

together for families

Issue 28
Winter 2019



Mary and Mum Donna

Our free Helpline is for any parent, carer or professional who looks after or knows a child or young person who is expected to have a short life.

Open Monday – Friday, 10am-4pm

Outside of these hours, please leave a message and we will respond as soon as we can.

Together for
Families Helpline

0808 8088 100

info@togetherforshortlives.org.uk



You can also access our free legal advice service by calling the helpline.

If you would like to receive our newsletter by post or email, please contact info@togetherforshortlives.org.uk

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When a child's life is expected to be short, there's no time to waste. Together for Short Lives is here to make sure the 49,000 seriously ill children and their families across the UK can make the most of every moment they have together, whether that's for years, months or only hours. We stand alongside families, supporting them to make sure they get the vital care and help that they need.

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
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lives



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Mum, Donna, introduces us to her beautiful daughter, Mary

Email info@togetherforshortlives.org.uk to receive our newsletter via email or if you would like to contribute to future editions.

Keep in touch

Call the Helpline
0808 8088 100

Email us
info@togetherforshortlives.org.uk

Visit us
www.togetherforshortlives.org.uk

Follow us

 @Tog4ShortLives

 togetherforshortlives

Our new Parent Trustee

We are delighted to introduce readers to our new Parent Trustee, Adam Smith.

Adam is a registered mental health nurse with over 10 years' experience working in promoting excellence in dementia, frailty and palliative care. Alongside Adam's professional experience he also has poignant personal experience as a parent of a child with a life-limiting condition. At 17 months old Adam's daughter Emily was diagnosed with Rett Syndrome, a debilitating neurological condition. Emily and her family received wonderful



support from local hospices and hospice at home teams during life and at end of life with this support continuing into their bereavement.

Speaking out and standing up for families

Over the last year, Together for Short Lives has pushed for change, provided support and made a lasting difference for children expected to have short lives in the UK. We are proud to have supported more children, families and professionals than ever before.

Our new Impact Report details the work we've been doing in 2018 to lighten the load for families.

Our helpline is a lifeline for families. This year we helped more families than ever.



We were thrilled to be joined by mum, Kirsty Murray, who we introduced you to in the last edition, to launch the report at an event in London. She told us what it meant to her to be such a big part of our successful campaign for funding for children's hospice services:

"Getting the news about the increased funding was the best present I could have wished for. It was as if Ella had given me a present herself. I sat and sobbed; I was so happy for all the families I had never even met."

Read more at:

www.togetherforshortlives.org.uk/impact

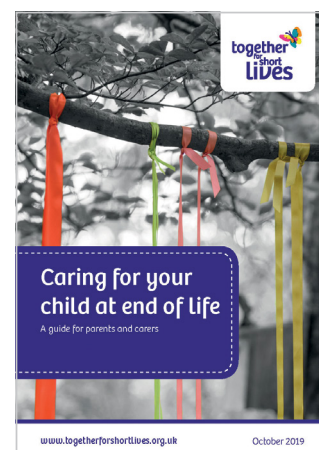
Support for families at end of life and beyond

We know that every family's experience of losing a child is unique. Some will care for a child with a life-limiting illness for years, others only hours. Our new End of Life Guide for families provides practical information, answers questions and provides support.

Families might want to work through the guide with their care team one step at a time, when they are ready. We hope that it will enable families to make informed choices and help them to have conversations with their care teams about their wishes for their child's care.

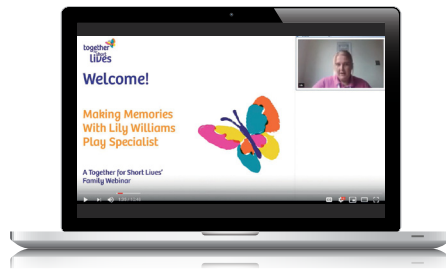
Available to download here:

www.togetherforshortlives.org.uk/family-resources



Precious moments together

Moments to treasure



Taking opportunities to make special memories as a family is so important and can be lots of fun! In September we shared a short film with members of our Family Facebook group of a hospice playworker providing creative ideas about things to do as a family. You can still watch the film at:

<https://youtu.be/PSgY0wrZqZQ>

Whether it's scrapbooking or hand printing, making memories that will last for years needn't be complicated or expensive. While you're having fun, why not take some photos to capture the moment!

Our friends at Hobbycraft have kindly donated some crafting materials to share with our families. If you feel inspired to get crafting do email info@togetherforshortlives.org.uk to

request a small bag of craft materials – there is a limited supply so these will be posted out on a first come first served basis.

If you're planning to spend some quality time together, our Family Factsheets 7: Grants and Wishes and 8: Short Breaks and Holidays include details of charities and organisations that offer opportunities to make extra special memories.

Charities that provide grants and can help with special wishes

Together for Short Lives holds a small list of charities throughout the UK which provide grants or are wish granting charities. If your child has a special wish or if you have a something you would like to do as a family, contact our helpline or talk to your care professionals about opportunities they might have access to. Here's a few charities that you may not know about.

The Starlight Foundation

Provides wishes and provides hospital entertainment.

www.Starlight.org.uk

React

Provides grants and holidays in the UK.

www.reactcharity.org

The Muscle Help Foundation: Muscle dreams

This charity aims to deliver once in a lifetime experiences for children and young people with Muscular Dystrophy.

www.musclehelp.com

Download or order a printed copy of the full list of charities via our website:

www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/grants-and-wishes/



Together, there for each other

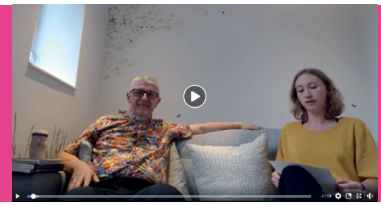
We know that families draw strength from spending precious moments together as a family and that's why we're thrilled to be joining forces with M&S and Disney to show how together we're stronger... with a little Frozen II magic.

Marks & Spencer has a new festive collaboration to celebrate the return of Elsa, Anna, Kristoff, Olaf and Sven in Walt Disney Animation Studios' Frozen II. As part of the Frozen II collaboration, M&S is joining Disney in supporting our work, and funds raised through the in-store partnership between Disney Frozen II, M&S and Together for Short Lives will support children's hospices right across the UK.

This Christmas, M&S is showing its support for Together for Short Lives by selling an exclusive 'together, there for each other' tote bag. M&S Food also joined forces with Disney to sponsor a special Together for Short Lives & Frozen II Ball in November and the team has worked with Disney on a couple of special events to bring families caring for seriously ill children together and create lasting memories this Christmas. We couldn't have hoped for a better Christmas present!



Out and about



Interview with senior chaplain Paul Nash

We met up with senior chaplain Paul Nash at Birmingham Children's Hospital to discuss the role of the chaplain and how they can support families. Paul didn't disappoint us by wearing one of his signature colourful shirts, renowned throughout the hospital. He provides spiritual care covering the six major world religions, as well as pastoral care.

Paul says pastoral care can be best described as active listening and an active presence, "this means we are able to offer different types of care to people of all faiths, beliefs or none and that's a real privilege." It is a 24/7 service that is open to patients, families and staff.

Chaplains can support families caring for a seriously ill child from diagnosis through to bereavement and onwards.

Paul tells us how he receives a call every year from one dad on the anniversary of his daughter's death. As Paul stated, "it's really important to have that continuity of care".

One of the phrases he likes at the moment is 'lifting spirits' as this seems to encapsulate the nature and purpose of how he sees his role – having the time and emotional energy to give to families.

- One form of chaplain support is through something he describes as 'spiritual play', involving the use of dolls and activities to help children express their emotions. He gives an example of one girl who decorated babushka dolls to reflect her different emotions, allowing her to show others her feelings through the dolls.
- Other activities include caring trees, where families are asked to think about the wider network of care

they have around them, opening up conversations around loneliness.

There are so many stories and anecdotes Paul could recall about his personal interactions with families and children in the hospital. He described how they received permission to hatch chicks in their chapel during Easter and the reactions this received, bringing people of different faiths together.

Paul left us with this, "I just want to say to families, please make use of your chaplaincy whether at hospital or hospice. I hope you will find they are very approachable and are able to engage and support you, it's what we are here for and we take your journeys very, very seriously. Chaplains are there to help you find appropriate hope."

A full video of the live interview can be found on the Together for Short Lives Facebook page.

Building Connections

We were delighted to secure funding earlier this year from Her Majesty's Government (HMG) and National Lottery Community Fund Building Connections programme to support the development of our new Family Support Hub.

The Building Connections programme aims to build knowledge and understanding about the most effective ways to reduce and prevent loneliness in different groups of society.

We are building our hub to help families feel better protected at vulnerable points in their life when they're at a particular risk of experiencing loneliness. Through our Helpline and resources we aim to help families navigate systems that can seem complicated and scary and, where appropriate, offer free legal advice and support.

We also recognise the importance of keeping strong social relationships or forging new ones; so during the year we are trialling different ways to better connect people together digitally. While our closed Facebook group for families is growing, we recognise that this platform doesn't suit everyone, and we continue to explore alternatives. We are looking to provide opportunities for small groups to discuss particular themes of care together so do keep an eye out for our programme of webchats.

Being able to talk to parents and carers in person is always a highlight in our calendar and we have taken opportunities to share our resources at Kidz to Adultz and other events around the country. Look out for us and come and say hello!

This is me

Take part in a brand new project to celebrate the young people we're here for and their incredible creativity! Open to all young people aged 13-30, with a life-limiting or life-threatening condition, submissions which have been supported by parents, carers and helpers are very welcome too.

Be creative: Submit creative work in almost any form on the theme of 'This is me'. You can send us photos, artwork, writing, music, poetry, or even a selfie. All work submitted will be available on our website and may even feature in an exhibition.

Explore what makes you, you: This project is an opportunity to explore your identity, share what is most important to you, what a part of your legacy will be or just a way to express yourself.

Make a difference: Did you know there are over 49,000 children and young people in the UK who have life-limiting conditions? This is your chance to show the importance of listening to the people behind the numbers.

Submit your work to info@togetherforshortlives.org.uk. Submissions close 20 January

If you are a professional planning to take part in this project with young people you work with or for more information please email: annie.dahl@togetherforshortlives.org.uk

Need to know

Workforce crisis: sign our open letter to ministers today

Together for Short Lives has published a **new report** highlighting the growing crisis in the children's palliative care workforce. A shortage of skilled children's palliative care doctors and nurses across England is leading to seriously ill children and their families missing out on crucial out of hours care and vital respite breaks.

Our new report, 'A workforce in crisis: children's palliative care in 2019', shows a children's palliative care workforce at breaking point:

- There are just 15 children's palliative care consultants in the UK when there should be 40-60.
- On average, children's hospices have a nursing vacancy rate of 12.2%.
- Two thirds of children's hospice nursing posts remain vacant for three months or more.

Hannah Hodgson, 21, who has been diagnosed with Ehlers Danlos Syndrome and a currently unnamed degenerative neuromuscular disorder, attended the reception to share her story with MPs – and to press them to take action.

"In my experience, the staff working in hospices couldn't be more dedicated – they are expected to do more for less constantly – and still provide the essential services. However, this isn't fair for patients or staff because it removes choice at such a tender and devastating period of people's lives."

Please join us in calling for urgent action to end the crisis in the forthcoming NHS People Plan by signing our open letter to the health and social care secretary today (<http://bit.ly/2CbYiVF>)

Why not get in touch with your MP after the election?

A new Parliament is a great opportunity for young people and families to get in touch with their MPs – especially if they have been newly elected. If you can, email them straight after the election, asking them to help implement Together for Short Lives' policy priorities in the new Parliament:

www.togetherforshortlives.org.uk/TfSLGE19

Another route would be to make an appointment to see them at one of their local surgeries; this way, you can introduce yourself in person, tell them what life is like for you and your family and describe the challenges you are facing in accessing services.

MPs often meet regularly with their local NHS organisations (such as trusts and clinical commissioning groups in England) and local authority leaders. They and their staff can help take cases up on behalf of their constituents. They may be able to resolve challenges you are facing in getting the care and support you need – whether the barrier is at government level, with your local NHS organisations or local council. Meeting you will make them aware that they represent children who need palliative care – and make them much more likely to want to work with Together for Short Lives to campaign to improve the lives of seriously ill children at Westminster.

Following the election, you will be able to find the name and contact details for your local MP at www.parliament.uk/mps-lords-and-offices/mps/

We have created a template letter for you to use to approach your MP here: <http://bit.ly/newMP19>



Government review into SEND in England

Five years on since the Children and Families Act came into force in England, the government has begun a review to examine how it can improve the system for children with special educational needs and disabilities (SEND).

Ministers say the review will consider how staff in schools and colleges can be equipped to respond effectively to their needs – and how the postcode lottery families often face can be ended.

Check our website and social media channels to find out how families can get involved in the review.

Increase planned for Funeral Expenses Payment

The government has committed to increasing the maximum support available to benefit claimants through the Funeral Expenses Payment from £700 to £1000 from spring 2020.

Funeral Expenses Payments are paid to eligible benefit claimants bereaved of a loved one and help to meet the costs of expenses such as a coffin, flowers and funeral directors' fees. This payment is available on top of existing allowances, such as the Children's Funeral Fund which was introduced in July 2019.

More information can be found at www.gov.uk/funeral-payments



Mary's story

Mary is a happy little girl and lives with her six siblings in our very busy household!

Mary is just five years old, but has faced lots of challenges in her young life and it's been quite the journey to reach the point of diagnosis for her – with three key diagnosis milestones along the way. At only five months we were told she had hydrocephalus, with a further diagnosis of Macrocephaly Capillary Malformation at 19 months old. Soon after, at around two, Mary began suffering with seizures in earnest, though it was years later in February 2019 that we finally got the dual diagnosis of Megalencephaly Polydactyl Polymicrogyria Hydrocephalus Syndrome – due to an extremely rare genetic mutation.

Mary will have little absences daily – minor seizures – but these don't trouble Mary or myself. However, when she has large seizures, approximately every eight weeks, she requires rescue medication and we need to call an ambulance. Recently, she has needed two general anaesthetics in order to stop the seizures. It is terrifying when it happens. Sometimes we have warning that it is coming, and sometimes it just comes out of nowhere.

As a result of Mary's condition she is only able to communicate with us in tiny amounts. She can say the words "choccie" and "milk" – very important choice words I'm sure you'll agree!



She's also learnt to say "turn the page" recently, which makes for precious family time reading.

Despite her conditions, Mary is a force of nature. She loves singing and will sing along to songs like nobody's business. She's recently been introduced to Disney by her big sister Grace, which gives her a whole new repertoire. Mary is thoughtful and appreciates the little things, like the wind which makes her giggle, and listening to the birds.

Mary goes to a specialist educational school and over the last few months we have gradually built up her hours so that she attends school full time.

My first contact with Together for Short Lives was in September 2018 when I called the Helpline. I was so worried about Mary starting school and so I spoke for an hour about my fears. It made a tremendous difference, having somebody to listen. Thankfully, Mary's school has been incredible. I was so worried about letting Mary go, but their support and care has really made a difference in my confidence in sending Mary out every day.

Due to Mary's requirements, we face a lot of challenges. There are six other children at home and I want to make sure they all get attention. Mary takes a lot of time of course, especially when she is in hospital, and I worry that her brothers and sisters are missing out on time with me.

That's where our local hospice comes in. In 2018 we visited Hope Hospice for the first time and the whole family came along. They assign a member of staff to Mary which gives me a little extra time to be with Mary's siblings. They have a lovely playground and sensory room. They also have a pool and access to a local farm park which we used. We had a great family day.

I worry everyday about Mary. There is always that thought: "Will her next seizure be today?" And then the long-term worry about her future. We don't know what her prognosis is. There is the fear that one of these seizures might not end up being controlled. I know I should just be enjoying each day but it is always in the back of my head.

Despite all of the worry though we absolutely adore Mary. She brings happiness to the entire family. She is a true blessing.



Pass it on! When you have finished reading this, please share it with your family and friends