

Our Impact



2022-2023



Welcome



Tiggy Atkinson
Chair of Trustees

This report really captures the busy year that we have had at Jessie May and the significant changes that we have seen with the launch of a new strategy and the appointment of our new CEO.

On behalf of the Board of Trustees, I would like to offer our sincere thanks to our fantastic Jessie May team for their commitment, support and dedication. We would also like to thank our children and their families for being the inspiration they are and in guiding us in the work that we do.

We also want to thank our supporters and funders for everything they do. Thank you everyone, for your continued support, and we hope you enjoy reading this report.

Since joining this amazing charity in August 2022, taking over from Chris Roys after 18 incredible years at the helm, I have been humbled by the real difference that we make for our Jessie May children and their families. I am also in awe of the dedicated care team who walk alongside families at the most difficult of times.

I am so proud to be leading this very special charity in providing hospice care at home. Last year we launched our ambitious and exciting five-year strategy, 'No Place Like Home' and at its heart is our commitment to support more children, young people and their families with life limiting and life threatening conditions. While the strategy is about looking forwards, this impact report highlights the remarkable work undertaken by Jessie May in the last twelve months.

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 palliative care and support to children with life shortening conditions, and their families, in their own homes.

Home is the place where children are loved, where they thrive, and where they are most comfortable with their own family, friends, pets and toys.

There really is

No Place Like Home

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 & families first

We are kind, passionate & committed

We are honest, respectful & collaborative

No place like home

- Our 5 year strategy

2022 marked the launch of 'No Place Like Home', Jessie May's five year strategy. At the heart is a commitment to working with more children and their families in providing hospice care at home. The strategy has six key areas which focus on:



Underpinning our six key areas are **3** further focus areas:

- 1 Financial Model** – ensuring that we have the financial systems in place to support our growth as a charity
- 2 Nursing Model** – ensuring that we have a scalable nursing model in place to support our expansion into new geographical areas
- 3 Impact Model** – ensuring that we have evaluated the difference Jessie May makes to the children and families we support and the impact that we have on health and other services, by supporting a child in their home

No Place Like Home

Find out more about the strategy on our website **HERE.**

Dear diary...

Jessie May nurse Vicky, wrote this diary entry to share with us:



"Morning, before my first visit:"

Before setting off for my first visit of the day I log onto my emails from home; the families I'm visiting today are known to me and Jessie May, so I don't have loads of preparation to do.

However, I do call the families I'm seeing today to check that the visit time still suits them - sometimes visits are subject to last-minute changes due to the instability of the child's condition.

I also use this time to call another of our families whose child is currently in hospital. I want to check in with them to find out if they need any supplies or help with anything.

"We have to make sure that our time is best used to help the families achieve the most from their much needed 3 hours of care."

If the children being visited today weren't well known to Jessie May, this would be a good time to look ahead at their diagnosis and any relevant medical history that we, as nurses, should be aware of.

This could include a seizure management plan, emergency care plans and drug charts; it is also useful to have a look at recent hospital admissions or anything from the wider medical team.

Having this knowledge before we enter the home gives parents a sense of reassurance and confidence in our abilities, and it also highlights that we have an eye on things outside the Jessie May team.

It is not always obvious, but we do work and communicate regularly with other professionals from other services.

"My first visit of the day - Ariana, a little renal patient with a huge personality (travel time 45 mins):"

I know Ariana well as I previously cared for her on the dialysis ward before I started working for Jessie May. She is a bubbly, determined and mobile child who enjoys getting stuck in to play and chatting about all things princesses.

Regardless of this, there are sadly many concerns living in hers and her family's shoes.

My main concern with Ariana is that she regularly has a blood thinning drug as part of her dialysis treatment, therefore any trips or falls could be catastrophic; resulting in a bump to the head could lead to a bleed. Despite this, she's mobile and wants to play in all four corners of her house, top and bottom, up and down the stairs, like any child would.

She also has a vascular catheter which is a direct route into her heart and central blood



system. This is her lifeline - she can only receive her dialysis this way, so we need to protect it.

Ariana also has an unsteady gait so she's wobbly, and has previously knocked her front teeth out by falling forward. Worryingly, she's also a lot faster than she looks. And as we know, appearances can be deceiving.

"I know it's going to be a busy visit!"

I arrive and have a brief catchup with mum, Hayley. She knows me well and her free time is precious, so I have a quick tour of the new house (from Ariana - she's proud to show off her new room and big garden), and then Hayley heads off to run errands and we begin baking. Ariana does tire quickly, so soon afterwards we're sitting quietly reading and looking at stories, which is a good chance for us both to catch up on her home record book.

During the visit, I administer the medications she is due, and her special milk feeds through her gastrostomy (a tube which goes straight into her stomach), but first I assess the condition of the gastrostomy to make sure all is ok. This is also a good chance to look at Ariana's tummy as she has several scars from other procedures and a failed transplant - it's always good practice to have a little look at scar tissue and make sure there are no concerns.

She receives her feed and, conscious that this could cause vomiting, we play a quiet game of dolls and dress ups while we wait for mum to come back, then hospital transport arrives to take them in for a long

afternoon of dialysis. The morning has flown by; thankfully it's been a morning of fun and play without any hiccups.

However, since writing this, I have recently received a distressed call from mum to say that after a dialysis session, Ariana had two seizures. This is completely new for her; it hasn't happened before and is obviously a really worrying time for mum. We will do all that we can to support them following this.

"Despite how it looks, there is always a subconscious awareness that our Jessie May child is on a tightrope of stability."



Our year in numbers



74%
of specialist nursing visits were made in the home



179
families have benefited from Jessie May's support



13
children were cared for at end of life

.....

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



53
families supported through bereavement



5
Purple Group meetings were held to support bereaved parents



15
nurses worked to provide specialist support for children



4,377 hrs
spent providing direct support to children and their families



19
children joined Jessie May



893
phone calls were made to support families in need



81
visits made to children and families when in hospital



5
big family events were held including Jessie May celebrations



1,567
specialist nurse visits were made to families in need – over 1,310 of these in their own home

we are rated

Good

overall by the Care Quality Commission




Key members of local palliative care network

.....

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 Advance Care Planning Group

10
Trustees served during the year, including:

.....

- 1** Chair of Trustees
- 3** Jessie May parents
- 2** Medical professionals
- 2** Business professionals
- 1** Finance professional
- 1** HR professional

1 Honorary President, 1 Patron and 5 family ambassadors and 6 ambassadors brought onboard, including 3 new announcements: Sir Steve Webb, Laura Tomlinson MBE and Zara Nanu MBE.

A look at our year...



MAY '22

Family Survey - Jessie May service evaluation

Received a great response for our Service Evaluation. It was great to see how happy our children and families are with our nurses.



JUNE '22

First family picnic

Held our first family picnic of the year and the weather was glorious for it. It was a great opportunity for families to meet other families.



JULY '22

Purple groups

The Purple Groups continued to be held to support our bereaved families. We held 5 Purple Group peer support meetings for bereaved parents throughout the year, including one in July.



AUG '22

Bereaved family picnic

Held bereaved family picnic at Bristol Blaise Castle Park. The families met Daniel for the first time.



DEC '22

Tree of Light Celebration

We were delighted to hold our annual Tree of Light Celebration, at St. Peter's Church, Henleaze.

It is always such a heartwarming event, with the chance to reflect on, remember and celebrate all Jessie May children.



NOV '22

Christmas party

At The Village Hotel Bristol, we hosted our first Christmas party since the pandemic. The staff dressed up as Elves and fairies to delight the children. There was a visit from Santa and the Christmas decorations elevated the festive spirit.



SEPT '22

Bristol Zoo Celebration

It was the perfect time to host a celebration, we bid farewell to our previous CEO, Chris, warmly welcomed our new CEO, Daniel, and introduced our new 5-year strategy.



JAN '23

Nurse training days

Our nurses received refresher training on end-of-life care, as well as crucial training in gastrostomy care, catheter management, non-invasive ventilation, paediatric intermediate life support, and safeguarding. These skills are essential in providing comprehensive support to our families.



FEB '23

Amazing legacies received

We received amazing legacies with our largest to date. We are forever grateful as they will make a huge difference to our children and families.



MARCH '23

First charity dinner in 10 years

This was a Wizard of Oz themed night, named 'Ruby Slippers', because there really is 'No Place Like Home.'

We welcomed 100 people to share the evening with us, raising over an incredible £18,000.

Started by a family, for families & now shaped by families

Families remain at the heart of everything we do and each year we run a survey to look at what we are doing well, what we can improve upon and ask families what additional support we could offer them.



What our families say

From the responses we received, thoughts were as follows:

100%

of the children feel happy and secure with their Jessie May nurse(s).

93%

of parents are happy with how Jessie May nurses communicate with their child.

96%

feel confident that our nurses provide the care their child needs.

96%

of families feel that having Jessie May's support has a positive effect in their health & wellbeing.

100%

of parents feel that the Jessie May nurses spend time focusing on things the child likes to do.

82%

of parents feel that the nurses allow the children to make choices when they can.

88%

feel that Jessie May has a positive effect on siblings' health and wellbeing.

81%

feel that they receive the support they need from our Jessie May nurses.

52%

of families would like more weekend visits, which is something we would love to offer more of.

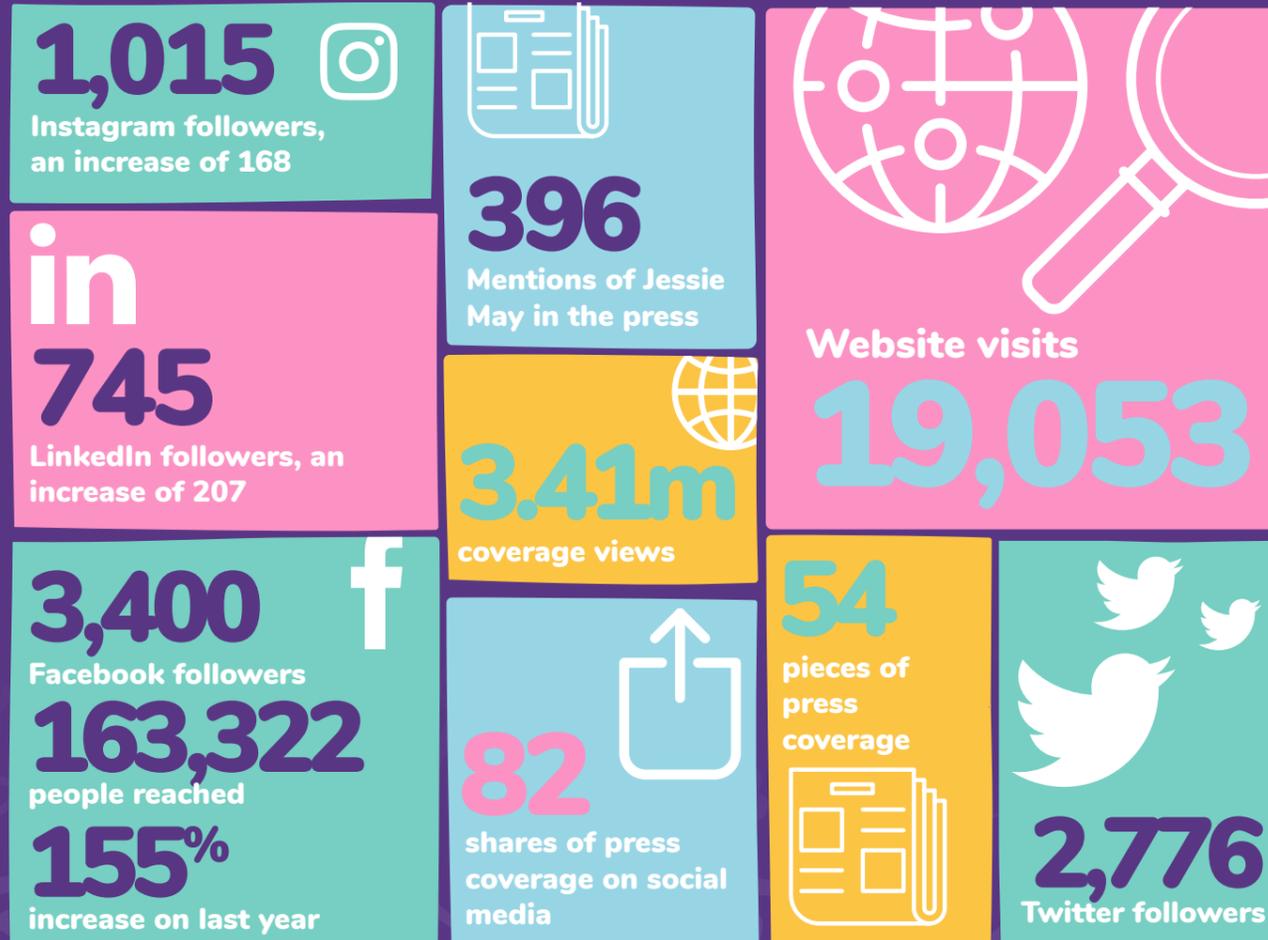
Summary

Receiving feedback is very valuable to us. We carefully consider each input, using them as building blocks to continuously enhance our services. Our ultimate goal is to provide the best possible support to our children and families, and their feedback plays a crucial role in driving our development.

In the media

This past year has been a busy one for us in the media.

Highlights include our celebration event in September, the TV coverage of ambassador and fundraiser Lloyd Kembrey and our nursing lead Claire Matson on BBC Radio Bristol on Boxing Day. **In all we have had 54 pieces of press coverage reaching over 1.5 billion people.**



Social Media

Social media has become crucial for keeping our supporters and increasing our followers. This increase across channels aid in retaining donors, boosting donations, and informing supporters and our families.

Facebook, Instagram, and LinkedIn show a steady growth in followers and engagement.

LinkedIn leads in follower increase, followed by Instagram.

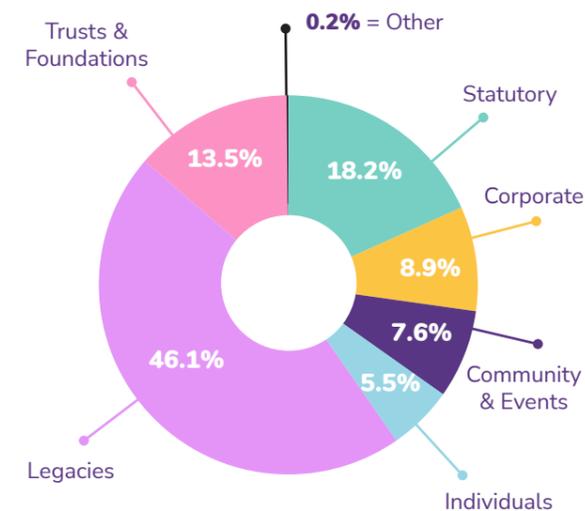
Facebook remains vital with a 155% reach increase; engaging our families is particularly noticeable on Facebook.

Our finances

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

£1,668,789

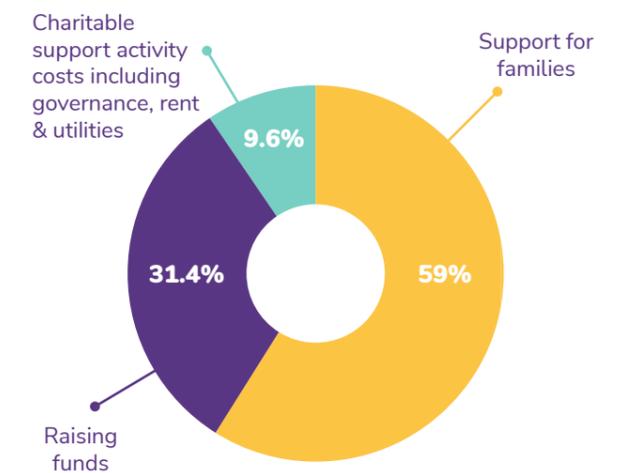
Where did our funds come from?



We achieved a record-breaking sum of £1,668,789 for Jessie May. Only 18% of our income comes from statutory sources, while the remaining 82% relies entirely on the generosity of individuals, companies and trusts & foundations through grants, donations, events and other fundraising activities such as **charity of the year**.

To expand our reach and assist more families, Jessie May has invested in enhancing our **marketing, communications, and fundraising strategies** for sustainable income growth over the next 5 years and beyond.

Where did our funds get spent?



Nursing provision and bereavement support care costs were 10% higher in 2022-23 than in the previous year. With our strategic commitment to invest in our care, we expect further increases over the next five years.

For every £1 spent on fundraising we raised £4.20.

Family story - bereavement

“Jessie May nurses empowered us to meet the increasingly complex care needs our children required”

- Julie Kembrey tells the story of her daughters Francesca and Josephine:

At just 3 ½ years old, our twin daughters, Francesca and Josephine, were diagnosed with a degenerative neurological condition – Sanfilippo disease/ MPS 111A. At birth, most children do not show signs of the disease, but as it progresses the children degenerate; losing the ability to speak, walk and eat.

Their diagnosis was completely unexpected and a massive shock to the whole family. As we adjusted to a ‘new normal’, grandparents, family and friends also needed to adapt and to cope with the fact that our girls were not expected to live beyond their teenage years. It was a bewildering time for us and everyone around us.

A couple of years later, in 1998. Our family was referred by the Paediatric Consultant to a newly formed, local children’s hospice at home charity called Jessie May.

In the early years, Francesca and Josephine were very active and cheeky. Jessie May nurses visited our home to play, sing, read stories and provide teatime help. As the girls’ health deteriorated, the highly skilled Jessie May nurses adapted to the increasing needs of our family.

The continuity of care, kindness and compassion offered by Jessie May meant



that Francesca and Josephine always enjoyed their visits. Over time, Chris (the girls’ father) and I came to trust the Jessie May nurses wholeheartedly. We knew that they would give the highest standard of care, enabling us both to leave the girls and be out of the house at the same time.

As Francesca and Josephine progressed through their condition, they lost all of their physical skills and mental capacity, requiring 24/7 care. Jessie May nurses empowered us to meet the increasingly complex care needs our children required and supported us to maintain the best quality of life we could manage in such difficult circumstances. They were a source of strength as we approached the end-of-life phase, and helped us to plan and prepare for this, knowing they would be alongside us at every stage and through bereavement.

Francesca died aged 15 years and Josephine aged 18 years.

Francesca died at home after a sudden downturn in health over the course of a weekend. She was visited by her consultant, but there was no time to organise nurse visits.

Chris and I cared for Francesca and Josephine, keeping everything peaceful and calm.



We were very aware that this would be our last weekend as a family of four. Jessie May nurses came to give Francesca very tender care following her death, which really helped us to process what had happened.

This was carried out with such dignity, love and sensitivity. They also supported us around the time of her funeral, and afterwards with ongoing visits for Josephine who had lost her twin sister.

Francesca and Josephine were our only children. When Josephine died, we were totally devastated and lost; our busy home was suddenly very silent and empty. I had no sense of self or purpose and no idea how to move forward.

I wanted to meet with other bereaved parents and turned to Jessie May for a solution. Volunteering alongside the bereavement team, I helped to set up a bereavement support group for parents; the Purple Group, which is now an established part of the service.

Grief following the death of a child is life-long. Chris and I don’t want to forget our children, but we have had to learn to live without them.

“Jessie May have been a source of strength for us both through this time. We view Jessie May as an extension of our family. We appreciate everything they did for us while Francesca and Josephine were alive and following their deaths.”



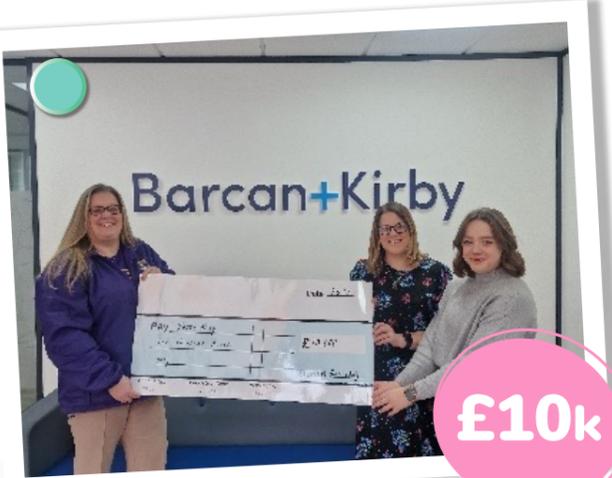
How you've made a difference

Castle Combe Steam Rally raised a whopping £15,000 at their Annual Dinner for Jessie May.



Lloyd Kembrey and team ran the Rome Marathon raising £1,172 and **'Team Jessie'** took on the Sodbury Slog and raised over £6,000!

Laura Hoy organised a Santas grotto and bought smiles to lots of faces while also raising a fantastic £2,802.68



Barcan + Kirby supported Jessie May as their charity of the year, raising an incredible £10,000

A big thank you to...

The generous trusts and foundations that provided funding for our work with children and families in 2022. Your support has made an enormous difference in enhancing the available support.

We also extend our sincere thanks to the compassionate people who have left remarkable legacies by generously including us in their wills. Your wonderful gifts will have a lasting impact on the lives we touch.

How you can make a difference



Fundraise

Join 'Team Jessie' and fundraise for Jessie May; our brand new fundraising pack is bursting at the seams with ideas to help get you started and our calendar is full of events you can take part in.



Organise your own event

From coffee mornings to wrestling nights, you can put on your own event to raise funds for Jessie May and our fundraising team will be there to support you along the way.



Spread the word

Follow us on social media and share content to help us grow our audience and raise awareness of our work.



Volunteer

Donate your time to us by volunteering to help our cause. You can be on the cheer squad at a marathon, attend a World Snooker Tour event and more. Volunteer on our website [HERE](#).



Donate

Make a donation through our website [HERE](#). Every donation counts! We promise that the donation you make will be used to support our families who are going through an unimaginably difficult time.

You can also follow us:



@jessiemaytrust



@jessiemaytrust



The Jessie May Trust



Jessie May

Get in touch

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Follow us:



Jessie May
Children's Hospice at Home

Registered Charity Number: 1086048

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