

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).

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together
for short
lives



Welcome to the December issue of *Together for Families*.

As Christmas fast approaches, we're already starting to plan lots of exciting things for next year. We want to build on this year's success and make sure we continue to tackle the issues that matter to families the most. That's why we'd love to hear from you, and we hope you'll take a moment to fill in our short online survey.

We're so grateful to Mum Hayley, who talks powerfully about her struggle to get support for her daughter Holly, and why Christmas is such a special time for her family. If you want to share your story in one of next year's editions of *Together for Families*, then please get in touch at: families@togetherforshortlives.org.uk.

We want to make sure you always have the latest information on policy changes, so on page 3 we've summarised some of the most recent developments that could impact families caring for a child with a life-limiting condition. If you need to talk to someone about these changes, then give our free helpline a call on 0808 8088 100.

On behalf of everyone at Together for Short Lives, we would like to wish all of our readers a very Merry Christmas and Happy New Year... see you in 2017!

Julia, Helen and Charlotte



Christmas Appeal

This year we're running our first Christmas appeal to raise vital funds for our work. The campaign shines a light on how important it is that families caring for a seriously ill child get the help they need, so that they can focus on treasuring their time together and making memories at this special time of year.

We know that caring for a child with a life-limiting condition turns family life upside down. It can be an incredibly lonely time, not knowing where to turn. For Carly, finding out her daughter Effie had Late Infantile Batten Disease was devastating and she said:

"Christmas is a very emotional time. Each year, we try to make it as special as possible, but it's always in our thoughts that it might be Effie's last Christmas with us."

We think life could and should be so much easier for families like Carly's – so we are asking our supporters to donate to help us continue to lobby for change, improve services and help families when they need it the most.

We'd appreciate it if you could help us spread the word about our campaign, sharing our social media posts or sending this link to friends and family:
www.togetherforshortlives.org.uk/Christmasappeal.



Help shape our campaigns

We are calling on all our readers to help shape our campaigns to improve services and care for children, young people and their families.

Our campaigning, media work and lobbying is shaped by what families, children and young people tell us. We want this to be as powerful as possible and, of course, to reflect your experience and voice. We also need facts and quotes from families and young people to support our lobbying work.

Can you help us?

We would love you to take part in a very short online survey on how isolated and alone some families say they can feel when caring for a seriously ill child. We want you to tell us what you think. We've kept the survey short with a few questions and some space to share your thoughts.

Everyone who completes the survey will be entered into a draw for a £50 high street gift card.
www.surveymonkey.co.uk/r/isolationforfamilies.

If you would prefer to complete a hard or email version of the survey, please call **0117 910 2461**. We would love to hear from you!



New digital tools to help simplify benefit claims



As government services increasingly move online, new digital tools have been launched in Northern Ireland and the rest of the UK to simplify benefit claims for families.

The Northern Ireland Executive has launched a new online portal to help those who are eligible for Carer's Allowance. The Carer's Allowance is available for anyone who provides more than 35 hours of care each week to someone who is in receipt of Personal Independence Payments, Disability Living Allowance, or a range of other benefits.

You can now apply for the Carer's Allowance, or report a change in circumstances, at www.nidirect.gov.uk/services/apply-carers-allowance. Paper applications are still available for those without access to a computer.

Universal Credit is currently available to people living in England, Scotland and Wales. It is a single, monthly payment which is gradually replacing new claims for income support, income-based jobseeker's allowance, income-related employment and support allowance, child tax credit, working tax credit and housing benefit.

It can be claimed online but there is also a helpline for people who encounter difficulties (0345 600 0723).

However, this gradual roll out means that Universal Credit is available in some areas but not others, which means many parents are unaware about which benefits they should be claiming.

To help simplify this, a new website has been created which features a postcode checker and information about Universal Credit. To get started, go to www.universalcreditinfo.net and enter your postcode. The tool will then tell you whether Universal Credit is available in your area and will direct you to the relevant government website.



Exemptions from Work Capability Assessments

Damian Green MP, the Work and Pensions Secretary, has announced that people who claim Employment and Support Allowance or Universal Credit due to a severe health condition or disability will no longer have to face reassessments to confirm their eligibility.

Currently, anybody who claims these benefits must undergo Work Capability Assessments twice a year to determine their eligibility for the benefits. The minister announced that "claimants with severe, lifelong, often progressive and incurable conditions, with minimally fluctuating care needs, who are unlikely to ever be able to move closer to the labour market and into work" will now be exempted from the assessments.

A full list of conditions which will exempt people from reassessments is yet to be announced, but the minister has pledged that the department "will work with key stakeholders, including disabled people, disability charities and others to develop a set of criteria, set out in guidance, to switch off reassessments for those that are eligible." While this move has been welcomed by many disability charities, others retain concerns that the current test is still too onerous for those with illnesses and disabilities.

Follow @Tog4Policy on Twitter to receive all the latest news on welfare and policy developments.



Call for paid leave for bereaved parents

Currently in the UK there is no statutory right to compassionate leave for bereaved parents. There is an entitlement to 'reasonable' time off, but this is unpaid.

Campaigners are asking that the UK mirrors the rest of Europe and provides a protected period of two weeks paid leave for parents to have time to grieve.

Conservative MP Will Quince and his wife sadly lost a child in 2014, and he tabled the private members bill. He said "My wife and I lost our son who was stillborn full term and I was entitled to two weeks off work protected by statute under the paternity rules. Thinking about the parents of children over six months old, why should they not have the same protection in law as those that lose a baby under six months old? Upon losing a baby, the bereaved mother and father are entitled to full maternity and paternity leave. But if you were to lose an older child? Nothing. Surely this cannot be right."

The Parental Bereavement Leave (Statutory Entitlement) Bill, had its second reading in parliament on 18 November. The bill is proposing to amend the Employment Rights Act 1996 to provide parents with a statutory right to two weeks of paid leave following the death of their child. Will Quince has been keen to highlight that the expected cost to business of introducing the bill will be low, and that by providing bereavement leave it could benefit employers by supporting the wellbeing of their staff and fostering goodwill.

We are supporting the bill, although we would like to see a longer statutory leave period than two weeks. Despite that, we think the bill is an important first step in improving bereavement support for families. If you want to get involved, write to your MP to ask them to support this legislation. Go to www.writetothem.com, enter your postcode and click on your MP's name to send them a message.

Making special memories



Memory making is a conscious decision to set aside time and energy to capture precious moments in meaningful ways. Often when parents are told their child has a life-limiting illness they also hear the words; 'You should make memories.' If your child is very sick and their health deteriorating, making memories might seem impossible. However, we know from talking to parents that taking the time to make memories brings a sense of fulfilment, control and happiness.

Memory making doesn't always have to mean big wish fulfilment events; it can be as simple as producing lovely mementos together that you can treasure.

Sharon Thompson, whose only daughter Victoria was diagnosed with a life-limiting illness at five months old, told us, "The medical professionals said I should make memories. Our baby had no nerve insulation and horrendous symptoms so I had no idea where to start! Also, as Victoria was a baby, I felt it was a pointless exercise. But, the simple little things we did moved us away from her suffering. I have times I can smile about now. The physical process of making memories asks us to try to see past the illness and enjoy the now with your child – so you can have it forever; stored in your heart."



Top tips for memory making

Sharon and members of the Extra Special Kids Facebook group (Ireland) made a list of some of the things they did to make memories; some of their suggestions are below:

- It sounds simple, but take lots of video and photos – make sure you include yourself in them too! Having a professional photographer take photos can be a good idea as well.
- Take hand and foot prints. You can do these yourself at home or with the services that support you. There are also businesses that can turn these into clay prints or pieces of jewellery.
- Create a scrapbook or memory box of important pictures and keepsakes.
- Write letters to your child at various stages of their life.
- Read to your child. Even if they seem unresponsive or not engaged. Stories can transport you anywhere together.
- Organise a trip out to the local park, seaside or farm.
- Write a bucket list of things you want to do together and have fun ticking them off.

Make-a-wish organisations

If you are interested in wish fulfilment then there are a number of UK wide charities that organise special experiences for seriously ill children, including:

- Dreams Come True www.dreamscometrue.uk.com
- Fulfil the Wish www.fulfilthewish.org
- Promise Dreams www.promisedreams.co.uk

For more information, use the service directory on our website: www.togetherforshortlives.org.uk/families.

The impact of fulfilling wishes

Being aware that there was little known about the impact of memory making, the children's charity, Dreams Comes True collaborated with a research team at Stirling University, headed by Professor Liz Forbat. Their three-year project looked at the impact for both the child and their family. As part of the research, Dr Jayne Galinsky spoke to many families who had had a wish fulfilled by Dreams Come True. She found that dream fulfilment gave children and young people a sense of control over a part of their future. Many of them, as a result of being ill and being young, had many decisions made on their behalf by parents and health professionals. Choosing a dream provided them with a sense of empowerment.

The research also found that during the event itself, children and young people become distracted from their illness, routines and pain. Illness shifted from its central position in the family to the background. Dream experiences additionally gave families a chance to create memories. For some of the children and young people with short prognoses, dream experiences such as holidays were final family trips, making them extra special.

Dr Galinsky found that memories are powerful and sometimes 'the blues' came after the larger dream making events. The study hopes to have a better understanding of this effect so that charities will have ways to reinforce a dream's positive impact.

 dreams come true

Leah's Bucket List

From an early age I have had to deal with a lot of limitations due to my disability but I was determined to have goals, hopes, dreams and wishes. My way to do this? Bucket List!

My Bucket List keeps me focused on the things that I want to achieve in my life. Some are small, some significantly bigger.

I have completed a few but I'm hoping for many more! It reminds of how far I have come and what I'm capable of. Plus, it's great to see them turn Gold when I complete them – it makes me feel like a Paralympian with Gold Medals. Check out my Bucket List on my website www.shouldhavebeenamermaid.com/bucket-list.



Support on social media

We know families can feel like they spend their whole lives talking to doctors, nurses or other professionals – it can be overwhelming and confusing. Hearing from mums and dads who are able to share in your experience can be really valuable.

That's why we have created a new private family forum for parents who are currently caring or have cared for children with life-limiting conditions. Our Families Together Facebook group went live back in September and we now have over 50 members in the group.

One of the parents involved in the group said: "No matter how much support I get from family and friends, it's difficult for people to relate to or understand what you are going through day by day. I've had such care and encouragement from parents I've met through social media who are going through similar challenges...at the darkest of times, there is something so comforting in hearing someone say "Me too, I get it".



Another parent said "You should join the Families Together Group because life with children like ours can leave us feeling isolated and like no-one understands. In Families Together we all understand".

If you would like to sign up for the group, please email: families@togetherforshortlives.org.uk.

My adult, still my child: New website for parents on decision-making

The Mental Capacity Act 2005 applies to everyone over the age of 16 and provides a legal framework for making decisions when a person cannot give consent for themselves.

Whilst day to day decisions about care will often still be made by the young person's primary care giver, from 16 the law regards decisions about serious medical treatment to be the responsibility of the person delivering the treatment – such as doctors or medical professionals.

For parents that are used to making every decision in their child's life, this can be a difficult and confusing change. Parents and carers supported by Rainbows Children's Hospice in Loughborough wanted others to know that it is best not to wait until your child turns 16 before you begin to consider how the Mental Capacity Act affects you and your child, when health and social care is required.

In September, Together for Short Lives, along with Rainbows Children's Hospice, Murray Hall Community Trust, Browne-Jacobson Solicitors and parents from the East Midlands, launched a new website



which acts as a hub of useful information for parents caring for a child over 16 who cannot make decisions for themselves. Funded by the NHS England Mental Capacity Act Improvement Programme, the website aims to help parents better understand their rights and options in decision-making as they continue to love and care for their adult child. The website offers guidance on what the law says and includes an A-Z jargon buster, as well as case studies of families' experiences. It also signposts visitors to sources of further information and support.

Head to the website to find out more: www.myadultstillmychild.co.uk.

The Mental Capacity Act came into force in England and Wales in 2007. If you live elsewhere in the UK, download Factsheet 20 from our website for further information: www.togetherforshortlives.org.uk/Factsheet20.



Transition Summit

In 2013 we set up the Transition Taskforce to overcome the barriers to good transition for young people with life-limiting conditions, working to build and strengthen bridges between adult and children's services. The Taskforce met in early November for their annual summit which brought together over 100 people, including many of our Young Avengers and parents, and we reflected on the Taskforce's key successes.

We wanted to share some of the key highlights, including that there are now regional action groups in all eight regions of England, with a formative group starting in Northern Ireland. The Taskforce has also joined with National Forums in Scotland and Wales. If you would like to join the Transition Taskforce Parent Reference Group or would like to discuss any aspect of transition, do contact us at transition@togetherforshortlives.org.uk.

One of the key highlights to date has been the creation of 'Stepping Up' a blueprint for transition, ensuring that service providers are aware of best practice and key standards that need to be achieved. The Taskforce recognised that young people should be at the heart of decision making and we have welcomed their input in the development of our guidance including advice on personal budgets, sexuality and relationships and moving to adult services.

We were also delighted to announce at the Transition Summit that we have secured funding to lead a grants programme to support innovations, new services and developments in transition across the UK. This exciting new programme will begin in 2017 and we are committed to ensuring the fund will make a difference to young people in transition.



Holly's story

When Holly was born 14 years ago, I was over the moon; we were anticipating a healthy baby without any complications. To move from that to the knowledge that your child isn't well is incredibly confusing, it changes your whole life plan.

I'll always remember the moment we were sat in hospital, and they said "We're going to turn off Holly's life support machine tomorrow and we need you to all come in. We need you to get your family in to say their goodbyes to her". That was the worst moment of my life. It was a surreal situation, feeling like an outsider at such a significant moment, with no control over what was happening. The next day, we turned Holly's machines off but thankfully, she showed us signs that she wanted to stay with us.

Once we were discharged from the hospital, I found it hard adjusting to a new version of motherhood that I'd never experienced with my son, Josh, who's healthy. I was a mum to both of them, but now I had to be a carer, nurse, and advocate for Holly too. In the early days, we received very little support or guidance, and I remember feeling so lost and alone. We were a family unit, but all of a sudden we'd become completely different to everyone else around us. I felt isolated from our community, from everybody we had known and been close with.

A lot of the time it was because people didn't know how to act around us. They didn't know how to interact with Holly and they were scared to approach us because this little person was suddenly life-limited, very fragile, and completely dependent on us. Accessing help felt almost impossible, and we got very little support from medical professionals, who told us "Don't do this, it'll be the worst thing, you can't imagine how difficult your life is going to be". We'd presumed they would provide the knowledge and expertise to guide us, but in reality we felt very alone. Even though we had great support from friends and family, we desperately needed reassurance and support from medical staff.

Unfortunately, difficulty finding support became a fixture of our lives and we faced so

many barriers to getting what Holly needed. From equipment to school, from social inclusion to transport and access to medical advice, we had to fight for all of it. It felt like no-one wanted to invest in Holly. They wanted to deal with the "here and now" and that was it, but my hopes and aspirations for her went far beyond that. I don't get up every day and think "This could be the last day with Holly". I get up and think "How can we make this day as exciting and memorable as we can?"

Luckily, Claire House thought the same way. When we found the hospice, we finally had access to the reliable, knowledgeable, supportive system we'd been searching for. With their help, we've been able to get Holly out and about enjoying life and making memories.

Even with the support of medical professionals, there can be long periods when Holly is unwell, so we try to make the most of the times when Holly's feeling better. I used to be so worried that something would go wrong, so we'd live day to day. We didn't think it was possible to make plans or live life really. It just hit me one day and I thought "Our family isn't living the life a family should live."

Since then, I've tried to pack our lives with as much fun as possible, from camping to outward bound activity weekends. While our plans can change at the last minute, it's



important to get out and do things when you can. That's why I'm trying to build a good social network in Liverpool, where we live. I've worked with other parents to create a social circle for children with similar needs to Holly. We plan lots of activities so the children can have fun and build friendships. It's also a great opportunity for parents to get together. Without other families to identify with, it's easy to become quite isolated. Just leaving the house with so much equipment, when you've had no sleep, can be a huge challenge. It's easy to fall out of touch and feel very alone, so we really value the times when we can get together to have fun.

Hayley, Holly's mum

