



# Winter Newsletter 2021



**Jessie May**  
Children's Hospice at Home

## Welcome to your Winter edition newsletter!

We are just a couple of weeks away from the big day now, and the festivities are certainly in full swing here at Jessie May!

The last few months have still been tough on everyone, but we hope that the stories in this newsletter can help to bring you some, what we like to call, Jessie Joy.

In the next few pages you will read some beautiful stories about the incredible children that we have had the privilege of supporting over the last year, as well as all the ways that you can continue to support us and help to make a real difference.

So get comfy, make yourself a cup of hot chocolate and enjoy your festive edition of the Jessie May newsletter.

*Chris Roys*

Chris Roys, Chief Executive



# 143

terminally ill and life-limited children are receiving specialist Jessie May palliative nursing care.



# 4 Purple Group meetings

have been held this year. These groups support parents through Bereavement for 5 years after the death of their child.

# 41

families are currently receiving Bereavement Support.

# 688

3-hour specialist palliative care visits have been made to families in need.

# £597,699

raised out of £1,148,906 needed to provide specialist palliative nursing to families for FREE each year.

# 500

phone calls have been made to support families in need

# 398

communications in other forms used to support families including; video, text & email

You can help us to continue to provide essential palliative nursing to Jessie May families and achieve our goal by making a donation today - either by using the donation form or visiting [www.jessiemay.org.uk/donate](http://www.jessiemay.org.uk/donate).

(All figures accurate April-November 2021)

## Isla's Story

**"I don't know how we would have made it through without the support of Jessie May. It meant the world to have someone who knew us and Isla there."**

Isla was born with microcephaly; a rare condition where the baby is born with a small head or the head simply stops growing. This means that the brain doesn't have the chance to develop properly, which leads to further complications. In Isla's case she was affected by regular severe seizures and recurrent chest infections.

She was referred to Jessie May at the end of 2019, and we quickly got to know her very well. Isla loved cuddles, her giraffe toy and chilling out with lights and music.

Unfortunately at the beginning of 2020, Isla had to spend quite a bit of time in the children's hospital. As it was the height of the pandemic, things were very stressful for Isla and her family.

In a time where social restrictions were still in full force, it made such a difference to our Jessie May nurses to be able to put on PPE and provide the close care and support to children that we were used to - and of course there was always time for cuddles! What a difference it made to our days when Isla gifted us with one of her beautiful smiles.

Despite everyone's best efforts, Isla became sicker and the decision was made by the family to transfer to the local children's hospice instead of remaining in hospital. This meant the family could be together and Isla would have the specialist care she needed at the end of her life.

Isla died just before her second birthday. It was an honour to care for her during the last year of her life, right up until her last minute. We continue to offer bereavement support to Isla's family and will do so for up to five years following her death.

The hard times are really hard, but we're determined to be there and make a difference for the families who need us.



## Letter from the Nursing Care Lead

Dear all,

I have had the privilege of supporting the Jessie May team over the last year in the position of Nursing Care Lead, and will continue to do so as we move in to 2022. This opportunity has coincided with a combination of challenges that none of us could have foreseen 2 years ago – that being COVID-19 and the associated restrictions the Pandemic has forced upon us both personally and professionally.

We have all had to endure the ongoing uncertainty in our daily lives, and constant changes both locally and nationally – and I want to take this opportunity to thank you all on behalf of all of the Jessie May nurses.

You have risen to the challenges put in front of you, taking things head on and been so creative with your 'virtual fundraising' and ongoing commitment to Jessie May.

Without your unwavering help we wouldn't be able to continue to provide our specialist palliative nursing care to the 143 families that we support.

As I write this I am pleased to say we are now looking forward as a team, to new beginnings and moving forward as a service into the new year. We are aiming to continue delivering the highest quality of care, as well as opening up to more wider family focused events (subject to restrictions); increasing the reach and support provided by Jessie May. You can find out more about this on the next page.

Wishing you well this festive period, as we head forward hopefully to a sense of new normality into 2022.



**Ken Hull**

Nursing Care Lead



# Service Update

With the ups and downs of the last year and a half, we have found ourselves having to readapt to the ongoing changes in social restrictions and Government guidelines. Moving forward to 2022 we are now looking to offer a streamlined service offer for care and support to the families of terminally ill and life-limited children in the South West.

The new offer comes into effect on 1st January 2022 and will include;



Providing an equal offer across all of the locations, currently including; Bristol, North Somerset, South Gloucestershire, Bath and North East Somerset, and Swindon and Wiltshire.



An update to our current framework scoring system, to ensure that we are supporting those children most in need of our help.



Prioritising End of Life care and support to make sure we are there for families when they are going through the most challenging of times.



Provision of a number of family events throughout the year\* to encourage the children and families we support to come together and help to form the wider Jessie May community.

\*These will be a combination of virtual events and face-to-face depending on restrictions and other potential risk factors.



## Help to nurture two beautiful friendships

Hopefully you will have seen our Christmas appeal by now\* which tells the lovely story of two best friends Ariana and Noah, who found each other on the children's dialysis unit.

Our lovely supporters have been responding to the appeal to fund our Jessie May nurses, but there is a way to go for us to reach our target, if you have any pennies spare this Christmas and would like to donate you can do so using the below link or you can send a donation into the office.

We have a lovely update to the story where the siblings of Ariana and Noah have told us their side of the story; what it's like to have a little brother/sister who's life-limited and what Jessie May means to them.

**"It's really nice when a Jessie May nurse comes to visit because we get to do the things with Daddy and Beccy that we can't do with Noah, like go swimming or to soft play. Noah can't go there because of his line and in case he gets sick."** - Lorelei, Noah's half sister

Head on over to our website to read more at [www.jessiemay.org.uk/christmas](http://www.jessiemay.org.uk/christmas). Thank you for your ongoing kindness and support.

\*if not, don't forget you can opt in to our email communications via our website or simply by getting in touch with us.



## Leave a legacy

Jessie May children will all leave their priceless mark on the world, their lives may be short, but they hold precious memories. There's a very special way that you can leave your mark too – by including a gift to Jessie May in your will.

Jessica May Purrington died at just 4 ½ months old, her parents Chris and Philippa established the children's hospice at home service, Jessie May, 27 years ago allowing her to leave her legacy to the terminally ill children and families of the South West.

We honour Jessica May's legacy daily by continuing to do all we can to support families who need us, and like her, all the children supported by Jessie May will leave their priceless mark on the world. There is a special way that you can leave your mark too, by leaving us a gift in your will.

We know that including a gift to Jessie May in your will is a big decision and we understand that you will want to provide for your loved ones first. We have put together a very special pack that should answer any questions you may have, including the impact a gift in your will would have.

Please contact us on **0117 9582174** or email [fundraising@jessiemay.org.uk](mailto:fundraising@jessiemay.org.uk) for your pack today.



## Get your tickets for our Christmas Raffle!

We are delighted to announce the launch of not one, but TWO very special raffles, just in time for Christmas!

Our Christmas Raffle will run from **Wednesday 1st – Friday 31st December 2021**, and for just £1 a ticket you can be in with the chance of winning one of 3 incredible prizes including:

**1st Prize:** Nintendo Switch Games Console

**2nd Prize:** Amazon Echo Show 10

**3rd Prize:** Facebook Portal

**1st  
Prize**



## Calling all sports fans!

Over the years we've had a plethora of sports memorabilia donated and we're now giving you the chance to own it! Some of the prizes include:

- A signed pair of shoes worn by World Championship winner Judd Trump
- Bath Rugby Ball signed by the team
- Parris snooker cue signed by many of the top players and more!



Every ticket bought in one of our raffles will support the vital work of our specialist Jessie May nurses and make a real difference to our children and families this Christmas.

Find out more on how to get your tickets today by heading over to our website: [www.jessiemay.org.uk/raffle](http://www.jessiemay.org.uk/raffle).

## Introducing our new Chair of the Board

Tiggy Robinson, Partner at Bath-based management consultancy Nine Feet Tall has been announced as the new chair of board, hoping to continue steering the wonderful work the organisation performs.

Tiggy first discovered Jessie May in 2019 when Nine Feet Tall were seeking local charities to support as their Charity of the Year. Jessie May was shortlisted and after a touching presentation from Corporate Partnerships Officer, Lindsey Horton, Jessie May was chosen.

Still wanting more involvement with the charity, Tiggy was nominated to be a Trustee, and was accepted in September 2020. Becoming a member of Jessie May in the middle of the pandemic proved difficult, having to wait until July 2021 to actually meet the team face-to-face.

However, this didn't stop Tiggy's determination to become an important part of Jessie May, going to considerable efforts to get to know the organisation inside out. When current Chair of the Board, Linda Parker, stepped down in July 2021, there were some big shoes to fill. Tiggy put herself forward as the newest Chair, and took on her new role in September.

**"My aim is to provide the best contribution I can. My tenure as Chair started in September and so far it's been going really well. I hope that I can continue taking the great work our Board does forward for hopefully many years to come – it's a very exciting time here at Jessie May and I'm proud to have been given this honour."**

To find out more about the work of our Trustee's visit  
[www.jessiemay.org.uk/about-us/board-of-trustees](http://www.jessiemay.org.uk/about-us/board-of-trustees).



Cut here to return

## 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

£65

could buy one hour of Jessie May care and support

## Your Details

Name:

Address:

Postcode:

Email:

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:

I wish to be contacted by:

Email ☐

SMS ☐

I do not wish to be contacted by:

Post ☐

Phone ☐

I would like to make a single donation of:

£10 ☐

£20 ☐

£50 ☐

Other £

Gift Aid: ☐

(Please tick here)

I enclose a cheque payable to 'The Jessie May Trust' ☐

Please debit my Visa/MasterCard/Maestro/Deltacard ☐

Card number:

Valid From:

Expiry Date:

Issue Number:

Security Number:

Last 3 digits on back of card

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 using the Freepost envelope enclosed, or to:  
Jessie May, 35 Old School House, Kingswood Estate, Britannia Road, Kingswood, Bristol, BS15 8DB.





# Stay in touch

0117 961 6840 ★

[info@jessiemay.org.uk](mailto:info@jessiemay.org.uk)

[www.jessiemay.org.uk](http://www.jessiemay.org.uk)



**Jessie May**  
Children's Hospice at Home

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Registered Charity No: 1086048

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