



Summer Newsletter 2022



Jessie May
Children's Hospice at Home

Welcome to your Summer edition Jessie May newsletter!

The weather's getting better, the days are getting longer, and hopefully we're all feeling a little more optimistic about things at the moment.

Here at Jessie May we've just released our latest Impact Report, looking back at how we've continued to provide specialist support to 190 children, and their families, over the last 12 months – and so we're filled with incredible pride and determination for the year ahead.

We're also looking at some organisational changes across Jessie May which you will be able to read all about in the pages that follow, as well as some exciting new initiatives and upcoming events at which you can lend your support.

So get comfy, grab yourself a cooling glass of lemonade, and enjoy this Summer edition of your Jessie May newsletter.



Chris Roys, Chief Executive



Prioritising the Family Voice

As part of our Reset & Recovery Plan, we made 'family voice' a priority over the last 12 months, giving the parents and guardians of children supported by Jessie May the opportunity to have their say on how their service is developed.

In August 2021, we sent out the annual Family Engagement Survey to all families currently receiving support, and followed this up with 2 family engagement events to run through the results of the survey.

We have taken these results to the Service Development Group, and together revised our offer of support to families to incorporate some of the preferences that families felt most important to their wellbeing. This new offering was implemented in January 2022.

We continued to support families through alternative methods, including via the established Family Facebook Group. This group gives the parents, carers and guardians of our children an additional space through which they can talk openly and honestly about their child's condition, offering them much valued peer support. It also allows us to keep them further in touch of any developments at Jessie May, including changes to the service, upcoming events and support they can access, as well as new fundraising initiatives to take part in.



Arthur's Story

Arthur, age 7, was born with Worster-Drought Syndrome (WDS), a form of cerebral palsy that affects the muscles around his mouth and throat. His WDS causes additional complex side-effects, with Arthur experiencing multiple seizures a day. The most common of these include drop seizures, meaning that those around him have to be extra-vigilant as he can fall to the ground at any moment.

Jessie May nurse Andy has been supporting the family since April 2021. Even though Arthur is non-verbal, and has some developmental delay he understands everything you say to him and is very much a lively seven year old. He gets excited when Andy visits, his face lights up, he beams a huge cheesy grin, and he starts to do a little 'wobble-dance'. Despite his limitations, he's not one for sitting still. Melanie, Arthur's mum says "Andy's visits are fun for Arthur and he has a good understanding of what's going on and what we're going through. When visiting us at home, we never have to worry about the house being in shambles or the difficult times. Andy just comes in and takes it all in his stride. His presence is reassuring. He's calming and takes the pressure off us"



To improve his condition, Arthur was offered a life-changing surgery by the team at Bristol Children's Hospital (BRHC): a Corpus-callosotomy. Arthur was on the list for a long time, and in October 2021 that moment finally came and he was able to have his surgery.

In the weeks after his operation, Melanie would sit vigil by his bedside for hours on end, while dad looked after two of Arthur's sisters at home. This is where Jessie May nurse, Andy, was able to step in. He would visit Arthur on a weekly basis, to provide him with a friendly face and offer his support to Melanie. During Andy's visits, Melanie was able to take a break for herself after being with him 24/7. Melanie says

"I don't know how to tell you how important Andy's support in hospital is. It's invaluable because no one else can offer the support he can. Arthur lost trust in the doctors and nurses because of all the procedures he had to have, but he retained that relationship and trust with Andy. That makes a huge difference."

The rehabilitation after a surgery of this kind can take months. Arthur was in hospital for three months and is now home with his family, though still has to go back twice a week. Andy will continue to be there for Arthur and his family through the rest of Arthur's recovery and into the future.

"Thank you for giving money. It's such a massive thing for us as families. Jessie May know how to help us, they are highly trained with years of experience which is so valuable to families. So the best support you can give is to make sure we have Jessie May."



What will you do #ForTheChildren?

This year's theme for Children's Hospice Week (20th-26th June) was For The Children, and this year we introduced you to two of our incredible nurses, and let them tell you, in their own words, why they do what they do for the children supported by Jessie May.

"Very recently I supported a family whose child was at the end of their life. I knew the family so well; I was able to advocate for their wishes for their child which essentially was to be at home as a family spending as much time together as possible. By being at home the child was able to see all their family and feel the love that they had for him. If my role means that the child can die in the most comfortable way possible, in surroundings that they're familiar with and people who they know and trust and love – then that's why I do it. For the children."

Gemma Warren, Jessie May nurse

To read Gemma, and Andy's full stories, or to make a donation #ForTheChildren; visit www.jessiemay.org.uk/for-the-children. Alternatively, you can help us raise vital awareness and help shine a spotlight on the incredible care our Jessie May nurses provide to children and families in the South West, by sharing our story.

We've partnered
with Farewill!

Are you thinking about how you can leave your mark on the world?

Leaving a gift in your will is vital to the work Jessie May do, and we've made it even easier for you to make a real difference by partnering with will-writing experts, Farewill to offer you a FREE will!

Gifts in Wills allow us to reach the children and families that need us most, just like Annaleise and Finley; **"I couldn't cope without Jessie May. They provide expert care and they give us the security that Finley is being so well cared for."**

Will you leave your mark and leave a gift to support children likely to die in childhood?

Just follow the link, and your voucher code will be automatically applied at checkout:

www.farewill.com/jessiemay-newsletter

Book a free callback by visiting:

www.farewill.com/jessiemay-phone.

Alternatively, you can call Farewill on 020 8050 2686, please note you must tell the Customer Support team you are a Jessie May supporter.



Take part in an event...

To find out more about any of our upcoming events, visit [jessiemay.org.uk/events](https://www.jessiemay.org.uk/events) or get in touch with our Fundraising Team.



Play in support!

Playing the Local Hospice Lottery in support of Jessie May gives you a chance to win £2,000 every single week - along with 200 other cash prizes - and a possible £25,000 rollover! Players are also automatically entered into Super Draws, taking place every March, September and December, with an additional guaranteed top prize of an incredible £10,000! Visit www.jessiemay.org.uk/support-us/local-hospice-lottery to sign up today.



A fond farewell...

We are going through a significant, but exciting change at the very top level of the organisation, as after 17 years with Jessie May, CEO Chris Roys has announced his intentions to retire.

Chris has seen many changes in the organisation; from widening the service area, expanding the team to the 29-strong workforce we are today, and placing us in a strong position to take the organisation forward.

“I am extremely proud to have played a part in leading Jessie May over the past 17 years. I am sad to be leaving Jessie May, but knowing that we are in such a good place, and with such exciting plans for the future, I feel that it is the right time for me to pass on the baton to a new leader who has the drive and energy to take Jessie May forwards, and realise our ambitions.

I want to take this opportunity to thank everyone I have crossed paths with during my time as CEO at Jessie May; from the incredibly inspiring children and families we've supported, to the phenomenal supporters who have helped us to fundraise and ensure we continue to be here year after year. None of what we have achieved would have been possible without the hard work and commitment of all of the staff, those that are part of the team now but also those that have since moved on. All have played their part and I thank them for all their support and encouragement through thick and thin. Thank you.”

Meet the Team: Jessie May nurse, Andy

In a new series for this year, we've been introducing you to the faces behind the service that make up the Jessie May family. First up; Jessie May nurse, Andy!

I'm a Children's Community nurse, supporting families and children with life-shortened conditions in their own home. It's a multi-faceted role, meaning that my days are always different!

One day you can be providing a vital respite visit to allow a family to spend quality time together, or I can be visiting the most vulnerable of children at the Bristol Children's Hospital.

We create such a strong link with the families that we support, and those I have supported for many years I have an incredible bond with that nothing can compare to. It's not just the physical side of the job, but also the mental and emotional advice and support that we can offer. We are able to talk through some of the most difficult conversations a person will ever have, and it's getting our families through those hardest days that truly makes me proud to do what I do.

There's not a lot that I can say that hasn't already been said other than a really big thank you. Without your support we wouldn't be able to do what we do, at all. It's thanks to you that we can do that.

To read Andy's full story, visit our website;

www.jessiemay.org.uk/blog/meet-the-team-jessie-may-nurse-andy



How your donation can make a difference...

£25

could buy a memory box or a memory bear for families to remember their child

£40

could buy a 3D hand sculpture of a child's hand for parents to keep forever

£68

could buy one hour of Jessie May care and support

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Please tick if you would like to receive the newsletter via email in future, and hear about the latest news, events and updates from Jessie May:

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If I have ticked the box headed 'Gift Aid' I confirm that I am a UK Income or Capital Gains taxpayer. I have read this statement and want Jessie May to reclaim tax on the donations detailed below, given on the date shown. I understand that if I pay less Income Tax/or Capital Gains tax in the current tax year than the amount of Gift Aid claimed on all of my donations it is my responsibility to pay any difference. I understand that the charity will reclaim 25p of tax on every £1 that I have

Please send your completed donation forms to: Jessie May, 35 Old School House, Kingswood Estate, Britannia Road, Kingswood, Bristol, BS15 8DB.



Stay in touch

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