

Impact report

2021-2022



Jessie May
Children's Hospice at Home

jessiemay.org.uk



Welcome Tiggy

As we move forward out of the shadows of the Pandemic and start living our daily lives alongside COVID-19, it is good to take time to look back and reflect on what the last year has held for the 190 children and families we have continued to support.

Here at Jessie May we have developed our services further to ensure we can support our children and families, whilst we establish what “normal life” looks like for us all. For me this year has been very special, as in September 2021 I was asked to take on the role of chairing our talented Board of Trustees. It is a very exciting time here at Jessie May. We have great ambitions for the future and I’m very humbled to have been given this honour.

Throughout this report we will highlight the incredible work undertaken by our team, some of the areas we have been able to develop during our ‘reset’ period, as well as a look ahead to the year to come.

On behalf of the Board, I would like to offer our sincere thanks to our fantastic Jessie May team for their unwavering support and dedication. We would also like to thank our amazing children and families, for being our inspiration and for guiding us in the work we do and finally we want to thank our wonderful supporters. Without you none of this work would be possible.

Thank you everyone, for your continued support, and we hope you enjoy reading this report.

T Atkinson

About Us



Started by a family, for families, and now shaped by families. Jessie May is an innovative service with a reputation for providing exceptional care and support to children with life shortening conditions, and their families, in their own homes.

Jessie May is a Bristol-based charity, providing specialist palliative and nursing care at home for children and young people with life shortening conditions who are not expected to live beyond the age of 19 across the South West.

Our vision...

is that all children and young people with life shortening conditions are supported to have the very best quality of life possible and to choose to live and to die in their own homes with their families.

Our mission...

at Jessie May is to provide the very best care and support possible, at home, for children and young people with life shortening conditions and their whole families - in life, at the end of life, and in bereavement.

Our values...

We put
Children and
Families First

We are Kind,
Passionate and
committed

We are honest,
respectful and
collaborative.



You've helped to nurture a beautiful friendship between two families

Meet 4 year olds **Ariana & Noah**. They spend more days in hospital than not, but they're two mischievous little monkeys whenever they're together!

Noah's mum, Becky, was convinced something wasn't right with Noah straight after birth. After projectile vomiting blood on a car journey home, 14-week-old Noah was diagnosed with the very rare condition Primary Hyperoxaluria (PH1). (Noah is just one of six children diagnosed with this condition in the UK.) If left undiagnosed and untreated this condition would result in all of Noah's organs calcifying. Hayley found out that Ariana had kidney problems during her pregnancy, but

they didn't know to what extent. Ariana was born a week early and diagnosed with Renal Dysplasia, which means that one of her kidneys hadn't developed properly.

Becky and Hayley met within the first year of their children's lives on the Dialysis Unit at Bristol Children's Hospital. Ariana and Noah are in the unit for the same treatment, and remain bright and bubbly, but their conditions come with many complications. Their feeding tubes and main lines into their hearts come

with risks, their blood pressure is never stable, and they wear out very quickly.

Being on the unit at the same time as each other means that Becky and Hayley became firm friends very quickly, supporting each other through additional complications that arose – they now can't remember a time when they weren't friends. Ariana and Noah are also the very best of friends.

Due to their conditions making them immunocompromised neither of them are used to big groups of children their own age so having each other as a buddy is so important for their wellbeing.

Jessie May came into their lives within both of their first years, and where possible try to synchronize Ariana and Noah's visits so that Becky and Hayley can have time together as friends to focus on themselves.

While we were talking, we asked Becky what Jessie May means to her and her family, and this is what she had to say:

"No parent expects to go through this. When they're pregnant I think every parent says the same thing; "I don't mind what gender the baby is as long as it's healthy", but I don't think much thought is given to what if the baby isn't healthy."

"Without the support of Jessie May ... well, I just don't know ... it's difficult to put into words ... until you've needed and had the support of Jessie May, you would never understand how much that means and what a difference it makes."



Our Impact in 2021/22

11

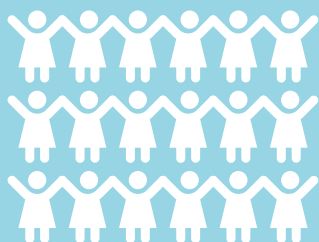
children were supported through end of life

We further supported these families through early stages of bereavement and in attendance at the funerals



80%

of children were visited in their home



188

children and families supported



43

families supported through bereavement (and we will continue to support for at least 5 years)



94%

of children and families received some form of support

We provided additional support to families

746

text messages



over

263

hours of telephone support

8hrs

50

minutes on video calls



289

emails



5

Purple Group meetings were held to support bereaved parents



10

Trustees served during the year, including 2 new Parent trustees



159

visits made to children and families when in hospital



1,774

specialist visits were made to children - over 1,550 of these in their own home.



We remained key members of local Palliative Care Networks including;

Avon Children's Palliative Care Network • End of Life 24/7 Steering Committee • BNSSG Children's Palliative and End of Life Care Strategy Group • Royal College of Nursing Community & Continuing Care Forum • Southwest Palliative Care Network • Neonatal Working Group and Advanced Care Planning Group

2



virtual family engagement events were held to give families the opportunity to have their say on the service development

we continue to be rated

Good

overall by the Care Quality Commission



1 Honorary President, 1 Patron and 9 ambassadors, including 5 new ambassadors brought onboard; Bristol Bears', Dave Attwood and Bristol City Women's, Aimee Palmer, as well as 3 family ambassadors.

A look at our year



Thanks to our Digital Transformation Project we were able to acquire new laptops for the entire Jessie May team to work more efficiently whilst majority were still working remotely.

We launched the redeveloped **Jessie May website**, our new 'hub' for all things Jessie May.

We moved all our records onto a new database to enable us to communicate with supporters and manage our work more effectively and efficiently.

April 2021

June 2021

Aug 2021

May 2021

July 2021

We launched our **Reset and Recovery Plan**, outlining how we planned to navigate the next 12-18 months of the Pandemic.

We revived the **Bereavement Development Group** (started in 2015) scheduling in more regular meetings to look at the Bereavement service and future developments to be made to further support our Bereaved families.

After 8 incredible years as a Trustee, **Linda Parker** officially announced her plans to retire from her role as **Chair of the Board**. Following in her footsteps, we welcomed **Tiggy Atkinson** as our new Chair at the beginning of September.

If you haven't already, you can visit our shop by following

www.jessiemay.org.uk/shop

The first face-to-face **Purple Group** since March 2020 was held with bereaved parents.

We had an incredible team of 5 runners at this year's London Marathon who raised almost £9,000 between them!

We launched our very first **'Online Shop'**, allowing supporters to buy merchandise to support their fundraising efforts as well as download resources and reports.*

We were delighted to hold our first face to face family event since the start of the pandemic, with our annual **Tree of Light celebration**. This year held at St Peter's Church, the night saw many of our current and bereaved families attend to reflect on the lives of past and present children supported by Jessie May.

Thanks to the incredible generosity of Corporate supporter **Panoramic Associates**, the Jessie May team were able to come together (virtually) in a **Christmas celebration** featuring a seasonal quiz, Secret Santa and a scrumptious festive foodie hamper!

Oct 2021

Dec 2021

Sept 2021

Nov 2021

March 2022

Families were invited to 2 **Virtual Family Engagement events**, during which the results of a recent family engagement survey were discussed. This gave families the opportunity to vocalise their opinions on how they felt the service should move forward.

Our first face-to-face fundraising event since the Pandemic took place in the form of the **Bristol 10k & Half Marathon!**

We revised our **service offering** to families, to replace the interim arrangement that had been in place since June 2021. This was sent out to families, with effect from January 2022. More details on page 10.

Jessie May went international, as community supporter **Lloyd Kembrey** took on the **Rome Marathon!**

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 and give families the opportunity to vocalise their thoughts.

We have taken these thoughts 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 where traditional visits weren't available, 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, and share best practice and tips, as well as 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.



From the responses* we received, thoughts were as follows:

66%

think we should continue to use the FRIPP**, even if that means some families would not receive visits

60%

would still want access to family events and be part of the wider community if they weren't offered visits

71%

think that we should implement a waiting list for new referrals so as not to overwhelm our team

In place of tea-time or Saturday visits:

46%

would like out of hours visits

54%

would like more family days

49%

would like more visits during school holidays

Length of visit time

68%

would like visits to remain at the current 3-hour length

54%

would like more flexibility on the date and time

23%

would like either a fixed time or a fixed date

Other

71%

believe we should implement a 'dormant' list for those children who may no longer be classed as 'life-limited'

91%

are happy to receive updates via email while 26% would prefer to receive face-to-face, 14% via links on our website and 11% on the phone

* From 35 responses (25% of families who were sent the survey)

** The Framework for Respite in Partnership with Parents scoring system used to determine the level of support families receive

In the media



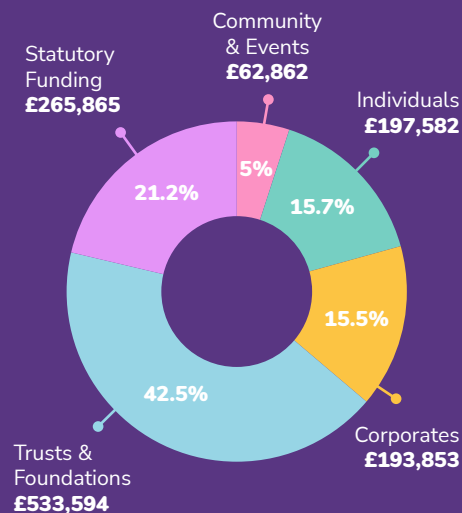
Our finances

We are delighted to announce that this year we raised a phenomenal

£1,253,840

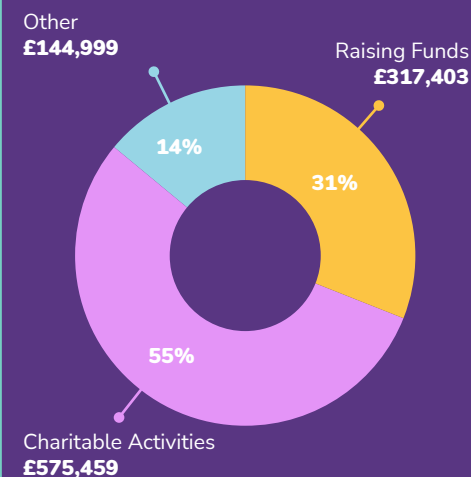
to help us to continue providing specialist nursing care and support to the families of children with a life-shortening condition.

Where did our funds come from?



2021/22 income

Where did our funds go?



2021/22 expenses

Fundraising efforts throughout the year:

Our supporters continue to amaze us year in, year out, with some incredible fundraising ideas and initiatives taking place over the last 12 months.

Jessie May takes flight!

The phenomenal **Debbie Kearney** took to the skies on 2nd October as she loop-de-looped her way to raising **£2,716** for Jessie May by wing-walking!

Bristol By Bridge

Long-standing Corporate supporters, **Blackstar Solutions**, took on a very unique challenge in the form of crossing all 45 bridges in Bristol, covering 45km in one-day. They absolutely smashed the challenge, raising **£2,565** in the process!

Jessie May goes international

In March 2022, **Lloyd Kembrey** flew the Jessie May flag on the starting line of the Rome Marathon. He raised a fantastic **£1,172** in memory of his cousins, Francesca and Jo.

An honorable mention to two incredible individual contributions;

Raymond Gibson and **Lily Adelaide Edith Porteus**, who both made their mark on the world by leaving a legacy in Jessie May's name.



Thank you so much to all of the generous Trusts and Foundations who have funded work with the Jessie May children and families in 2021. You really have made a huge difference to the support available.



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. Having supported the charity throughout some of its very highest and lowest moments, including navigating a global Pandemic, Chris has seen many changes in the organisation; in widening the area to enable us to support even more children who need us, 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 privileged and proud to have played a part in leading Jessie May over the past 17 years. I have always been motivated by hearing about, and seeing the work that we do, and the real difference we make to the children we support. Along the way I have met many amazing families, who will stay in my memory forever. 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 over the last 26 years, 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.

Of course I will follow developments closely - and will still be available to fulfill an important role at Christmas if needed!

Thank you.”

How we've 'reset'...



Our services

We will continue to improve and develop the services we offer to families during and after the pandemic.



A menu of support was developed to enable families to continue to access support either face to face, virtually or on the phone as the pandemic continued.

We improved the way that families are referred to Jessie May through the introduction of a digital referral form.

Family events were on hold due to social distancing restrictions but the Christmas Tree of Light was able to go ahead. We held this in person and virtually.

Family engagement

We will increase family involvement across all levels of the service.



Through family consultation we introduced a steering group to enable Jessie May to help shape the services we offer to families

We have recruited an additional parent/carer to the trustee board to ensure that family representation is present during all decisions made at board level.

Influencing

We will continue be active contributors and influencers on paediatric palliative care.



With membership in the key groups such as Royal College of Nursing, 24/7 End of Life Steering Group, Together for Short Lives strategic Advisory Board (to name a few) we have held a strong presence advocating the Jessie May model of palliative care.

Digital Transformation

Utilising new technology we will transform the way we will operate.



We identified new software and hardware to enable Jessie May to automate and increase efficiencies.

Liaising with Bristol Royal Hospital we have been integral to enable a trial of replacing paper drug charts to digital prescribing.

In May 2021 we released our 'Reset and Recovery Plan', a document outlining a roadmap of how we planned to move forward with the service alongside some of the innovative ways we have been working during the pandemic. Here we document how we've performed against those goals that we set out at the beginning of the year.

Finance, administration and governance

We will continue to improve our governance and management of Jessie May throughout the pandemic.



We have improved the way we monitor and report on service delivery and income forecasting to allow for agile decision making.

We appointed an Executive Assistant to work with the Board of Trustees and the Senior Leadership team to support the governance of the charity,

We reduced the size of the office space we leased as we continue to offer a hybrid style working pattern for staff.

Fundraising

We will raise £1,081,770 to fund the free service children and families receive.



Despite still facing a challenging fundraising landscape, through the generosity of our supporters we exceeded our target to raise £1,253,840

Marketing & Communications

We will increase the profile of Jessie May and build the number of supporters who support Jessie May.



We revitalised the Jessie May website and launched our first online shop.

We developed an interim media plan that increased our social media and press activity to recruit supporters and promote awareness.



Planning for the future...

Looking forward to 2022 and beyond, Jessie May are now working towards implementing a new 5-year strategy that has been redeveloped with 6 key areas of focus for the organisation.

24/7 End of Life Nursing Support

We will work with others to develop and provide 24 hour care and support, 7 days a week, for children who are at the end of their life and their families, in their own home.

Children & Family Services

We will expand and develop the services we provide to ensure that children and families are fully supported and that we are there for the wider family, especially siblings.

Family Involvement

Jessie May was set up by a family and we are clear that families are the experts about their own needs and the needs of their child. Everything we do will be shaped and guided by those who experience caring for a child with complex health needs and a life-shortening condition on a daily basis. We will ensure that families are supported and empowered to be involved in shaping and developing the services we provide.

Each of these areas will help us to take great strides in working towards our overall vision; that all children and young people with life shortening conditions are supported to have the very best quality of life possible.

Influencing

We will offer our learning and experience, working with key stakeholders to facilitate the further development and improvement of services and to enable similar services to Jessie May to be established in areas where they do not exist.

Sustainable Fundraising

We will strengthen and diversify income streams through investing in new and existing initiatives, people, and technology to improve income ratios, growth and increase long-term sustainability.

Volunteers

Our staff and volunteers are our most precious resource. We will invest in our workforce to ensure that everyone is able to develop to their full potential and are supported to ensure their health and wellbeing at work.



How you can make a REAL difference



With your help we can continue to be there for the whole family, for the whole journey in life, at the end of life and in bereavement.



Make a donation

Our Jessie May nurses are only available through your continued support.

£68 pays for an hour of Jessie May support



Help raise funds

Organise fundraising events for Jessie May; either on your own or as part of a group!

We are only able to provide specialist care and support with your help.



Take on a challenge

Whether you want to take on one of our half marathons or marathons, our international challenges or 'Do It Your Own Way', you can support our nurses by pushing yourself to your limits.



Leave a lasting gift

Leave your mark on the world with a gift in your will and help ensure that children with a life-shortening condition are supported in years to come.

Get in touch

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Registered with
**FUNDRAISING
REGULATOR**



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Children's Hospice at Home

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