

# together for families

Issue 11

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Together for  
Families Helpline  
7am-Midnight,  
7 days a week

**0808 8088 100**

[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)  
[www.togetherforshortlives.org.uk](http://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 seven days a week between 7am and midnight. 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](mailto:families@togetherforshortlives.org.uk) to subscribe to *Together for Families*, or if you would like to contribute to a future edition – we'd love to hear from you.

Follow us and join the conversation!



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

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

together  
for  
short  
lives



## It's been a busy few months at Together for Short Lives HQ with lots of exciting campaigns taking us up to Christmas!

Text Santa will be returning to our screens on Friday 19 December so make sure you save your seat on the sofa for an action packed evening filled with lots of surprises. We will be tweeting live throughout the show so make sure you're following **@tog4shortlives** for all the latest news.

The Global Radio Make Some Noise appeal day took place on Thursday 9 October, raising a fantastic £1.1 million through donations, auctions and fundraising events. Together for Short Lives was the main beneficiary charity for the appeal – turn to page five for a round up of the day's events.

Our family factsheets are available to download from the Together for Short Lives website for free. Turn to page three for further information on how these can be used alongside our new Family Companion. The factsheets detail further information on a wide variety of subjects, helping to support families caring for children with a life-limiting or life-threatening condition.

You will see that we are starting a new regular feature in this edition of *Together for Families* called Meet the Team. Meet the Team will highlight someone from our organisation, asking them five quick questions to give you some bite size information on their role and involvement with Together for Short Lives. Turn to page four to see our Q&A with parent trustee Richard Strawson.

On behalf of everyone at Together for Short Lives, we would like to take this time to wish all of our readers a very Merry Christmas and Happy New Year... see you in 2015!

Claire



# Text Santa

Save your seat on the sofa as Text Santa will be returning to our screens on Friday 19 December at 8pm! It promises to be an evening filled with festive delights including a George Clooney Downton Abbey special, live music performances from chart topping stars and surprise celebrity guest appearances!

Together for Short Lives has been chosen as one of six charities benefitting from the funds raised during the appeal, which will help us continue our work with local children's hospice services that support and care for seriously ill children and their families.

## CITV

Throughout December in the lead up to the Text Santa appeal show, CITV have been broadcasting a series of short films, highlighting young fundraisers.

One of the short films features an inspiring young girl called Abbi who fundraises for Rainbows Hospice for Children and Young People. Her brother Ryan, who was diagnosed with Duchenne Muscular Dystrophy at the age of six, is supported by the service and Abbi also attends the sibling support service.

Abbi and Ryan share a love for art and have both sold paintings to raise money for the hospice. Abbi enjoys creating canvas art and uses her skills to produce bespoke pictures made from buttons. Over the past couple of weeks, she has been producing Christmas cards and selling them at the hospice, raising money for ITV Text Santa.

The film shows the family at their home with Tricked magician Ben Hanlin, who stopped by to perform magic tricks for the family with buttons! The footage also shows Abbi selling her Christmas cards in the hospice. Abbi is hoping to raise hundreds of pounds selling her cards for Text Santa!

Abbi told *Together for Families*: "I really enjoyed selling my cards for Text Santa and was so pleased to have raised as much as I did. People said they were surprised I had made the cards as they looked so professional and that made me feel very proud. It was also great fun when Ben came to our house, that was the best part of the day. He did lots of magic tricks with buttons, which were brilliant. I have seen Ben on TV so it felt weird and really special to have him in my house."



## Center Parcs short breaks

Over the past year, ten of our families have enjoyed short breaks courtesy of Center Parcs. We are delighted that Center Parcs have once again donated ten more short break holidays for Together for Short Lives family members. The breaks can be taken at any of the five UK Center Parcs village locations – Whinell Forest in Cumbria, Sherwood Forest in Nottinghamshire, Elvedon Forest in Suffolk, Woburn Forest in Bedfordshire and Longleat Forest in Wiltshire. Accommodation will be in a three bedroom New Style Woodland Lodge. The breaks can be taken either for a long weekend (Friday to Monday) or midweek (Monday to Friday) but excludes school and public holiday periods. We are inviting members of Together for Short Lives' Family Community to enter a draw to go on one of these holidays. To register your interest, please email your contact details to **families@togetherforshortlives.org.uk** by Friday 9 January 2015. Please include details of your child's condition and access requirements. Together for Short Lives will contact the lucky families and organise the holiday for a convenient time. All holidays need to be taken by 1 August 2015. Good luck!

# Family Factsheets

We're delighted to launch our updated range of family factsheets that can be used alongside the new Family Companion. There are a total of 17 factsheets available that offer key information in bite size chunks, detailing information on the following topics:

- Parent Support Groups
- Children's Hospice Services
- Making a Complaint (one for each UK nation)
- Grants and Wishes
- Short Breaks and Holidays
- Emotional Support and Counselling
- Care Planning in Advance
- Transport
- Aids and Equipment
- Spiritual, Religious and Cultural Wishes
- Benefits
- Understanding Siblings' Needs
- The Child Death Review Process (England)
- The Mental Capacity Act (England and Wales)

To give an idea of the type of information that is included, we have highlighted two factsheets to describe in further detail.

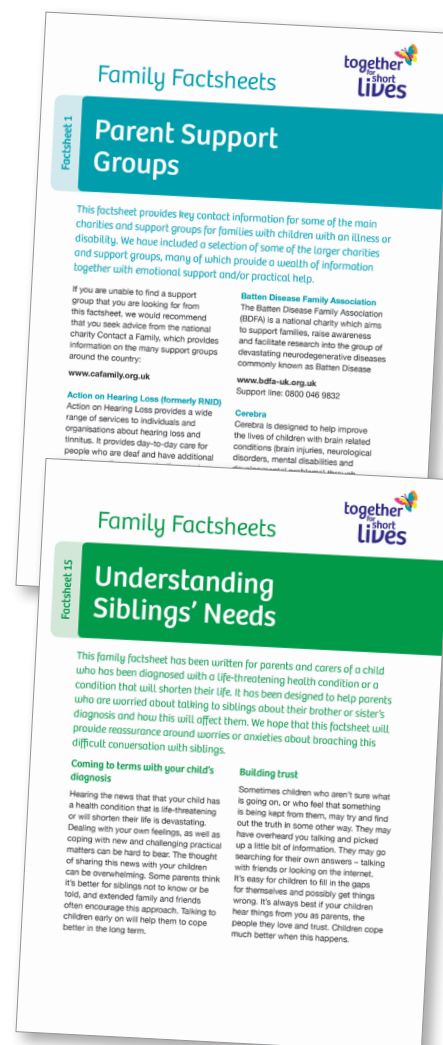
## Parent Support Groups

This factsheet provides information for families that care for children with life-limiting or life-threatening conditions, detailing some of the main charities and support groups available for them. It includes links to organisations offering a wealth of information together with emotional support and/or practical help.

## Understanding Siblings' Needs

This factsheet has been designed to help parents who are worried about talking to siblings about their brother or sister's diagnosis and how this affects them. The factsheet also lists some useful organisations that can support parents and siblings.

You can download these resources for free at the Together for Short Lives website: [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk).



## Special Educational Needs and Disability (SEND) Reforms

Since 1 September, key parts of the new SEND system, brought about by the Children's and Families Act 2014, have been in place across England. The reforms, which include joined-up assessments, plans and services for children and young people with SEND aged 0-25, should be fully implemented by April 2018.

In the next edition of *Together for Families*, we will hear from James Cooper, our Public Affairs and Policy Manager, on whether children with life-limiting conditions and families are benefitting from the new system. In our summer 2015 edition, we plan to reflect on how the first six months have gone and we would love to hear from you about any changes you have noticed as a result of the act – good or bad! Are education, health and social care services working in a more integrated way for your child? Does your child have an Education, Health and Care (EHC) Plan? Do you have a personal budget? Have you used your local offer – and does it include helpful information about your local children's palliative care services? If you have an experience you are happy to share with us, please contact Julia at [julia.hodgson@togetherforshortlives.org.uk](mailto:julia.hodgson@togetherforshortlives.org.uk).

Don't forget that we provide a number of online resources to help make sure children who need palliative care can benefit from the reforms: [www.togetherforshortlives.org.uk/sendproject/resources](http://www.togetherforshortlives.org.uk/sendproject/resources).

Independent Parental Special Need Advice (IPSEA) has also created more new resources to empower parents and carers of children and young people with SEND. These are available free of charge from their website: [www.ipsea.org.uk](http://www.ipsea.org.uk).



## Share your experiences of childcare

The Family and Childcare Trust want to speak to parents of children with special educational needs and disabilities.

They are making a series of short films and written 'top tips' with parents of children with special educational needs and disabilities offering advice to other parents about accessing, choosing and paying for childcare. These are funded by the Department for Education and will be shared on their website, through their network of Family Information Services and with other partners in the childcare sector.

The stories will be compiled over the next few months (likely to be filmed in February) and they would like to speak to a range of parents about all aspects of childcare; the benefits, the barriers, concerns, funding, inclusivity and transport.

By contacting them there is no commitment to take part; but if you are willing to share your experiences with other parents, please contact them by emailing Pip Dorkings at: [pip@familyandchildcaretrust.org](mailto:pip@familyandchildcaretrust.org).



# Meet the Team!

Meet the Team will be regular feature in *Together for Families* where we introduce one of the Together for Short Lives team to our readers. In this edition, we meet Richard Strawson, one of our parent trustees.

**Richard, thank you for agreeing to feature in *Together for Families*. First of all, would you like to introduce yourself to our readers?**

My name is Richard Strawson and I am one of three parent trustees for Together for Short Lives. I have worked in Trading Standards for over 20 years which I find extremely varied and very rewarding. I live in a village in Kent with my wife, Susannah and 4 children – Thomas (14), Hannah (13), Lydia (6) and Faith (4). After Thomas and Hannah were born Susannah and I became foster carers before, in 2007, our third child, Daniel, was born. He was a normal, happy baby and Thomas and Hannah loved having a new sibling to play with. However, in the summer Daniel became unwell and was diagnosed with a rare and extremely aggressive brain tumour in September. Despite an operation to remove the bulk of the tumour he continued to need significant care and sadly Daniel died on 31 December 2007, aged just 11 months.

**Why did you apply to become a parent trustee for the Together for Short Lives' board of trustees?**

Even before Daniel was born, Susannah sold Phoenix cards from home and their chosen charity was Children's Hospices UK (which subsequently became Together for Short Lives). As a family, during Daniel's illness and after his death, we were greatly supported by members of Together for Short Lives and they were such a blessing. I became interested in the care support being offered and visited a number of hospices as well as taking part in the Square Table Event in 2011 aimed at exploring the future development of children's

palliative care. In 2013 I saw an advertisement in the Together for Short Lives newsletter asking for a new parent trustee and applied.

**Why do you think it is important to have parents on the board?**

I think it is extremely important to have parents on the board of trustees because, as parents, we are able to offer such a valuable input from the unique perspective of being users of services from a wide variety of care providers. I hope our contributions to the charity at board level ensure that everything the charity does has the care of children and families at the centre.

**What happens at a board meeting?**

To ensure that children and families are in the centre and at the forefront of our minds, we have recently introduced the telling of a family's story at the beginning of each board meeting. Hearing words written by a parent most definitely grounded our discussion and we were able to reflect back on the decisions made to ensure that the charity's activities would be benefiting the likes of families such as the one we had heard. Typical board meetings look at various activities of the charity such as its influencing role in policy and care matters, fundraising, publicity, etc. Most recently we have been overseeing and contributing to the development of the Strategic Plan for 2015-18 which, although it might not sound like it, is an exciting document which sets out where we would like to see the charity develop over the next three years. It is exciting because it enables us to see what we are capable of achieving in the future; we have achieved much but there is still plenty to do!



**Out of all the priorities for Children's Palliative Care, what do you personally think is the most important one?**

There are so many important areas for children's palliative care but I do have a real passion to see effective advocacy support for families – that is having someone on hand to represent the views of the family and help to co-ordinate or establish various support mechanisms. As I experienced, life does not stop when you are caring for a sick child. As well as all of the hospital visits, medication and other matters associated with the child, there are still bills to pay, jobs to keep, houses to maintain, shopping to get, etc. This all brings added pressure. With this in mind, I would like to see local communities involved in some of the practical care for families in the future to help where they can as I believe many neighbours would love to support local families but sometimes just need co-ordinating and directing. I am reminded of this when we occasionally get to see the programme 'DIY SOS' on the television which mobilises a great number of individuals to help families going through a tough time, for whatever reason. I'd love to see a similar practical response in the community on an ongoing basis to support children with serious life-threatening or life-limiting conditions and their families.

## A-Z Social Media Campaign

**Each week this year, we have been using Twitter and Facebook to highlight a different charity that supports children and families with life-limiting and life-threatening conditions.**

We're following the A-Z theme using #AZ, from Action Duchenne to Young Epilepsy.

Some of our posts have been extremely popular, encouraging parents and friends to share their experiences.

The aim of the AZ campaign has been to help:

- raise awareness of the variety of conditions, some very rare, that affect children and young people

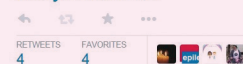
- raise awareness of the breadth of voluntary organisations supporting children and families with life-limiting and life-threatening conditions
- provide information for families
- build our social media audience and connections

Our tweets for Epilepsy Action had a reach of 30,000 (Twitter users & their followers). Our tweet for CHFED was clicked on the most (180 clicks).

During the campaign our Facebook posts reached an average of 2,200 people. You can follow us on social media and join the conversation at [www.facebook.com/togetherforshortlives](http://www.facebook.com/togetherforshortlives) and [www.twitter.com/tog4shortlives](http://www.twitter.com/tog4shortlives).



This week we're highlighting the work of [@epilepsyaction](https://twitter.com/epilepsyaction) 4 our #AZcampaign. They offer info, support & fund research [bit.ly/18tmFIO](http://bit.ly/18tmFIO)



We found out at our 20 week scan that Alfie was going to be poorly. Nothing prepares you for the journey that follows [bit.ly/1gTNIA1](http://bit.ly/1gTNIA1)



# Make Some Noise

On Thursday 9 October, Global Radio's national charity Make Some Noise held their first ever appeal day and some of the Together for Short Lives team visited the Leicester Square studios, helping out with all of the fun activities taking place on and off air.

Heart FM hosted Bike Some Noise on the roof of the studios where volunteers cycled the distance of John O'Groats to Lands' End. The challenge was reported live on air and some of the children's hospices that Together for Short Lives work with put forward volunteers to take part in the cycle. During the day, lots of exciting celebrities also popped in to take part including Olly Murs, Jenni Falconer and Torvill and Dean.

The appeal day was extra special for one family supported by Richard House Children's Hospice who were given the opportunity to watch the Capital FM

Breakfast outside broadcast from The Top of The Shard, presented by Lisa Snowdon and Dave Berry. Mum Sara, dad Peter, daughter Hannah and son Wolf (pictured) watched a guest appearance from music star Taylor Swift and Lisa Snowdon cleaning the windows of The Shard as part of one of the fundraising activities for Make Some Noise.

One year old Wolf has William's Syndrome, a rare disorder that affects his development. Wolf had open heart surgery when he was just three months old and developed a rare and serious form of epilepsy. His mum Sara told *Together for Families*: "The experience

was amazing. The whole family had a great time. It's not easy when you're constantly dealing with hospitals and illness but we love coming to Richard House and the experience at The Shard has created a long lasting memory for us all."

The appeal day raised an amazing total of £1.1 million for a number of children's charities with Together for Short Lives as their main charity partner. The money raised for Together for Short Lives will help support the UK's 53 children's hospice services.



## Transition Taskforce National Summit

The UK Transition Taskforce held its first national summit on 22 October at the National Star College in Cheltenham.

The meeting brought together leaders of the regional action groups, key stakeholders, young people and parents to celebrate the progress of the taskforce in its first year and to think about priorities for the future.

Delegates heard a wide range of speakers, covering topics including:

- joining up health and social care for young people through transition
- expanding an adult hospice service to meet the needs of young adults
- helping young people with disabilities and complex health needs into employment or meaningful occupation
- developing solutions for independent living
- young people's own experiences

If you would like to see the presentations that were shared on the day and the priorities for 2015-6 that were identified, do visit our website and click on the Transition Taskforce button on the top of the homepage. If you are interested in getting involved in our work on Transition, email [transition@togetherforshortlives.org.uk](mailto:transition@togetherforshortlives.org.uk).



## New website for families in Northern Ireland and Ireland

A website dedicated to palliative care for children and young people in Northern Ireland and Ireland has been developed by the All Ireland Institute of Hospice and Palliative Care (AIHPC).

The Children and Young People Palliative Hub aims to assist parents, guardians, carers and the wider public in understanding what children's palliative care is, and make it easier to find the right information.

AIHPC Director Paddie Blaney said: "The palliative care community, both in the Republic of Ireland and in Northern Ireland recognised the need for a 'go to' point that parents, carers and the general public could access to get independent information on a topic which is difficult to talk about or gather information on. This initiative led by AIHPC was supported by other agencies all seeking to fill the information gap."

[www.cypph.com](http://www.cypph.com)





# Keir's Story

**Keir was born on the 11 January 2000 – a millennium baby. We were filled with the same hope and optimism as we had been three years earlier when his sister Erin was born. Keir's birth was uneventful and calm(ish), a fact that I would have to repeat to so many doctors in the years following. We took him home and settled into family life together.**

He was a good baby, the kind that sleeps through the night and doesn't really cry unless they want something. He reached all his milestones with no evidence of the devastation that would be wreaked on him in the not too distant future. Fast forward five years, I remember clearly one visit to the wheelchair clinic when he announced to the Occupational Therapist that: "I think it's time that you and I arranged a heart to heart". This was a line from a song from his beloved Lion King but she thought he was offering her some kind of counsel. It was a funny moment and I'll never forget the look on her face.

On the 21 June 2005, we made our way to Pendlebury Children's Hospital grim and silent in the car, knowing that we were going to hear some bad news. Keir had undergone numerous tests a couple of months earlier after developing some worrying symptoms. He had previously been diagnosed with Charcot Marie Tooth disease in 2003 which is a condition of the peripheral nervous system. Bad enough we thought. What we would give to go back to that diagnosis. On arrival at Pendlebury we were ushered into a small room with windows all down one side. There were people playing football outside, not a care in the world and we were inside receiving the most devastating news of our lives. "Keir has Metachromatic Leukodystrophy, you've probably never heard of it". As a matter of fact I had, after furiously 'Googling' conditions of the metabolic system since Keir's MRI scan and I knew the terrible implications of what we had been told.

Our child was going to die before us. That was certain. Now we had to try and live with it.

After the initial shock had subsided, we tried once again to settle into some form of family life but forever altered. We also had to explain the situation to Erin which is a lot to take in for a seven year old. She actually handled it with great stoicism which she has demonstrated ever since. Siblings are often forgotten in the process of grief, but their loss is as great as that of the parent. They will suddenly go from being a carefree child to dealing with emotions that most adults would struggle to endure.

Our life became one long cycle of appointments, home visits, carers, nurses, doctors, hospice workers. I won't bore you with the details, but rest assured there were plenty of battles ahead, most of which I was able to fight and win. I had to, after all, who else was going to advocate on my son's behalf and get him the equipment and services he so desperately needed. When it all became too much, we were able to formulate our own small team of extremely dedicated professionals who were our lifeline. We were fortunate to have an excellent paediatrician, named nurse and physiotherapist. We also had access to fantastic specialist seating. All of these things combined, kept Keir well for much longer than expected.

It was during one of his few hospital admissions that we had that difficult discussion with clinicians which all parents of children with life-limiting conditions have to endure. Luckily for us, Keir's fabulous consultant paediatrician had the foresight to plan with us about what we would want for Keir when this circumstance arose. Keir's personal resuscitation plan had evolved over the years that it had been in place. We began by wanting full resuscitation but as the years progressed, we could see that this was no longer in our beautiful son's best interests. We came to the conclusion that the only reason we would want him to be ventilated would be for our own selfish reasons and not for him. We would know when he had had enough. I am not saying that it is never right to choose to intervene, after all every circumstance is different. It just wasn't right for our boy.

Inevitably, Keir's body let him down once again but his time was different. It wasn't just a chest infection. The neurological changes he was undergoing were creating havoc in his body and everything started to go wrong. His potassium was low, sodium high, blood gases all over the place. It was a massive rollercoaster, one minute he was shattered and needing CPAP, the next his body was fighting it and he came off his oxygen support altogether.

Honesty is always the best policy in these situations and thankfully that is what we got. We had a small window of opportunity to get him home safely and to the comfort of his own bed and surroundings, so we made the decision to take him home. Immediately he got home, he fell into a settled and calm sleep. The house was filled with people for the next two days, all wanting to say their goodbyes. He was settled and peaceful for the first time in over a week. He slipped away on the 9 January 2014 at 1.10pm surrounded by all those who loved him so much. We were able to tell him all we wanted to say.

Keir lived and loved life to the full and he in turn was loved and cherished by us and all he met. He was without doubt, the bravest most amazing person I will ever have the pleasure to know and I'm so proud to call him my son. He had a good life and a calm peaceful death and that has made all the difference.

**Michelle, Keir's mum**

