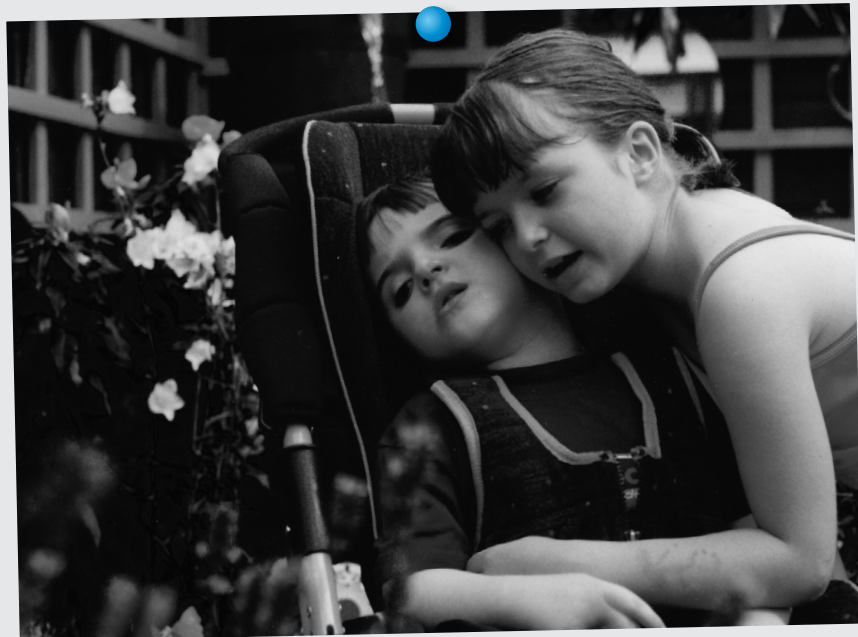


together for families

Issue 20
March 2017



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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.

Follow us and join the conversation!



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

Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is incorporated as a company limited by guarantee (7783702).

together
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short
lives



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

We've had a busy start to the year with the launch of our new Transition Awards Programme in February which will fund innovative transition projects for young people with life-limiting conditions, you can find out more on page 5.

In December, we asked you to tell us how caring for a seriously ill child has impacted your social life and relationships. We're so grateful to those who responded and a big congratulations to Charlotte Huzzey who won a high street voucher for completing the survey.

We're gearing up for this year's Children's Hospice Week, which will take place between 22-28 May. There'll be lots of ways for you to get involved so make sure you save the week in your diary!

We know that having a child with a life-limiting or life-threatening condition affects the whole family, so on page 4 we share information to support brothers and sisters growing up with a disabled brother or sister. We're grateful to Lowri and Emily who share their experiences with us on page 6.

This year we will be producing *Together for Families* three times a year. If you'd like to receive more regular news from us then head to our website where you can sign up to our e-bulletin, or if you would like to connect with other parents, please join our private Facebook group.

Julia, Helen and Charlotte



Take on the challenge of a lifetime

Our work just couldn't happen without the amazing people who fundraise for us. If you, or one of your friends is thinking about running the London Marathon, trekking the Brecon Beacons or cycling from London to Paris, then why not sign up to one of our challenge events! You can find out more on our website: www.togetherforshortlives.org.uk/events

Shaun McCabe is running the London Marathon in April for us. He said: "My nephew, James, was born with a rare condition known as Vein of Galen. James is severely disabled as a result of the condition. As you can imagine, we owe a great deal to charities like Together for Short Lives and I really wanted to provide something in return to say thank you for all of the tremendous support and care. I have always wanted to do something worthwhile to raise funds for such a fantastic charity and what better than running the London marathon."

Our CEO, Barbara Gelb OBE has also been inspired to take on a challenge of her own this year. In April, she'll be heading to Snowdonia with Catriona Marshall, CEO of Hobbycraft, to do a tough night climb. They'll be sleeping in a tent suspended from the

rock face and then abseiling down the next morning. Hear more about it on our YouTube channel:

www.youtube.com/Together4ShortLives.



Parliamentarians shine a light on the 49,000

In February, we held a Westminster Reception, hosted by Stuart Andrew MP to highlight the reality of caring for a child with a life-limiting condition, to share the challenges families face in getting support and setting out what needs to change. Parliamentary Under-Secretary of State for Community Health and Care David Mowat MP addressed the event, sharing his reflections on what needs to be put in place to improve children's palliative care. The Minister said that good end of life care for children was a priority, stressing the importance of families having open conversations with professionals and being offered real choice in where end of life care is delivered. He also noted that there is still a postcode lottery of care for seriously ill children.

The event also marked an important milestone for children's palliative care, with the launch of the first dedicated All Party Parliamentary Group for children who need palliative care. It's significant as children and young people who need palliative care

are often treated as mini-adults – their voice and unique needs get lost in adult palliative care policy discussions. This parliamentary support will help to amplify the voices of the 49,000 seriously ill children and young people, and their families, and show why there's an urgent need to invest in the services and care they desperately need.

Launching the new APPG, Stuart Andrew MP for Pudsey, Horsforth and Aireborough said: "Having worked in two children's hospice services I have seen first-hand what a vital role they play in supporting children and families – without this many families would be at breaking point. Sadly, we have a long way to go to ensure that each and every child, young person and family get the care they need. That's why I'm passionate about speaking up for the 49,000 through setting up and chairing the new All Party Parliamentary Group for Children Who Need Palliative Care."

If you want to hear all the latest from our policy work, join us on Twitter [@Tog4Policy](https://twitter.com/Tog4Policy).

Family of disabled grandson win appeal against 'unfair' bedroom tax

Paul and Susan Rutherford have won their legal battle against their bedroom tax ruling, after a three-and-a-half-year dispute with the UK government.

The Rutherfords care for their severely disabled grandson, Warren, who requires overnight care and therefore an additional bedroom for his carer. The additional bedroom is also used to store equipment for Warren, who has a rare genetic condition which means that he is unable to walk, talk or feed himself and is doubly incontinent.

The family won their initial court case at the Court of Appeal in January 2016 after the Lord Chief Justice and fellow judges ruled that the bedroom tax was not justified in their case and that it violated the family's human rights. However, the Department for Work and Pensions elected to appeal against this decision, which meant that the Rutherfords were forced to contest the case at the Supreme Court.

The existing bedroom tax rules stipulate that an adult who requires an overnight carer is



entitled to an additional room, but this does not apply for children. In their ruling in favour of the Rutherfords, the Supreme Court judges unanimously agreed that the rules as they stand are 'manifestly without reasonable foundation'.

Contact a Family, a national charity for families with disabled children, runs a free helpline to provide information and advice to families affected by the bedroom tax. You can contact them from 9am-5pm, Monday-Friday on **0808 808 3555**.

NICE sets the standard for transitions to adulthood

The National Institute for Health and Care Excellence (NICE) has published quality standards for transition from children's to adults' services.

NICE quality standards set out priority areas for improvement and are used by commissioners to ensure that high quality care is being delivered. They are also used by service providers and professionals to monitor and develop their standards of care. The standard sets out five 'quality' statements which indicate high quality care for young people transitioning from children's health or social care services to adult services. These are based on the areas for improvement that NICE has identified and they cover the periods before, during and after the young person moves to adult services:

- 1. Young people start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.**
- 2. Young people have an annual meeting to review transition planning.**
- 3. Young people have a named worker to coordinate care and support before, during and after their transition.**
- 4. Young people meet a practitioner from each adults' service they will move to before they transfer.**
- 5. Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.**

Together for Short Lives played an active role in shaping these new standards, which relate to the recently published NICE clinical guideline on transition to adulthood.

We are a registered supporter of the new quality standard. We submitted evidence to the consultation on the quality standards which reflected the views of young people with life-limiting and life-threatening conditions in addition to individuals and organisations providing palliative care to children and adults.

The NICE 'Transition from children's to adults' services' quality standards are available here: <http://bit.ly/2kZtUn3>.



Major new children's palliative care strategy for Northern Ireland

In December, the Northern Ireland Department of Health published a new 10-year strategy for palliative and end of life care for children and young people.

The strategy recommends a series of actions to enhance the existing care and support available for children and young people with life-limiting or life-threatening conditions and their families. To achieve this, the strategy contains 23 objectives for transforming children's palliative care in Northern Ireland. A 'New Care Model' set out in the strategy identifies that the child, their family and carer must be at the centre of their care and that their care plan should be based on a holistic assessment of the child's needs.

Heather Weir, Chief Executive of Northern Ireland Hospice, has welcomed the strategy, describing it as a "milestone in the way in which children's palliative care is planned and delivered in Northern Ireland". While Northern Ireland Hospice has welcomed the Minister's announcement regarding the strategy, it is now calling on the department to clarify how the plan will be implemented over the long-term – and to set out how children's palliative care can be sustainably funded.

Together for Short Lives echoes this. We have welcomed the strategy as rightly recognising that children's palliative care is an active approach to care which begins when a child's needs are diagnosed or recognised and continues through their life, death and beyond. We are also pleased that the strategy recognises the needs of the whole family and includes bereavement care for those who are affected when a child dies. We have made an open offer to support officials and health and social care services to implement the strategy – and to bring about the best quality of life and death for children with life-limiting conditions in Northern Ireland. You can read the new strategy online at <http://bit.ly/2l0XFUe>.

 Department of
**Health, Social Services
and Public Safety**
www.dhsspsni.gov.uk

Supporting brothers and sisters

When a child has a complex life-threatening health condition, we advocate that the whole family should get support to enable them to make the most of their time together. Sadly, parents often tell us that they feel their other children may not be getting the support they need.

We have a factsheet: 'Understanding Siblings Needs' which is available to download from the Family Resources section of our website and details the organisations that are there to support brothers and sisters: www.togetherforshortlives.org.uk/SiblingsFactsheet.



Harvey Hext Trust – A Siblings Wish

In 2015, Sarah Hext's 9-year-old son Harvey died of cancer. At the time, his brother, Spencer, and sister, Olivia, were given a cardboard memory box, but Sarah worried that it wasn't durable or special enough to contain such treasured memories of their brother. Instead, she worked with Olivia and Spencer to design a personalised, wooden memory box to keep all their important mementoes of Harvey in.

Sarah wanted to ensure that other bereaved siblings had the opportunity to create similar memory boxes, so in 2016 she set up the *Harvey Hext Trust – A Sibling's Wish*. The charity works to help children design bespoke memory boxes using their own choice of images, special drawings and themes. The design is then printed and heat wrapped onto an A4 sized wooden memory box, creating a beautiful and durable place for them to keep their important keepsakes. The bereaved child is also given a 'Harvey bear', which has a concealed pouch to keep their favourite item from their sibling in. This means they can keep it with them at all times, helping them to feel close to their sibling. To see examples of the beautiful memory boxes and Harvey bears please visit www.asiblingswish.com.

Sarah said; "The memory boxes can be an important part of therapy to encourage children to show emotions and to talk about their bereavement. The boxes are a very simple but effective way of helping a sibling remember their brother or sister and a special way to preserve their memory. But importantly the memory box is theirs and theirs alone to keep forever."

Harvey Hext Trust – A Sibling's Wish is completely self-funded and there is no charge to the family for the service. The charity works with many bereavement charities and referrals can be made either by bereavement professionals or bereavement charities to sarah.asiblingswish@gmail.com.



The impact of a sibling's death on adult brothers and sisters

A recent study undertaken by the Children and Families Research Team at Coventry University focused on the long-term well-being of bereaved adult brothers and sisters of siblings diagnosed with life-limiting conditions. To the team's knowledge this was the first study of its kind in the UK which has enabled adult siblings to share their untold stories.

Ten adult siblings aged between 18 and 31 were recruited from across the UK. In-depth telephone interviews were undertaken, with questions structured in a way that took participants on a journey from their brother's or their sister's diagnosis to death and beyond.

All the siblings agreed that their brother's or their sister's diagnosis had an enormous impact on the family collectively and on individual members. However, there was evidence that families developed strategies to help siblings adjust to living with a brother or sister with complex needs and that they were able to spend happy times together. Three of the siblings referred to how their family sustained an ongoing relationship or a 'continuing bond' after their brother or sister died. This was perceived as "quite normal, because after all, her memory didn't die with her."

One of the most significant findings of the study is the resilience demonstrated by siblings and how they perceive their experience as shaping their world-view. One respondent said: "Having the experience has helped me empathise more with other people and it has definitely moulded who I am." Three female siblings and one male sibling spoke at length about how the experience had impacted on their thoughts about parenthood. These young adults viewed prospective parenthood with apprehension and those who had children of their own, spoke about added anxiety.

Siblings drew the researchers' attention to the importance they placed on professionals listening to their stories and they viewed such opportunities as cathartic. The young people also reflected on the benefit of being included in conversations with their parents and with professionals from the time of diagnosis, bereavement and beyond.

This study has provided new insights into the experiences of bereaved siblings, whether they were born into a family before or after a brother's or a sister's death. What seems clear is that, despite their own experience of grief, most brothers and sisters develop huge resilience in the face of adversity.



New ground-breaking transition awards – a catalyst for change for seriously ill young people

In February, we launched a ground-breaking new Transition Awards Programme to fund innovative transition projects. Advances in medical technology mean that the number of young people with life-threatening conditions is increasing, but many young people are not getting the support and care they need. There is an urgent need for new initiatives to transform the experience of young people with life-limiting conditions as they move from children's to adult services.

The new Awards Programme will act as a catalyst for change, encouraging and supporting services to work together to improve the experience of young people in transition between children's and adult



services and to maximise their opportunities as they settle in to life as an adult.

We are reaching out to services across health, social care, education, employment and housing to work together to overcome the barriers seriously ill young people face, helping them to live life to the full. We are hoping to see a wide range of applications and partnerships across these five sectors and are seeking projects which have the potential to be reproduced regionally and up scaled nationally.

To find out more about our Transition work head to our website:

www.togetherforshortlives.org.uk/transition.

Voices for Families: Advocacy Support Service

The scale of the daily challenges faced by families caring for a child or young person with a life-limiting or a life-threatening condition can sometimes feel immense, from getting the right care package, housing or adaptations, to making sure the child has a smooth transition to adult services. Often speaking to professionals and agencies can be very frustrating – especially with a busy and often emotional home life.

We have been working in partnership with LawWorks, the national pro bono group for solicitors to run the Voices for Families: Advocacy Support Service. The advocacy service can provide you with a volunteer support advocate to assist you and your family though some of the problems you are facing, acting on your behalf to help you get the support you need. When we talk about support advocates we mean someone who can help you plan an approach, explain a need, present a request, and carefully and fairly make sure that request is addressed. The support of an advocate can help you and your family to spend more time being just that – a family.

One family supported by the service said “Words can’t describe the impact the Voices for Families support project has had on my family. All that has been achieved has been through the hard work and tireless dedication the support advocates provided. They have been a blessing to my family.”

One of our fantastic partners, Clyde and Co supports the Advocacy Service at Richard House, and Claire Curtis, a lawyer from the firm, recently won an award from LawWorks for her work on the Advocacy Service. Over the past four years, Claire has supported and advocated for a number of families, helping them with a range of issues including health and care packages, housing benefit and benefit entitlements. Claire has recently supported a family whose daughter suffers from a complex multi-system disorder to get help with housing and healthcare issues. As a result of Claire's advocacy, a multi-agency health and care plan has been put in place to support the little girl and her family.

If you would like to speak to someone about how you can access advocacy support, please contact the Together for Short Lives Helpline on **0808 8088 100**. We are currently piloting drop in clinics providing free advice for families at a number of children's hospices and other children's palliative care organisations. If you would like any further information on the clinics, please do contact the Together for Short Lives Helpline.

Campaigning success

We were overwhelmed by the success of our very first Christmas Appeal at the end of last year.

The appeal was supported by *The Daily and Sunday Mirror* and they featured a number of articles that shone a light on the needs of children and families, and the amazing services that support them. The media coverage has really helped us to help break taboos, build awareness and ultimately encourage people to support our work.

Sadly in February, we received the news that Effie Hadman had passed away. We had shared Effie's story during the appeal and we were incredibly moved by her amazing spirit and her very special family. Effie has touched many lives and will be so missed, our thoughts go out to her family and friends.

We want to say a big thank you to all of those who kindly donated. We were absolutely delighted to raise almost £31,000, which will support our work to ensure that families get the help they need.



Children's Hospice Week



22-28 May 2017 **Let's turn up the volume!**

This year, Children's Hospice Week will be held on 22nd - 28th May. We're going to be using the week to encourage our supporters to 'Turn up the volume' on children's palliative care; dispelling myths, changing people's perceptions and raising awareness of the needs of children with life-limiting conditions. There will be lots of ways for you to get involved so make sure you save the week in your diary!



"I must have been a nightmare": A sister's story

I suppose it's unusual that my first memories of Iwan took place in the hospital. From the word go, long hospital stays were the norm, but that didn't stop me wanting to visit my new brother.

I always wanted to go with my parents to see him in hospital, but restrictions on visitors in intensive care often made that tricky. More often than not, I'd stay with relatives, friends, or anyone who was willing to help us out.

When you're little that's really hard – not being able to spend time with your parents. I remember once they bought me a Barbie doll to make up for the fact that they weren't around as much. I don't think it was until I took the Barbie and threw it on the floor, that my mum realised their time was far more precious to me.

I struggled with that, and like a lot of siblings, I tested the boundaries a bit. Once, I put on my rollerblades and kicked through our patio doors, then denied all knowledge of it when Dad found me, still wearing the roller blades,

with the patio covered in glass. Another time, I poured dark purple Ribena all over our carpet and curtains. Looking back, I think "I must have been a nightmare", but Mum reassures me I was just craving their attention, rather than being pointlessly naughty.

When it comes to friends, I was lucky growing up. I went to a small, local school, where I made friends who I keep up with even now, and I didn't experience any of the bullying or social issues that I've heard can be a struggle for other siblings. I remember one incident when a boy had seen me on a TV show, which had transformed our garden into a sensory space for Iwan. He said "oh, you're the girl with the disabled brother, aren't you?" and laughed at me. I never really take things like that to heart, and that's thanks to Iwan himself in a roundabout way. The experience of having him as a brother has made me so much stronger than I could ever have been without him. Even then I felt sadder for the boy than for myself. I thought "you really don't have a clue".

I'm 23 now, and my thick skin isn't the only thing Iwan's given me. For someone so quiet, he's been pivotal in shaping my career. After

high school and college, I went on to study physiotherapy at Manchester. Nowadays, I work as a physio for children with complex needs, and I've also helped create a scheme that gives comfort bags to patients' families during unexpected hospital stays.

For Iwan, his journey hasn't been as clean-cut as mine. He's 20 now, and transitioning to adult services has been a big change for him. The support and crucially, the structure, given by children's services has now gone. Going to a special school gave Iwan a group of friends, and activities appropriate for his age and abilities. Now, there isn't a place for him to go. He doesn't currently have any day support, and is back at home where he's looked after by my parents, who split their time between working and caring for him. Luckily, we still get some support from our local hospice, Ty Gobaith, but that doesn't give him the daily routine he enjoyed at school. In the future, I'd love him to have somewhere to go – an adult school, somewhere he could have fun and give my parents a rest. That would be amazing.

Lowri, Iwan's sister



Living with my disabled brother

I have lived with my brother Ben who has Spinal Muscular Atrophy all my life. At first it didn't bother me but then I started to notice that Ben got lots of attention and I was sometimes just left to get on with stuff. I feel a little left out when Ben gets more attention than me, and some of the things I don't like about his disability are:

- We don't get to do the things that a normal family would
- I don't get a lot of attention compared to my brother
- I have to help him all the time which can be annoying when I am busy and want something else done

But things aren't all that bad. Because he is disabled and unwell at times, we get support from a lot of charities and other people. We also get to go on treats that probably normal families don't. So, some of the things that I like are:

- My family and I get to go on outings and trips
- We get to meet people like celebrities
- I go to activities with the young carers

If I had a magic wand I think I would like to change our money situation because I think it could help my family be a bit happier. Ben's disability has stopped mum and dad working properly. Also our house could do with a makeover. We have a special lift for Ben to get upstairs but I think our house could be bigger. And; it's a bit small for a big wheelchair and all the equipment for my brother.

Having said all of that, there is one thing I won't change, and that is my family.

Emily Morris (Aged 13), Ben's sister