

together for families

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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.

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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).

www.togetherforshortlives.org.uk

together
for short
lives



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

We are aware of the different demands on your time and are therefore very grateful to those of you who completed the survey in the March edition. It is important for us to listen to what you tell us and we couldn't do our work without you.

In this edition we are pleased to shine the spotlight on the practical and emotional support offered by one of our member organisations. Rainbow Trust Children's Charity offers support to families wherever it is needed, often in the home.

This year's Children's Hospice Week highlighted the importance of family time and having the right support in place to enable families to spend quality time together. During the week, Rachel Wright launched her account of her journey following her son's birth in a book called *The Skies I'm Under*. We are so grateful to Rachel for sharing Sam's story with us on page 6 as it really does highlight the importance of creating the time to put families first.

Julia, Rebecca and Charlotte

Together for Short Lives' Transition Taskforce



In 2012 Together for Short Lives established a UK wide Transition Taskforce to develop a coordinated approach to improving the planning and delivery of care and support for young people as they transition from children's to adult services.

Supported by three years of funding from the Department of Health (England), the Transition Taskforce has made excellent progress in laying the foundations for improving the experience of transition for young people. All regions in England have established Regional Action Groups and several of these have launched Local Action Groups to develop services for young people. A Transition Action Group has been established in Wales, and in Scotland the taskforce there has joined forces with an existing National Forum with responsibility for transition. Planning is currently underway to set up a new transition group in Northern Ireland over the next 6 months.

The Taskforce published a guide for professionals on transition called *Stepping Up* and a guide for Clinical Commissioning Groups on commissioning transition services. In addition, we worked with the Open University and a wide alliance of organisation to publish a guide on sexuality and relationships. For young people

themselves, two new online resources have been developed: *Young Person's Guide to Personal Budgets in England* and *Moving to Adult Services: What to expect*.

Essential to all this work has been the involvement of young people and parents. Our young avenger and parent groups have helped produce the resources and represented the Taskforce at a number of parliamentary and media events.

The Transition Taskforce also inputted into a number of key policy initiatives including the Care Quality Commission (CQC) report *From the Pond into the Sea* and the new NICE guidance on transition.

There has been a lot of learning and in developing our new strategy for 2016-18 we have considered how best to adapt our approach to maximise the impact of the Taskforce. If you would like to get more involved, please email transition@togetherforshortlives.org.uk.

Talking about children and young people

Some of our family community and readers may have noticed that we have begun to introduce the term "life-shortening" conditions in some of our communications.

You may also know that we have to date used the terms life-limiting and life-threatening conditions to describe the conditions that affect the children and young people that we are here for. And often we will also talk about children who are seriously ill. It's helpful to have a range of different words that describe children and young people for lots of different audiences.

We are starting to introduce the phrase "life-shortening" in some communications to help us better describe those conditions affecting children for which there is no reasonable hope of cure and from which children may die before they reach adulthood. This is

partly because we have had feedback over the years that the term life-limiting is confusing and sometimes ambiguous.

We appreciate that language and how you like to talk about your family will be very personal to you. Everyone will have a form of words that they feel most comfortable with. We want to be sensitive and responsive to our family audiences and welcome your feedback on how we talk about children and young people. So please do share your thoughts and views with us. If you'd like to get in touch, please email: myra.johnson@togetherforshortlives.org.uk.



Coming soon! A new guide to support young people during transition

Over the summer we will launch *Moving to adult services: What to expect*. The guide is written for young people from the age of 14 years with the ability to make decisions about their future care themselves. The Transition Taskforce's Young Avengers group were involved in the development of this electronic guide that outlines what happens at different stages of the transition process and what help there is to help young people move into adulthood.

Further details of how to download the guide will be included in September's edition of *Together for Families*.



Children's Hospice Week 2016

It's been an amazing Children's Hospice Week 2016, raising awareness for children with life-shortening conditions and the hospices and children's palliative care services that support them. This year Children's Hospice Week focused on families, calling on people to put families first.

The campaign helped to raise awareness of what life is really like for families caring for children with life-shortening conditions and the need for the right support so families can treasure their time together.

Our Patrons Holly Willoughby and Simon Cowell backed the campaign, along with support from our Ambassador Rebecca Front. As part of the celebrations, Rebecca visited Richard House Children's Hospice and joined children and young people for their film club and a Q&A. She wrote a fantastic article about the experience for The Telegraph.

We were delighted that Her Royal Highness, The Duchess of Cambridge, offered a supportive message, as Royal Patron of East Anglia's Children's Hospices (EACH). You can read the full message on our website.

We were overwhelmed by how many people shared #ourselfie images and #myfamily memories with us on Facebook and Twitter. Thanks to all of you who shared how special family time is to you.

Rainbow Trust Children's Charity

Rainbow Trust Children's Charity provides bespoke emotional and practical support directly to families who have a seriously ill child. They support over 2,000 families across the country.

When a child is diagnosed with a life-threatening condition the whole family is affected and Rainbow Trust appreciates how hard it is for all of them. Rainbow Trust family support workers care for the whole family: from diagnosis, during treatment and, if needed, through bereavement and beyond. They support families in hospital and at home; they help with transport to hospital appointments; and spend time with siblings, helping to keep life as normal as possible for them.

Any family can receive support from the moment their child is diagnosed (including when a diagnosis is made antenatally or neonatally) as well as supporting young people during transition to adult services up to the age of 18.

Anyone can refer a family to Rainbow Trust, provided consent from the family has been given for the referral to be made. To make a referral please visit rainbowtrust.org.uk/support-for-families/ask-for-support.

Marie, Jack's mum said: "We've all built a relationship with Dawn, our family support worker, we all know and trust her. She has spent time with each one of us in our home. I dread to think where we'd have been without her. I honestly don't think we'd all be together as a family if she hadn't been with us. She helped us stay together; she helped ease the tension that built up around us in our grief. Dawn was there for all of us, each and every one of us. She's been with us for the year since Jack died and I know I can call on her if we need her in the future."

RAINBOW TRUST
CHILDREN'S CHARITY

Resources to help in times of emergency

ACTION DUCHENNE

With today's advanced technology you might expect there would be a simple way of sharing information about your healthcare story with professionals to avoid having to repeat this at every consultation or admission.

However, in the absence of a universal electronic system, a number of organisations have developed tools to try and reduce the need for parents and carers to regularly describe their child's condition, medications and care preferences. Health Passports (sometimes known as Hospital Passports or Emergency Passports) are being adopted by many care settings across the UK. They are particularly valuable on admission to hospital when important details need to be shared with healthcare staff in a short space of time.

Action Duchenne has developed an Accident and Emergency (A&E) file for young people living with Duchenne Muscular Dystrophy (DMD), in partnership with the Centre for Life in Newcastle.

The file ensures that vital information can be passed to doctors.

The file can be downloaded from www.duchenneemergency.co.uk and is also available as a free app for Android from the Google Play Store. If you would prefer a hard copy of the file please email angela@actionduchenne.org.

Janet, a mother of a teenager with DMD said: "This app is incredibly important for young people with complex conditions like Duchenne. Too often we hear of unnecessary tragedies that happen in A&E due to lack of information for emergency staff. Hopefully this will now mean, should someone with Duchenne have an emergency, all those involved in their care will have a better understanding of their needs and be able to act appropriately."

Travel insurance tips

When planning your holiday it's easy to get excited about your destination and the things you want to experience. But it is also important to think about travel insurance. You should arrange insurance as soon as possible after you have booked your trip.

We know that families often face problems and challenges when trying to obtain travel insurance when a member of their family has a pre-existing medical condition or disability. There are a few things to remember when looking for specialist travel insurance:

- Buy holiday insurance through a specialist provider as most standard travel insurance policies do not cover complex medical conditions, which means you won't be able to claim if you need emergency treatment abroad.
- Try to include everyone who is travelling on the same insurance policy, this will ensure there are no gaps in cover.
- It is important to disclose all medical conditions. Have information to hand when applying for a quote so you can accurately answer all the questions.
- The cost of travel insurance is likely to be higher than for someone without medical conditions so it is worth checking the price of travel insurance before booking the trip. It can be less expensive to get travel insurance for some countries due to varying healthcare costs.

For more information on travel insurance visit www.togetherforshortlives.org.uk/families/your_questions_answered.

Bereavement services

The loss of a child is the most devastating experience a parent can face. There is no right or wrong way to feel after the death of a child. Parents often describe a roller-coaster of emotions, ranging from numbness to furious anger and profound sadness.

Many parents have told us that their bereavement journey began when they received their child's diagnosis. There are many organisations that provide information and support to people affected by bereavement. Below we have listed just a few of the charities and organisations that provide bereavement support for families.

The Child Death Helpline is a free helpline answered by bereaved parents, for anyone affected by the death of a child; of any age, from pre-birth to adulthood; under any circumstances; however recently or long ago.

Website: www.childdeathhelpline.org

Helpline: 0800 282 986

Email: contact@childdeathhelpline.org

The Compassionate Friends is an organisation of bereaved parents and their families offering understanding, support and encouragement to others after the death of a child or children. They also offer support, advice and information to other relatives, friends and professionals who are helping the family.

Website: www.tcf.org.uk

Helpline: 0845 123 2304

Email: info@tcf.org.uk

A Child Of Mine is a charity that offers help and support to anyone affected by the death of a child. The website hosts information for families after a child's death and details of support groups around the country.

Website: www.achildofmine.org.uk

Email: hello@achildofmine.org.uk

Children of Jannah is a bereavement services for Muslim families. They provide practical, emotional and spiritual support, whilst educating friends, families, professionals and others to be better able to support them.

Website: www.childrenofjannah.com

Helpline: 0161 480 5156

(Open 10am-2pm, Monday-Thursday)

If you think you or a member of your family would benefit from talking to a counsellor you can find a local qualified counsellor using www.counselling-directory.org.uk.

Call our *Together for Families* free helpline on **0808 8088 100** for details of local services that can support you.

New animation shows daily challenges faced by families with a seriously ill child

This June, *Together for Short Lives* will be launching a new animation that introduces the daily challenges facing parents who have a seriously ill child. The animation focuses on the 'everyday' pressures of family life as well as the child's immediate medical needs.

Told from the point of view of a mother looking after her daughter, the animation raises awareness of the pressures facing families and highlights the services that can provide support such as community nurses, family support workers and volunteers. At the end of the animation the family finds support and the film concludes with a positive message that caring for a child with complex health needs can also be an uplifting experience.

The script was developed using the words of real families, and produced at no cost to *Together for Short Lives* by creative animation studio, The Like Minded. It complements the family films we launched in the previous issue of *Together for Families* and will be shared across social media to raise awareness and support for families and children who have life-shortening conditions. Visit the *Together for Short Lives* website to watch the animation. www.togetherforshortlives.org.uk.



Whizz-Kidz

Whizz-Kidz is a national charity which provides disabled children and young people with vital mobility equipment to fit their clinical, social and educational needs.

Whizz-Kidz' young people's service provides young wheelchair users with opportunities to make friends, have fun and learn skills to increase their independence. One aspect of this service is the Whizz-Kidz work placements and work skills training scheme.

The work placements scheme is for young wheelchair users, aged 14-25, to gain experience in a wide range of businesses and sectors. Placements generally last from three to ten days.

Whizz-Kidz also deliver work skills days in collaboration with an employer, organisation or school to help young people develop the key skills they need to start work. Areas covered include CV writing, interview preparation and techniques, and disability employment rights.

Paige went on a work placement through Whizz-Kidz and said: "I worked on the digital



news desk at the Telegraph. I proof-read some articles and even got a piece of my own published on the website; it's got my name on it and everything!

"Through my placement I gained confidence not only in my work but in every aspect of my life, I was able to use transport confidently and know that I could do things for myself."

If you are interested in finding out more about these opportunities, email workplacement@whizz-kidz.org.uk or phone 0800 151 3350.

Whizz-kidz
move a life forward

New SEND guide for families

Together for Short Lives has published a new guide to help families of children and young people with life-limiting conditions join-up their education, health and social care.

The interactive online guide helps families to understand their rights and make the most of the new special educational needs and disability (SEND) system, which is being implemented by government, the NHS, local councils, schools and others across England. It has been funded by the Department for Education and written by Anna Gill OBE, a parent-carer of a young person with a life-limiting condition.

We know that many families spend a long time co-ordinating the multiple appointments, services and professionals required to meet their often complex needs. For many parent-carers, this burden reduces the precious time they get to spend with their seriously-ill children and their brothers or sisters.



The new interactive resource aims to make it easier for families to navigate and find information about the new SEND system. It helps by describing the important parts of the system, including:

- what local offers, education, health and care (EHC) plans and personal budgets are, who is eligible for them and how they can help children and families
- what families' rights are and how they can complain and appeal against decisions relating to their child's assessments, plans and SEND provision
- who holds the local SEND system to account and how families can influence it.

The guide can be downloaded for free from Together for Short Lives' website at www.togetherforshortlives.org.uk/sendfamily.

What the government's Budget means for families

On 16 March, the Rt Hon George Osborne MP, the Chancellor of the Exchequer announced the government's annual Budget. While he did not make explicit reference to children's palliative care, there were a number of new policies announced that will potentially have an impact on the lives of children with life-shortening conditions, their families, and the services that support them.

Following the Budget, the headlines were grabbed by the government's proposal to reform personal independence payments (PIPs), which are replacing disability living allowance (DLA) for adults over the age of 16. The changes would have led to the government reducing the number of assessment points awarded for needing to use an aid or appliance to carry out two of the 'daily living' activities.

The government reversed this decision after widespread opposition. However, its plan to change the way in which terminally ill claimants migrating from disability living allowance (DLA) to a PIP has stayed in place. It will mean that those claimants who are granted a greater award under PIP will get that higher award from the date of the decision, rather than remaining on their DLA award for the standard four week waiting period.

Elsewhere in the Budget, the government announced new peer and specialist support to help young disabled people work. Later this year, the government will propose policy changes which aim to make sure health, care and welfare services can support disabled people and those with health conditions to get into and stay in work.

The government will also allocate £700,000 in banking fines to Birmingham Children's Hospital Charity. This will complete fundraising for the 'Eye Believe' appeal to transform the hospital's Eye Department, and support the 'Star Appeal', to create the UK's first centre for children with rare diseases and undiagnosed medical conditions.



Sam's story

It was mid-October 2005 when my first son was born. "It's a boy!" the doctor exclaimed. "A boy," we said in unison. Immediately our son was carried away and a silence swept the room. "I can't hear him cry," I whispered to my husband, Tim.

The hours that followed tumbled into one another. We hurriedly named our son Sam, fearful he would not live through the night. As a doctor and nurse, the hospital was familiar to us but everything suddenly felt alien. We were now parents, rather than medical professionals, and we had a new and unwanted perspective.

I finally held Sam when he was three days old. As I sat beside his incubator, the military operation to manoeuvre all of the tubes and leads began. Amidst ringing monitors, Sam was gently laid into my arms. The machines faded and my son came into clear focus. This was my precious boy. I was a mother.

Amazingly, Sam was discharged at eleven days old fully breastfed and on no medication. We hopefully attended an MRI scan eight weeks later, eager to hear good news. After the MRI, the doctor guided us through a maze of hospital corridors before showing us into a small office. We entered, clinging on to our hopes of a miracle.

"I'm afraid it isn't good news. The scan shows severe brain damage." The doctor's words were spoken lightly, yet the room began to close in. She explained in detail how the scan showed Sam had been very unlucky. Her words echoed around the room as I began to think 'What did I do wrong?' and 'How had I allowed this catastrophe to happen to my baby?'

That day, we weren't told Sam would never walk, talk or sit, but it was made clear nothing could be guaranteed. Our hopes and dreams were abruptly erased and what remained, felt daunting rather than full of potential.

In the coming weeks and months we began to tread a new path, one with milestones we hadn't foreseen. Instead of first steps and first words, we had to deal with with life-limiting epilepsy, being registered blind and artificial feeding. Yet we had much to be thankful for. Our beautiful boy smiled and engaged with us. He created so much love that we struggled to balance our emotions. How could we feel so heartbroken and yet treasure such perfection?

With time, the impact of Sam's disabilities became clear. The reality of all the disabled equipment he was beginning to need shouted 'Disabled boy, different from everyone else!' The fact that it was so ugly and cumbersome didn't help.

The process of trying to get the right equipment required phone calls, letters and arguing. Yet I didn't really want the constant physical reminder of what Sam couldn't do and how different he was. Over the years, I have started to see beauty where I once saw brokenness. Today, a wheelchair isn't a contraption that contains or segregates; it's a vehicle of opportunity and integration.

Sam's birth catapulted me into another world, a hard and beautiful, tiring and rewarding world. Three years ago, I began writing mine and Sam's story – available for others to read in *The Skies I'm Under*.

Last year, we had a party to celebrate Sam's 10th birthday with his younger brothers, family and friends. The life I live seems a million miles from the one I anticipated. Today, I take nothing for granted and treasure every moment, I take photos and create memories, because I don't know what tomorrow will bring.

Rachel, Sam's mum and author of *The Skies I'm Under*
www.theskiesimunder.co.uk

