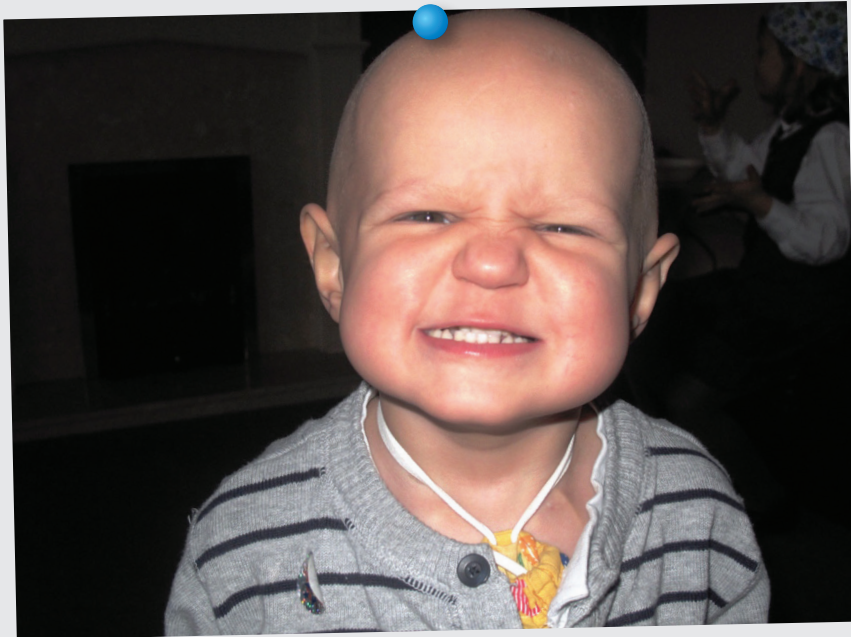


together for families

Issue 12
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In this issue:

Lewis' Story

Children's Hospice Week

Difficult Conversations

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



0808 8088 100

info@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk

The Together for Families helpline provides information for families, carers and professionals; and for those calling on behalf of a friend or relative. It is open to anyone who looks after or knows a child or young person with a life-limiting condition.

The helpline is open 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 to subscribe to *Together for Families*, or if you would like to contribute to a future edition – we'd love to hear from you.

Follow us and join the conversation!

 twitter.com/Tog4ShortLives

 facebook.com/togetherforshortlives

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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).

together
for
short
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Welcome to the first Together for Families of 2015! We have lots in store this year and here's a few things to look out for in this issue...

Over the last couple of months, we have been very busy planning Children's Hospice Week which will take place between 11-17 May. This year's theme is **making every moment count** which focuses on how precious time is for families. There are lots of ways for you to get involved so make sure you save the week in your diary!

We've teamed up with the National Council for Palliative Care (NCPC) to produce a brand new resource called *Difficult Conversations – making it easier to talk about end of life issues with young adults with life-limiting conditions*. The publication highlights the thoughts of young people about their end of life plans. We're so grateful for all of the participants who spoke to us so openly on such a sensitive subject. We hope that we have produced a document that will help young people, families and professionals feel more comfortable talking about dying and planning for end of life.

As part of our regular 'Meet the Team' feature, we interviewed James Cooper, Together for Short Lives' Public Affairs and Policy Manager. He tells us about his role in helping to improve services for children and families. We have also highlighted a couple of services and resources that might be helpful for your family. It's always great to hear from our readers so please get in touch if you're a family and would like to share your story with us. You can e-mail families@togetherforshortlives.org.uk.

Rebecca and Claire



Our CEO Barbara Gelb Awarded OBE

We're thrilled to report that our Chief Executive, Barbara Gelb, has been appointed Officer of the British Empire (OBE) in the Queen's New Year Honours list. This is in recognition of her ongoing work to improve care services for children.

Barbara said: "I am deeply honoured and thrilled to receive this award. I am privileged to work with a highly committed and talented team of staff and trustees at Together for Short Lives and the award would simply not have happened without them. Together, we are determined to lead change to make life better for children who may not live to see adulthood, and for their families. The award also marks the extraordinary courage of the children, young people and families themselves, and importantly recognises the tremendous work of all those involved in children's palliative care, right across the UK."

SEND Reforms – Your Views

Together for Short Lives has been working with local areas in England to ensure that children with life-limiting conditions and complex health needs benefit from the reforms to Special Educational Needs and Disability (SEND) that began in September 2014.

Do you have an education, health and care (EHC) plan in place? Have you been offered a personal budget? Does your local offer tell you about the services you need? If so, we want to hear from you to learn how these changes have had an impact. If you would like to tell us about your experience, please email families@togetherforshortlives.org.uk. Sharing your thoughts, good or bad, will help other families and we plan to publish your feedback in our June issue.

Meanwhile, the Department for Education and Mencap have jointly developed two easy to read guides for parents, children and young people to help them understand the changes to SEND support. These are available to download from the Mencap website www.mencap.org.uk – search for 'SEND Reforms'.

New Guides Available

Contact a Family has recently produced two guides to support families of children with additional needs.

Money Matters is a comprehensive checklist detailing the range of benefits that are available to you and *Help with Fuel Bills* provides useful advice and information to help your family stay warm in cold weather. The guides have been produced as part of Contact a Family's Counting the Costs campaign, launched in response to the thousands of families with disabled children telling them that they are regularly going without the basics like heating and food. If you would like to order printed copies of the guides or would like a full benefits check, do call their freephone helpline on **0808 808 3555** (Monday-Friday, 9.30am-5pm) or email helpline@cafamily.org.uk. To find out more about how you can get involved in the Counting the Costs campaign visit www.cafamily.org.uk.

Difficult Conversations For Young Adults

“Knowing that I won’t live as long as other people, makes me live more and make the most of every day. I’ve got to make sure every day is worth it.”

Talking about plans for the future, including the end of life, can be a very difficult subject for young adults with life-limiting conditions. It can also be hard for parents, friends and the professionals who support them.

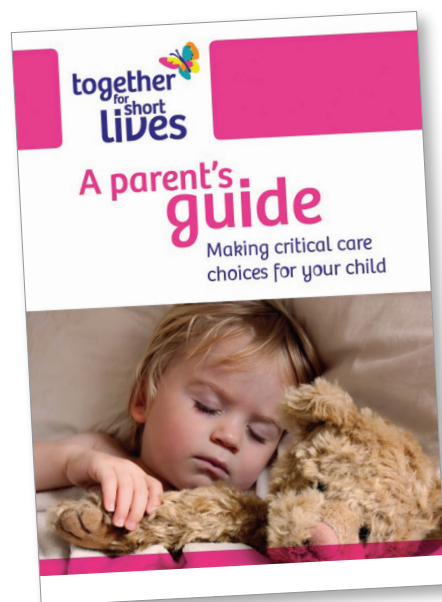
We know that professionals, especially those in the adult sector, find it difficult to initiate conversations with young people to discuss their end of life plans. To address this, Together for Short Lives has been working with the National Council of Palliative Care (NCPC) and have been talking to a group of young adults with life-limiting conditions, asking them to share their personal experiences and views on dying. We have jointly produced a new resource called *Difficult Conversations – Making it easier to talk about end of life issues with young adults with life-limiting conditions*. It highlights the thoughts and opinions of young adults on discussing their end of life.

The resource has been designed to help families and professionals talk about dying. We hope it will make it easier to have a conversation that is comfortable for everyone involved, especially the young adult.

We are grateful to all young people, organisations and individuals that helped us develop this resource, especially those who agreed to discuss this sensitive matter with us. It wasn’t easy to get young people involved as the overall feedback was they wanted to focus on living, not dying.

The resource has been funded by the Roald Dahl Marvellous Children’s Charity’s Family Resilience Programme.

If you would like a copy of this resource, please e-mail families@togetherforshortlives.org.uk with your name, postal address and the number of copies you require.



Critical Care Choices

Together for Short Lives has recently updated its booklet, *A Parent's Guide – Making Critical Care Choices for your Child*. This has been developed to help parents, carers or legal guardians make informed decisions about critical care.

It has been written in a simple question and answer style format and includes some of the key questions or concerns regarding critical care. These include:

- What are critical care choices?
- What is an end of life care plan?
- Will my child carry on getting the care and support they need?
- Do I have a choice in my child’s critical care?
- How are critical care decisions made?
- What if I change my mind?
- What if my doctor and I do not agree?

Parents, carers, families and health professionals were all involved in developing the content, which has been reviewed and revised to include an updated directory of helpful services.

The booklet is available to download in the family resources section of our website or you can request copies by emailing families@togetherforshortlives.org.uk.

Over The Wall

Over The Wall is a national UK children’s charity that provides free of charge therapeutic recreation camps to help children with life-limiting illnesses and their families. Each year they run a series of three types of camps. Applications are being accepted until 1 May for the siblings camp. For more information and details of which camp may be suitable for you, visit www.otw.org.uk.

Meet The Team!

Meet James Cooper, our Public Affairs and Policy Manager.

Tell us more about your role as Public Affairs and Policy Manager – how do you help families?

My job is to influence national and local government and the NHS so that they make decisions which improve outcomes for children with life-limiting conditions and their families. Public policy can have a big impact on things which are important to families, such as being able to access sustainable children's palliative care when and where they need it. It can also help to join-up assessments, plans and services. My work involves talking with officials, parliamentarians and commissioners across the UK. I also monitor developments in policy and politics, and report back to families and those who provide children's palliative care.

What do you think is the most recent important policy change that families should know about?

The new Special Educational Needs and Disability (SEND) system in England brought about by the Children and Families Act 2014. It has the potential to bring about more integrated assessment, plans and services for families of disabled children.

What will the SEND reforms mean for our families and do they specifically mention children's palliative care?

Yes. All local areas (including the NHS and local councils working together) must now produce a 'local offer' for families of disabled children which sets out all the services which are available to them. The government has said that local offers should include children's palliative care services and that local areas should consider the number of children with life-limiting conditions as they plan and commission services.

Where can I find out more?

Together for Short Lives has been running a project designed to make sure that children who need palliative care can benefit from the SEND reforms. Read more here: www.togetherforshortlives.org.uk/SENDproject.



Policy Change

In England, the Care Act will come into force in April. The new law includes duties on local authorities to assess the future social care which young people and their carers will need when they reach adulthood, so that their transition is smooth and well-planned. The Social Care Institute for Excellence (SCIE) provides helpful information and resources about the new duties that are available at www.scie.org.uk.

Concern About Short Break Services

Short breaks are a fundamental and a much valued support service to families with disabled children. However, after successive years of cuts to local authority budgets, the 2015/16 financial year is likely to see cuts to children's services generally including short break services for disabled children.

Every Disabled Child Matters has produced a legal resource for parent carers of disabled children. This resource aims to help parents and carers challenge cuts to short break services. The resource aims to:

- explain what short break provision families with disabled children should expect to be available in their area
- explain the legal framework around short break services
- provide template letters to families with disabled children to help challenge decisions by local authorities
- signpost families to sources of legal support.

You can download the resource by visiting <http://bit.ly/shortbreakslaw>.

Don't forget, you can call our Helpline to access the Advocacy Support Service which can take referrals from any family living in England or Wales. If you feel you would benefit from the support of a legal professional, acting as a volunteer advocate to assist you in getting the support you need, call **0808 8088 100**.

Children's Hospice Week

**Children's
Hospice Week**

11-17 MAY 2015

Making every moment count

This year Children's Hospice Week will take place between Monday 11 - Sunday 17 May. The theme is making every moment count, focussing on how precious time is for families.

Raising awareness

A social media campaign will run throughout the week inviting people to share their special moments together using the hashtag **#momentscount**.

Through pictures, videos and comments we will capture what life is like for families and highlight the wide range of services helping families make the most of every moment. We would love you to get involved by sharing the moments that matter to you on Twitter and Facebook.

We are also looking for family case studies that link to the 'moments' theme. If you would like to share your moments, whether it be the time when you realised life was going to be different than planned, a moment you saw real progress being made at a therapy session or perhaps a moment from a holiday or a special occasion, please email your story to **families@togetherforshortlives.org.uk**.

During the week we will be encouraging children and young people to get creative by capturing their special moments through art, photography and poems, sharing on social media. Visit **www.togetherforshortlives.org.uk/childrenshospiceweek** for more details.

#momentscount

Love Tea and Cake? Feeling Crafty?

This May, Together for Short Lives and Hobbycraft are launching a brand new fundraising initiative called Craft-tea. Hobbycraft customers will be encouraged to host their own Craft-tea party and wow their friends and family with signature sponge, fabulous flapjacks and gorgeous garlands. Hobbycraft will also be hosting events in store. Craft-tea will launch in Children's Hospice Week (11-17 May). For further details visit The Together for Short Lives website **www.togetherforshortlives.org.uk/craft-tea**.

Bridging The Gap

In 2013 Together for Short Lives funded a research team from Bangor University to see how the link between children's and adults palliative care services can be improved to better meet the needs of young people and their families.

The project called Bridging the Gap, looked at the gap in resources available to support the successful transition of young adults with palliative care needs.

The project produced a toolkit, developed by young people, parents and professionals. It includes person-centered tools to be used with existing care planning documents designed to improve transition plans over six key areas:

1. My pain profile
2. Managing my symptoms and keeping me comfortable
3. My worries and concerns and how best to support me and my family
4. How best to support me with short breaks and respite
5. What is important for you to know about my mobility and how to support me with transfer?
6. Nutrition, food and drink

If you are interested in reading more about the project and to view a film that was made to accompany the project, visit **www.bangor.ac.uk/so/bridging-the-gap**.

PEAPIP Research Project

Are you are a parent caring for a child with a long-term or complex condition? Are you responsible for carrying out nursing or healthcare procedures that you think your child finds painful and/or invasive? Is your child aged 10 years or younger?

If so, you might be interested in being involved in the PEAPIP project, which is funded by the children's charity, WellChild. The PEAPIP project wants to find out about parents' experiences of being responsible for carrying out nursing or healthcare procedures that you think your child finds painful and/or invasive. This is important research, which will help health professionals to learn how to better support parents in this situation.

If you're interested in taking part you will be asked to complete a simple form followed by a telephone interview. If you are interested and/or would like further information, please contact Charlotte Simmonds on **0117 910 2461** or **families@togetherforshortlives.org.uk**.



Lewis' Story

In September 2007 our family was complete when our beautiful son Lewis was born. Lewis was a happy, healthy baby and a little brother for our daughter, Georgia. In May 2008, weeks after returning from a family holiday in America, Lewis became unwell.

His right eye had swollen and our GP was convinced it was nothing more than hay fever or an eye infection. The swelling got worse and eventually Lewis was admitted to a local hospital when he started with a high fever. We spent a week having various tests and observations, when finally they performed a CT scan. The scan showed a large mass that was explained as either a tumour, inflammation or infection. We were immediately sent to Birmingham Children's Hospital where Lewis was diagnosed with an aggressive childhood cancer called Neuroblastoma. Further diagnostics confirmed the cancer was MYCN amplified which meant that the tumour contained a gene that 'amplifies' the cancer, making it more aggressive and also giving an unfavourable prognosis.

We tried to remain positive as we began our long and very emotional journey. Birmingham Children's Hospital became our home, spending many nights on camp beds and surviving on microwave meals. However, Lewis took it in his stride, charming every nurse he met and always smiling. We learnt so much from our little boy and he was the one who inspired us to remain positive.

Lewis responded well to chemotherapy and towards the end of the treatment his scans showed no evidence of disease. All that he had left to complete was a six-month course of oral drugs which were taken at home. However after the fifth month Lewis showed worrying signs of relapse. Almost a year to the day after his initial diagnosis, further scans confirmed the cancer was back. I think that hearing he had relapsed was far more emotional for us as a family than hearing his initial diagnosis. We knew at the time there was no cure for relapsed Neuroblastoma

and we were facing a very uncertain future. However, there were some treatment options available to us as Lewis had responded so well to his initial chemotherapy.

Lewis also responded well to the new treatment but not as well as we had expected. In January 2010 we were told the devastating news that Lewis could not be cured, and that any treatment he would now receive would only be palliative. He still had a couple of options available to him and although palliative we travelled to London for radiation therapy. Whilst we were there further scans showed the Neuroblastoma had progressed much more than we had expected, it was now in his spine and brain. We were sent home to receive some external radiotherapy to his brain which he received daily for five weeks. But six months after being told he was terminal our beautiful, brave boy passed away peacefully on 3 July 2010. A day that will remain embedded in our souls forever.

When I look back at our journey we were very positive as a family. We knew only too well how serious Lewis' condition was and from the start we knew his prognosis was poor. However, this was our son, we had to have hope and we had to believe that he may be able to get through this. We found that we used humour and positivity as a coping mechanism to get through each day because it helped. We find that even in bereavement we still use this strategy as it works well for us.

During our journey we met and became close to many wonderful families in the same situation as ourselves. Some of the children we met are now in remission but there are many families who have also lost their child. For us personally, the support of these families who have walked the same path was invaluable. We were connected by an invisible bond, an understanding with someone who just 'knows' exactly how you are feeling. This real support is wonderful and has helped us all so much during our journey.

After Lewis' death it became apparent to us that there was a large unmet need to provide support and information for bereaved

families. We were conscious that not every family has the support network around them that we were lucky enough to have. Like many families who have been through a challenging journey, we felt strongly about giving something back. We wanted to try and help address these gaps in some way and also reduce the stigma and taboo attached to such a loss, and so, *A Child Of Mine* was born.

A Child Of Mine is now a registered charity supporting families across Staffordshire and the UK when a child dies. We provide practical information, guidance and signposting, together with emotional and financial support to families when they need it most. We have already started to make positive impacts in families' lives by increasing wellbeing, improving emotional health and by providing access to much needed information during the difficult days that lie ahead.

To find out more please visit www.achildofmine.org.uk or follow us on our social media pages:

 twitter.com/achildofmine

 facebook.com/AChildofMine

Gayle, Lewis' mum



**A
Child
of Mine**
Help for Bereaved Parents