



Jessie May
Children's Hospice at Home

Schools Pack

**Putting your school at
the heart of the community**



What's in the pack?

We'd love children to understand a little more about how life is for families with children with a life-limiting condition, so we have interviewed Izzy. Izzy explains why she has missed so much school, what exactly the kidneys do to keep a person healthy, and why disabilities can be hidden. Izzy's story is on page 3 & 4.

We've also explained why we're called Jessie May (p2) and how you could help, if you choose to support us (p5 and 6).

We're sending this pack to schools in the area in which we provide care – Bristol, South Gloucestershire, North Somerset, Bath and North East Somerset and Swindon and Wiltshire – because we need both your understanding and your help.

Many of the children we care for are invisible because it's such a challenge for their parents and carers to get them out of the house, except to go to hospital appointments. Some, like Izzy, are more mobile but they have invisible disabilities, so giving them support and understanding is really important.

And of course, we'd love you to get on board and help us raise the funds we rely on to continue to give our care to the children and families in our community who need it most. Less than 20% of our funding is statutory – the rest comes from generous donors like you. If you are able to fundraise for us, we'd be so grateful for your support.





Who was Jessica May?

Our charity was started by a family. It serves families. And continues to be shaped by families.

Chris and Philippa Purrington knew when their baby daughter, Jessica May, was born that they wouldn't have her for very long. She had a genetic condition known as severe Spinal Muscular Atrophy, which meant that she wouldn't see her first birthday.

On a family visit to Bristol, she was admitted to hospital, and Chris and Philippa were shocked to find that the support they received at home in High Wycombe wasn't available to families in Bristol and the surrounding area.

Jessica May died peacefully at home in her father's arms, in privacy and with dignity, surrounded by the people who loved her most.

The Purringtons decided to do everything they could to make sure that other children with conditions like Jessica May's had the same

support and care in their lifetimes as their daughter had.

Jessie May was established in 1996, and provides specialist nursing care for children with life-limiting and life-threatening conditions in their own homes. We provide end of life care and bereavement support, as well as vital respite and emotional support to the children, their siblings and their parents and carers. Our work allows families to make the most of the precious time they have together, making treasured family memories and letting children be children, if only for a short while.



Meet Izzy

Izzy is eight. She's in Year 3.

Like a lot of children, her school life was disrupted by the pandemic. But unlike a lot of children, Izzy's education has also been disrupted by her stays in hospital.

Izzy was born with kidneys that didn't work properly. The kidneys regulate the whole body. They filter out toxins, control blood chemistry, regulate hormones for bone health, and produce red blood cells. Without working kidneys, the person dies.

Hours after she was born, Izzy's parents had a big decision to make. She was so tiny, and she needed so much treatment to survive – and even then, there were no guarantees. So, should they just allow her to die comfortably and peacefully?

But even though she was very small, Izzy already had a big personality. Despite the challenges, her mum and dad, Emma and Neil, decided to give her the best chance of life they possibly could.

They didn't have many choices. Dialysis, which cleans the blood when the kidneys aren't working, is temporary. Even a kidney transplant, in which Izzy would get a kidney from a donor, isn't a cure. It usually lasts between ten and twenty years, but it's the best way for a person to live a normal life. Until she had her transplant, Izzy couldn't walk.

Because Izzy spent most of the first three years of her life in hospital, she started school a year later than most children. She needed to catch up on being

a preschooler before she joined a reception class.

These days, she loves school and hates missing it for hospital appointments. In an average year she has 25 to 30 hospital appointments not including any unexpected hospital admissions. She takes medicine every day and sees her doctors at least every six weeks for a blood test and for her health to be checked.

Izzy can do most of what her friends can do and she loves being in school shows, reading books, writing stories and playing with her girlfriends. Because she looks just like any other child, sometimes when Emma and Neil park in a disabled space, people get cross because they can't see that Izzy has a disability.

Since she was first brought home from hospital as a baby, Izzy has been looked after by Jessie May nurses. For a long time, she had to be fed through a tube, and she couldn't walk, so caring for her while setting up the machine to keep her alive kept Emma and Neil very busy. They really needed the help of nurses Steve and Charlotte to help care for Izzy, as well as doing some of the things you like to do, like trips out, playing and reading stories, with her. Steve and Charlotte were there to give Emma and Neil a much-needed break, even if it was just a chat about the stress and lack of sleep.

Kidney disease isn't the only medical challenge Izzy faces. The Jessie May nurses are still there for her, Emma and Neil, and Izzy's little brother Sebby, who is six. By helping with Izzy's medical care and supporting the whole family when life is really stressful, they make a real difference.

Could you make a difference to children like Izzy too?



How you can help

Put the FUN into FUNdraising

You will probably have lots of brilliant ideas of your own, but here are a few of ours to help you get started;-

Get messy for Jessie

Make and sell Christmas wreaths & stockings

Children can craft and sell Christmas wreaths/stockings to raise money while spreading festive cheer.

Run a themed bake-off day & cake stall

Organise a school bake-off and cake stall to raise funds, with the children showcasing their baking talents. Throw on your aprons and get baking!

Design and print Christmas cards

A great way to raise funds - encourage the children to get creative! They can design their own cards to sell at your school fair.

Or if you prefer;-

Get dressy for Jessie

Themed fancy dress day! £1 to get dressed up - to raise funds for Jessie May.

Jumpers for Jessie Day

Join our annual #jumpers4jessie day in December! Get in touch for more details.

Hold a school disco, play or concert

Every parent wants to come see their child perform, have fun and show off their skills!

And if those don't float your boat;-

Book project

Why not encourage the children to write their own book, to sell to family and community members? You could produce a storybook or cookbook, including some of their family recipes. This would be a great project to develop artistic and writing skills.

School fair

Do any of the children and their families have any unwanted items they would like to sell, such as old books or toys? It's a fab way to raise money and stay green by recycling and repurposing!

Quiz night

A great opportunity to get parents, teachers and pupils together in a fun environment. Test your general knowledge and raise some funds for a great cause. You could even hold a raffle on the same night.

This is how your fundraising helps

£60 pays for a whole hour for a Jessie May nurse to help a family and care for a child

£100 pays for specialist travel to help families come along to our events, to make memories that will last a lifetime

£300 pays for a portable toilet - essential for Jessie May children - making events spaces accessible to them

£450 pays for a nurse for a whole day

Fundraising Guidelines



We know schools are well versed in risk assessments, first aid, insurance and all the other things you'll need to consider for your fundraising activities. Here are a few extra hints and tips, but if you need to check anything out, just get in touch!

Fundraising@jessiemay.org.uk
0117 9582174

Health & safety tips

You should carry out a risk assessment to ensure you have properly addressed any hazards at your fundraising event; we can provide a template to help.

Make sure you have first aid cover and you inform the local police if your event is in a public area. Always get copies of insurance and certificates from any suppliers.

Please make sure that you refer to latest event guidance for England, Scotland, Wales and Northern Ireland to help you in planning for your safe and successful fundraising.

Raffles

Books of raffle tickets are available to stationers: rules state the raffle should be drawn on the same day that you sell the tickets and each ticket should not exceed £2. If your raffle lasts longer than 24 hours there are strict rules that apply. Call us for more guidance.

Sponsor forms

When completed, your sponsorship form will contain lots of personal information, so please keep it safe before you send it to us, and avoid leaving it on public display.

Letter of authority

We can write you a letter which you can show to prove you are fundraising for Jessie May. If you would like one of these, please get in touch.

All information is for your guidance. Individual event organisers are responsible for event compliance.

A big bunch of resources to get you started

Head to our website for everything you need - jessiemay.org.uk/resources/

A fundraising form for Jessie May. It has a header with the logo and 'You making a difference for Jessie May Children's Hospice at Home'. The main heading is 'Please support me in my fundraising'. There is a section for 'What I will be doing...' with a large text box. Below that is 'My details' with fields for Name, Address, Phone, Email, and Date. To the right, there is a 'My fundraising target' section with a '£' symbol. At the bottom, there is a table showing how much a donation can make a difference. The table has three columns: '£25', '£40', and '£65'. The first column says 'I could help more than 1 child have a specialist assessment or treatment'. The second column says 'I could help more than 1 child have a specialist assessment or treatment'. The third column says 'I could help more than 1 child have a specialist assessment or treatment'. At the bottom, it says 'Find out more: jessiemay.org.uk', 'Email us: fundraising@jessiemay.org.uk', and 'Call us: 0157 908 2174'.

How to pay your money in

We have lots of ways you can send your fantastic donations and fundraising money in.

Please choose the best one for you and if you need any support, contact our fundraising team.

Online giving

If you are taking part in an event, you may choose to set up a fundraising page. Our main platform for this is Just Giving. If you have raised funds for Jessie May that didn't require a fundraising page, you can pay the funds to us in a way that suits you:

On our website

You can pay money directly to us from our website:

www.jessiemay.org.uk/donate

By bank transfer

Please contact our fundraising team for the details email:

fundraising@jessiemay.org.uk

or

tel: **0117 9582174**

By cheque

Please make cheques payable to Jessie May Trust and send them to:

Jessie May
35 Old School House
The Kingswood Estate
Britannia Road
Kingswood
Bristol
BS15 8DB

Want to use contactless payments?

If you are running an event and need access to take contactless payments, please contact our fundraising team for details.

Make your money go further.....

Gift Aid

If your supporters are UK taxpayers and their donation is totally voluntary, they can add 25% at no extra cost to their donation. This really makes a big difference, so please make sure your UK tax-paying donors fill in their details on your sponsorship form. Please note that purchases of tickets or goods cannot be Gift Aided.



A big THANK YOU from our CEO



“Helping people is such an important thing to do – you make a real difference! So from me to you, a very big thank you for choosing to help us at Jessie May to care for the children and families we work with.

“I think this is a very special charity, doing very special work. Our supporters – people like you – are very special too. Your help means the world to us and to all the Jessie May children we look after.

“So from the bottom of my heart – thank you!”

Daniel Cheesman

Get in touch

Let us know what you're up to! We'd love to see your pictures and hear your stories.

0117 9582174

fundraising@jessiemay.org.uk

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The Jessie May Trust



Jessie May



FUNDRAISING
REGULATOR



Jessie May
Children's Hospice at Home

Company Limited by guarantee
(England and Wales No: 04118341)
Registered Charity No: 1086048