

# Impact Report



2020-21



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

[jessiemay.org.uk](https://jessiemay.org.uk)



## Hello!

Over the last 25 years, Jessie May has adapted and evolved to support the needs of terminally ill children and their families across the South West. This last year throughout the pandemic Jessie May has had to adapt quickly in how we provide palliative care in what has been an incredibly tough time for the children and families we support. Hopefully, we are beginning to see 'light at the end of the tunnel' with the vaccination programme.

Despite all of the many challenges of the last year, Jessie May is still going strong and doing our very best to maintain and improve our support to terminally ill children and their families.



This report demonstrates how Jessie May has continued to make a difference to the lives of the children and their families that we have cared for over the last year, and I hope you enjoy reading it.

*Chris Roys*

**Chris Roys**  
Chief Executive



# Our story

## Started by a family, for families, and shaped by families

Jessie May was established by parents Chris and Philippa Purrington following the death of their baby daughter, Jessica May, in September 1994.

Jessica died from a genetic condition known as severe Spinal Muscular Atrophy when she was only 4 ½ months old. Jessica was cared for by her family, in her own home, throughout her illness.

She died peacefully at home in her father's arms; in privacy, with dignity and surrounded by all those who loved her.

During one of their visits to family in Bristol, Jessica was admitted to the local children's hospital in Southmead. It was here that the family learnt that the incredible support that they received in High Wycombe was not available to families who care for their child at home in the Bristol area.

The Purrington's were determined to do what they could to make sure that other children with conditions like Jessica's, and their families, could access support in their own homes and have the choice to die at home when the time comes. After a lot of hard work and perseverance, initial funding was secured and The Jessie May Trust was officially launched in 1996.

Now known as Jessie May, we as a charity provide specialist nursing care for terminally ill children in their own homes. We offer end of life care and bereavement support, as well as vital respite sessions and emotional support to those children's families. This allows families to make the most of the precious time they have together and to create treasured family memories.



# Finley's story

Finley was born with a very severe muscle weakness. He has a genetic condition which affects every muscle in his body. He remained in the Neonatal Incubation Unit for 5 and a half months and eventually came home on a palliative route. He has one brother and seven sisters.

Although he has shown tiny improvements since coming home from hospital, he still requires complex 24/7 care from his family, carers and Jessie May nurses.

**"It's 24/7 pressure on the family. He requires suctioning and ventilation although he is slowly spending more time off the vent,"** says Mum, Annalise.

Finley is immobile and has less movement than a new-born baby. **"Jessie May come in for a couple of hours and this enables me to leave Finley and sleep or spend time with his siblings at the park, for example. It allows the kids to have some 'normal' time, just being children. Having a child with complex medical needs means that life changes forever. It's never as it was before. The pressure on the other children is huge. They give up a lot for Finley."**

With the start of the Pandemic, the family started shielding in March 2020, which became more difficult as time went on:



Finley, his sister, Charlotte and Jessie May nurse, Tina

“It has been very isolating and very difficult. Emotionally, it has been a struggle. Especially for my older children who aren’t able to see people that we rely on regularly. They miss their friends and school and normal life.”

Overnight, the family’s support network of friends were forced to step back from the usual help they provide to the family: “I miss the cups of tea and chat with friends. We are really starting to feel the impact now, we are under each other’s feet. Everybody needs their own space at times.”

The impact of isolation on the family has been substantial but as Annaleise explains: “**Lockdown won’t ease for us a family for a long time. If you have a seriously ill child, it is like being in limbo. Everything is so uncertain. Now more than ever.**”



**Finley and his sister, Charlotte**

The visits from Jessie May enable Mum Annaleise to have a few hours rest as she is up through the night caring for her son: “**They provide expert care and they give us the security that he is being so well cared for.**

They really are an extension to our family. They are a breath of fresh air when they arrive. They are amazing people. I would be completely lost without them. Jessie May provide a lifeline to my family.”

Annaleise says that with the COVID-19 pandemic, Jessie May’s support has meant more than ever: “**They have helped to support emotionally as well as caring for Finley’s medical needs. Charlotte, my daughter, waits at the door for them to arrive. The whole family love it when they are here.**”

# Our Impact!

# 747

people have benefited from Jessie May's work, including terminally ill children, their parents/carers and siblings



We are rated

# Good

by the Care Quality Commission

# 191

families of terminally ill children have been supported through clinical nursing

# 14

children joined Jessie May



# 97%

of specialist nursing visits were made in the home

# 4

children were cared for at end of life



Over

# 1170

three-hour palliative care specialist nursing visits were made to families in need

# 1957

phone calls were made to support families in need

# 75%

parents have been supported through their bereavement

## 3 Purple Group meetings

were held virtually throughout the year. These groups support parents through Bereavement for 5 years after the death of their child.

# 294

individual support sessions for bereaved families were held. A mix of face-to-face visits and phone support following COVID guidelines.



# 15

nurses worked to provide specialist support for children in their own homes

# 4516

hours spent providing direct support to children and their families

# 12

Trustees served during the year; 2 parents, 6 healthcare professionals, 2 legal professionals and 2 finance and business professionals

# A Look At Our

The **COVID Pandemic** hit the UK and all Jessie May staff started **working from home** in accordance to Government guidelines

The Government introduced the **furlough leave** to help charities pay for salaries when the fundraising income dropped dramatically. Some of our **Jessie May administrative and fundraising staff** were placed on furlough leave.

We received **£162,000** through the **Government Emergency Hospice** funding initiative

March  
20

April  
20

June  
20

Through a **COVID Emergency Response Team**, Jessie May supported statutory agencies and other organisations to ensure the **most vulnerable of children** were continued to be supported by specialist nurses, this included overnight stays. Daily meetings were held to review each child that needed support

We developed a **COVID menu of support** to ensure that families could continue to receive support. Priority was given to **children at end of life and those with most complex needs**. Support **phone calls and video chats** were also available for families. This helped to reduce the sense of isolation and ensured a specialist nurse was available for questions and support.

Jessie May nurses had to wear **full PPE** when providing nursing care. This included **FP3 masks** that had to be specially fitted, goggles, gowns and gloves.



# Our Year...

Two of our Jessie May nurses were seconded to the **Children's Intensive Care Unit in Bristol (PICU)** for a period of time to support specialist teams at the height of the second wave of the pandemic to ensure enough nurses were available for the most vulnerable children.

**Father Christmas** virtually visited the homes of Jessie May families and read festive stories

We published our **Reset & Recovery Plan** - setting out the next stages 12 to 18 months of the Jessie May service.

**Sept  
20**

**Dec  
20**

**Feb  
21**

**March  
21**

Our **Bereavement Team** held their first **Purple Group** meeting on Zoom - we've held **3 of these meetings** in total to continue supporting our Bereaved parents.

The Jessie May **COVID menu of support** has been extended to support the most socially vulnerable, for example single parents caring, and those that Jessie May have identified as being stretched to the limit

In lieu of a physical event, due to social restrictions, we held our first ever **Virtual Tree of Light ceremony** - a pre-recorded video tribute that we premiered to families on our website.

# How we adapted...

The last year throughout the pandemic has been difficult for everyone involved, but none more-so than the children and families that we support. We have had to adapt and develop so we can continue providing essential services. Our new menu of support includes socially distanced options as well as face to face support where appropriate.

Each child is supported by a small team of specialist palliative care nurses who get to know the child and their family. Every family is unique, and the amount of support needed varies from family to family and child to child. Jessie May works hard to ensure we support the family whatever the circumstances.

In March 2020 we ceased many of our physical respite and support visits in-line with Government guidance in all but the most seriously ill. We developed new methods that would allow us to continue to support the parents of terminally ill children - including wearing PPE kit. Inventive ways were used such as drawing pictures on the masks to ensure that the children were not scared in the sudden change from seeing full faces.

We increased our telephone support, as well as introducing the use of video calls to parents who felt comfortable doing so. Across the year our nurses made over 1,000 telephone calls to families, to provide additional support to those families we were unable to physically visit.

We also started to cover night shifts for the local Lifetime service, helping to cover 50+ of them since. If Jessie May nurses hadn't stepped in and helped out in this way, the care packages around these children could have fallen apart.

End of life care was prioritised over the last year. This ensured Jessie May nurses were able to continue offering our specialised end of life care to children as well as emotional support to parents.

Bereavement support has continued, though in a socially distanced way. Our bereavement support is available for up to 5 years after

a child's death. This is often carried out by the nurses who have built up a trusting relationship with the parents. Support can include attending the child's funeral, visits to parents to enable them to talk about their child, support telephone calls, sending cards to remember the children on their birthdays and anniversaries and continuing to invite the whole family to the Jessie May family social events.

Throughout the 5 years, parents also receive invitations to the Purple Group. This is a peer support group for all Jessie May parents and is organised and facilitated by the Jessie May Bereavement Team.

With social restrictions due to the pandemic, the Purple Group meetings were able to continue online. This even allowed parents who were previously unable to attend in person, to take part.

In December 2020, staff who had been on furlough leave were able to return to work. However, with the decline in some traditional forms of fundraising, some difficult decisions had to be made to reduce unnecessary costs. As a result, two posts within the Fundraising team were made redundant to ensure we could continue to provide specialist Jessie May nurses.

In January 2021 we sent two of our Jessie May nurses to support the Paediatric Intensive Care Unit (PICU) at Bristol Children's hospital. PICU staff were being sent to the adult intensive care unit at the Bristol Royal Infirmary (BRI) to care for the increasing numbers of people being treated for COVID. At times, up to 50% of PICU staff were re-deployed. So our nurses played a vital role in keeping the PICU service running.

# Our Families' voice



In 2020/21 we sent our annual survey out to families who had received support from Jessie May throughout the pandemic. Feedback from families is critical for Jessie May to enable us to shape, improve and adapt the services we offer.

The following results are from the 13% that responded to the survey.

"I feel comfortable with all the Jessie May nurses who come into my home"

100%

"I think my child feels happy and secure being with the Jessie May nurses"

100%

"I think the Jessie May nurses understand how to communicate with my child"

92%

"I am confident Jessie May nurses are able to give my child the care they need"

100%

"I feel confident that the Jessie May office will listened to my views when I call"

82%

**"The respite, reassurance and headspace Jessie May gives us is invaluable."**

*"It's been difficult with all of the restrictions and minimal contact with friends and family. The Jessie May nurses have been a much-needed support throughout."*

**"The support of the Jessie May nurse visits has been so valuable."**

*"I think that there was plenty of communication to families, and visits started again as soon as they could."*

**"We really value the service, (although we didn't receive any visits through lockdown), we appreciate the difficulties around this and the priorities that were made."**



# Working Together

Jessie May is committed to working in partnership with other service providers for the benefit of the children and families we support.



During COVID Jessie May joined an emergency response team working with **UHBW** and **Lifetime** to ensure that, as a team, we could provide continuity of care whilst nurses were requested to directly support COVID patients.



Jessie May nurses maintain a close working relationship with **Bristol Children's Hospital**. This enables us to visit the Neonatal and Paediatric wards to identify and discuss potential referrals and to provide support to parents when their child is in hospital.



Many of the children we support also use the local **children's hospice** and we work closely with them to provide as integrated a service as possible.



We are founder members of the **Avon Children's Palliative Care Strategy Group**. These groups bring commissioners and providers together to agree on priorities and to pool resources and learning. In Bristol we have worked on a collaboration to establish a 24/7 end of life care service at home



We are active members of **Hospice UK** and **Together for Short Lives** - with our Director of Funding Development sitting on the TFSL Strategic Advisory Group.



Our **Nursing Care Lead** represents Jessie May at the Steering Committee **Royal College of Nursing, Community & Continuing Care Forum** and the **South West Palliative Care Network**.

We have two nursing teams operating across the South West:

1. Bristol - covering Bristol, South Gloucestershire, Bath, North East Somerset and North Somerset
2. Swindon and Wiltshire

## The Stats



**2,986**  
facebook  
followers



**34,743** hits to  
our website

**4** press  
articles  
published



**656** Instagram  
followers



**362** LinkedIn  
Followers



**2,704** Twitter  
followers

# How you've made a difference

Like many charities, fundraising became extremely difficult over the last year with many of the traditional areas of activity just not possible due to the ongoing social restrictions. We could not have continued supporting Jessie May families without the brilliant efforts of our fundraisers.



## Our 'Home Heroes' in the 2.6 Challenge

Upon the cancellation of the London Marathon 2020, the fundraising landscape looked bleak. In response, the organisers of the biggest mass-participation sports events launched the **2.6 Challenge**, encouraging the community to become 'Home Heroes' - raising money in a COVID-safe way for the thousands of charities across the UK affected. We were supported by **6 incredible Home Heroes**, raising over **£1,000 between them**.

## 'Marvellous' mask sales!

Facemasks quickly became the norm for us all during lockdown - and one of Jessie May's incredible supporters used them to do some good.

**Traceydawn aka The Marvellous Mask Machine** created thousands of homemade masks, of all fabulous patterns and themes, selling them in support of Jessie May and raised a phenomenal **£1,725** in doing so!



## 'Magical' tech donation

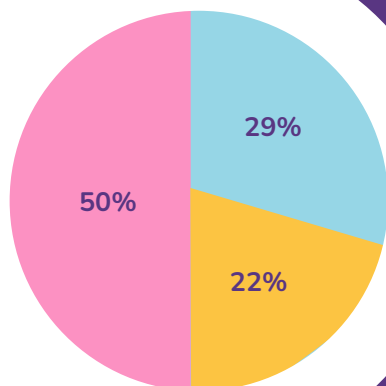
In February, Jessie May received a donation of 'magical technology' from Lifelites. The donation now means that each of our specialist Jessie May nurses are now fully equipped with a new iPad, stocked full of sensory play apps and educational games that the children can enjoy.

When Jessie May nurse, Lois, comes to visit, Noah can't wait for her to crack out her brand new iPad. He just loves all of the different animal games that he can play!



# Where your donations are spent

We are over the moon to announce that, despite the difficulties in the reduction of traditional fundraising methods, we raised an unprecedented £1,661,011 this year. This was only possible because of the dedication and support of companies, trusts & foundations, individuals and community groups as well as the Department of Health and Clinical Commissioning Groups. This collective funding has allowed us to deliver expert care to support Jessie May children, parents and siblings.



- **Costs to support Jessie May families** - includes specialist Jessie May nurses, expenses and professional fees
- **Raising funds** - Includes raising donations through companies, individuals, groups and events
- **Other** - includes Governance and support costs such as equipment, vehicles and administration support for the nurses.

Like many charities, fundraising became extremely difficult with some traditional areas of activity just not possible due to ongoing restrictions in place, as a result we had to reduce our workforce, and many of the fundraising and administrative staff were put on furlough and/or have been working remotely.



# A year to 'reset'...

Jessie May published a Reset and Recovery document in March 2021 that sets out our plan for the next 12 – 18 months to enable us to reset and recover following the impacts of the pandemic. The plan focuses on key areas including:



**Jessie May service** - We will refine our menu of palliative care support to improve the level and quality of support we provide to children and families.



**Family Engagement** - Jessie May was set up by parents and we ensure that the voice of parents/carers (and children) is heard within the organisation to help shape the service and set its priorities.



**Influencing** - We will continue to work with many of our palliative care partners and influencer groups to help shape and improve palliative care services in the sector.



**Digital Transformation** - We were fortunate to receive a large legacy in 2020 that has enabled us to implement a Digital Transformation Project. We updated many of the systems, software and hardware capabilities to allow our Team to work as seamlessly and efficiently as possible. We will also be looking at making our Drug Charts and Patient Records digital.



**Finance & Administration** - We are introducing a flexible approach to working, developing a requirement of regular reporting and ensuring that we maintain strong reserves.



**Fundraising** - We aim to improve and increase the reach of Jessie May supporters with our Marketing & Communications plan, adapting our fundraising approach in a post Pandemic community alongside traditional fundraising when it is allowed, as well as developing and increasing our campaign activity.



**Governance** - We will work with the Board of Trustees to include further recruitment.

This plan will be monitored on a monthly basis by the Senior Management Team and quarterly by the Board of Trustees through Key Performance Indicators.










## **With your help**

**Jessie May can continue to be there  
for the whole family,  
for the whole journey in life,  
at end of life,  
and in bereavement.**

**Thank you ♥**

## Help Jessie May provide specialist palliative care by:

-  Taking part in an event such as the London Marathon, Bath Half or do a Charity Skydive
-  Hold an event for us like a coffee morning or bake sale
-  Hold a dress down day at school or work
-  Ask for a 'Get Messy for Jessy' pack for your children's activity groups
-  Nominate us as your Charity of the year where you work
-  Make a one-off or regular donation
-  Leave a gift in your will



## Stay in touch

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[Jessiemay.org.uk](http://Jessiemay.org.uk)

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Registered Charity Number: 1086048



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