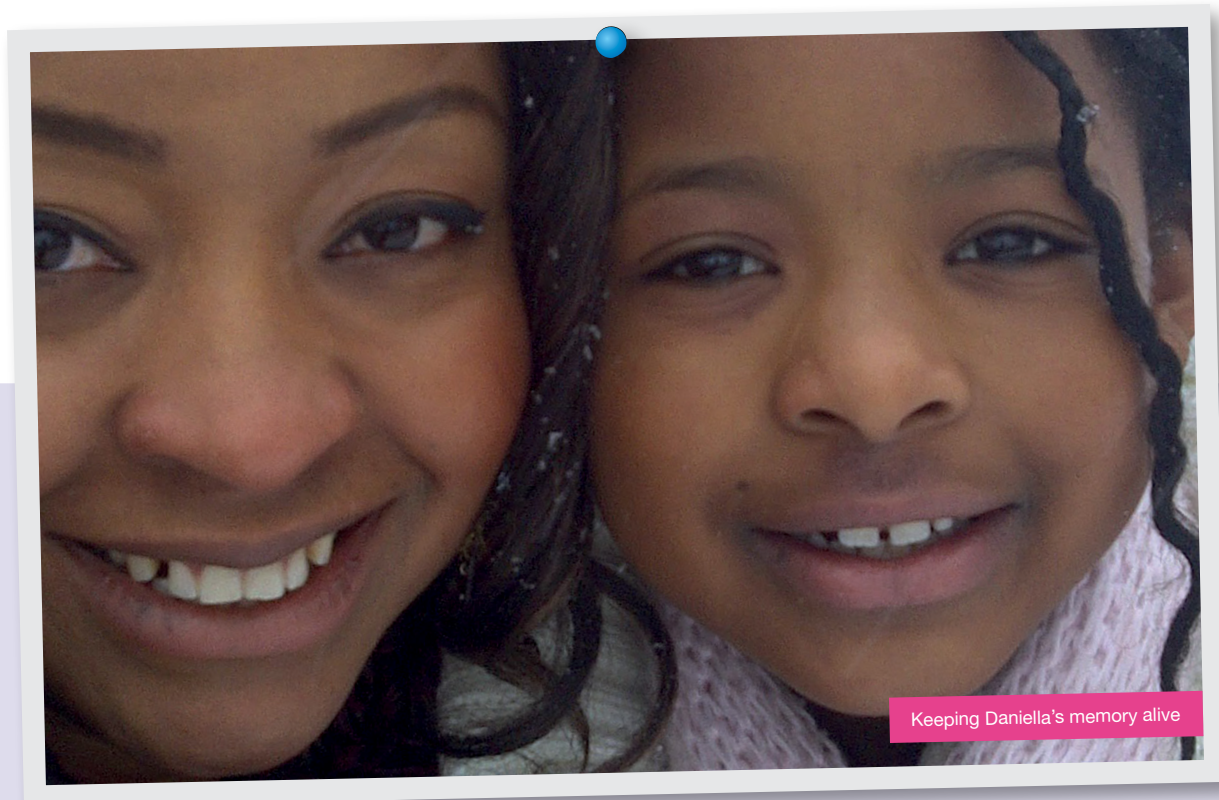


# together for families

Issue 29  
Spring 2020



Keeping Daniella's memory alive

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](mailto: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](mailto:info@togetherforshortlives.org.uk)

Editors: Julia Hodgson, Annie Dahl & Katrina Kelly

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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  
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short  
lives



## Welcome to our Spring newsletter Inside this issue...

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In these troubled times we are here to provide information and support

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Young people express themselves with incredible new artwork

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An opportunity to get involved and a new report on parents' mental health

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We look at the impact of COVID-19 and what's happening to help families

### 6 Family Story

Keeping Daniella's memory alive

Did you know that we are also Intermediary Partners for the Turn 2 Us Response Fund? This means-tested fund is available to families facing additional financial hardship following a significant event in the past 12 months. Do call the Helpline for further information.

## Keep in touch

Call the Helpline  
0808 8088 100

Email us  
[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)

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

Follow us

 @Tog4ShortLives

 togetherforshortlives

# Troubled times: COVID-19 and its impact

**Here at Together for Short Lives, we know what an incredibly distressing time it is for families – living with the restrictions brought about by COVID-19, still trying to navigate family life and understanding what it means for children already living with very serious conditions.**

We are here to support you in any way we can – and one of the most important ways of doing that is by keeping in contact. We were keen to still publish this edition of Together for Families, knowing that some content by its very nature will be out of date even by the time it hits inboxes, to keep our sense of community and share stories and initiatives from across the sector. Whilst our family support team are all working from home, we will only be publishing it in digital format as we are not able to send printed copies.

We have a dedicated COVID-19 hub on our website, sharing practical questions and answers as well as collating information from other charities that you might find useful. This resource is being updated regularly: **COVID-19 hub**. We also look at COVID-19 in more detail later in this issue.

It's worth remembering that some charities or grant-making bodies might need to change how they function in this climate - for example wish-making and transport charities. Do check individual websites for more information.

## Helpline

**In 2019 we received twice as many family enquiries to our Helpline service than we did in 2018 and this growth is being seen to continue into 2020, especially with the COVID-19 pandemic firmly on parents' minds.**

To ensure that we don't miss any opportunities to offer support to those needing information, signposting to support or perhaps just a listening ear, we have made some changes.

We were thrilled to be joined by Emma, an experienced Helpline advisor in March and this extra capacity means that we can now answer calls directly between 10am-4pm Monday-Friday. If the line is

busy, just leave a message and we can call you back.

By emailing [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk) or calling 0808 8088 100, we offer a range of help through our Family Support Hub. We can email you our publications, sign you up to our Family Facebook Group or Family Expert Group and/or talk through some of the issues you may be facing, in confidence.

## Simon Cowell's fun new book series to benefit seriously ill children

In brighter news to look forward to we are thrilled to be benefitting from Simon Cowell's exciting new children's books, which he has written alongside his son Eric. We can't wait to read all about the magical creatures in the WISHFITS series. Three picture-led children's books, will begin to be published in spring 2021, supporting Together for Short Lives and Shooting Star Children's Hospice. Four more books will then follow the next year.





# This is Me

Together for Short Lives has completed a new youth-led pilot project for young people through creative art.

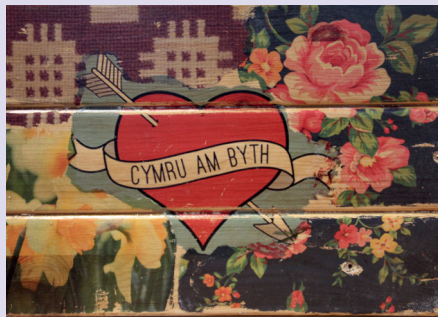
'This is Me' gave a valuable opportunity for seriously ill young people to express their thoughts, feelings, fears, ambitions and interests in a creative and powerful way through the arts.

The pieces were initially intended to be unveiled in a visual exhibition at our sector-wide conference 'Time for Change' in Manchester in March, however due to developments around COVID-19 the conference has now been postponed.

What we did not want to postpone however, was sharing the amazing creations of the young people we work with, as now more than ever we need inspiration and creative ways of expressing ourselves. So we present to you, our very talented young contributors and their work.



1.



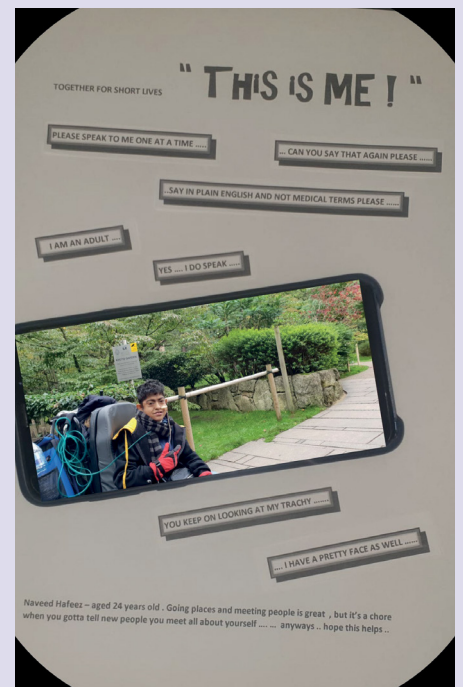
2.



3.



4.



5.

1. Anonymous, age 17. This piece was inspired by henna and uses her handprints as a focal point; her sister supported her to create this lovely artwork at Ty Hafan.

2. Students Molly and Sophie (both 20) produced the 'Cymru am Byth' piece on recycled wood with support from staff. The artwork uses transfer printing technique – a technique which works well for students with PMLD allowing them to participate in creative art and recycling.

The Welsh theme reflects both students' family and roots, as they both live in Wrexham, travelling over the border to Shropshire on a daily basis.

The two students with profound and multiple learning disabilities (PMLD) attend specialist further education college Derwen College, in Shropshire.

3. Photo taken by a young person who accesses Jigsaw Children's Hospice.

4. Caitlyn, age 14, accesses East Anglia Children's Hospice.

5. Naveed Hafeez, age 24, shares his feelings and wishes in this honest piece.



## Football and Joe

Joe is part of Teeside Powerchair Football Team.

This is his Blog: Football and Joe

- o Powerchair football
- o Teeside Team
- o 9 years
- o Goalkeeper

Rules:

- Kick in's, goal kicks, corner kicks
- Two on one rule
- 4 a side, as many subs as you want
- 40 min match

Travel around UK and Europe and coached for a while.

Enjoy the competition and team spirit. It has allowed me to meet people and make new friends.

Helps to concentrate my mind and offers new experiences.

Supports my social skills.

6. Joe is part of Teeside Powerchair Football Team. This is his Blog about football.

**With huge thanks to our friends at the Flourish Arbonne Foundation for supporting our 'This is Me' creative arts project and exhibition.**



6.

# New research

## Be part of new Kings College 'C-POS' study

**Would you like to be involved in a research study to develop a tool measuring symptoms and concerns in children with life-limiting and life-threatening conditions?**

The team at King's College London are looking for a small number of parent/carer representatives to be part of their steering group for the 'C-POS' study, in order to provide ongoing views and input. In order to develop a measure that asks about the right symptoms and concerns, in the right way, it is essential that experts such as yourself are involved so that we include what is important to you and your child.

If you are interested in being involved, or would like to find out more then please contact:

Lucy Coombes  
[lucy.coombes@kcl.ac.uk](mailto:lucy.coombes@kcl.ac.uk)

Anna Roach  
[anna.e.roach@kcl.ac.uk](mailto:anna.e.roach@kcl.ac.uk)

Debbie Braybrook  
[debbie.braybrook@kcl.ac.uk](mailto:debbie.braybrook@kcl.ac.uk)



## Parents Matter: The impact on parents' mental health when a child has a life-threatening illness

In January 2020, Rainbow Trust Children's Charity published this report, bringing to light the shared experiences of some parents and carers who have cared for a seriously ill child or young person, drawing on in-depth interviews and case studies.

Parents Matter shares parents' stories of managing their mental health, and their advice to other parents in the same situation. The report considers what mental health support exists for them, what services these parents were offered, and what they themselves feel would be most helpful.

The full report and the summary can be accessed here [www.rainbowtrust.org.uk/parentsmatter](http://www.rainbowtrust.org.uk/parentsmatter)

# Need to know

## COVID-19: doing whatever it takes for families

**We understand that the coronavirus (COVID-19) outbreak is concerning for everyone, but especially so if you are a parent carer of a baby, child or young person who has complex health needs.**

We also know that families have a number of questions about a wide range of clinical and practical issues relating to the pandemic. Where we have answers to these, we have set them out on a dedicated webpage at [www.togetherforshortlives.org.uk/coronavirus](http://www.togetherforshortlives.org.uk/coronavirus). Where we don't, we are working hard with the government, the NHS and others to try to find out.

Families should know that if their child becomes ill, for whatever reason, they should speak to their care team as soon as they can. Trust your instincts - if your child's health deteriorates, don't delay - call your GP and don't be afraid to use A&E. Children's palliative care teams have been keen to impress on us how important it is that they assess seriously ill children as soon as possible if emergencies arise, despite the pressures placed on the NHS by COVID-19. We want to reassure you that PICU's have capacity - care & equipment is on hand, so please don't wait until your child becomes seriously unwell to take action.

If you have questions about wider issues affecting children who need palliative care, or are finding it hard to cope during the pandemic, please contact our Together for Families Helpline free on 0808 8088 100.

At a national level, NHS bodies are working hard to try to make sure that seriously ill children who can be cared for at home and in children's hospices are discharged from hospital as soon as possible. In England, officials have asked Together for Short Lives to help them understand what capacity children's hospices have to provide these urgent services - including in cases where parents are unable to provide the care themselves if they have COVID-19 symptoms. We have helped NHS England to develop a COVID-19 guide for those who plan, fund and provide

children's palliative care services which we are expecting to be published shortly.

There are a number of pieces of guidance produced by the UK's governments which are relevant to families of children who need palliative care. We are linking to the most relevant on our coronavirus webpage, but we recommend that families continue to check the following places:

**Northern Ireland**  
**Scotland**  
**UK Government**  
**(including England-only guidance)**  
**Wales**

The ability of children's hospice and palliative care charities to support families at this time depends on whether staff have access to specialist personal protective equipment. As their charitable funding streams suffer as a result of cancelled events, shut hospice shops and stock market falls, this care will also depend on whether they have access to enough money from the government and NHS. We have worked with Hospice UK and other partners to secure a financial package from government to help children's hospices react to the COVID-19 challenge - and to make sure hospices have the equipment they need. We have also been part of the #everydaycounts campaign to secure a package for the wider charitable sector, mindful of the range of vital non-hospice children's palliative care charities that families rely on for social care and other types of support.

The UK Parliament has passed the emergency Coronavirus Act 2020 to increase the availability of health and social care workers, ease the burden on frontline staff and contain the virus. The law also relaxes the regulations on notifying and registering deaths. You can read the new law at [www.legislation.gov.uk/ukpga/2020/7/introduction/enacted](http://www.legislation.gov.uk/ukpga/2020/7/introduction/enacted)

## Jack's Law

**On 6 April the Parental Bereavement Leave regulations will come into force. The regulations will allow parents who lose a child under the age of 18 to get two weeks' statutory leave. Parents will be able to take the leave as either a single block of two weeks, or as two separate blocks of one week taken at different times across the first year after their child's death.**

These regulations are also known as Jack's Law in memory of Jack Herd, whose mother Lucy has fought tirelessly for this support to be introduced since he died in 2010. These new regulations will mean that those who have been employed for at least 26 weeks will be entitled to a minimum payment of up to £148 a week during their bereavement leave.

Jack's law is a really good step in the right direction, but there is so much more that can be done to support parents who lose a child, and we are continuing to fight for this. In the government's 2020 Budget we called for funding to enable more flexibility within the law. At present, the law excludes parents who are self-employed and restricts the period of paid leave to weeklong blocks. We are calling for the government to allow more flexibility with this.

[www.gov.uk/government/news/uk-set-to-introduce-jacks-law-new-legal-right-to-paid-parental-bereavement-leave](http://www.gov.uk/government/news/uk-set-to-introduce-jacks-law-new-legal-right-to-paid-parental-bereavement-leave)







# Daniella's story

**Intelligent and mature for her age, Daniella had just started at a Church of England High School in September 2015. With her new blazer and school bag in place, she was raring to go!**

Things started to change for our family in November 2015, when Dannie (as she was fondly called by family and friends), started having difficulty looking to the right with her right eye. To begin with, we didn't think much of it, but took her to the local high street Optometrist for an eye test. All tests came back negative and Dannie was sent home. The situation escalated in the coming weeks – from the local hospital all the way to Great Ormond Street Hospital (GOSH). Dannie had a 3mm growth on her brainstem.

We were distraught and in shock. A biopsy was carried out in December which revealed very little. Plans for a follow-up biopsy were immediately set in motion but given the circumstances at the time – anxiety and mixed emotions – it was difficult to make a clear joint decision. Sadly, after the biopsy, Daniella suffered partial post-operative palsy and family life changed forever. She was diagnosed with a terminal brain tumour and given a prognosis of just two and a half years.

In the same month that Daniella was diagnosed, life was pretty hectic for our family, caught in the middle of a house-move, I was also nine months pregnant; and her lovely eight year old brother was just trying to live a 'normal' life. We were suddenly overrun with medical appointments, tests and jargon.

**As Daniella's parents, we were forced to stop work and devote ourselves to caring for her.**

Soon, I gave birth. And things were not straightforward. Our baby was born with special needs and required intensive care. Family life stopped dead in its tracks, the colour faded, the music stopped and suddenly there was nothing. It felt as if no one could understand or no one could help.

With our faith keeping us going, we knew that there had to be a way through this, if not out of it. And as if in answer to our prayer, we were introduced to a local brain tumour charity. Finally a lifeline.

The local charity, Hillingdon Brain Tumour and Injury Group was absolutely crucial for us. In our circle of friends and family, no one had any knowledge of what we were going through; but this group gave us access to a whole new set of faces at a time when we so desperately needed them – not medical but more of a listening ear and peer support. It sounds so simple, but their support meant the world.

Becky, the founder of the group, acted as a 'buddy' to us – we built up a close relationship and it's true to say she became almost part of our family – giving us sanity and strength, in a world that had just been a medical haze.

Devastatingly, Dannie passed away on 19 May 2016, not long after her 12th birthday. While our life together had been full of love, life and laughter, sadly Daniella's final hours were fraught with panic, confusion and impromptu decision-making pressures as her emergency and advance care plans were not fully established.

My experience really crystallised for me how important it was to help guide others facing up to the same experiences we did – supporting and helping families at the high stress points of their journey and navigate key care needs. With this in mind I created the Daniella Logun Foundation, to do just that.

**Families need a human face to be there for them and help them absorb critical information, at a time when their world feels like it's falling apart.**

Someone to cushion the shock. Like Becky was for me, we all need a buddy when facing up to the toughest times we have known.

I am so thankful that I can keep Dannie's memory alive and support families facing the hardest of times, using my own experiences.

Thank you Together for Short Lives for sharing my story.



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