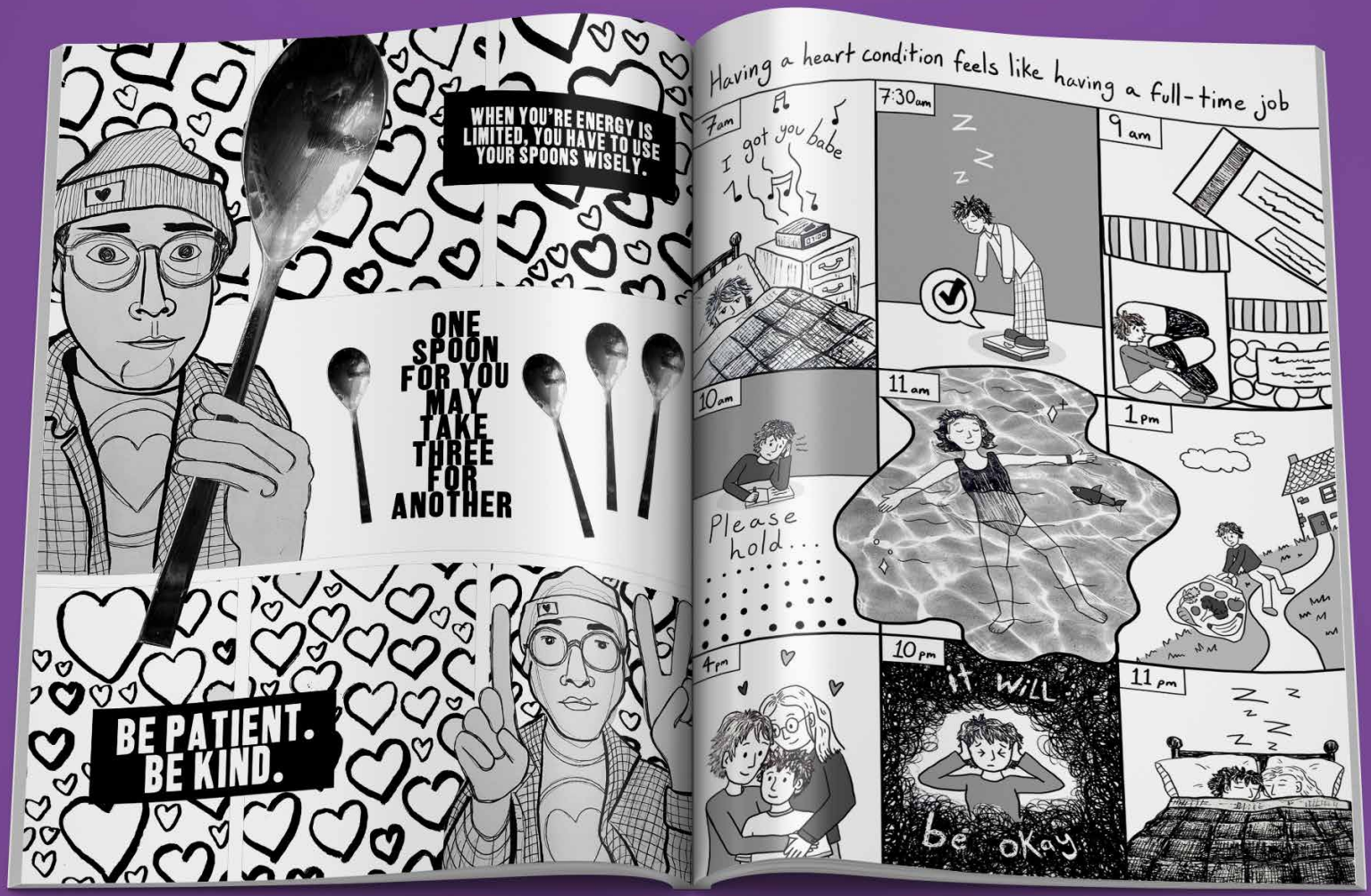
Little Hearts Matter Newsletter

June 2025



Supporting every step of the half a heart journey

Trustee News

Written by the **Trustee Board**

Thank you Suzie

It is with great sadness that we have to bid farewell to Suzie Hutchinson, who left LHM on 23 May.

This has not been an easy decision for Suzie to make. She remains as devoted to our members today as when the charity formed more than 30 years ago. As a Board of Trustees, we want to thank Suzie for everything she has done for LHM and for all those whose lives have been touched by single ventricle heart conditions.

LHM would not be the charity it is today without Suzie's devotion. She has been instrumental to the creation, growth, and longevity of LHM and has played a pivotal role in shaping the support we provide.

Suzie has supported many of our members during their most difficult times. She has also been a vital source of information and an advocate in medical and political forums. Her work has made a lasting difference to so many lives and we were delighted to see this recognised when she received her MBE from Prince William last year.

Please join us in thanking Suzie for her incredible contribution and wishing her well. Suzie will be greatly missed by us all. As an individual, she is simply irreplaceable.

However, the Trustees and our wonderful staff remain committed to providing a high level of care and support for you as our members.

We are working hard to ensure we provide the services and the expertise that you need, now and in the future. To help us do that, we are delighted to welcome our new Chair, Asha Ghosh, who brings a wealth of experience as a leadership coach.

In memory of Valerie Howarth

It is with great sadness that we announce the death of our much-loved Honorary President, Baroness Valerie Howarth. Valerie became involved in the work of Little Hearts Matter as both our President and Trustee over 22 years ago.

With a history of supporting and advocating for children all her working life, Valerie was the Chief Executive of Childline, Chaired the Children and Family Court Advisory and Support Service and was the Patron of TRACKS (a charity dealing with young autistic children), she was drawn to Little Hearts Matter because of the work the charity does to directly support families.

She brought a sound wisdom to Little Hearts Matter helping to guide the growth of the charity, working to raise awareness of the charity's work, seeking out funding where she could. Most of all she loved meeting the children, teenagers and parents that sit at the heart of the Little Hearts Matter family.

We send our love to Val's family and friends. She is in our thoughts as she flies high.

Suzie's Top Tips

Written by **Suzie Hutchinson**

What you can do to help with your stress levels

Everyone has times when they feel stressed but for some people the stress can be overwhelming. Here are some ideas of ways you can reduce your stress. If the feelings continue and you feel you need help reach out to friends, family or your local GP for help. The LHM team are always here for a chat if we can help.

Be active - Get out in the fresh air for a walk or take up an activity or sport.

Take control - The act of taking control is in itself empowering, and it's a crucial part of finding a solution that satisfies you and not someone else.

Connect with people - Talking things through with a friend may help you find solutions to your problems.

Have some "me time" – Even if it is just time reading a book, having a bath or going out for a coffee with friends.

Challenge yourself - Setting yourself goals and challenges, whether at work or outside, such as learning a new language or a new sport, this can help build confidence.

Avoid unhealthy habits - Don't rely on alcohol, smoking and caffeine as your ways of coping. They might provide temporary relief, but in the long term, these crutches won't solve your problems. They'll just create new ones.

Help other people - Evidence shows that people who help others, through activities such as volunteering or community work, often become more resilient.

Work smarter, not harder - Working smarter means prioritising your work, concentrating on the tasks that'll make a real difference. Leave the least important tasks to last. Accept that you will not have time for everything.

Try to be positive - Look for the positives in life, and things for which you're grateful. Writing a diary every day and including 3 things that went well, or for which you're grateful, at the end of every day can help you to feel more positive.

Understanding Mental Health Challenges

Trigger Warning – This article may be tough to read

Written by **Suzie Hutchinson**

The parents of children with complex, heart conditions worry about so many aspects of their life. The health of their child, financial strains, the emotional strain and sometimes social isolation.

The first thing to remember is that you are not alone. Many other LHM parents feel the same, they just don't tell anyone.

Throughout this article we hope to explore a little of what mental health challenges can mean for mums and dads, to reassure you that you are not alone and to assist people who want help to find it.

It is an emotional rollercoaster travelling the half a heart journey. There are many highs and lows. There are of course some predictably stressful times, around diagnosis, clinic appointments and surgery. For some parents' the longer-term worries about their child are pushed to the back of their minds, they can stay hidden there for many years but usually they will emerge at some time and when they do they need to be safely explored and when possible acknowledge and addressed.

It can help to understand more about why you are feeling the way that you do. It is also essential that when you feel low you are kind to yourself and that you recognise that it is ok to feel emotional and to seek help when you need to.

Following the stress of a diagnosis there is usually a plan for the treatment of the children. In most cases there are three stages of surgery and recovery time. After the last operation, the Fontan operation, the treatment for their children becomes less structured, for some parents this unknown future is stressful in itself. For some families there is no third stage leaving them with a less predictable future. Understandably some parents suffer with poor mental health. To help you understand some of your feelings here we explain many of signs of stress and anxiety.

Grief – Grief is not just experienced after a death, parents who worry about the future for their child are often grieving for their normal, healthy life. This is very normal response to the complexity of life when a child has half a heart. Grief can create a myriad of different feelings. Sadness, doubt, anger, fear and depression.

Post Traumatic Stress – There is a great deal of evidence to show that it is not just the children who suffer with PTSD. It can develop after a very stressful, frightening or distressing event or after a prolonged traumatic experience. Your child's repeated surgery and their complex recovery is often stressful.

Sufferers experience flashbacks and nightmares. They would like to avoid the places and people who remind them of the stressful experience. They are often tired, anxious and depressed and often suffer with insomnia.

Anxiety – We all get anxious from time to time. This is a normal response to difficult situations. If the anxiety continues for long periods, it can become detrimental to long term health.

Signs of anxiety are feeling tired, restless or irritable, feeling shaky or trembly, dizzy or sweating more, being unable to concentrate or make decisions, trouble sleeping, worrying about the past or future, or thinking something bad will happen.

Depression – we all feel low at times the difference with that and being depressed is that the feelings do not go away and without support it can become a downward cycle.

Signs to look for – Continuous low mood or sadness, feeling hopeless and helpless, low self-esteem, feeling tearful, guilt-ridden, irritable and intolerant, difficulty making decisions and not getting any enjoyment out of life.

Where to get help

Be Kind to Yourself
If any of the conditions highlighted above ring a bell with you seek help. There is always support available from the LHM team, we will happily listen to your worries and help with any day-to-day challenges. Often the best help is local, both medical and counselling, offers better long-term recovery support. Ask your GP, they can start to find the right support for you.

Advice from the NHS

Causes - Post-traumatic stress disorder

Familial impact and coping with child heart disease - a systematic review

Mental health problems in parents of children with congenital heart disease

Mind a mental health support charity

LHM Kidz

Written by **Michèle Puckey** and **Olivia Hutchinson**

Talking About Single Ventricle Heart Disease (SVHD) with Your Child

Why Talk About SVHD?
Being open and honest with your child about their heart condition helps build trust. It also makes it easier for them to understand what's happening and why certain investigations and treatments are needed.

Giving clear, accurate information prevents confusion and helps a child feel more in control. Children and young people are naturally curious, so answering their questions in a way they can understand will help them feel empowered rather than scared.

It supports you to manage information shared with your child and avoids them seeking or accessing different, inaccurate or unhelpful information from other sources such as social media, school (CHD can be part of Key Stages 3 and 4 science curriculum), or hearsay.

Who Should Talk to Your Child About SVHD?
Consistency is key, so it's great if all family members are on the same page about how to talk about SVHD. As a parent, you're usually the best person to have these conversations, but doctors, nurses, and other healthcare professionals are there to help too.

If you're not sure how to explain something, don't worry your child's cardiology team can offer guidance.

When Should You Talk About SVHD?
Think of this as an ongoing conversation rather than a one-time talk. Pick a calm moment when your child is feeling relaxed, maybe during a quiet time at home or before a clinic visit.

Try to avoid bringing up big topics right before bed, as that can sometimes lead to anxiety. It's also a good idea to check in every few months to see how much they understand and if they have any new questions.

How Do You Talk About SVHD?
Keep it simple and use words that make sense for their age. Encourage their natural curiosity by answering their questions honestly.

Instead of overwhelming them with too much information at once, break it down into small, easy-to-digest bits. You can also use books, pictures, or videos to help explain things. The LHM Kidz page on our website has loads of helpful resources for children, just scan the QR code to check it out!

St James's Place Charitable Foundation

Our dedicated Kidz service has been generously funded by St. James's Place

Most importantly, try to make these discussions feel like a normal part of life, not something scary or secretive- your child(ren) will take their lead from your approach to their condition, both with them and with others.

What Should You Cover?
Explain that their heart is a little different and what that means for them day to day. Talk about how it affects things like their energy levels, activities, and medical care. They may already have noticed how they have to do some things that are different to their peers, ask for them to share their thoughts too.

Help them understand why they need medicines, surgeries, or check-ups, and reassure them that they're not alone. Doctors, family, and caregivers are there to support them every step of the way.

As they get older, you can slowly introduce more details about long-term medical care and lifestyle adjustments.

Setting Aside Time to Talk
It can help to have protected time, once or twice a week, just 15-20 minutes where your child knows they have your full attention to ask anything they want (not just about their heart!). Make sure there are no distractions, like phones or TV, so they feel heard.

Checking What They Understand
Every now and then, ask them to explain what they know about their heart. This helps you see if they understand it correctly or if anything needs more clarification.

Also, keep an eye on their emotions and behaviour, are they sleeping well? Eating normally? Seeming more anxious or withdrawn? Encouraging them to ask questions at medical appointments is a great way to boost their confidence too.

What If It Is Not the Right Time or Place?
If your child asks a question in a tricky situation (like in a public place), let them know their question is important and that you'll find a good time to talk about it properly.

Try not to dismiss their concerns or give them an answer you might later have to correct. If you don't know how to respond, it's totally fine to say, 'That's a great question! Let's ask your doctor together next time.'

Where to Get More Support
You're not in this alone! Your child's cardiology team can help you navigate these conversations, and paediatric psychologists or child life specialists can provide extra resources.

Talking to other families going through the same thing can also be really helpful, you might pick up great advice and reassurance from their experiences. By creating a safe and open space for your child to talk about their heart condition, you'll help them grow up feeling confident and supported, ready to take on life with a strong sense of resilience.

A sad goodbye.

It was with great sadness that I had to share my farewell from LHM. I have had the privilege of working with this charity, on and off in different capacities, for many years and I have met so many amazing families and children (some of whom are now adults) during my involvement. The LHM family has always been special, and I really value my time with them. During my latest role, as child support lead, I have met some truly incredible children, who have inspired me in so many ways. Their resilience, enthusiasm for life and desire to understand their conditions is truly amazing and I am so grateful to have got to be a small part of their heart journeys.

With love from
Olivia

Youth Zone

Written by **Lexie Katsaitis**

Life can change dramatically when any child transitions to their teenage years. In their mind they are no longer a child but not yet an adult, yet so many of the decisions they are asked to make or experiences they have, demand a thought process from either a child or adult perspective.

What are the teenage crossroads?
The term 'teenage crossroads' can often be used to describe this transitional time and how a young person might engage or disengage with the choices, decisions and behaviours that come with it.

When young people reach the age of around 14 there is pressure to start making some big choices that can shape and lay the foundations for their future education pathways and career. A pressure to make their GCSE choices, take their GCSE's and A Levels and start to look at what kind of career they might want to move into.

This is also the age that teenagers start to explore their identity and develop their social circles. Social circles that have a huge impact on their choices, reactions, outlooks and hobbies. Add to this a single ventricle heart and the introduction of a more independent heart journey and its clear to see why these developmental years might seem overwhelming and so many teenagers seem to disengage.

How can parents/carers support?
No one knows your teenager better than you do. You have loved and supported them from birth. This is a time that calls for you to adapt your support style to aid them in their journey to independence. To allow them to navigate these crossroads with your support net beneath them. What do they need?

Open conversations.
Creating a safe space in which teenagers feel like they can share their concerns, thoughts feelings and have the opportunity to change their mind is important. Teenagers may feel the need to be validated in their experiences, and decisions. They will be more likely to make healthy informed choices if they have a space to talk openly with their trusted adults without fear of judgement. A lot of teenagers feel spoken 'at' rather than 'to' at school, hospital and sometimes home – they want to be a part of their own journey.

Honesty.
Honesty goes a long way. If you're unsure about something, tell them and work together to figure it out. This will go a long way in empowering your teenager and taking steps to independence. Examples could include being honest in what they can expect when preparing them for hospital transition or looking realistically at their GCSE options together.

Joint boundary setting.
Your teenager may be moving towards adulthood and independence, but they still need guidance and boundaries. Working together to create boundaries will prepare them for making independent informed choices in the future. For example you could work together to set boundaries with energy management. Ask them what they feel they can manage in terms of social activities and whether this impacts their school experience and set some boundaries together so they feel a part of their journey.

Advocation.
Listening to your teenager and advocating on their behalf when they lack the confidence to do so will show that you are on the same team, working towards the same goals. The goal of future independence and happiness. They will feel heard, supported and may be more likely to come to you when and if they run into problems.

No two teenagers are the same, nor are their experiences but the challenges teenagers with a single ventricle heart face and the changes they meet are similar. Feeling isolated at this crossroads can impact their engagement. Feeling supported in what they need at this point in their journey is paramount, feeling a community of peers could also be empowering. If you think your teenager could benefit from the LHM youth hub, a safeguarded app where they can access support and community from LHM, mentors and others their age with a single ventricle heart they are welcome to scan the QR code here.

Youth Services

Accessing information about living life with half a working heart that is relevant and easy to understand is important when you're a young person walking this path. We are happy to share our latest releases written for our youth members with half a working heart.

Hospital transition with half a working heart
A brand-new book just for our youth members, explaining the journey of transitioning and transferring from children's hospital to adult hospital. Learn what to expect, what you are entitled to and come myth busting with us. Scan the QR code to read the eBook or email info@lhm.org.uk to request a physical copy.

Sibling survival guide
A book written by our sibling members for our sibling members. A book filled with understanding, community and prompts to navigate the journey for siblings of a child/ young person with half a working heart. Scan the QR code to read.

SVH Adults

Written by **Sharna Douglas George**

Charlie Andrews-Brown's Story: Overcoming My Disability and Mental Health Through Sport

Growing up with Hypoplastic Left Heart Syndrome has always been a difficult battle, especially when it came to dealing with my mental health. My condition often made me feel very secluded from others due to not being able to take part in sport and other activities. For years through school I found it difficult fitting in, being the only kid in the playground with a heart condition was something I just couldn't understand. This caused me to be anxious and very angry at why I couldn't be "normal" like the rest of my schoolmates. While trying to do my best fitting in, my peers made it impossible, they made sure I wasn't able to fit in, leaving me feeling completely alone throughout my school years. They made comments that made me fear my own condition, it affected me in ways I couldn't explain and still does to this day. My mental health has always been a massive part of my life and at times has made me struggle with the simplest things like leaving my room or even socialising.

Throughout most of my life I steered away from sports, finding it boring. That was until I discovered that playing football or supporting the beautiful game wasn't so bad after all.

After lockdown restrictions eased, I was able to watch the Euro 2020 competition with my friends. This ignited a passion that ultimately changed my look on life, leaving the house to be with friends didn't seem so scary if football was involved. Focusing on football made everyday life easier, it lifted a weight off my shoulders completely, there was no sense of seclusion anymore, no more anxiety when it came to meeting new people. The best part I've found with football is that everyone is included, everyone is welcome, no one cares that I have HLHS. I've been able to create lifelong memories with friends that I would never have had if it weren't for sport.

Not only has it helped crucially with my mental health, but it has helped a lot with my physical health too. Being able to play football at a pace that is right for me has increased my fitness and has made me feel overly stronger than I ever had while living with HLHS.

Our adult service receives funding from the Paul Hamlyn Foundation

phf Paul Hamlyn Foundation

Sharna says, "Everyone's education and career path is unique. It's important to recognize your options, passions, abilities, and goals. It might not always be easy but working hard for something makes achieving it feel amazing."

Jessenia Bostan's Story: Accessing employment through apprenticeships

"In October 2023, I started a 2-year level 3 apprenticeship at my local hospital in Milton Keynes to become a registered pharmacy technician. I chose this path because university wasn't right for me, given my struggles in school and the fact that there are no universities in Milton Keynes. I didn't feel comfortable moving away from home. The application process was daunting, especially after six months of rejections due to my lack of work experience, which was disheartening. But I reminded myself that something better would come. Since starting work, I've become happier, more independent, and gained confidence.

I think an apprenticeship was the best route for me because I enjoy the balance of completing written work and online courses alongside practical training. When applying, I wasn't required to disclose my heart condition, only to answer 'yes or no' to the question about having a disability. However, during my interview, I chose to be open and explain my condition, which wasn't necessary. After getting the job, I had a conversation with the occupational health team to record details of my condition and any adjustments I might need. My manager also conducted a risk assessment to identify potential issues, especially since I use an electric wheelchair for travel. I was able to discuss needing time off for appointments, and my manager was supportive in organising this. I was advised to complete an 'employee passport' detailing my condition and required support, which stays with me if I change roles. I also applied for the 'Access to Work' grant, which helps employers implement necessary adjustments. The training provider is aware of my condition and has offered additional support. I have regular reviews with my manager and tutor to assess my progress. Once I complete the course and become a pharmacy technician, I can register with professional bodies and explore further career opportunities and training."

At 20, Jessenia says, "Throughout my apprenticeship, I've earned my team's trust and gained more responsibilities, like training new staff. This has boosted my confidence and assured me that I know what I'm doing."

Communication & Awareness

Written by **Suzie Hutchinson and Lisa Davies**

How we keep in touch with you

We live in a digital world but we don't have all your digital contact details!
By the end of 2025 Little Hearts Matter will only be sending our invitations, news about support, governance information and updates by email or via text.

We need all parent, grandparent, SVH Adult and teenagers' email and phone details and agreed permissions to tell you about LHM services and more general contact. Please complete the form even if you think we have your details. We do not want to lose touch.

Thank you.

Dear Members

It is with great sadness that I am writing to tell you that it is time for me to step away from Little Hearts Matter. One of the most important things for me about being part of the charity has always been being able to meet with, talk to and share with our many members, I feel truly honored to have been invited to travel part of your half a heart journey with you. I will miss you all dearly.

Please take care. Sent with love from

Suzie

The Feeding booklet

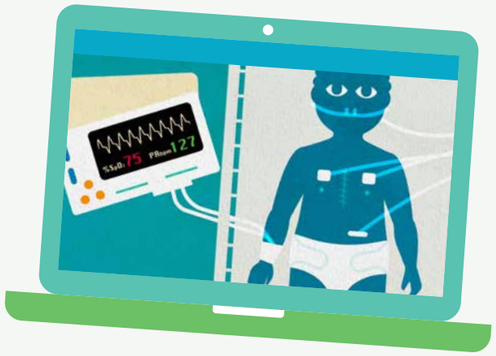
We know how tough it can be to help a baby or child with a single ventricle heart to gain weight, in the early years. We are delighted to introduce our new Feeding booklet. Jam packed with information about why feeding can be a challenge, the ways that weight gain can be encouraged and great ideas from members about how to encourage toddlers and children to enjoy food. The booklet can be found on the LHM website or a hard copy can be sent out, just email the LHM team and they will pop one in the post. info@lhm.org.uk

We would like to thank Jacqui Laydon from the Freeman and Niamh Brosnan from Dublin for their help in writing this booklet.

The Power of Storytelling

by Lisa Davies, Chief Executive

In 2024, our 30th Anniversary Year, we created Every Moment Counts, an animated film co-produced with parents and the Media Co-op. It shares the experiences of LHM families and was a finalist in the Smiley Charity Film Awards.



This year, we're experimenting with a new way to tell stories—Graphic Medicine. This means using comics and drawings to share real-life health experiences. It helps explain things that are hard to put into words and makes it easier for others to understand what living with a heart condition is really like. Projects like the Welcome Collection's Graphic Medicine series and books such as The Bad Doctor by Ian Williams show how comics can help people share their health journeys in a powerful way.

This year we worked with verynice, a design group that helps organisations use creativity for good. This project is about giving a voice to our adult members, making sure their experiences are recognised and shared. Together, we're creating a nine-panel comic series pairing some of our adult and youth members with professional illustrators to explore what energy means when living with a single ventricle heart. Energy is not just about feeling tired or active—it's about managing work or study, making big life decisions, and balancing daily life. For some, energy means carefully planning each day to avoid exhaustion; for others, it means learning to say no when something feels overwhelming. This project shows these experiences in a way that feels real and personal.

Please visit **www.help.lhm.org.uk** for the project and let us know what you think.

At LHM, storytelling is important because it helps us share what life is like with a single ventricle heart and helps others understand the realities of managing energy, work, and life choices. It is our hope that this project helps to educate others and makes sure our member's experiences are seen and heard. If you have ideas for future storytelling projects—whether through comics, writing, or other creative ways—we'd love to hear them. Just email lisa@lhm.org.uk

Fundraising

Written by **Katie Banks, Catherine Fletcher, Juliet Hanlon** and **Rebecca Wilkes**

Meet your LHM Fundraising Team!

Behind every fundraiser, challenge event, and vital appeal, our dedicated fundraising team is working hard to make each one a success. Whether it's supporting community fundraisers, building corporate partnerships, securing essential grants, or coordinating events, Juliet Hanlon (Community & Appeals), Katie Banks (Corporate & Events), Rebecca Wilkes (Grants & Trusts), and Catherine Fletcher (Fundraising Coordinator) are here to help every step of the way.

Got a fundraising idea or need support?
Get in touch—we'd love to hear from you!

2024: A Year of Growth and New Opportunities in Our Challenge Event Programme

In 2024, our Challenge Event programme saw major growth thanks to a partnership with Run4Charity. This platform allows supporters to choose from thousands of UK and international events while fundraising for Little Hearts Matter.

One of the greatest advantages of this platform is that it gives us access to a wide variety of events without needing to commit to paying for places in advance. This not only reduces risk for the charity but also offers more choice for our incredible challenge event heroes.

Over the past year, we've been proudly represented at running events across the UK and Europe, as well as virtual challenges where participants rack up miles over time. Looking ahead, we're excited to expand into swimming, inflatable, and cycling events—creating even more opportunities for supporters to raise vital funds for Little Hearts Matter.

Scan the QR code to explore your next challenge event.

Celebrating Our Incredible Fundraisers!

Over the past year, our incredible fundraisers have gone above and beyond, taking on marathons, walks, music events, boxing matches, bake sales, and birthday fundraisers. Thanks to your dedication, you have raised over **£90,000** to support families facing the challenges of living with half a heart.

We want to say a huge thank you to everyone who has taken on a challenge, hosted an event, liked and shared fundraising pages, or made a donation. Every bit of support has helped Little Hearts Matter deliver vital services at every stage of the half-a-heart journey. Your generosity has supported:

- **Our Expanding Adult Service**, offering guidance and community for adults living with half a heart.
- **Our Medical Symposium**, bringing together medical professionals to discuss "Living the best life with a Single Ventricle Heart Circulation"
- **Our Ever-Successful Activity Weekends**, giving young people a chance to learn about their heart, meet others with similar conditions and have lots of fun too!

Big Hearted Friday Success!
Our Big Hearted Friday celebrations for World Heart Month were another great success! We loved seeing your creativity in action—from fantastic bake sales to exciting fundraising challenges. Thank you for making it such a special event once again!

Looking Ahead – Even Bigger Impact!
Thanks to your incredible generosity, our Little Lives Matter Appeal in November, through Big Give match funding, exceeded our £12,500 target and achieved an amazing total of **£14,680!** We are so grateful for your support in making this possible. Building on this success, we're thrilled to announce even more match-funded opportunities coming soon. This means every donation will have double the impact—so stay tuned for details on how you can get involved!

Join Us in 2025!
We have exciting plans for 2025, including our Christmas Appeals, and we'd love for you to be a part of them! Whether you're looking to take on a challenge, host a community event, or explore new fundraising ideas, we're here to support you every step of the way.

Ready to get involved? Email us at fundraising@lhm.org.uk, or scan the QR code, we'd love to hear from you!

£2540 has been raised in memory of Helen Marino, aunt to LHM Adult member, Jake, following her passing in February. Helen was a constant source of support to her sister, Anna, and the family through the difficult time of diagnosis and surgery. In her honour, the family created a Little Hearts Matter Tribute Page, which is now filled with heartfelt messages of love.

Keep your eyes peeled for exciting announcements!

Bumble Bees Nursery raised £1754 in support of Emelie (HLHS), a child in their care, by completing 280,000 step challenge and 5 mile walk on Friday 7th Feb.

Sammi Jude took on the Brighton half Marathon in March, raising £1661, in support of her niece, Lili.

Olivia Waters (SVH Adult) swam 400 lengths (10,000m) raising £233, and heling to advocate the benefits of activity for people with chronic heart conditions.

Great North Run
Event Date:
7th September 2025

Amsterdam Marathon
Event Date:
19th October 2025

Noticeboard

Little Hearts Matter

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Publication List

Don't forget the following publications and packs are available free of charge to members.

Antenatal
- Antenatal information pack

Diagnosis
- Fontan Associated Liver Disease (FALD)
- Left-sided single ventricle heart conditions
- Single ventricle heart conditions that affect the flow of blood to the lungs

Treatments
- Fontan booklet
- Heart transplantation - a guide for families
- MCT diet
- Preparation for hospital booklet
- Living with anticoagulation

Education
- Support for a Child with Special Educational Needs within Nursery, School, or Further Education
- Healthcare Plans for Children and Young People with a Single Ventricle Heart Condition
- Understanding what having half a working heart means for a child in school – a guide for school teachers
- Early Years Foundation Stage (EYFS) and Key Stage 1 education booklet
- Key Stage 2 - Junior School education booklet
- Transition to Secondary School education booklet
- Key Stage 3 Secondary School booklet
- Key Stages 3 - 4 Secondary School booklet
- Your guide to university with half a heart

Benefits/DLA/PIP
- Benefits - a guide for parents
- Baby/child DLA booklet and sample pack

Resources for Children
- Jessica has a heart operation - children's storybook
- Jack has a heart operation - children's storybook
- My baby sister has something wrong with her heart - storybook for brothers and sisters before a baby is born.
- My new baby sister has something wrong with her heart - storybook for brothers and sisters after a baby is born.

Lifestyle
- Sport and exercise
- Travel and trips
- Puberty for young people with half a heart
- Sex and relationships with half a heart