

together for families

Issue 15

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www.togetherforshortlives.org.uk families@togetherforshortlives.org.uk Office: 0117 989 7820 Helpline: 0808 8088 100



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New resources for families and young people



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. It is open to anyone who looks after or knows a child or young person with a life-limiting condition.

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

Editors: Julia Hodgson, Rebecca Ellison and Charlotte Barry

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Together for Short Lives is the leading UK charity that speaks for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. When children are unlikely to reach adulthood, we aim to make a lifetime of difference for them and their families.

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).

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Welcome to the December edition of *Together for Families*

As the end of the year fast approaches we've already begun to plan activity for 2016 to ensure that good quality children's palliative care and support is available to all families who need it. In October we were delighted to publish our impact report: *Making an Impact, 2014-2015 Delivering change for children and families*. The report tells our story and shows the results of our work over 2014-15. If you would like to receive a printed copy please email info@togetherforshortlives.org.uk. It is also available to view and download from our website www.togetherforshortlives.org.uk/about/who_we_are. None of our work would be possible without funding and in this edition we introduce Stephen Ballantyne, our Director for Fundraising. Stephen talks about his vision for Together for Short Lives and what motivates him.

This issue of *Together for Families* also launches two new resources – a factsheet for families giving advice on how to talk to children about their life-limiting condition and an e-resource about personal budgets for young people living in England. Find out more on page 3.

As daylight hours decrease and temperatures fall, you may already be thinking about next summer. To inspire you and to inform any planning, we have dedicated a whole page to the theme of holidays. We share travel tips and information on holiday insurance, as well as details of some organisations that offer breaks to individuals and families on page 5.

This issue's family story is from Joshua's mum, Karen. We were delighted to meet Joshua and Karen at our conference in 2014. Many thanks to Karen for sharing her story and explaining why Christmas is so special for her family.

Julia, Rebecca and Charlotte

VIP treatment for families at One Direction Concert

We were thrilled to be able to offer some families the opportunity to see One Direction at the O2 Arena in September.

They enjoyed VIP treatment – getting to watch the show from the comfort of a private box. Amongst those joining us were three families:

Lily, an avid One Direction fan, has a life-threatening condition that affects her breathing and eating. Her mum, Vanessa, said: "Lily had a particularly tough week the week before winning the tickets and it was simply the most perfect surprise to put a smile back on her face".

The Edge family had a brilliant time. Their youngest son, Dylan, was born with Patau's Syndrome and has complex health needs that require 24/7 care – impacting on the whole family. His mum, Claire, was delighted to



have the opportunity to spend quality time with Dylan's brother and sister.

Jane has worked hard to raise the profile of our work and has openly shared her experience of caring for her son, Callum, who was born with severe brain damage. Sadly, Callum died in 2014 aged nine. Callum's brother, Connor, did not have a conventional childhood as a result of Callum's short life, so Jane and her husband loved having this opportunity to do something exciting together as a family.

Huge thanks go to a very generous donor who made the night possible.



A huge thank you to everyone for your support this year. We wish you all a Merry Christmas and a Happy New Year. Thank you to Helaina's mum, Cath, for sharing this lovely Christmas photograph with us.

"When Helaina was younger many Christmases were spent in hospital, not knowing if she'd live or die. Christmas is a very special time now, a celebration of the fact that she is still with us."

Cath, Helaina's mum

Together for Short Lives hosts parliamentary reception to call for care around the clock

Together for Short Lives and Stuart Andrew MP held a joint reception last month in the House of Commons to call for palliative care to be available when and where children and families need it.

The reception, on 17 November, was attended by over 50 MPs and peers, as well as young people who receive palliative care, representatives of children's palliative care services and supporters of Together for Short Lives.

The reception was opened by Stuart Andrew MP, followed by a speech by one of our parent members, Lizzie Hornby, about the importance of 24/7 children's palliative care. Lizzie's son has Edwards Syndrome, which means he requires complex, highly specialised care.

Attendees also heard from Dr Bee Wee and Dr Jackie Cornish, NHS England's National Clinical Directors for end of life care and for children, young people and transition respectively. Barbara Gelb OBE,

Chief Executive of Together for Short Lives reminded everyone of the funding and workforce challenges facing the sector.

The reception called on parliamentarians to make care around the clock a reality for children and families and it was an opportunity for them to demonstrate their support for the sector. Together for Short Lives will now be meeting with supportive MPs to call for a truly 24/7 service.

A Young Person's Guide to Personal Budgets in England

"Overall the personal budget is the best thing ever to happen for me. It gave me the freedom and means to explore life just like other people my age. It allowed me to find myself and learn to be the person I am today. I have always had a determination to do what others have done and the personal budget has allowed me to do that. It has given me the independence I craved and allowed me choice and control for the first time in my life." Leah, 24.

We are delighted to launch our *Young Person's Guide to Personal Budgets in England*, a new e-resource designed to help seriously ill young people have more choice and freedom in how their care is delivered. The guide is written for young people with a life-limiting or life-threatening condition who may be considering a personal budget. The easy to use guide aims to help young people decide if a personal budget is right for them. Using simple and clear language the guide explains what a personal budget is, the different ways they may be funded and managed and how they can be used.

Leah, Heidi and Chris – three young people who understand the complexity of having a personal budget – help readers navigate the guide – sharing their personal experience of taking control of their lives and making the most of personal budgets.

The guide was written for Together for Short Lives by In Control, a charity which works to build a society that includes everyone equally. The *Young Person's Guide to Personal Budgets in England* was launched at the Kidz to Adultz up North Event held in Manchester in November.



Download your copy of the *Young Person's Guide to Personal Budgets in England* for free: www.togetherforshortlives.org.uk/ypguidetopersonalbudgets.

New resource to help parents talk to their child about their condition

Starting a conversation with your child about their life-limiting condition can seem extremely overwhelming.

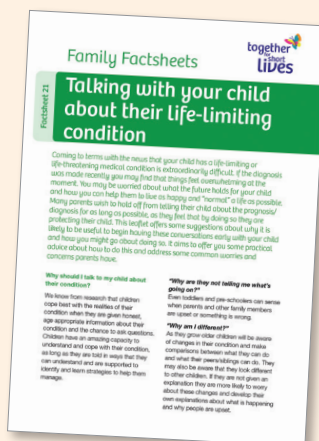
Many parents wish to hold off from telling their child about their condition for as long as possible. Though it may seem scary, we know from research that children cope best with the realities of their condition when they are given honest, age appropriate information about their illness and the chance to ask questions.

Together for Short Lives, has worked with a team of clinical psychologists from Bristol Children's Hospital to develop a new family factsheet called *Talking with your child about their life-limiting condition*. The factsheet explains why it is important to begin these conversations with your child early on and some guidance on how you might do so. It offers practical advice and looks at the worries that families may have when talking to their child about this difficult subject. The factsheet aims to help families feel more comfortable and confident about discussing life-limiting and life-threatening conditions with their child and his or her siblings.

You can download or order printed copies of *Talking with your child about their life-limiting condition* for free from www.togetherforshortlives.org.uk/familyresources.

Whilst this factsheet will set the scene for talking to your child about their condition and address key concerns, please do call our Together for Families helpline on 0808 8088 100 or email info@togetherforshortlives.org.uk if you would like to talk about an approach that's right for you and your child.

If you would like to share your experience about talking to your child about their condition we would love to hear from you. Please email families@togetherforshortlives.org.uk.



Kidz events are growing up

You may be familiar with the Kidz events that are held across England, Scotland and Wales each year.

To mirror the changes to health and social care legislation (Children and Families Act 2014) that came into effect on 1 April this year, the November event was the first Kidz to Adultz event held. The theme of the free seminars and range of exhibitors promoting services and equipment reflected the increase in age to 25 years.

At Kidz events during 2015, Together for Short Lives had the opportunity to meet with families directly and to talk about our work and the support available for families. We will continue to attend these events in 2016 to raise awareness of our helpline, advocacy service and the range of resources that are available to support families. If you are going to one of the Kidz to Adultz events next year and would like to volunteer some time to support us on our stand, please email families@togetherforshortlives.org.uk.

Kidz to Adultz in the Middle
Coventry
10 March 2016

Kidz to Adultz South
Reading
9 June 2016

Kidz to Adultz Wales
Cardiff
7 July 2016

The right equipment – at the right time

Newlife is the UK's largest charity funder of children's specialist equipment and runs an emergency equipment service for terminally ill children. Over recent months the charity has witnessed an increase in the number of families asking for help to access essential equipment for their child's care. *The right equipment at the right time* campaign being led by Newlife highlights the issues faced by families whose children, through a lack of equipment, may be left in pain or at risk.

As part of their campaign for change they are asking people to share a link via social media to a blog post written by Fiona Smith, the professional lead for children and young people's nursing at the Royal College of Nursing.

The post highlights the stark reality that despite Clinical Commissioning Groups and Local Authorities having a statutory obligation to make provision for equipment prescribed to disabled children (Children's Act 1989), it is estimated that one in three disabled children live without the specialist equipment they need. Please read the article and share through your social media to help raise awareness.

www.huffingtonpost.co.uk/fiona-smith/disabled-children-in-the-uk_b_8169096.html

Little Stars film

We are proud to support a new film called Little Stars which features children and young people across the world living with life-limiting conditions. The film, presented by David Suchet, shows young people making the most of every moment with the support of their families and the professionals who care for them.

For more information and to watch the trailer visit:

www.littlestars.tv/short-films/trailer/.



Butterfly Wishes Network



The Butterfly Wishes Network provides photography shoots to children with life-limiting and life-threatening conditions.

The organisation was founded in 2013 and was formed by a group of professional photographers who wanted to provide families with a free photography shoot and at least ten digital images. The aim is to give families the opportunity to capture some treasured memories. There are over 285 photographers across the UK in the network and every photographer gives their time and talent for free from their own businesses to provide the service. To apply for a session, complete the online form and you will be matched with a photographer.

www.butterflywishesnetwork.co.uk/familyinformation



For further information email team@butterflywishesnetwork.co.uk or visit the Facebook page www.facebook.com/TheButterflyWishNetwork



Meet the team

Meet Stephen Ballantyne, our Director of Fundraising

Tell us more about your role as Director of Fundraising

I am privileged to lead a fantastic team of 11 fundraisers, who are all dedicated to trying to raise as much money as possible for our work. The best thing about fundraising is the variety. I can be head down in the office writing a funding proposal or a report one day and out at a fun event or meeting a potential supporter the next.

What motivates you when fundraising for Together for Short Lives?

Like most fundraisers, I am naturally quite competitive and the team is motivated by wanting to be the best fundraising team going! However, of course, the most motivating thing is meeting families, hearing the impact that good palliative care has on their lives and knowing that we are contributing to that.

What is your vision for Together for Short Lives and the children and families it supports?

I want us to be the 'go-to' place for any family that needs support so they can get the best care possible.

What is your most memorable moment working for Together for Short Lives?

There have been quite a few. It was fantastic to meet our patron Holly Willoughby. Her support over the years has been a real boost to the charity.

Missing the sunshine?

Research shows that many summer holiday bookings are made early in the new year, once the Christmas festivities are over.

To help with any holiday plans you might be making and to ensure that you do not miss out on opportunities during 2016, we've put together some information from other charities and organisations that specialise in providing experiences that help you create everlasting memories.

One specialist holiday company – Disabled Holidays – attended our conference *Living Matters for Dying Children* earlier in the year. We have invited them to advertise their offer to families here and asked them to contribute to our top tips.

DisabledHolidays.com has the UK's largest selection of adapted family holidays catering for all disability needs. With access to a wide selection of accommodation to suit all budgets and tastes, they help families to plan holidays both in the UK and overseas.

Many of their properties include full wheelchair access and wet room showers. Where shower chairs and hoists aren't fitted as standard, Disabled Holidays can help arrange hire and delivery to your accommodation. They are able to accept Family Fund cards too.

Disabled Holidays prides itself on taking the stress out of finding and booking a holiday, giving families precious time together.


DisabledHolidays.com
— travel without limits —

There are several organisations that provide special holidays for a seriously ill child either with their family or on their own. Below is information on just a few of these organisations:

- Over The Wall is a national UK children's charity that provides free of charge therapeutic recreation camps to help children with life-limiting illnesses and their families. For more information and dates for 2016 camps visit www.otw.org.uk
- The Calvert Trust enables people with disabilities, together with their families and friends to achieve their potential through the challenge of outside activities. Activities include canoeing, abseiling, swimming or sliding down a zip wire. The Calvert Trust does charge a fee for their holidays. For a full price list and more information on its centres in Exmoor, Kielder and the Lake District visit www.calvert-trust.org.uk
- PHAB is a charity which creates opportunities for children of all abilities to enjoy life together. PHAB offer a range of holidays and projects for people aged between eight and 25, with and without disabilities, at a variety of locations across England. PHAB aims to make holidays affordable and there are a range of bursaries available, for more information visit www.phab.org.uk

Top tips for travelling:

- When choosing a travel agency, make sure they have strong experience of arranging travel for those with disabilities.
- Make sure all the equipment you would have at home is available for your holiday.
- When booking accommodation, make sure that it is guaranteed accessible and not just requested.
- If you're booking a city break, make sure that not only is your accommodation accessible but that it is in an accessible part of town. Are local restaurants accessible? Will cobblestones and steps be a problem?
- Ensure that you have insurance in place which provides adequate cover for pre existing conditions.
- If travelling by air don't forget to book assistance to ease your passage through the airport.

For further information please download our free *Short Breaks and Holidays factsheet* from www.togetherforshortlives.org.uk/familyresources and Contact a Family's *Guide to Holidays, Play and Leisure* www.cafamily.org.uk/media/682496/holidays_play_and_leisure.pdf.

Changing Places

The lack of suitable changing facilities in toilets for people with disabilities is one of the most restrictive practical problems preventing families from going out.

Changing Places is a national campaign with the aim of ensuring that 'standard accessible toilets' (disabled toilets) are made fully accessible. The Changing Places Consortium now has 170 organisations supporting the call for improvements. As part of the campaign they have developed an online map to help people locate fully accessible toilets. They hope to convert this into an app in the future to make it even easier for families to plan days out.

More information about their campaign and access to the map is available online at www.changing-places.org/find_a_toilet/location_map_and_national_register.aspx.



Holiday Insurance

An internet search will pull up a list of insurance companies that offer insurance for disabled travellers. Below we have included contact details for companies that have been used and recommended by those travelling with children with pre-existing conditions and disabilities.

Remember:

- Each insurance policy is unique for that person and trip. Shop around for the cover that will meet your particular needs.
- Check with your doctor before getting travel insurance. You might need written permission to make sure your insurance is valid – you won't be covered if you travel against your doctor's orders.
- Make sure you list all pre-existing medical conditions, you won't be covered if you don't and you'll invalidate any claim that you then make.
- When visiting a European Union country, as a UK resident you are entitled to medical treatment that becomes necessary, at reduced cost or sometimes free. However

only treatment provided under the state scheme will be covered. To access treatment you will need to take a European Health Insurance Card (EHIC) with you. Please visit www.nhs.uk/NHSEngland/Healthcareabroad/EHIC?Pages/about-the-ehic.aspx or call 0845 605 0707

- If your trip is being funded by the Family Fund, insurance may be included. However, check carefully for any exclusions www.familyfund.org.uk/insurance-for-travel

Recommended agencies for travel insurance:

Able2Travel www.able2travel.com
01892 839 501

AllClear www.allcleartravel.co.uk to apply for a quote online

Fish Insurance www.fishinsurance.co.uk
0333 331 3770

Free Spirit www.freespirittravelinsurance.com
0800 170 7704 or 02392 419 865

Good to Go www.goodtogoinurance.com
0330 0249297 or 01279 621 654



Joshua's story

We had placed the last bauble on the Christmas tree and turned the fairy lights on. It was 18 December 2008, a week before Christmas day, when we received the call we had been waiting for. We were told: "Baby of eight weeks and a three year old. We'll bring them around at 8pm tonight".

As foster carers we had to be prepared for anything, so the next few hours were a mad rush of organising, including a quick trip to the shops for baby essentials. Alan had just finished tightening the last nut on the cot when they arrived. Our journey had begun.

Not long after Joshua arrived, we noticed something wasn't quite right with his hips and explained this to the GP at his late eight week check. X-rays showed nothing abnormal but over the next few months we made careful notes of his development: when he was still losing balance, hadn't crawled, only cruised around holding on to furniture, constantly rocking back and forth and only sleeping around eight hours out of 24.

The following September we were joined by Joshua's baby sister straight from the maternity unit and our family expanded. More sleep deprivation! It was now Christmas 2009 and we made putting up the tree on 18 December a symbolic reminder of when our first foster children came into our home and changed our lives.

As Joshua failed to reach even more milestones we insisted that he was looked at again and eventually received the devastating news that he had a terminal muscle wasting condition called Duchenne Muscular Dystrophy or DMD as it's more commonly known. It was June 2010 and only a few days after he had taken his first steps alone. He was 20 months old. The dystrophin gene in your DNA is made up of 79 exons, like jigsaw pieces that fit together, if one or more is missing, duplicated or spliced then DMD is diagnosed. It destroys all voluntary muscles — eventually reaching the heart and breathing muscles. To date there is no cure. The diagnosis of DMD changed Joshua's future as the care plan for him and his two

siblings altered and only they went together to live with a forever family. The day they left our care, we held Joshua that little bit tighter and made the decision to adopt him. Our love for him was unconditional. We were going to fight with every breath we had to ensure he became our son.

We were told "he's such a complex child". With each month that passes we discover something new about how DMD affects him and what could help. From the initial diagnosis in a small consulting room and just being handed a leaflet; I have become like a detective, researching everything I can about Joshua's condition so that I get as much support as I am able, to help him live a full life. Currently we're waiting for an autism assessment, a wheelchair assessment and access to hydrotherapy. Nothing is easy when you have a child with special needs, including the most profound one of all, housing. We worry about Joshua's needs now and in the future and how we will be able to provide the safe family home he so desperately needs and deserves. Every day brings challenges but we try to make treasured happy moments for him and find ourselves looking back at photographs and videos reminding us all of when we made those wonderful family memories.

Last year we were given a special guardianship of another foster child. To Joshua, Summer-Jane is his sister. They do everything together. Joshua loves dinosaurs,

Transformers, Minions and spending precious time with his biological siblings who were adopted separately. At the beginning of this year we relocated to be closer to them and this gives him more opportunity to see them.

After we attended the Together for Short Lives conference in Birmingham in April 2014, we had the courage to talk to Joshua about what it means to have a life-limiting condition. He speaks about different stages in his future with such maturity: from what colour wheelchair he would like, to positively thinking about the type of car he could eventually drive. It's always "not if he could do things", it's "how he can do things". Joshua has made a bucket list which includes: holidaying in a caravan we can drive, a trip in a classic car, meeting the real Father Christmas and going to the top of the Empire State Building – like King Kong! Christmas is a positive time for us, one where dreams can be imagined and hoped for, a time when we're thankful for the day he came into our lives and changed it forever.

Karen, Joshua's mum

