

myLife

The magazine for people affected by cardiomyopathy and myocarditis



Our Impact
in 2022


Nurses Q & A

Lauren's
story

Contact us

If you would like more information on our services, please get in touch

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Welcome to our spring edition of MyLife.



I do enjoy winter walks, when I'm wrapped up warmly, especially when the days are dry and crisp, together with comfy nights in front of the fire. That said, as I write this introduction, I am pleased to see that the evenings are getting much lighter, and signs of spring and the new life that it brings, fills me with hope and a sense of well-being.

In this issue of MyLife we take a look back at our achievements in 2022 (page 6-7). I am delighted to report that for only the second time in the history of the charity, we ended the year having reached income levels in excess of £1 million pounds. A remarkable achievement.

Each of us has a right to have control over decisions and actions that affect our health. On page 10 our Specialist Nurse Jayne shares how access to information and support is key to patient empowerment, putting patients at the heart of their healthcare. You will also find your questions answered in our regular Q&A with our nurses on page 8-9.

Five years ago, we agreed to provide 5,450 support groups over the five-year duration of the grant funded project from the National Lottery Community Fund. Remarkably, especially given our COVID-19 years, in just 4 years 3 months we exceeded that target. Congratulations to all concerned. You can hear from Tash, our West London Support Group Leader on page 14-15.

Thank you to those of you who responded to our 2022 National Survey, the results have been collated in our State of Cardiomyopathy Care Report. You can read the key results on page 12-13.

Many of our fundraisers take on challenges in memory of a loved one for which we are incredibly grateful. On pages 16-17, meet Ben Cole and hear about his 10-year anniversary cycling challenge in memory of his brother. Be inspired.

Time for me to start the spring cleaning now.

Until the next time all, good wishes,

Rita Sutton, Chair of Trustees

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Lauren's Story

L Lauren and her sister Rachel were both diagnosed with dilated cardiomyopathy (DCM) in February of 2020. Lauren has shared her journey with us, from her diagnosis to now living with cardiomyopathy.

“

It took them a while to understand what cardiomyopathy is, but my family and friends have been very supportive.

”

In February 2020 I was due to have an operation to have my gallbladder removed. The day before my operation was meant to take place, I received a call from a nurse at the hospital who told me they couldn't go ahead with the procedure. The anaesthetist had reviewed my ECG and wasn't happy, they said something was wrong with my heart.

The following Monday I was seen by the consultant cardiologist and heart failure nurse, who told me I had dilated cardiomyopathy. I was referred to Bart's Hospital for an MRI to see if I'd had a heart attack. I was 31 years old.

Before my diagnosis, I had no idea I could be suffering from a heart condition, and I had no obvious cardiomyopathy or heart failure symptoms. I felt dizzy sometimes, but I didn't think it was anything serious. After being told I had dilated cardiomyopathy, I felt shocked, confused, and angry. I remember going through the MRI scan, crying every time I was asked to breathe and hold my breath, I didn't understand what was happening to me or why.

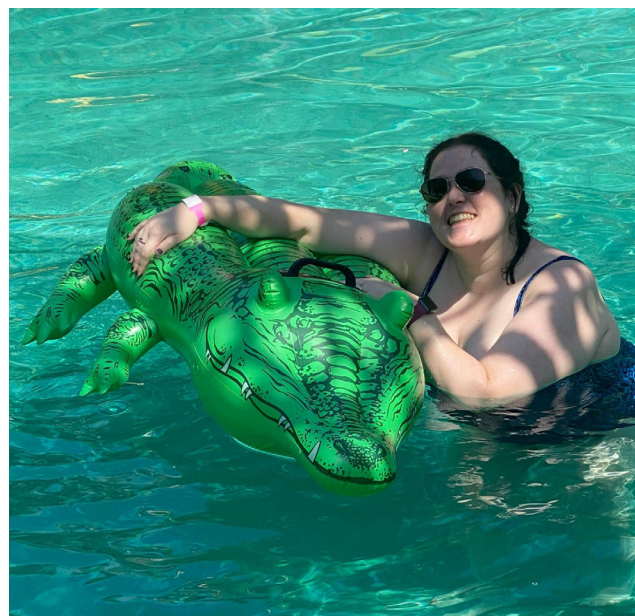
The same day I was having my MRI, my sister Rachel, who was eight and a half months pregnant at the time, was attending the hospital for her routine ultrasound scan and midwife appointment. At this stage Rachel was struggling to breathe, she couldn't walk far, and she couldn't lie down. When she asked her GP and midwife what could be wrong with her, they said it was just the baby pushing everything up and it would pass. At the scan, she was asked to lie on her back and once she got up, she started to cough up blood, and she was rushed to the maternity ward.



After being hooked up to several monitors, the hospital made the decision to call the team from Bart's to come to the Hospital in Romford with the resus machine. Her heart was failing, and she wouldn't have made the journey from Romford to London as her heart function was at 12%.

Once the team from Bart's had arrived, it was decided that the baby would be delivered by C-section and Rachel would be put in an induced coma and taken to intensive care at Bart's. She was in an induced coma for just over 24 hours, not knowing what had happened, or even if she had a girl or a boy. She then spent ten days in the care of the team at Bart's. After three days she was reunited with her baby girl, Ava and the rest is history.

She was diagnosed with peripartum dilated cardiomyopathy and a leaky valve. At her bedside when the doctor asked if she had any family history, I held my hand up and said, 'Well yes, I have it too, I found out on Monday'. The doctors were shocked that two sisters could be diagnosed with the same condition within 24 hours of each other.



As I was diagnosed just before lockdown, I was locked in the house for the best part of six months. I felt very down, and I still didn't fully understand what was wrong with me. Before my experience, I always thought heart conditions were something that older people, heavy drinkers and smokers had. I didn't think someone at the age of 31 could be diagnosed with anything like this. It felt like just when I thought I'd gotten over it, it hit home that I have a life-changing condition.

Since the world has opened up again, I have been testing the waters to see what I can and can't do, and I have learnt to take every day as it comes. I love going to concerts and seeing live music. My first concert after the lockdown was to see my favourite band McFly and I cried before they even walked on stage (embarrassing my husband)! I have also managed to travel, first to the Maldives for Christmas and then to Canada and America.

It took them a while to understand what cardiomyopathy is, but my family and friends have been very supportive. My husband has been my shoulder to cry on since my diagnosis, and he has been with me through every stage. I think I am still coming to terms with having cardiomyopathy, but I have a better understanding of it now.

Our Impact in 2022

2022 has been another successful year for the charity and, despite some real challenges for us all, we have been able to continue to deliver fantastic support and information services, spread awareness and keep driving forward our research and advocacy work.

Here are some of the highlights:

Providing support and information



Our 38 support groups held a total of 180 meetings



Our telephone peer support volunteers helped 317 people



Our closed Facebook group now has 2264 active members



Over 700 calls were taken by our specialist nurses



96% of callers said their call was 'very helpful'



Our National Conference returned in person

Raising awareness



During International Cardiomyopathy Awareness Week the campaign's video reached over 6 million people.

Improving care and treatment



632 responses to our National 'My Cardiomyopathy Care Survey'



We provided patient insight to the NICE review of a new medicine for obstructive hypertrophic cardiomyopathy

Research



Our first Head of Research and Policy joined Cardiomyopathy UK



CureHeart won the British Heart Foundation's "Big Beat Challenge" winning a £30million research grant to find the world's first cures for inherited cardiomyopathies



Thank you to everyone who has supported our work and made these achievements possible



Q&A

with our nurses

If you have a question for our experts to answer, please email:
supportnurse@cardiomyopathy.org



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Q.

I have DCM and have been experiencing palpitations and breathlessness for a few weeks, what does this mean?



Nurse Caryl

If you are experiencing palpitations and breathlessness, it is important to rule out atrial fibrillation (AF), the most common type of irregular heart rhythm (arrhythmia).

The main characteristics of AF are:

- You can feel your pulse jumping around (irregular)
- You have a fast pulse
- Palpitations (feeling of fluttering sensation in the chest)
- Feeling breathless
- Feeling faint
- Fatigue / tiredness

It's important to be aware of your heart rhythm as nearly 5,000,000 people have undiagnosed AF in the UK. You are at increased risk of AF if you have cardiomyopathy. Other risk factors are age (increased risk over 65), high blood pressure, and heart failure.

If you have AF but you're not aware of it, you could be at increased risk of having an AF related stroke. If you have any of the above symptoms it is important to contact your doctor or nurse so that they can carry out the appropriate investigations.

Q. Why did my Cardiac/heart failure nurse check if I am anaemic?



Nurse Jayne

Anaemia is a condition where you have less red blood cells than your body needs to carry oxygen to your body's tissues. Some people can feel tired and weak. Sometimes people who are diagnosed with heart failure can also have anaemia. There are different types of anaemia, and your GP will advise which type you have and the likely cause; it may be that your body isn't making enough red blood cells or is breaking red blood cells too quickly.

Your GP, practice nurse, cardiac or heart failure nurse will have arranged for you to have a full blood count test (FBC). This test will show the number and shape of your blood cells. Treatment for anaemia will depend on the cause and will vary from person to person.

Scan the QR code to find further information about anaemia:



Q. What are the risks of vaping for someone with cardiomyopathy, particularly for young people?



Nurse Emma

Vaping is the act of inhaling and exhaling the vapour produced by the heated nicotine liquid of an electronic cigarette vape pen, or personal vaporiser. Long-term outcome studies on the cardiovascular risk of vaping electronic cigarettes are still a way off, however, we do know the immediate effects. The risk factors for cardiovascular disease include increases in blood pressure, heart rate and blood vessel constriction, as well as arterial stiffness. This is seen immediately after vaping compared to people who did not use any nicotine.

If you have cardiomyopathy, the risks that come with vaping could have a negative impact on the care and management of your cardiomyopathy. If you are a parent or guardian of a teenager with cardiomyopathy and you're concerned about the effects of vaping, talking to your teen about vaping and its negative effects will be a good start and Cardiomyopathy UK are here to offer additional support and advice.

This is general advice only. If you have any concerns, speak to your GP, cardiac or heart failure nurse.



Expert patient Uncertainty or a quest for answers

We all have three basic needs: to feel effective in dealing with our environment, be able to control the course of our lives and have close relationships with others.

These needs are 'nutriments' which help with our development and function - our overall wellbeing.

Patients will have frequent interactions with different medical professionals, and this is especially true when you have been diagnosed with a heart condition. Being confident to ask questions and make informed decisions about your care and treatment jointly with your cardiologist or cardiac nurse is important for many people.

A diagnosis can mean we are faced with new and sometimes complex medical information and emotional distress. Together, these can contribute to feelings of uncertainty, fear and loneliness.

In many cases it can be difficult to speak to friends and family and cardiologists don't always have the time to talk about living with cardiomyopathy.

Hearing other people's experiences and learning more about your condition through patient support groups and one-to-one peer support can be one of the most important first steps towards feeling less isolated and frightened.

Starting your journey to ultimately feeling more comfortable talking about your diagnosis with other people can begin by speaking to people with the same condition.

This can help you to feel:

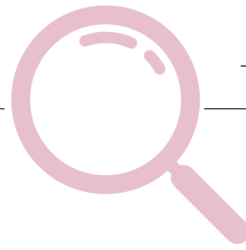
- Less lonely, isolated or judged
- More upbeat, relaxed and energised
- That you have the time and space you need to talk honestly and openly about your feelings
- More able to manage aspects of your condition
- More confident, in control and hopeful

Becoming an expert in your own condition can take time, so don't put too much pressure on yourself, we're here to help. Being actively involved in your own treatment by making informed decisions about your care can, for some people, help to improve their longer-term health.

We can help you to feel empowered by:

- Providing up-to-date, accurate and clear information
- Advising you about who and what to ask to get the information you need
- Listening - sometimes we just need time to talk things through, and that's absolutely ok
- Using our specialist knowledge to suggest specific information or support options tailored to you

To find out more about how we can help you, visit www.cardiomyopathy.org/peer-support



Take part in research

Non-ischaemic cardiomyopathy & ICDs

In August 2022 a team of researchers led by Dr Andrew Flett, consultant cardiologist at Southampton General Hospital were awarded a £1.8 million research grant by the British Heart Foundation to look at how people with non-ischaemic cardiomyopathy might benefit from an ICD (implantable cardioverter defibrillators).

What is Non-ischaemic cardiomyopathy?

Non-ischaemic cardiomyopathy (NICM) is a common cause of heart failure accounting for around a third of cardiomyopathy cases. 'Non-ischaemic' refers to the fact that the weakness of the heart muscle that characterises the condition is not primarily due to the blood flow down the coronary arteries. Some patients with NICM can be at the risk of sudden cardiac death due to dangerous, very fast heartbeats which can cause cardiac arrest.

What will this study involve?

ICDs can treat cardiac arrest and stop fast, abnormal heart rhythms by delivering an electric shock to the patient's heart. The current guidelines look at how well the heart is pumping to decide which patients should get an implant.

Previous studies had found that ICDs did not improve life expectancy for people with NICM. However, this study aims to reassess these findings by recruiting people who have not had an ICD fitted already but who do have scar tissue as shown on an MRI scan of their heart.

Participants in the study will be randomized into two different groups: Group A will have an ICD fitted, and Group B will not have an ICD fitted. Both groups will then be monitored over several months.

Find out more

The researchers hope to recruit around 2,500 people in total from around 35 locations in the UK. **If you're interested in finding out more about this study and whether you meet the specific criteria for taking part, please email the research team at british@soton.ac.uk**

You can find out about other cardiomyopathy research currently taking place across the UK on our website here:



State of Cardiomyopathy Care

REPORT 2023

In June 2022 we launched a national survey asking people living with cardiomyopathy, and their loved ones, about their experiences of accessing care and treatment in the UK. Our aim was to develop a clear understanding of the current state of cardiomyopathy care and treatment and identify areas of inequality and gaps in service provision.

632 people responded to the survey from across the UK, read our findings below:



Diagnosis

GP's struggle to diagnose cardiomyopathy



53% of people who first went to their GP with cardiomyopathy symptoms were diagnosed initially with a non-heart related condition



No one seemed interested in taking my concerns seriously or willing to investigate my symptoms further.



Where you first go for your care affects how long it takes to be diagnosed: Of the people who went to accident & emergency (A&E) first:



92% of the people were immediately diagnosed with a heart related condition



76% saw a cardiologist within 3 months. This is compared to 51% of people who went to their GP first.



Care plans and involvement in treatment

Having received an agreed treatment or care plan enables a person with cardiomyopathy to have a much better understanding of their condition and a clearer idea of the support and treatment that they should expect to receive.



I have to really push to be listened to sometimes.





Only **36%** of people surveyed said that they had a plan in place for their cardiomyopathy care.



42% of respondents did not feel that they had a say in what their treatment should look like or that their personal views were heard by the clinicians.



Family screening and genetic testing

Location and the **type** of cardiomyopathy a patient has affects access to genetic testing.



LOCATION:

54%

in England

62%

in Scotland

TYPE OF CARDIOMYOPATHY:

71%

Hypertrophic

42%

Dilated



Mental health and wellbeing



50% felt that they struggled to cope emotionally over the last 6 months.



46% feel access to counselling & therapy would help their emotional wellbeing.



9% with cardiomyopathy had been offered mental health support as part of their care.

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I live alone and I get very scared about my condition and how to cope with it. Also I feel anxious a lot of the time as I never know what will happen next in my body."

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Scan the QR code to read the full State of Cardiomyopathy Care Report 2023



Meet Tash

Our wide range of support groups are run by a network of amazing volunteers. One of those volunteers is Tash, who is our West London Support Group Leader

Please tell us a bit about yourself

My name is Tash and I'm from London. I am a mother with 3 daughters, a son, and also 2 grandchildren. I have a background in law and integrative counselling. In my spare time, I enjoy writing, reading, cooking, baking and most importantly family time and creating new memories daily. I also enjoy playing the saxophone and singing when my heart permits.

Why did you decide to become a Support Group Leader?

When I was diagnosed with dilated cardiomyopathy and heart failure in 2013, there was not much support available to me and I hadn't heard of Cardiomyopathy UK until

much later on. I did not know anyone with the condition, so it felt lonely and it was very hard to expect anyone around me to understand how I was truly feeling being diagnosed with this life-changing condition. I wouldn't want others to feel so alone on their own cardiomyopathy journeys, as although it is a physical condition, it can also affect your mental well-being. My aim is to offer support and create a safe space for our members to share their feelings and meet others with the condition.

Please tell us about what your volunteer role involves.

The Support Group Leader role is nice and varied. It involves a little bit of admin, inviting



expert guest speakers to present on topics our members would like more information on, ensuring our members feel safe and comfortable, and signposting to other Cardiomyopathy UK services where necessary.

What do you enjoy most about your role and what have you learned?

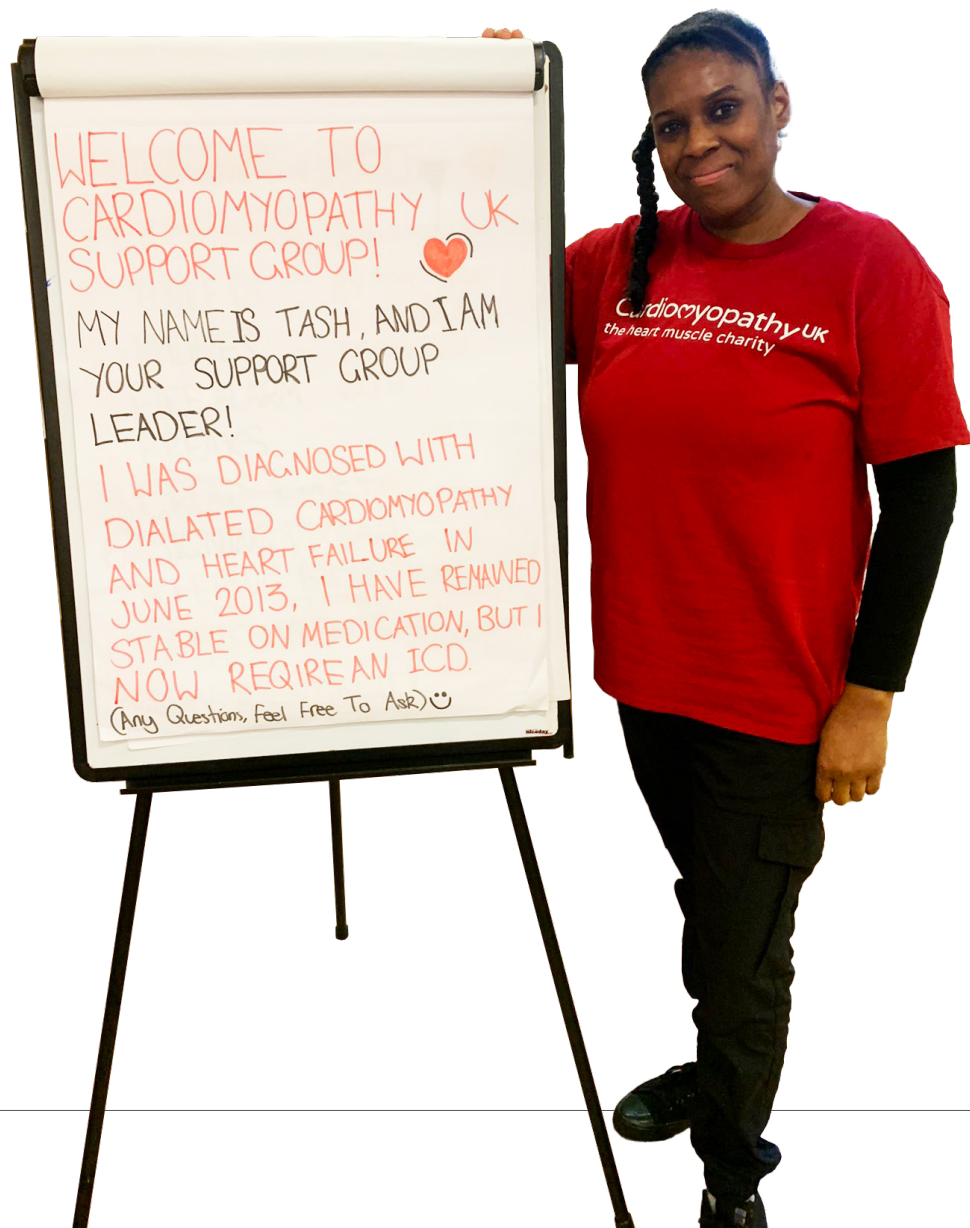
I enjoy seeing our members coming together and sharing their different experiences and journeys. I also love receiving feedback and knowing that I am making a difference to people's lives by hosting these meetings. This role has taught me that I have a lot to offer others affected by cardiomyopathy, and just how important it is to support one another.

What would be your message to others considering volunteering?

It is very rewarding knowing you can make such a difference to people's lives. These groups can actually be a lifeline, as not everyone is fortunate enough to have a supportive network of loved ones who live close by.

To find out more about our groups, visit:

www.cardiomyopathy.org/supportgroups



WELCOME TO
CARDIOMYOPATHY UK
SUPPORT GROUP! ❤️
MY NAME IS TASH, AND I AM
YOUR SUPPORT GROUP
LEADER!
I WAS DIAGNOSED WITH
DIALATED CARDIOMYOPATHY
AND HEART FAILURE IN
JUNE 2013, I HAVE REMAINED
STABLE ON MEDICATION, BUT I
NOW REQUIRE AN ICD.
(Any Questions, Feel Free To Ask) 😊

Remembering Mitchell 10 years on

My brother, Mitchell Cole, passed away on the 30th November 2012 from hypertrophic cardiomyopathy. Before Mitchell passed away, he was an ambassador of Cardiomyopathy UK and was keen to raise awareness. Mitchell died doing what he loves – playing football. There has been so much amazing support from Mitchell’s family and friends over the last 10 years and we are proud to have raised over £80,000 for Cardiomyopathy UK.

I wanted to do something big to remember Mitchell in 2022, as this marked 10 years after his passing. I decided to go with cycling. I am not a cyclist. Before my challenge I didn’t even own a bike and I’d never cycled over 10 miles, so I knew it would be extremely hard. I wanted to do a big challenge that would incorporate Mitchell’s love of football, so I decided to cycle to each of the football teams’ stadiums that Mitchell played for professionally. The route was just shy of 400 miles and was going to take 5 days.

My uncle, Cliff, agreed to join me, following me every day on his quad bike. It was great having Cliff there to help with any issues, to talk to (or vent to) when I was struggling and to encourage me. My partner, Kimberly, did all the behind the scenes work and made sure we were stocked up with everything we needed.



On November 26th, we left at 6:30am and headed to the starting point (Upton Park, former home of West Ham). On the way there, a song that me and Mitchell used to sing together came on the radio - Don't Stop Believing by Journey. I got goosebumps and the memories of Mitchell helped my nerves at the start line.



We arrived at Gray’s Athletic, but the stadium wasn’t there. A man walking nearby told us that the stadium had been demolished. I told him about my challenge and about Mitchell. It was amazing to hear that he remembered Mitchell and had even seen him play. It was conversations like this which motivated me throughout this challenge, and I could feel how many people Mitchell made his mark on.

//

We had people stop us to ask what we were doing and how they could donate. This felt as though we were really making a difference with our challenge!

//



Day 1

As we continued on Day 1, Cliff took a slight turn for the worse, so I decided to carry on by myself before it got too late and dark. Within 30 minutes, it had become pitch black. At this point, I started getting a lot of encouragement from passers-by. The beeps and waves from the people I passed helped me through the darkness.

Day 2 & 3

Day 2 went by without too many problems and just like that, I was nearly halfway through the challenge. We set off early on Day 3, having to navigate through the Northampton rush hour and the freezing cold. Although it was hard to get started, me and Cliff were able to enjoy the sun coming up over some nice scenic routes, Mitchell always on our minds. My legs were starting to become heavy now and it seemed like there was just hill after hill! Me and Cliff started to beep and cheer ourselves when we could see some downhill in the distance. Due to Cliff's quad bike, we caught a lot of attention and on Day 3, we had people stop us to ask what we were doing and how they could donate. This felt as though we were really making a difference with our challenge!

Day 4

Day 4 felt like it was all hills, which led to a lot of beeping and cheering from me and Cliff again to keep us motivated. The kindness of everyone we met kept us motivated on Day 4. We met a curious local that asked us about our journey and even offered us tea! We then arrived at Aylesbury where we were greeted by Adrian from Cardiomyopathy UK, who kindly bought us some food.





Finally, we made it to the Oxford United Stadium and had a lovely reception from Christie and Jaye from Cardiomyopathy UK and two Oxford United Staff who remembered Mitchell. They were kind enough to offer for me to go pitch side with my bike for some pictures. We shared some stories of Mitchell and some history of Oxford united.

“ I was really flagging. But with Mitchell in my mind, I kept pedalling. ”

Day 5

On Day 5, I was really struggling with my legs and I was in pain. I decided to set off by myself at 6am. Today marked 10 years since Mitchell’s passing. I knew I could just be in my own company and keep pedalling away. It was really dark, and I had a few hours where I couldn’t see too much into the distance. My legs were hurting, I was hungry, I didn’t feel I had any energy and was really flagging. But with Mitchell in my mind, I kept peddling.



As I finally got to the last stop, I am surprised by friends that have come along to support and congratulate me. We all take a walk round to Mitchell’s tree for a few moments of reflection.



Fundraising Superstars



Stef and Jenna's knitting challenge

"We met in March 2022 in the Coronary Care Unit in the Queen Elizabeth Hospital Birmingham. After getting to know each other we realised we were both on the urgent list waiting for a heart transplant. We soon became good friends. We wanted to give something back and decided to join the 30-day challenge to raise awareness and money for a fantastic cause and charity that's a big part of our lives. We challenged ourselves to try something new that's out of our comfort zone, and so we decided to learn to knit!"



Baking a difference

Cathy and the catering staff of Sullivan Upper School in Northern Ireland raised just over £1,000 from their bake sale held in memory of one of their former pupils.



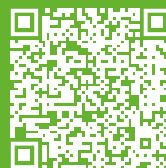
Family fundraising

Kyren and her two sons, James and Lewis, are taking on both the London Marathon and RideLondon cycle this year and held a fantastic Ceilidh Dance and raffle as part of their fundraising, raising £690.



Have you seen our new fundraising pack?

Our new and interactive digital fundraising pack is now available online. It's packed full of tips and inspiration for planning, promoting and making the most of your fundraiser.



Cardiomyopathy^{UK}
the heart muscle charity

Great North Run



10th September 2023



Join #TeamCardio and run for people living
with cardiomyopathy

www.cardiomyopathy.org/great-north

