

together for families

Issue 16
March 2016



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Become an Expert by Experience



Together for
Families Helpline

0808 8088 100

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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!



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Together for Short Lives is the leading UK charity that 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).

www.togetherforshortlives.org.uk

together
for
short
lives



Welcome to the March edition of *Together for Families*.

We know that parents and carers are the real experts in the care of their child and we are delighted to partner with Choice Support in the Expert by Experience programme. Choice Support has been working with the Care Quality Commission for some time now, providing inspection teams with service users who can provide a real insight about their experience of health and social care services. However, they recognised that they did not have people with first-hand experience of children's palliative care services on their bank of Experts by Experience and came to us for help. Read how you may be eligible to apply for one of these roles on page 3.

This issue of *Together for Families* includes details of this year's Children's Hospice Week. The theme is 'Time to put families first' and the article on page 4 outlines ways you can get involved. Many thanks to everyone who has already contributed photos and stories to be included in the week.

Together for Short Lives works with a wide range of partners and supporters to improve access to high quality palliative care. One partner organisation is Children with Cancer UK which wants to help more children with cancer across the UK. The family story in this issue describes how one family chose to support their son at home once treatment was no longer available to cure his cancer. We are so grateful to Sacha for sharing this very personal experience and, like her, hope that her words encourage others who are on a similar journey.

Finally, we would like to encourage as many readers as possible to complete and return our bi-annual family survey. Your feedback – positive and negative – is so important to us. It is used to shape our future work and to improve on what we are already offering to families caring for children with conditions that may shorten their lives.

Julia, Rebecca and Charlotte

Recognition in the Queen's New Year Honours List

We were delighted that two active members of the Together for Short Lives community were awarded the Honour of Member of the Most Excellent Order of the British Empire (MBE) in the Queen's New Year Honours List.



Beverley Barclay, the Director of Clinical Services at The J's Hospice, a member organisation of Together for Short Lives, was awarded an MBE in recognition for her services to nursing – in particular the major impact she has had on the care and well-being of young adults with life-shortening conditions, at both a local and national level.

Lucy Watts, a member of our Young Avengers group, has worked with Together for Short Lives since 2013 and has used her experience to advocate for improvements in care for young adults as they make the transition to adult services. Lucy, aged 22, has a complex life-shortening form of a condition called Ehlers-Danlos Syndrome. Her condition means she requires 24/7 care and support. Along with other Together

for Short Lives' Young Avengers, Lucy has endorsed a number of campaigns on behalf of the charity – including sensitive subjects like talking about end of life choices and breaking taboos about young people with disabilities exploring their sexuality and relationships. Lucy was awarded an MBE in recognition of her services to young people with disabilities. Lucy said "My charity work keeps me going, gives me a way to contribute to society and feel useful and is a positive focus away from all the negativity of my conditions. To find out that my hard work has been recognised, and that I have been awarded something as prestigious as an MBE, has truly been the most wonderful experience."



Do give us feedback

Together for Short Lives aims to provide members of our family community with the information and support they need to ensure that they are able to make the most of the time they have with each other.

We are constantly developing our family offer to ensure that we are addressing those things that really matter to you. In addition to consulting regularly with our Parent Carer Advisory Group, we are keen to hear from you on how we are doing. This will inform how we work and what our priorities should be in the future.

To gather your views we have developed a survey which is enclosed with this newsletter. We would like to know how well we are meeting your needs and how satisfied you feel with different aspects of our offer to families, including:

- our newsletter
- our family resources
- our website
- our involvement groups
- our helpline service (telephone and email service) and advocacy support service.

Please do take the time to complete and return the survey – we really value your views. You can also complete the survey online using the link provided in the enclosed survey.

Children with Cancer UK

Since 2012, Together for Short Lives has been generously supported by national children's charity Children with Cancer UK. Thanks to this continued support, we have been able to build strategic partnerships across the children's palliative care sector and deliver a wide range of vital work aimed at improving quality of life for children with cancer and their families when, sadly, a cure is no longer possible.

At this devastating time, families need help finding the right information, support and care for their child, so that they can make the most of their precious time together. David's story on page 6 shows just how vital this support is to families in this situation.

We are enormously grateful to all of our valued supporters, funders and partners for helping us to reach out to families – like David's – to ensure that they have as full lives as possible and the best care at the end of life.

For more information about Children with Cancer UK, please visit www.childrenwithcancer.org.uk.



Parents, carers and young people needed for CQC inspections

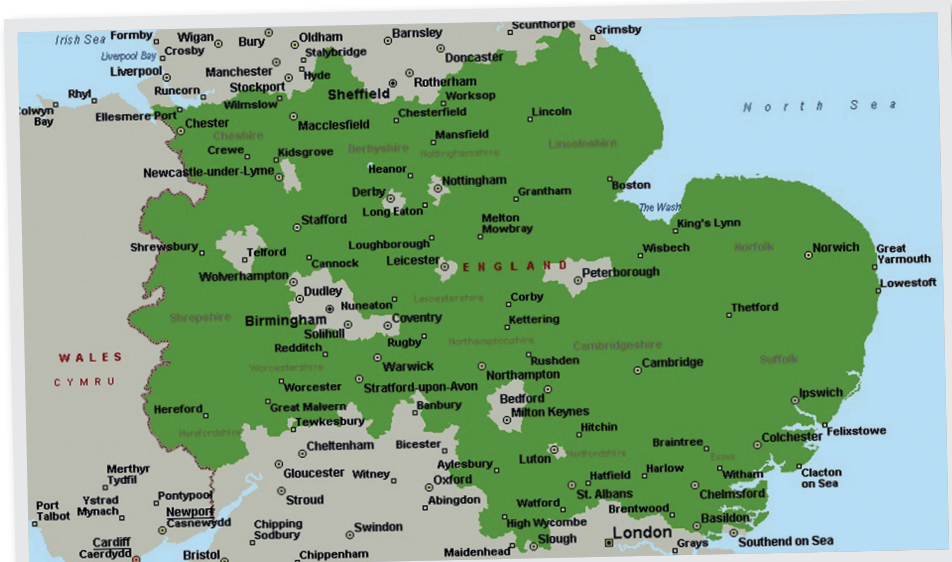
The Care Quality Commission (CQC) is the regulatory body responsible for inspecting health and social care services across England. Each inspection team includes people who use these services directly or care for someone using these services.

These inspectors are known as Experts by Experience (ExE) and provide a unique insight in assessing how well services provide care and treatment.

From April 2016 Together for Short Lives will be working with Choice Support in the central region of England (see map) to recruit parents, carers and young people with first-hand experience of children's palliative care to join CQC inspections. The roles are open to siblings, grandparents, parents and young people with direct experience of using children's palliative care services. Young people need to be aged between 16 and 25 years and not in full-time education. If chosen as an Expert by Experience, young people can bring a carer to inspections to support them in the role.

Experts by Experience are paid £15 an hour plus travel expenses. Although travel expenses are limited and priority will be given to those applicants who live within the central region. A typical inspection will take approximately 10 hours.

If you would like to know more or would like to apply to get involved, please contact Charlotte Barry on **0117 989 7820 (ext 242)** or email families@togetherforshortlives.org.uk. You will be asked to complete an application and personal profile form and may be invited to an interview. If successful, a Disclosure Barring Service (DBS) check and training will be arranged for you.



Free online resource for making life easier for children and adults with disabilities

The Disabled Living Foundation (DLF) has developed a free and easy to use online, guided self-assessment tool which gives impartial advice and information on the equipment and products that could make life easier for people living with a disability.

The resource is called AskSara and will assist anyone who finds that they have difficulties with everyday tasks. A version also exists specifically for parents and carers of children with disabilities. Users simply choose the subject they would like help and support with and then answer some questions about their child and their environment. AskSara then gives a personalised report providing:

- ideas and tips about ways to make life easier
- details of products that might help and where to get them
- contact details for more information and further help if needed.

For further information, please visit www.asksara.org.uk.

If you are unable to access the internet or would like further assistance, you can call the DLF helpline on **0300 999 0004**.

AskSARA

Children's Hospice Week 2016

Children's Hospice Week 2016 is all about families. The campaign takes place between 23 and 29 May this year and the theme is 'Time to put families first'. The aim is to show what life is really like for families caring for children with life-shortening conditions, highlighting the importance of family time. The week will also raise awareness of the wide range of children's palliative care services providing vital support to families across the UK.

Every family is unique. During Children's Hospice Week this year we're inviting people to introduce their family on Facebook and Twitter by sharing an **#ourselfie** family photo or drawing and a **#myfamily** memory. We were overwhelmed to see so many of you sharing photos with us last year – we really hope you'll get involved with the campaign on social media this year.

We'd also love to hear about your thoughts, stories and experiences on family time, for example:

- some of the challenges you face doing every day family activities like going to the park, a day trip or going to the shops
- the impact that having caring responsibilities has on your family
- the importance of family time and getting the right support to be able to spend quality time together.

Please email your experiences and thoughts to jo.barrell@togetherforshortlives.org.uk. For more information about the campaign visit www.togetherforshortlives.org.uk/chw and follow **#ChildrensHospiceWeek** on Twitter.



**Children's
Hospice Week**
23-29 May 2016 Time to put families first

Downing Street event

Earlier this month Together for Short Lives was given the huge honour of being guests of Samantha Cameron at 10 Downing Street. Samantha Cameron hosted an evening reception for us to raise awareness of the needs of families caring for a child with a life-shortening condition.

Over 100 friends and supporters of Together for Short Lives had the opportunity to meet Samantha and learn more about our vital work during the evening reception. The event was also attended by our celebrity supporters including our Patron Holly Willoughby and BAFTA award-winning actor, Rebecca Front.

Guests were joined by Amanda Harrison and her family. Amanda's son James has Batten disease, a complex condition that means Amanda and her husband, Ian, require highly-specialised support to care for James around the clock.

Amanda spoke passionately about the difficulties that families around the UK face and how important the work of Together for Short Lives and our members is to them.



Do you have a Digital Legacy?

Twenty years ago most people didn't have a mobile phone or use the internet and Facebook didn't exist. A flurry of technological advances has had an impact not just on the way we live, but also the ways in which we prepare for death and are remembered.

DeadSocial.org and The Digital Legacy Association were set up to educate and help people plan for death in today's increasingly complex world.

DeadSocial provides tools, tutorials and support specifically for the general public. Whereas, The Digital Legacy Association provides frameworks, training and support for professionals working with people at the end of life and in the hospice sector.

The content and the tone of voice used by DeadSocial is very different to what you may expect from a site addressing death and digital legacy. As well as providing support for the general public online, DeadSocial has also published a guide called *Five steps to sort out your digital legacy today*. The guide provides five simple steps to think about in relation to digital devices (like mobile phones) and internet services (like Facebook).

You can view and print the guides for free. The guides are available to download as PDFs in both English and Welsh. For more information and to download the guides visit www.deadsocial.org.



Family films

We have produced a series of films to help explain some of the ways we support families. The three films focus on the Together for Families Helpline, our advocacy service and our family community.

The aim of the films is to help families caring for a seriously ill child understand that there is a network of families in similar situations. We want families who may not know much about Together for Short Lives to be aware of the support we can offer and to encourage more families to get in touch with us.

Huge thanks to mums Tory and Lizzie for sharing their experiences with us and to the Botanic Garden in Bristol for allowing us to film there free of charge.

We will be promoting the films soon online and hope you will watch them and share them with your friends.

National online support for young people experiencing a family health crisis

Hope Support Services is dedicated to providing support to young people aged 11 and over when a close family member is diagnosed with cancer or another life-threatening illness. The support is available from the moment of diagnosis and for however long it's needed, whatever the outcome for the patient.

Hope Online was created because Hope Support Services wanted to expand its reach nationwide. The organisation uses social media platforms and technology, like Facebook and Skype, for young people to access regardless of where they live.

When a child has a life-shortening diagnosis the impact upon siblings, step-siblings or close cousins can be devastating, causing a number of different emotions and behaviours as the young person struggles to find a way to cope.

Hope Online offers safe and confidential one to one support with experienced professionals as well as a peer community where young people can connect and share.

Hope Online supported Jo, who said:

"Talking to Hope is completely confidential, and using *We Are Hope* makes you realise that even if you feel completely shut off with your own problems, there are others going through the same experience as you and are finding it just as hard – that you're not alone in what you're going through. It's just a friendly, chatty way of letting people know how I am, and being able to share it with others who want to know, it really makes a difference."

Hope Online welcomes self-referrals from young people as well as referrals from professionals, agencies and family members. For more information about services and referral routes please visit www.hopesupport.org.uk/online-support or phone **01989 566317**.

Your guide to the new SEND system

In April, Together for Short Lives will publish a guide to the new special educational needs and disability (SEND) system in England, written specifically for families of children with life-shortening conditions.



The new system is replacing statements of SEN with education, health and care (EHC) plans for children and young people aged 0 - 25. It is also introducing a single, joined-up assessment process and a right to request a personal budget for every child with an EHC plan. The guide will help families to understand:

- what reforms mean for them – and how they can benefit children with complex health needs
- what they are entitled to in their local area
- how to access information and support
- how to influence and complain about their local SEND system.

Look out for the new guide online at www.togetherforshortlives.org.uk/sendresources. In the meantime, don't forget that the Together for Families Helpline can help with queries about the SEND system.

New guide to continuing care for children in England

The Department of Health has published new guidance for NHS clinical commissioning groups (CCGs) in England to help them determine whether a child or young person needs a continuing care package:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/494230/children-continuing-care.pdf.

A continuing care package is required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. These children often have highly complex needs, including life-shortening conditions. The published framework includes Together for Short Lives' definition of children's palliative care, which includes the different categories of life-limiting and life-threatening conditions.



Childcare Bill completes Parliamentary passage

The government's Childcare Bill, which aims to increase the amount of childcare which working parents are entitled to, has been considered by the House of Lords for the final time.

Responding to calls to do more to help families of disabled children access suitable high-quality, affordable childcare, government minister Lord Nash acknowledged that the nature and level of support required by children with special educational needs and disabilities (SEND) can vary significantly.

He stated that funding for children with additional needs in the early years cannot be solved with a one-size-fits-all approach – and that ministers have committed to consider early-years funding for children with SEND as part of the government's work to consult on the ways in which funding is allocated. He said that the Department for Education is working with the childcare sector and local authorities on how this might work.

You can read the transcript of the debate at: www.publications.parliament.uk/pa/ld201516/ldhansrd/text/160202-0001.htm#16020267000557.



David's story

All deaths are different, like births, and obviously reflect the infinite variety of medical, personal, emotional and mental circumstances of the individual and family. My son David, DD as we called him, was diagnosed with a cancerous brain tumour called a medulloblastoma in October 2007, aged 11.

When David was diagnosed his cancer had not spread. Therefore, our expectations were that he would be in the lucky 75% who make five years at least having finished his 15-month long chemotherapy and radiotherapy protocol. Unfortunately, due to late diagnosis, DD had to cope with 10 extra brain operations. His first relapse was September 2010. Then we got spectacularly lucky: the palliative chemotherapy he took removed all the tumours down his spine within weeks. He was officially declared in remission in time for a stem cell rescue the following March. Unfortunately, it didn't work. His final relapse was May 2012 and he died in the August, aged 16 with severe dementia alongside multiple spinal tumours.

Nothing will ever be as painful as letting DD go but I know that having achieved an excellent death for DD, with our team led by Southampton General but encompassing Salisbury District Hospital and our local GP surgery, is without doubt the single biggest achievement of my life and it continues to be an immense consolation. But how on earth did we do this? I know people cannot imagine how we even got our heads into a place where we could decide to take him home after his final relapse? What gave me the confidence to know I could manage my child's death at home?

"Just follow the child" was what my friend had said when talking about the home death they achieved for their six-year-old with the same cancer. Her son had died with his young siblings all present and when I heard that I thought, if she can do it, I can do it. I know that's right: *for death to be a big event but one within the framework of a normal family life*. This was what I needed, the reassurance I could do it and I was not alone.

'Following my child' meant focussing on everything DD loved. That instantly meant home not hospital. We chose with our team a treatment plan of palliative drugs at home to remove the symptoms of his disease but positively rejected any like chemotherapy or even steroids that would prolong his life with such a ghastly disease and might mean facing uncontrollable pain. Stopping curative treatment was not giving up hope and being negative. True, the hope that we previously had that his cancer would be overcome had to be redefined after his second relapse. Our new hope was for DD to have the best time possible at all times! He loved home, studying science, flying birds of prey, playing with his sister, arguing with his younger brother, watching movies and talking to his friends – that was how he wanted to spend his time. The last thing DD wanted was to be treated as a dying cancer patient.

Fear was my main enemy – the temptation to deny what was happening and that the disease was going to cause the death of our beloved son but also fear of the process of death. I know now that is mostly fear of the unknown. The way I tackled it, was to tell the palliative-paediatric-oncology specialist nurse what I was scared of. The meeting was to plan so that we always had the equipment and medicines needed in advance of any possible crises. To keep DD calm and comfortable at all times required me to know what to expect, rather like when you give birth. It was so painful to face but within an hour the relief poured out of me as I understood: what to do with seizures; whom to call 24/7 and the paperwork in place that meant an ambulance called to our home was not allowed to take him to hospital or perform CPR, only to stabilise him. As to have done

otherwise would have increased his suffering and ruined his quality of life.

The morning DD died my husband and I and his brother were there with our nurse. His little sister had gone on a birthday sleepover that night. I know DD was completely happy as the last lucid thing he had said four days before was "I love it here". We knew we'd done absolutely the best job for him.

What I really want people to know is that you must not fear; grieve, yes, the grief of letting your child go – of understanding and accepting – but not fear death itself. You are not alone. The mum who reassured me said: "the death was okay". They stop breathing and their long suffering ceases. The pain of grief is not. Yet I feel so lucky that I was there to know DD was okay. I wouldn't say I was in control, any more than I had been for his birth but I did feel empowered by having made positive decisions and understanding what was happening – we weren't just being dragged by medical events. The hard bit now is to do what he asked which was to carry on with our lives and be alright – a life's work I'd say!

Sacha, David's mum and Lead Champion for The Brain Tumour Charity's HeadSmart Campaign
www.headsmart.org.uk

