year-old son, Ollie, to take care of. We tried to keep things normal for him so we took him to nursery but I couldn’t spend the time with him as I just wanted to be with Phoebe in the hospital. Nathan, my husband, would stay with him at home and I’d stay in the hospital with Phoebe. When I needed sleep, I’d come home and Nathan would stay in the hospital with Phoebe.

Our CLIC Sargent nurse put us in touch with the Rainbow Trust Children’s Charity – she could see we were struggling with being in the hospital and looking after Ollie. Nathan had to go back to work, so it was hard.

We were introduced to Rainbow Trust Family Support Worker, Amelia – I was so happy for the help. Ollie goes to nursery two days a week so on the days he’s home, it’s a struggle. I felt like I was pushing him out which I hated but I needed to be with Phoebe. Everything was about Phoebe. Ollie would cry a lot and when he didn’t get his way, he’d kick off. I didn’t know what to do for the best so when we were referred to Rainbow Trust, I was so relieved.

Ollie was only three and he didn’t understand the situation so Amelia spent time with him. They got on the minute they met. He still gets so excited when I tell him she is coming. It’s such a weight off my shoulders knowing there is someone looking after my little boy so that I can be with my sick child. Ollie loves Amelia and I think nothing of leaving her a key to collect him from school and take him home to play and then she brings him up to the hospital so he doesn’t have to be there too long.

He’s much happier now, he’s more confident and he’s more settled. Having someone there just for him has made a big difference. He can talk to Amelia and he can play with her when I am not around. She is there for him. Having someone there who you can trust with your child is amazing, I don’t know what we’d do without Amelia now. She’s just brilliant. If I know Phoebe has an appointment next week, I know I can call Amelia and ask her to fetch Ollie from nursery and that is such a relief for me.

I’d recommend Rainbow Trust 100% to anyone who needs them. They take care of you and your family, not just Phoebe but Ollie and me as well. Amelia doesn’t spend much time with Nathan as he is at work but her support makes me happy and that makes him happy.

Amelia is just brilliant but I think more people need to know about Rainbow Trust. I didn’t know about them before Phoebe got sick but more people need to know. Amelia is just wonderful; we couldn’t do without her now.

To watch Phoebe’s story online please visit Rainbow Trust’s Facebook Page: **www.facebook.com/rainbowtrust**.

Tell us about your superhero care giver

This year we have featured a variety of our member organisations in *Together for Families*, showcasing the fantastic work they do to support families.

Whether a children’s hospice, statutory organisation or voluntary organisation, all of our members are committed to improving children’s palliative care and delivering the best quality support to families. Next year we would love to feature individuals who have really made a difference. So if there is someone you think deserves recognition for their dedication, professionalism and kindness shown to your family, then please get in touch: **families@togetherforshortlives.org.uk**.