

# myLife

The magazine for people affected by  
cardiomyopathy and myocarditis

Issue 22/Summer 2020

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**'I was petrified I wouldn't  
see my daughter grow up'**

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

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 01494 791224

### Helpline

**0800 018 1024**

*(free from a UK landline)*

*8.30am-4.30pm, Monday-Friday*

### Find us online

 [www.cardiomyopathy.org](http://www.cardiomyopathy.org)

 [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org)

### Live chat

[www.cardiomyopathy.org](http://www.cardiomyopathy.org)

*8.30am-4.30pm, Monday-Friday*

### Social media

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# Welcome



## Welcome to this edition of My Life.

Despite the challenges for many of you trying to cope with heart disease, common illnesses and the threat of a coronavirus epidemic, work at Cardiomyopathy UK continues at speed.

I hope by the time you read this, it will have stopped raining too!

This issue features highlights from our 2019 Impact Report and some of the things we achieved last year.

Our board of trustees (turn to Page 12 to meet our latest members) decides the charity's strategy, but we are delighted with the impact our volunteers – supported by our staff – make to those affected by cardiomyopathy and myocarditis.

For some, their place is supporting other patients in face-to-face, telephone, or Facebook conversations. For others, their role is focused on raising awareness or fundraising.

On Page 14, read about how we are creating a new role for volunteers, by building a national network of patient/supporter representatives, who can work alongside us to influence health policy and local delivery.

Our aim is to support clinicians in providing the type of services that we need, such as one-stop specialist clinics.

While some services need more resources, much can be done by developing people in different ways and sharing best practice.

Keep well,

**Alison Fielding, Chair**

*Front page photo: Holly Aldridge and daughter Megan*



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# Guide to restrictive cardiomyopathy

## What is restrictive cardiomyopath (RCM)?

Restrictive cardiomyopathy is a rare form of cardiomyopathy in which the heart's ventricles (the lower chambers) become stiff and lack the flexibility to expand as they are filled with blood.

This poor filling function means that the ventricles receive less blood than normal, and so blood flow around the body and the heart is reduced.

Also, blood gets 'backed up' as it cannot enter the heart as normal, which causes a build-up of pressure. This can cause the atria (top chambers of the heart) to enlarge.

## What are the symptoms of RCM?

Some people have no symptoms of RCM, or very mild symptoms.

But over time, the restricted function of the heart can lead to heart failure (where the heart fails to pump enough blood, at the right pressure, to meet the body's needs).

This can cause symptoms that develop as the heart's function reduces. Symptoms can include

the following:

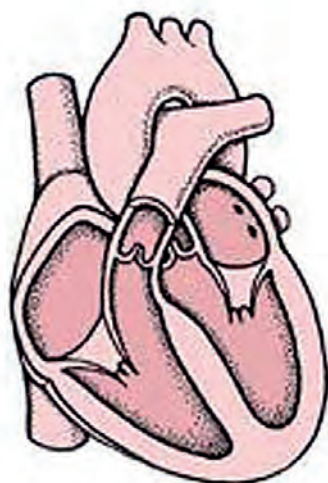
- shortness of breath;
- fatigue;
- swelling in the abdomen and ankles;
- weight gain;
- loss of appetite;
- palpitations;
- nausea and
- fainting.

## What causes RCM?

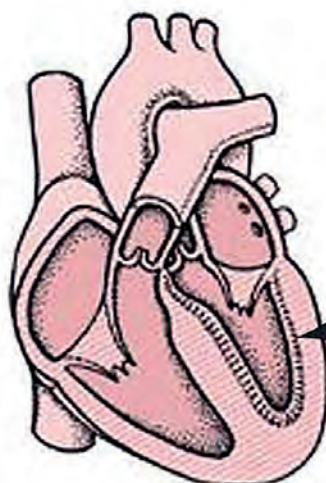
Although the cause of RCM is often unknown, it can be genetic and run in families. It can also develop owing to other conditions, such as:

- scar tissue in the heart;
- amyloidosis – a condition where there is too much of an abnormal protein (called amyloid) in the body, and it builds up in the heart muscle;
- haemochromatosis – a condition where too much iron from the diet is absorbed and it builds up in the organs, including the heart, and
- following some treatments for cancer, such as radiation therapy.





› A normal heart



› Heart with restrictive cardiomyopathy where the ventricle walls stiffen and lose flexibility

## Who gets RCM?

RCM is relatively rare compared to other types of cardiomyopathy.

It is most often diagnosed in children (rather than adults) at five to six years of age, although it can develop at any age.

## How is RCM diagnosed?

As symptoms can be subtle to start with, diagnosis may be difficult.

A diagnosis is based on medical history, a physical exam and tests such as an electrocardiograph (ECG) and an echocardiogram (ECHO).

Occasionally, a myocardial biopsy (biopsy of the heart

muscle) is done to determine the cause of RCM.

## What is the treatment?

Although RCM cannot be cured, treatment aims to reduce and control symptoms.

Some treatments may not be suitable, depending on the underlying cause of the RCM.

Doctors many recommend lifestyle changes, which might include a healthy diet and exercise.

They may also discuss using medications to treat heart failure, including beta-blockers and ACE inhibitors.

In severe cases, people with RCM may require a heart transplant.



## Charley's story

Charley is a member of our CYP&YA Panel that meets regularly to discuss how to improve services for young people affected by cardiomyopathy and myocarditis.

**Charley Maunder, 22, has never known what it's like living without a heart condition.**

Born with a heart defect, she had closed-heart surgery at six days' old and open-heart surgery at four months.

And since being diagnosed with restrictive cardiomyopathy (RCM) aged 11, she has been assessed three times for a

heart transplant.

However, the supermarket worker from Poole, Dorset says she felt "completely normal" as a child.

"I wasn't aware of any difference as my parents tried very hard to treat me exactly the same as my brother and sister," she says.

"But growing older, as my RCM got progressively worse and I got

more symptoms, I started to notice how different I was and throughout the years, it has affected every area of my life," she admits.

"As a schoolgirl, I had to stop trampolining and gymnastics. Later, I had to give up training to be a beautician because it was too physically demanding."

Today, Charley says her RCM affects 50 per cent of her lifestyle.

"I've worked hard to find a good work/life balance so my days feel full, but I don't feel ill by the end of the day.

"This has been particularly hard because I'm unable to work full time or pursue my dream of a career in health care as it would be too strenuous," she adds.

"I worked in a lovely cafe as a waitress, but again, this got too much and I had to give it up.

"But then I found a sympathetic employer at a supermarket with a strong disability policy where I work part-time doing short shifts. I also volunteer in a charity shop twice a week, which gives me a routine."

Although there have been many difficult times, Charley is grateful to Cardiomyopathy UK for helping her understand more about RCM and giving her a voice to speak out and raise awareness.

"As I get older and learn more

about the condition, I'm living a much more full life and there is so much support from Cardiomyopathy UK for people and carers in exactly the same position as me."

Charley is currently managing her condition with medication, despite knowing her RCM will continue to deteriorate and she'll need a heart transplant.

"I was on the transplant list from 2017 to 2018, but then I was taken off and I felt a huge sense of freedom.

"Although I don't know what the future holds, it's hard knowing I will probably need a transplant at some stage.

"But I'm putting it to the back of my mind while I try to get physically and mentally stronger," she insists.

The good news is that Charley is now well enough to go on her first solo holiday to Thailand in October.

"My condition has always been noticeable when I go away because I can't keep up with my family or friends and we have to make adjustments, or I don't join in with what they're doing.

"My brother and sister have both had the chance to travel, so I was so excited when I booked my first two-week trip on my own. I'm looking forward to seeing the world and being just like any other tourist!"

Get cooking and support Cardiomyopathy UK with our

## 2020 foodie fundraiser



› *Chocolate cake with raspberries. This cake recipe is also available with vegan-friendly ingredients*



› *Lemon and poppy seed drizzle cake. This cake has been made with 20% less sugar and spelt flour*

**O**ur gourmet chef Ian Human has created a delicious 2020 foodie fundraiser to help families affected by cardiomyopathy.

Fundraising events are so much fun to organise and take part in,

and are even more enjoyable when surrounded by friends and family.

Ian has created two recipes for you to try – a chocolate cake with raspberries and a lemon cake, made with alternative ingredients to reduce sugar and



dairy content. Ian has worked hard on changing the ingredients to create cakes we guarantee your guests will love!

Organising your coffee and heart-shaped cake event couldn't be simpler.

Whether you host it in the comfort of your living room with a few friends, organise it as a large social event with your support group, or anything in

between, the event is all about having fun and raising money and awareness.

**To request your foodie fundraiser recipe cards and fundraising pack, go to <https://www.cardiomyopathy.org/fundraise-for-us/fundraise-for-us>**

**Or contact our community fundraiser Jaye at [chassebi@cardiomyopathy.org](mailto:chassebi@cardiomyopathy.org)**

## Charity raffle is back with a bang



**Our annual Summer Raffle is back for 2020 with more amazing cash prizes to win.**

With tickets on sale for just £1 each and prizes worth £500, £250 and £100, why not try your luck and enter?

Use the raffle ticket booklet inside this My Life to buy tickets for yourself and sell to your family and friends, then simply send the booklets back to us. (Please recycle any unused tickets).

You can also visit our online shop to buy tickets at <https://www.cardiomyopathy.org/shop/shop/product/raffle-ticket--single>

Our goal this year is to sell 5,500 raffle tickets.

The closing date is August 31 and only tickets purchased online and received in the post by the end of the day on August 31, will be counted. The draw will take place on September 1.

Each £1 ticket helps support our vital work and enables us to be there for families who need us.

To find out more information, contact our community fundraiser Jaye on [chassebi@cardiomyopathy.org](mailto:chassebi@cardiomyopathy.org)



If you have a question for our experts to answer, please email [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org)



› Ali Thompson



› Jayne Partridge



› Emma Greenslade



› Caryl Evans

**Q: Why am I feeling so fatigued?**

**Support nurse Jayne Partridge** says: "Fatigue is feeling unusually tired and weak.

"It isn't the same as feeling drowsy or sleepy and can't be remedied by sleep or taking a rest.

"Being sleepy may be a symptom of fatigue, but it's not the same thing.

"When you are fatigued, you have no motivation or energy. Fatigue can be owing to health conditions such as cardiomyopathy and can also be as a result of stress, bereavement or anxiety.

"It can be caused by your muscles not getting enough oxygen and can also be caused by insufficient sleep.

"Some medications can cause fatigue – beta blockers, ACEs (angiotensin-converting-enzyme inhibitors) and calcium

channel blockers – which work by reducing the workload or slowing down your heart.

"Some diuretics, such as furosemide, can make you feel fatigued by eliminating some electrolytes.

"These effects may wear off once your body adjusts to the new medication or dose increase. However, if you are concerned, see your GP or cardiologist."

**Q: What are some developmental concerns associated with having cardiomyopathy as a child?**

**Support nurse Emma Greenslade** says: "The way a child deals with stress depends on age and developmental level, temperament, and family situation.

"Information provided to children should be tailored to their maturity level, health literacy, needs, and readiness

to understand their cardiac condition.

"Children often exhibit an increased readiness to learn at key points in development, so watch for teachable moments and provide education and counselling at your child's maturity level.

"Encourage them to take an active role in managing their cardiomyopathy. Talking about it by participating in taking medication and interacting with their paediatric cardiologist at appointments can help.

"Anxiety is the most common psychological symptom experienced by children with cardiomyopathies, and therefore, they may experience a greater need for affirmation from friends and family and counselling if the family feel they are not able to cope.

"Signs that a child is having difficulties adjusting to living with a medical condition include constant feelings of being sick ie: tummy pains (leading to school absences), social isolation, or avoidance behaviours.

"Always seek help and don't try to deal with the worries yourself. Other family members can help, as well as paediatric counselling therapy."

*Q: I had a cardiac MRI scan three weeks ago, and a transthoracic echo-*

*cardiogram last week at my routine cardiologist appointment that said my EF was 40%. I then received a letter a few days after from another doctor, stating systolic function from the MRI showed the EF is 30% with systolic function still severely impaired. Why the difference?*

**Support nurse Caryl Evans** says: "MRI is gold standard imaging for cardiomyopathy for assessing and evaluating the quantity of the heart's function including volume, and of course, ejection fraction (EF).

"Echocardiography is the most widely used imaging in practice as it is more widely available and less time consuming. However, any technician or cardiologist carrying out a transthoracic echocardiogram (Echo) follows set standards and protocol when evaluating and estimating the size and function of the heart.

"Each professional has a slightly different way, but in essence, this margin of difference is very small.

"Clinical research into this has shown cardiac MRI is more sensitive in distinguishing wall motion abnormalities and essentially a more accurate evaluation.

"If there is a discrepancy, you should go with the results of the MRI."

# Our impact in 2019



By Joel Rose  
Chief Executive of  
Cardiomyopathy UK

**2019 was another great year for the charity and I'm especially pleased that we were able to reach out to more people and make a deeper and longer-lasting impact on their lives.**

In our 30th anniversary year, it was amazing to think how far we had grown and I'm proud that while the range of our work and the number of people

we support has increased greatly since our early days, we still remain rooted in the community that we support and have kept true to our core belief that everyone affected by cardiomyopathy should lead long and fulfilling lives.

Take a look (facing page) at a few of our service highlights included in our 2019 Impact Report, which will be available soon.

**We're delighted to introduce three new volunteer members onto our board of trustees, which has overall responsibility for the work of Cardiomyopathy UK**



**Tootie Bueser** is the lead cardiac genetic nurse for Inherited Cardiac Conditions (ICC) services at King's College Hospital and Guy's and St Thomas' Hospital. She is currently completing a PhD on improving the care of patients with ICCs and will soon join St Bartholomew's Hospital as the Associate Director for Clinical Research, where she hopes to continue her research focusing on ICC patients and their families. Tootie is a member of the Clinical Expert Advisory Group for Cardiomyopathy UK and also volunteers for the patient support line.



**Elis Power**, 26, was diagnosed with Hypertrophic Cardiomyopathy, four years ago. HCM was found to be in his family after his father passed away suddenly. Elis is a founding member of the charity's 14-25 Young People's Panel and also runs the Bridgend Cardiomyopathy Support Group with his mother and fiancée. Elis says he hopes by working with the board of trustees, he can continue working towards his goal of supporting those who struggle with their diagnosis at a younger age.



**Alyson Smith** reached out to the charity more than 25 years ago to source information on HCM as her husband had been recently diagnosed. The telephone support and screening information was invaluable to the family. In 2019, the gene was identified in the family, with one of her grown-up children identified as a carrier. With a career in corporate social responsibility and 18 years' experience as a fundraising manager, Alyson says she is passionate to see the charity grow and increase awareness in the community.



› We welcomed an unprecedented 235 attendees to our 2019 conference in London with the aim — as always with our conferences — for people to leave more knowledgeable, more confident, and a little more hopeful for the future...



› Clinicians told us that attending our clinical education event had...

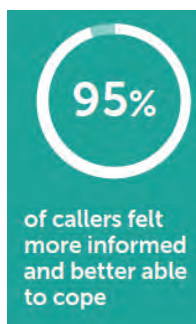
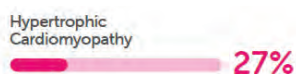
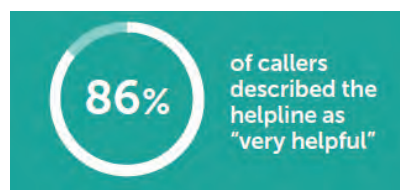
Improved their confidence in detecting and treating cardiomyopathy



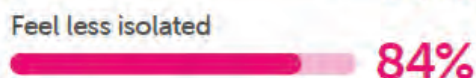
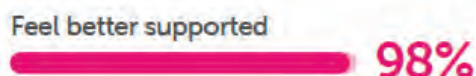
Greatly improved their knowledge of cardiomyopathy and related conditions



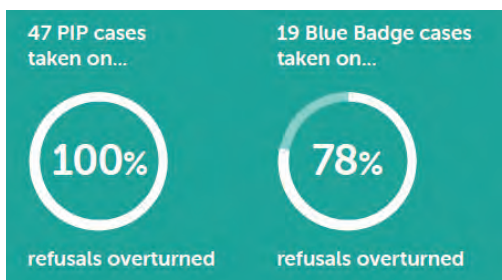
› We are delighted with the impact our Helpline made last year to people with the following conditions...



› People who attended our support groups told us it helped them...



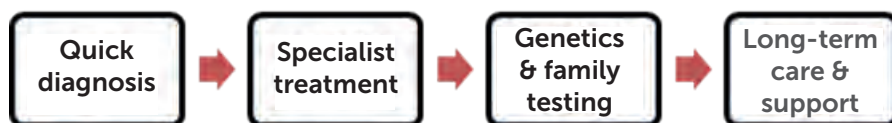
› The charity worked hard to ensure anyone entitled to welfare benefits was given the help they needed...



# 'Local volunteers will be crucial'

## Charity launches new Advocacy Project

›The ideal treatment pathway, which is experienced by only nine per cent of people we surveyed



**9%** of people with cardiomyopathy are receiving the ideal care and treatment

**I**n 2019, the charity undertook its own research project looking at the experience of people with cardiomyopathy in being diagnosed, treated and accessing screening and genetic testing.

Our work showed that only a small proportion of people received the ideal care and treatment and highlighted real problems with securing a diagnosis and receiving specialist care and long-term support.

It was especially worrying to see that far too many people are not being told about the potentially genetic nature of cardiomyopathy; asked

about their family; or offered genetic testing. The charity has been working to address this issue through our clinical education programme and our work with other charities and organisations within the heart failure community.

This has had some impact, but clearly there is much more that needs to be done.

This year, we will be launching a new project aimed at identifying and addressing problems in the care and treatment pathway.

The project will bring together volunteers, who are service users and clinicians, to form local teams that identify the improvements that can be made in their area and create a

"local action plan." Each plan will be based on an understanding of local shortcomings against best practice and NICE guidelines and map out specific goals, timescales and the actions to be undertaken, to improve care and treatment.

While it is important that we make our voice heard and are clear about what needs to be improved, we do see our role as a source of support; bring people together and facilitating change.

By working in this way and on a local basis, we believe that we can make the best use of our volunteers and clinical networks and have a better chance of making changes that will impact positively on people's lives.

This is an ambitious project and we will need a team of well-trained and dedicated volunteers to work in their local areas in order to help us shape our strategy across the UK.

Local volunteers who are service users are crucial to this project.

This is because the organisations that commission and deliver local service are required to have patient representation and are expected to respond to patient input.

So a focused attempt to highlight deficiencies in a regional by service users is likely to have a positive impact especially where this can be supported by local healthcare professionals and the charity.

Later this year, we will be starting the volunteer recruitment and training process so please look out for more information.

While this project gets underway, we will continue our work on a national level alongside other charities, medical associations and stakeholders in the heart failure community, making the case for better support and treatment for people with cardiomyopathy.



› Jaye Chassebi

## New to the team

A big welcome to two new staff members – community fundraiser Jaye Chassebi and Karen Gregory, challenge events fundraiser (maternity cover).

With so many ways to raise funds – from bake sales, to abseils and skydives – Jaye and Karen have done all sorts of events and can help you with ideas for yours, so please give them a call on 01494 791224.



› Karen Gregory



# What you need to know post-Brexit



*By Jayne Partridge  
Cardiomyopathy UK  
Support Nurse*

**We take a look at the implications for travel and healthcare within the European Union (EU), which may be a worry for some people with cardiomyopathy.**

## **Advice for Travellers**

Both the UK Government and the EU say UK citizens will still be able to travel to and from the EU following Brexit.

Despite the UK leaving the EU on January 31, everything will remain the same. This is because there is now a transition period until the end of 2020, while the UK and EU negotiate additional arrangements.

Flights will continue as normal between the UK and EU, as will ferries and cruise ships, which operate under international rules rather than EU rules.

A travel visa won't be required to travel to the EU, as long as travel is up to 90 days within a 180-day period.

It is important that whenever and wherever you travel, that you have adequate travel

insurance that covers your specific needs, including medical conditions.

You can also speak to your travel insurer about any specific cover for the post-Brexit period.

A link to travel insurance information can be found on our website <https://www.cardiomyopathy.org/insurance/travel-insurance>

## **Passports**

Newly-issued British passports will be blue and gold and lose all references to the European Union, but existing passports can still be used to travel to and within the EU, until they expire.

You do not need to have six months left on your passport to travel to the EU.

The UK Government has published an online tool to help you check the validity of your passport at <https://www.passport.service.gov.uk/check-a-passport>.

Remember that your passport must be valid for for the *whole* of your trip.

## **FIND OUT MORE**

*If you would like further information, please contact the support nurses on our Helpline 0800 019 1024 or via [supportnurse@cardiomyopathy.org](mailto:supportnurse@cardiomyopathy.org)*



## European Health Insurance Card and travel Insurance

The European Health Insurance Card (EHIC) allows any EU citizen to access state medical care when they are travelling in another EU country.

Therefore, UK registered EHIC will remain valid post Brexit and during the transition period.

ABTA advises holidaymakers and business travellers to also make sure that they have appropriate travel insurance, whether they have an EHIC card or not, as there are limitations to EHIC.

When travelling to the EU, it is important you take out travel insurance and check that it covers your current circumstances.

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The new rules for living, working, travelling and doing business in the UK and EU will start from January 1, 2021. Go to <https://www.gov.uk/> for more information.

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If you have an annual policy, make sure that you check the terms and conditions and contact your insurance provider if you are not sure.



## Driving Licences

As long as you have a full UK driving licence, you don't currently need an additional licence to drive in the EU.

Depending on your destination and the length of your stay, UK licence holders looking to drive in the EU will not need an international driving permit.

If required, driving permits are available from the post office at a cost of £5.50.

Green Cards for car insurance won't be required as although the UK has left the EU, the withdrawal agreement is in place.

## Data roaming

Under EU rules, the cost of making calls sending messages or using the internet on your phone in the EU is the same as in the UK.

For a complete breakdown of roaming charges, we advise checking with your network provider before you travel.



› Above: Holly and Megan, who is 'especially precious' as Holly has been advised not to have any more children

# 'I couldn't believe I had heart failure'

**N**ine weeks after giving birth, Holly Aldridge, then 33, started to get palpitations that "would stop me in my tracks and I'd need to sit down afterwards."

Holly, from Powys, Wales, had always been fit and healthy, with no history of heart problems in her family.

The hospital administrator had a normal, uncomplicated pregnancy and a straightforward birth. However, she felt constantly exhausted after her daughter Megan was born on October 29, 2012.

"I was overjoyed with relief and happiness, but also felt utterly exhausted," she recalls.

"I discounted this as the 'normal' feeling of a new parent and assumed my palpitations were owing to the stress of parenthood, but I began to struggle with my breathing and had to prop myself up with pillows at night."

Before long, Holly had to muster every ounce of energy to breastfeed her baby and husband Mike even had to hold Megan so Holly could feed her.

Things came to a head when

one night, the couple realised Holly was so ill they needed to call an ambulance.

Holly was taken to Nevill Hospital in Abergavenny and after hours of tests, she was told she had peripartum cardiomyopathy (PPCM) – news that changed her world.

"When the doctors said I had heart failure, I couldn't believe it," she admits. "Then, when it sunk in, I felt numb and petrified that I wouldn't live to see my daughter grow up."

Holly was transferred to the University Hospital Wales, where a week after her admission, she reacted badly to her medication and crashed.

Semi-conscious, Holly only remembers being surrounded by doctors working on her and when she quizzed her heart failure nurse in clinic a couple of years later, she confirmed that they had expected Holly to die at that point.

She was then transferred to the Queen Elizabeth Hospital in Birmingham, which is the transplant centre for Wales, and initiated on a heart transplant assessment.

"Through it all, my will to fight

and refusal to accept defeat never left me," she insists.

Over time, Holly began to feel stronger and her body began to accept the drugs. And despite her appalling medical profile, she baffled technicians by passing the final tests of her transplant assessment and was sent home "with a huge bag of pills".

A week after her discharge, Holly was determined to get back her independence and learnt how to pace herself.

Although her heart function improved, she was fitted with an ICD and gradually, began to get stronger.

"I had regular check-ups with the heart failure nurses, who very slowly and carefully titrated up my medicine, aiming for maximum dosage," she explains. "I reached a massive milestone on Megan's first birthday – a day I thought I'd never see."

In 2014, Holly was referred to her local cardiac rehab programme, which she says changed her life.

"When I started the rehab programme, I must admit, I did wonder how much benefit I would get from it, as I was the youngest by at least 20 years!

"But because of the way the fitness part of the programme was devised with circuit exercises that could be tailored to each individual's own level, I quickly found that I was getting

fitter and stronger and more able," she says.

By the end of the six-week programme, Holly says she felt like "a new person".

She was no longer too scared to try and do anything more than a quick walk, but also mindful that on tired days, she needed to go easy on herself.

"Today, I'm living a virtually normal lifestyle," she says.

"I work five days a week and attend the same fitness class that I did before I got pregnant.

"I have even walked up Pen-y-Fan – what an achievement and something I thought would never be possible!

"But thanks to my physiotherapist believing in me and all of the NHS staff involved in my care and recovery, I did it."



**Peripartum cardiomyopathy (PPCM) is a rare cause of heart failure with onset usually in the first month after delivery, but may occur in the last month of pregnancy and up to five months after giving birth.**

**In PPCM, the woman's heart becomes enlarged and its pumping action weakened and less able to pump blood than normal.**

**It can be difficult to diagnose PPCM as many of the signs are similar to symptoms that can also happen in pregnancy, such as swelling in the feet and legs, and some shortness of breath.**

**Around 70% of women recover one year following diagnosis (based on their ejection fraction, rather than their symptoms).**

# Legacy of love



**W**hen David Brooks died last year, aged 83, he left a wonderful gift in his will to Cardiomyopathy UK – given in memory of his beloved wife Kay, who had the condition.

David was a racing champion, until one day, his life changed forever after he was knocked off his bicycle in a hit-and-run accident.

He was admitted to Stoke Mandeville Spinal Hospital



in Bucks, where during his rehabilitation and adjustment to being a paraplegic, he met Kay, who was his occupational therapist.

They fell in love, got married and set up home in Chesham, Bucks.

After his Royal Air Force service in electronics, David took a job repairing televisions until he obtained a job with IBM and he remained with them for 30 years.

During that time, he rose to become the chief executive of his section, contributing many good ideas and practices that saved the company many thousands of pounds.

David also supported a number of charities and helped establish a fishing club for the disabled, taking part in many international competitions and on one memorable occasion, the House of Lords.

David and Kay were together for an amazing 47 happy years until Kay sadly died in 2007 and eventually, David moved into a residential care home after suffering a stroke in 2017.

The charity first met David's brother Ron, when he came to visit our office having raised £648 at David's funeral through his MuchLoved tribute page.

Then a few months later, he returned with a cheque for £5,000 to Cardiomyopathy UK, including his own generous



donation.

Ron told us: "David regarded his accident positively as he always said that it had brought him to Kay.

"They were totally devoted to each other and David was always concerned for her heart health as a result of her cardiomyopathy.

"That's why he left a gift to Cardiomyopathy UK, because he wanted to help other people with the condition."

Cardiomyopathy UK is most grateful to Ron and David for their support.

**If you would like to discuss leaving a gift in your will to help future generations, please contact Sheila Nardone, our Head of Fundraising, at [Sheila.nardone@cardiomyopathy.org](mailto:Sheila.nardone@cardiomyopathy.org)**

## Walks and treks



### May-December

There are a great choice of amazing walks and treks to choose from – from the Brecon Beacons trek with two distance choices; to Ultra Walking Events (from 23km to 100km) in the Isle of Wight, London to Brighton, Cotswolds, South Coast or Thames Path; to climbing the National Three Peaks or Yorkshire Three Peaks – check dates on our website.

## 30 Day Challenge

The 30 Day Challenge is your choice – maybe you want to give up snacking on sweets, read a book every day, help a neighbour, practise an instrument, or start an exercise programme?

Memory experts say it takes a minimum of repeating something 21 times for it to become a new skill, so what new skills do you want to acquire?

Simply decide on your challenge, sign up for our free 30 Day Challenge pack via our website, and then ask your friends, family and colleagues to sponsor you for each of the days on your challenge chart.

Whatever change you want to make, the 30 Day Challenge is for you.

## Why not make 2020 the year when you take on a challenge for yourself and for Cardiomypathy UK?

Notice your skills and confidence grow and experience a great sense of achievement while raising vital funds for our charity. From skydiving to a 30 Day Challenge at home, there really is an event for everyone.

■ To take part in any of the events listed, visit our website <https://www.cardiomypathy.org/events/> events or email [fundraising@cardiomypathy.org](mailto:fundraising@cardiomypathy.org) or call 01494 791224.

## Marathon achievements

On April 26, our #teamcardio of 50 runners ran the Virgin London Marathon 2020 (watch out for highlights in our next edition of My Life).

Congratulations and huge thanks to Dougie Paton and Pete Rutherford for running the Marathon des Sables from April 3-13 and raising (at the time of going to press) an amazing \$16,000.

Thank you, Dougie and Pete. To help them reach their target of \$20,000, donations came be made on their Just Giving page: <https://www.justgiving.com/fundraising/petedougmds>

# Join #teamcardio

## Skydive

June 27, 2020

Have the experience of a lifetime by skydiving over the beautiful countryside of Salisbury in June.

The skydive is an unforgettable way to raise money and help people affected by Cardiomyopathy.

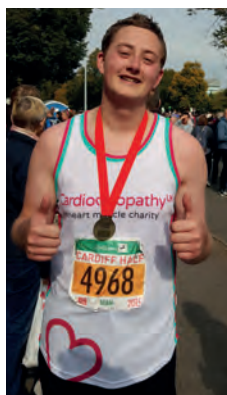
Attached to a professional instructor, you'll jump from up to 10,000ft, experiencing exhilarating freefall before the instructor deploys the parachute and then you drift gently to earth, taking in the beautiful views. All the training takes place on the day, and if you raise £450 you jump for free!

<https://www.cardiomyopathy.org/skydive/skydive-home>



**To apply for one of our charity places in the 2021 Virgin London Marathon, please register via our website from May.**

## Running events



If you're a runner, or an aspiring runner, there's a great choice of runs from fun runs to 10k to Half Marathons.

Sign up for a 10k in London, Bournemouth or Leeds or enter a half-marathon in Bournemouth, Cardiff, Edinburgh, London Hackney or Royal Parks London

Maybe there's a fun run near you that you could enter and run for Cardiomyopathy UK?



Gather your friends and family for some

# Coffee and Heart-Shaped Cake



Cardiomyopathy<sup>UK</sup>  
the heart muscle charity



Enjoy some tasty homemade treats by taking part in our brand new foodie fundraiser, Coffee and Heart-Shaped Cake

For more details, call Jaye Chassebi on 01494 791224  
or email Jaye on [jaye.chassebi@cardiomyopathy.org](mailto:jaye.chassebi@cardiomyopathy.org)