together for families

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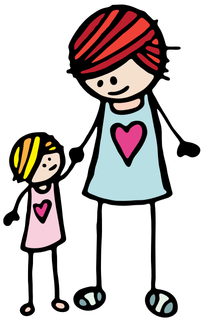


Together for Families Helpline

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. It is open to anyone who looks after or knows a child or young person with a life-limiting condition.

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!

twitter.com/Tog4ShortLives
facebook.com/togetherforshortlives

Editors: Julia Hodgson, Rebecca Ellison and Charlotte Barry

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 lives

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

We hope you all enjoyed the summer. We have had a busy few months starting work on our new three year strategy for 2015-18 and developing some new publications for families, including three new factsheets, one of which provides information about where to go for help if your child has been diagnosed with cancer. We are also busy developing a *Young Person's Companion to Transition* which will be available early next year.

Also over the summer we held our first Midsummer Ball hosted by our Patron Simon Cowell and showcasing celebrities including Marvin and Rochelle Humes, Katie Melua, Stephen Mulhern, Jack Pack, and Britain's Got Talent finalist, Isaac Waddington. The ball raised a fantastic £400,000 to support our work.

The September issue of *Together for Families* highlights the work we are doing to improve transition for young people; features two organisations that provide support for families; and gives you the chance to win a break at Center Parcs.

We would like to say a big thank you to our readers who were able to return the survey that accompanied June's edition of this newsletter. We had a fantastic response rate with over 40 new parents and carers signing up to get more involved in our work. To let us know if you would prefer to receive *Together for Families* by email in the future or would like to get involved in our work contact us on: **families@togetherforshortlives.org.uk**.

This month's family story is from Adam's mum, Zoe. During his life Adam inspired people from all over the world through his courage, Twitter account and poetry. In our regular 'Meet the team' feature, Myra Johnson, Director of Communications talks about how Together for Short Lives works with families to share their stories and how important they are to our work. If you would like to share your story please email **families@togetherforshortlives.org.uk**.

Julia, Rebecca and Charlotte

Center Parcs breaks

We are delighted to announce that for a third year running Center Parcs has donated ten holidays to Together for Short Lives' family members.

The breaks can be taken at any of the five UK Center Parcs village locations: Whinfell Forest in Cumbria, Sherwood Forest in Nottinghamshire, Elveden 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 for a long weekend (Friday-Monday) or midweek (Monday-Friday) but excludes school and public holiday periods. We are inviting members of Together for Short Lives' family community to enter into a draw to win one of these breaks. To enter the draw, please email your contact details to families@togetherforshortlives.org.uk by 31 October 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 April 2016. We wish you the very best of luck!

Emily, Paul, Adam and Orla recently visited Center Parcs after entering our prize draw in the December 2014 issue of *Together for Families*. Emily said:

"We had a great time. Our son Adam was very excited to go on holiday with us and take part in the activities such as swimming and cycling along with his sister Orla using the "Duet" wheelchair-adapted bike we hired while we were there. Thank you very much for this holiday – Center Parcs was a great place for us to go, it has been a long time since we've had a holiday that we have all enjoyed together. Having specially adapted accommodation, including a profiling bed with adjustable side bars made all the difference."

Save the dates

Together for Short Lives has been asked by NICE (the National Institute for Health and Care Excellence) to run a series of focus groups for children and young people aged 13 to 18 years old to hear their views about the services that they use. This will be used to inform important new guidelines that NICE is developing for the care of seriously ill children. We plan to hold three focus groups in the autumn:

- 25 September: St Gemma's Hospice, Leeds
- 26 September: Museum of London
- 10 October: M Shed, Bristol

Further details will be shared over the coming weeks, but if you think your child would be interested in coming to meet with us and sharing their views, please do save the dates and let us know by emailing **families@togetherforshortlives.org.uk**.

Are you Ready to Roll?

Together for Short Lives has launched a brand new partnership with Rolls-Royce Motor Cars – Ready to Roll! Rolls-Royce has generously donated a purple Rolls-Royce Ghost II to our charity for a year. Over the next 12 months, the purple Rolls-Royce will be travelling to children's palliative care services across the UK to raise awareness and vital funds for children with life-limiting conditions and their families. You can follow its journey on the website **www.readytoroll.org.uk** or Twitter using the hashtag **#ThePurpleRollsRoyce**.

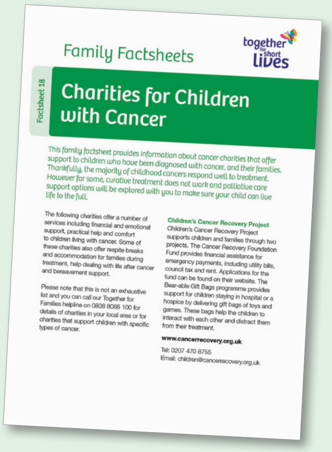
For your chance to win this one-of-a-kind car for a luxury weekend in London, chauffeur-driven, text **ROLLS2** to **82727**. Texts cost £2 and will support Together for Short Lives.

New family factsheets

We have recently launched three new factsheets to support families.

- *Charities for Children with Cancer factsheet* provides information about cancer charities that offer support to children who have been diagnosed with cancer, and their families.
- *Assistive technology factsheet* has been designed to signpost families to organisations and resources that provide information about making the best use of assistive technology.
- *The Mental Capacity Act factsheet* is a revised version of an existing factsheet providing information and guidance for parents of young people approaching adulthood.

These new factsheets sit alongside others in our suite of 19 factsheets for families. They are available free to order or download with all of our resources for families at **www.togetherforshortlives.org.uk/families/information_for_families/filter/factsheets**.



Family Factsheets

together for short lives

Factsheet 18

Charities for Children with Cancer

This family factsheet provides information about cancer charities that offer support to children who have been diagnosed with cancer, and their families. Thankfully, the majority of childhood cancers respond well to treatment. However for some, curative treatment does not work and palliative care support options will be explored with you to make sure your child can live life to the full.

The following charities offer a number of services including financial and emotional support, practical help and comfort to children living with cancer. Some of these charities also offer respite breaks and accommodation for families during treatment, help dealing with life after cancer and bereavement support.

Please note that this is not an exhaustive list and you can call our Together for Families helpline on 0808 8088 100 for details of charities in your local area or for charities that support children with specific types of cancer.

Children's Cancer Recovery Project

Children's Cancer Recovery Project supports children and families through two projects. The Cancer Recovery Foundation Fund provides financial assistance for emergency payments, including utility bills, council tax and rent. Applications for the fund can be found on their website. The Bear-able Gift Bags programme provides support for children staying in hospital or a hospice by delivering gift bags of toys and games. These bags help the children to interact with each other and distract them from their treatment.

www.cancerrecovery.org.uk

Tel: 0207 470 8755
Email: children@cancerrecovery.org.uk

Spinal Muscular Atrophy

Spinal Muscular Atrophy (SMA) is a rare, genetically inherited neuromuscular condition in which muscle weakness may affect crawling and walking ability; arm, hand, head and neck movement; breathing and swallowing.

There are four main types of SMA. **SMA Type 1** is the most severe with symptoms generally appearing before a baby is six months old. Sadly, usually due to breathing difficulties, most children with SMA Type 1 rarely survive beyond two years of age.

Children with **SMA Type 2** usually show symptoms between seven and 18 months and they are unable to walk. Though this is a serious condition that may shorten life expectancy, the majority of people live long and fulfilling lives with many going to university, gaining employment, learning to drive, living independently, and some having children.

Generally, children with **SMA Type 3** can stand and walk, although they may need more support with this over time. Symptoms usually show after 18 months and life expectancy is normal.

SMA Type 4 is also known as Adult Onset SMA and is not life-threatening. Symptoms appear in adulthood and may include mild to moderate muscle weakness in hands and feet, and some difficulty with walking.

Spinal Muscular Atrophy Support UK

Help for today • Hope for tomorrow

Lack of public awareness of the different types of SMA, with their wide ranging symptoms, severity and very different challenges, can make it even more difficult for individuals and families faced with a diagnosis. They may themselves read incorrect information or be confused about the future. This is why the charity SMA Support UK works to raise public awareness and is accredited by the Information Standard to produce up-to-date, accurate information about the types of SMA.

SMA Support UK also offers personalised support to families and individuals affected by SMA who live in the UK, as well as to the professionals supporting them. The outreach service provides emotional support, practical advice and guidance by phone, email and home visits.

Other SMA Support UK services include: free multisensory toy packs for babies with SMA Type 1; a peer support service which connects people with personal experience of SMA; social activities, events and conferences which provide opportunities to meet others and share experiences; research updates; and small equipment grants that can be provided swiftly to make a difference when needed.

For more information about SMA Support UK please visit the website **www.smasupportuk.org.uk** or contact support services by emailing **supportservices@smasupportuk.org.uk** or phoning **01789 267 520**.

Round Table Children's Wish celebrates 25 years of wish granting

Round Table Children's Wish is a charity dedicated to granting 'handcrafted' wishes for children and young people with life-threatening illnesses. The charity has a personal and caring approach to its wishes, ensuring every wish granted reflects the needs of both the child and their family circumstances.

Round Table Children's Wish is a national charity delivering wishes at a local community level. It grants wishes to children in the UK and Ireland. Its mission is to grant a wish that creates everlasting memories of a happy time in amongst everything else that is going on.

This year the charity is celebrating 25 years of wish granting. Over the years it has granted a variety of wishes: from a trip to Disneyland to building a cowshed in a young lady's back garden! The charity endeavours to grant a wish that is meaningful and can also include brothers and sisters. It also strives to reduce any stress related to wishes so provides spending money to the family so they don't have to worry about how to afford transportation, travel insurance or a treat during the wish.

Round Table Children's Wish would love to hear from any family who have a child with a life-threatening illness to see if it can help grant a wish. For more information, please email **info@rtcw.org**, phone **01202 514 515** or send in a referral form via the website **www.rtcw.org**.

If you would like to find out more about the charity; how it is marking the 25 year anniversary of wish granting; or how you can support the charity in some way please get in touch.

Round Table Children's Wish

Handcrafted wishes for children with life-threatening illnesses

Meet the team!

Meet Myra Johnson, our Director of Communications.

Tell us more about your role as Director of Communications
I work in communications and my job is all about raising awareness of what families need and helping families to find help, information and support. Our work is very varied – we publish information for families and professionals; work with the media; run the website and social media; and organise awareness campaigns like Children's Hospice Week.

Why is it important to use family stories in your work?
Your stories are central to our work – whether we are lobbying government for better policies and support, fundraising, working with the media, or reaching out to other families. We want to find stories to illustrate our new areas of work including personal budgets, short breaks, writing end of life plans and young people's transition. We especially want to hear from families who have called our helpline or used our family resources, so we can reach out to other families in need. If you would like to share your story please email **families@togetherforshortlives.org.uk**.

What is the most important development in your work and how will it impact on families?
We now live in a digital world and the way we access information today is radically different. New developments mean that we can now reach more families and provide information in seconds. Social media is helping us to put families in touch with one another and can help to break down isolation.

Together for Short Lives is just embarking on developing a new digital strategy to help us improve our reach and awareness raising. Over the next year we have some exciting plans to develop digital publications; explore a new mobile friendly website; and research the best digital channels to put families and young people in touch with one another.

What is your most memorable moment working at Together for Short Lives?
It's always a joy to see the real impact of our awareness raising and know that families can find the help and the support they need. I have been very lucky to meet so many remarkable and courageous children, young people and families. I have a lovely memory of meeting the Somerville family and their little girl called Tilly-May. We had a lot of fun working together and went on to make a special film that was aired on *The X Factor*. Their remarkable story made such a difference – raising awareness and funds for children's palliative care services across the UK.

Please share our new resource with your local schools

We have produced an online resource to help schools, early years and further education providers give children with life-limiting conditions access to education. The resource sets out what education providers must do by law. It also describes what they should do to support children and young people who need palliative care, as well as those who teach and learn with them. If your child is accessing education, please share the resource with their school, college or early years provider. You can download it at **http://bit.ly/1zt7PmR**.

What should our new SEND family toolkit include?

As local areas across England continue work to implement the new 0-25 special educational needs and disability (SEND) system, Together for Short Lives is delivering a project to make sure that children who need palliative care can benefit from the reforms.

As part of this work, we will be developing a guide to help you understand what the reforms mean for you and your family – including local offers, education health and care plans, personal budgets and joint commissioning. We want the guide to help families feel able to navigate, influence and – if needed – complain about their local SEND system so that their child can experience assessments, plans and care which:

- are more joined up
- are centred on them
- help them and their families to achieve the outcomes they want from their lives.

To help us create a guide which is most useful to you, please tell us:

- what you would like it to include
- how you would like it to look
- how you would like to use it. (In electronic format, in hard copy, or both?)

Please email **families@togetherforshortlives.org.uk** with your thoughts by 15 October 2015.

In the meantime, if you have any questions or concerns about how the new SEND system might affect your family, please call us on **0808 8088 100**.

Levelling the Playing Field: the childcare campaign for disabled children

Every Disabled Child Matters (EDCM), Contact a Family and Family and Childcare Trust are leading the 'Levelling the Playing Field' campaign to call for equal access to childcare for disabled children. Parent carers – usually mothers – are too often forced to cut their working hours or give up careers altogether because they cannot access the childcare they need. The aim of the campaign is to make sure that:

- disabled children can access free early education and childcare in the same way as other children – and that helps them to progress, learn and make friends
- families with disabled children are supported financially to help them access high quality and suitable childcare in the same way as other families
- families with disabled children can access information and resources through their local offer to help them choose the childcare in their area that meets their individual needs – and enables them to work as much as they want.

For more information about the campaign, visit **http://bit.ly/1HFrr44**.

The UK Transition Taskforce

There are 55,000 young adults aged 18-40 living with a life-limiting or life-threatening condition in England. And this number is growing.

Growing up with a life-limiting condition can be a challenging prospect and it can seem daunting to leave behind trusted staff in children's services, with whom close bonds have been built. The transition to the world of adult services might seem bewildering.

We know from recent research that each year more young people with life-limiting conditions are making this move, yet services to meet their needs have not kept pace.

At Together for Short Lives we want to ensure that all young people have a good experience of transition and have the support they need to achieve the things in life that are important to them. Whilst it is critical that young people's health and palliative care needs are robustly supported, we also want to work with a wide range of services to help them to understand and better meet the needs of young adults with a range of life-limiting conditions.

In 2013 we established a major UK wide project, the Transition Taskforce, which aims to reduce the barriers to good transition for young adults with life-limiting conditions. We hope that the Taskforce will enable young people to have more choice and control about where and how they live their lives.

- Across the UK the Taskforce is working to influence policy; devise sustainable funding models; and develop and share research, information and good practice. This year we are organising a programme of masterclasses for adult palliative care professionals to enable them to better understand, reach out to and meet the needs of young people.
- The Taskforce is establishing and supporting Regional Action Groups (RAGs) to bring together representatives from a range of services from the children's and adult sector. The RAGs provide a body of expertise on how to best provide care and support for the growing number of young people and are building bridges between children's and adult services. We have eight RAGs in England and groups in Scotland, Wales and Northern Ireland. The RAGs have been mapping available services in their regions and consulting with young people and their families to identify what the priorities are for new service development.

At all levels we provide a platform for engaging directly with young people and families to ensure that their voices are heard.

Get involved in transition

Young people and their families must be at the very heart of transition planning. Across the UK, the Transition Taskforce Regional Action Groups (RAGs) have been tasked to consult with young people and their families to ensure that the priority areas of work they identify resonate with genuine need. If you want to get in touch with your RAG, do visit our website for contact details.

At a national level, there are various ways that we are working to keep the voice of young people and their families at the heart of the Transition Taskforce. Whether you have an experience to share or questions to ask, we'd love to hear from you.

The Transition Taskforce Young Avengers Group (YAG) was established in 2013 to be ambassadors for the Taskforce and to help influence policy and service developments. Over the past two years, members of the group have spoken on behalf of the Taskforce on several occasions and have been brilliant at sharing their thoughts and experiences of transition. We are keen to ensure that the group includes young people aged 14 years or older from all four UK nations.

We welcome parents and carers to join a Transition Reference Group. This email group is invited to comment on all aspects of the Taskforce's national work. We are particularly keen to recruit those who act as an advocate for their teenage child approaching adulthood.

To register your interest in the Taskforce, email **transition@togetherforshortlives.org.uk**.

Landmark ruling gives Disability Living Allowance hope on long hospital stays

The Supreme Court has ruled that taking away Disability Living Allowance (DLA) from a disabled child after he had been in hospital for over 84 days violated his human rights and is therefore unlawful.

The Department for Work and Pensions had argued that if a child is in hospital for 84 days or more their DLA should stop as their care needs are met free of charge by the NHS.

The Mathieson family from Warrington challenged this decision following research which showed that 99% of the estimated 500 families affected by the '84 day rule' provide more or the same level of care when their child is in hospital compared to when at home.

The court did not, however, state that the '84 day rule' is unlawful in all cases. Contact a Family has published a guide on its website for families who are affected by this rule to help support their requests for their DLA to be reinstated (**http://bit.ly/1KhbR0F**).

Resources to support transition

Last year we published our highly acclaimed guide for professionals on transition called *Stepping Up*. To accompany this we are now developing a *Young Person's Companion to Transition*. This downloadable resource will provide valuable and age-appropriate insight and information to help young people with life-limiting conditions prepare for adulthood. By providing key information, case studies and signposting, it will help to increase young people's autonomy and independence; so that they can make important decisions about their future and access the right support at each stage of their journey.

As part of this resource, we have been working with In Control, a national charity advocating self-directed support for those with disabilities, to develop a *Young Person's Guide to Personal Budgets*. Available digitally, this guide will outline how personal budgets can be used (in England) and will include case studies on how individuals are making the most of the opportunities they offer.

To bring these resources alive, we are looking to include case studies and short films that showcase possibilities of what can be achieved if the right support is in place. If you have an experience of transition to share or would consider being filmed for the resource, do get in touch by emailing **transition@togetherforshortlives.org.uk**.

Adam's story

This month we are delighted to feature Adam's story as told by his mum, Zoe. During his life, Adam was supported by several member organisations of Together for Short Lives and inspired people from all over the world through his courage, Twitter account and poetry.

My son Adam had a very difficult last few months, so it was a huge comfort to us that he was able to spend his last 36 hours in the loving and peaceful environment of Martin House Children's Hospice preparing for, but accepting, the inevitable. Adam's last visit to Martin House was also his first. A long hospital stay prior to his death meant he and our family had been unable to enjoy the care and support provided by so many children's hospices to children with life-limiting and life-threatening conditions, in the last 18 months of his life.

Martin House was one of the children's hospices which played a huge part in Adam's life. During Adam's 15 years we moved twice. So Adam had close connections with Naomi House and Rachel House. We remember Adam's visits to Naomi House with great fondness. In the early days of Adam's life, he spent happy times at Naomi House, sometimes with us (his mum and dad) and sometimes with his granny, known to everyone as "Granny Sparkles". Adam's complex health needs meant, unlike most small children, he couldn't be left with his granny for even a couple of hours. But Naomi House, and later Rachel House, made it possible for Adam and his granny to spend some of that special one to one granny and grandson time together, knowing experienced hospice staff were around to take care of all Adam's health needs while Adam and his granny concentrated on doing what they did best – having fun.

Once we moved to Scotland, Adam's visits to Rachel House were few and far between. His health often meant he couldn't travel far and in holiday times when he was well enough Adam was keen to explore the world, with trips to London, York and the New Forest. But when Adam did get to Rachel House, he loved it. Once he was a teenager Adam used to enjoy using his trips to just "chill". His favourite activity was listening to Rachel House's large library of story CDs. During one visit he even did a 24 hour sponsored listenathon; listening to stories continuously to raise funds for Children's Hospice Association Scotland (CHAS).

Fundraising for causes he believed in was one of Adam's hobbies. Often the funds were raised by his growing band of loyal Twitter followers, where he tweeted about his life and shared his poems as @AdsthePoet. Adam had a real talent for writing poetry. It was a painstaking task, with some poems taking weeks or even months to complete as Adam wrote each poem by determinedly blinking each letter or word. Adam gained recognition for his poetry writing at a very young age, winning a Brit Writers Award and a Gold Blue Peter Badge aged just 10 years. These were the first of the many awards he received.

One of Adam's most popular poems was "Christmas Gibbons", which tells of how Santa is helped by gibbons to distribute presents to children around the world at Christmas. In 2012 musician Tom Harrison set Adam's poem to music and illustrators brought it alive with an amazing animation. With support from Ewan McGregor, Christmas Gibbons was launched to raise funds for and awareness of CHAS. The gibbons really did go all around the world, with the poem appearing in the media in Australia, Vietnam, India, Russia, USA and closer to home. It reached number two in the iTunes children's music chart.

Christmas Gibbons was not Adam's only musical connection with the children's hospices he visited. A year later he was asked to write a lullaby for the then yet to be born Prince George, to celebrate Her Royal Highness, The Duchess of Cambridge's visit to Naomi House. Adam chose a piece by Mozart and wrote two verses. One for night time, urging the royal baby to "sleep softly" and the other for day time, encouraging the royal baby to "play boldly".

During his teenage years Adam was embraced by several senior NHS leaders who welcomed and valued his tweets about his experiences; his poetry and according to one leader, Adam's bad jokes! Adam became an important voice for children and young people with complex health conditions; especially those with neuro-disability. His blog "What Does Good Care Look Like" was read (and is still read) at many NHS events. He was commissioned to write a poem on Leadership by Rob Webster, CEO of the NHS Confederation for their conference. The poem has taken on a life of its own. It is read at NHS Leadership Academy graduations and will be used to raise funds for the UK Sepsis Trust, as Adam died of sepsis and the work they do to raise awareness, is something Adam asked should be supported in his memory.

Adam was recognised for his campaigning when he was made Young Epilepsy's Inspirational Hero in 2013; and for his influence when he was named as one of the Health Service Journal's "Patient Leaders", three months following his death.

Adam's life was an all too short one; but it was a rich and full one and hundreds of people have told us Adam really did make a positive difference to their lives.

You can read Adam's poems and details of his many achievements on his blog **http://intheblinkofaneyepoemsbyadambojelian.blogspot.co.uk**.

Zoe, Adam's mum