

# my life

Issue 14/April 2018

Cardiomyopathy<sup>UK</sup>

The heart muscle charity magazine for people affected by cardiomyopathy



The beat  
goes on

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# IS THIS YOUR FINAL COPY OF MY LIFE?

From 25 May, changes to the law mean that we need your permission to contact you.

Without your permission we can no longer send you a copy of My Life magazine, or stay in touch via email.

This is the last issue of the magazine you will receive unless you have already contacted us to tell us that you want us to stay in touch.

Time is now running out, so please let us know that you want us to keep sending you information.

There are three easy ways to do this:

- By post – return the form enclosed with this magazine (if you have already opted in there won't be one enclosed)
- Online – visit our website [www.cardiomyopathy.org/stayintouch](http://www.cardiomyopathy.org/stayintouch) (if you are already in contact with us) or [www.cardiomyopathy.org/hear-more](http://www.cardiomyopathy.org/hear-more) (to sign up for regular communications)
- Call our office on 01494 791224 and let us know what you would like to receive

**Please make sure you opt in today to make sure you keep hearing from us.  
Thank you.**



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# Welcome

from Alison Fielding  
Chair of Cardiomyopathy UK

The past six months have been tough for me - not because of my cardiomyopathy, but because my parents have both had significant health problems requiring my help and support.

I stopped going to the gym, meeting friends or doing anything for myself (other than my voluntary commitments.)

It really drove home how easy it is for carers to allow their own health to suffer. So whilst the rest of this issue of My Life focuses on what patients can do to live well with cardiomyopathy, my message to carers is that

it's your life too and maybe it's your dreams that are on hold? We know from our face to face events and research that you are affected as much as the patient and sometimes more.

So try and take time for yourself to socialise and keep healthy. Few patients are helpless, so let them help when they can and work together on a life that gives you both satisfaction. You may like to join our new Facebook closed group, Cardiomyopathy UK Carers, which is a patient-free zone for you to share your experience with others. It's as they say on the planes: 'Put on your oxygen mask before helping others.'

## INTRODUCING The Fundraising Team

What do you love about spring?



**Sheila Nardone**

Head of Fundraising  
'The splash of colour of spring flowers brings hope'



**Danni Devine**

Challenge Fundraiser  
'When the trees begin to blossom and the days become brighter'



**Christie Jones**

Community Fundraiser  
'Being able to go on an after-work run in daylight'



**Lesley Warren**

Fundraising Assistant  
'Walking my dogs and being able to garden again'



**Patricia Dean**

AJF Fundraising Manager  
S = sunshine, P = puddles  
R = rabbits, I = invigorating  
N = newborn G = gardens

## Bex takes on a new digital role

Some My Life readers may remember one of our team members, Bex Noble, (right), who used to be our Community Fundraising Manager.

Bex has now taken on a new role as Digital and Data Manager for Cardiomyopathy UK.

Bex says: "I'm delighted to have been given the opportunity to have a change of direction in my career, but to continue working for a charity that I love and whose work I truly believe makes a difference.



"I'm looking forward to getting stuck into our website and social media - especially our Instagram channel, as well as GDPR (General Data Protection Regulations).

"It's so important that you let us know if you want to hear from us, as shortly we won't even be able to ask you and sadly, we'll lose touch," adds Bex.

(\* See how to stay in touch at the top of Page 2).

"A huge thank-you to everyone who has already opted in - and for those of you that haven't yet, please do it today!"



# Organ donation changes



**By Joel Rose**  
**Chief Executive**

In the last issue of My Life, we reported that on the 50th anniversary of the first heart transplant, new figures from the NHS Blood and Transplant service showed a 162% increase in the number of people waiting for a new heart.

We know that there is a real shortage of organ donors in the UK, with only 1 in 3 people on the donor register. Right now there are around 250 people waiting for a new heart and many of these

people will have cardiomyopathy.

The Government recently ran a consultation on changing the way the organ donor register works in England. These changes would mean that you are presumed to consent to being an organ donor unless you opt-out of the organ donation register.

Separate to this consultation, last February, a Private Members Bill supporting the move to a presumed consent system was passed in Parliament. This means that the law is very likely to change in the near future.

We support this change. A presumed consent system is already in place in Wales and Scotland is soon to follow. Presumed consent increases the number of people on the donor register and makes a clear statement about the importance of organ donation. Changing the rules can also prompt conversations among families about an individual's wishes and help create a culture where organ donation is seen as the norm.

Cardiomyopathy UK would like to see a presumed consent system in England, but only as part of a series of measures to improve the whole organ donation and

transplantation process. These include:

- A properly-funded national publicity campaign to ensure that the public is aware of the changes to a presumed consent system.
- An increase in efforts to encourage individuals to make an active decision to be on the register and to discuss their wishes with their families.
- A guarantee that appropriate funding and training is in place for NHS staff working on the front line of the donation and transplantation service.
- Continual assessment of the whole system for donation and transplantation within the UK to ensure that no opportunity to achieve successful transplantation of an organ is missed.

I put this to Jackie Doyle-Price MP, the health minister in charge of transplantation and one of the driving forces behind this change in the law.

She agreed that it was important to see the proposed change to presumed consent as only part of the solution and that the holistic approach, which we believe in, was the right way forward.

So while the change to presumed consent is important, it will not solve the problem on its own. There must be no let-up in efforts to encourage people to actively sign up and make

their wishes known to their loved ones and we need to make sure our organ donation and transplant service is well-funded and fit for purpose.

We also want to encourage all efforts to develop alternative options to transplantation, whether these are better artificial pumps, or improvements in stem cell therapies.

Finally, we encourage everyone to consider signing up to the register and telling their family about their wishes. Visit the NHS organ donor register for more information about organ donation and how to register.



## Having fun while helping myocarditis cause

**By Patricia Dean**  
**AJF Fundraising Manager**

2018 is a very exciting year for the Alexander Jansons Fund (AJF) as now we have joined forces with Cardiomyopathy UK, we can offer people with myocarditis much-needed support and advice.

We rely on fundraising to provide support to people affected, spread awareness of the disease and to fund further research into myocarditis.

This year, our fundraising calendar is full of variety. Many activities are held in or near Buckinghamshire where we were founded, or in London. However, we welcome everyone to join in with our events and social media.

### Upcoming events:

- Film Night @ National Film and Television School in

### Beaconsfield

- Wine Tasting @ Jansons Beaconsfield
- Interactive Quiz Night in Buckinghamshire
- Spirit & Sparkles Evening @ McKenna & Co Knightsbridge
- Golf Day @ Haryleford Golf Club
- Black Tie Dinner Dance @ Bisham Abbey
- Rowing @ Eton Dorney
- SkyDive @ Salisbury Plain
- Clay Pigeon Shoot @ EJ Churchill
- Tennis Tournament in Buckinghamshire
- Eton Bike Ride
- Race Night in Buckinghamshire
- Rugby Night with the Stars @HomeHouse London
- Christmas Wreath Workshop in Buckinghamshire

For further information on the events listed, visit the website: [www.alexanderjansonsfund.org](http://www.alexanderjansonsfund.org)



# Songs in the key of life

Jane Gibson, 75, from the West Country, tells My Life how taking a holistic approach to her wellbeing helps her to lead a 'deeply fulfilling' life

Being diagnosed with hypertrophic cardiomyopathy with obstruction in November 2016 came as a huge shock to retired musician Jane Gibson, who has since found ways to adapt her lifestyle while waiting for an ICD implant.

Living alone, Jane's family and friends were subjected to frequent and prolonged phone calls as she felt the need to talk about her condition.

"They were loving and generous in their listening and this helped me in processing the diagnosis, which was finally confirmed after what seemed like endless periods of waiting for both the various tests and their results," she recalls.

As she gradually came to terms with the diagnosis and its implications, HOCM started to become more of a companion than a threatening invader and Jane began to take back control of her life.

"Becoming more informed through Cardiomyopathy UK's excellent literature was invaluable at this time and I became determined to take responsibility for living well," she says.

However, the tiredness and at times, sheer exhaustion, were utterly overwhelming and a two-hour afternoon nap was a daily necessity. And despite a determination to 'live well' Jane was constrained by two overriding symptoms -

tiredness and a restricted walking capacity - no more hills!

But after joining a seated Tai Chi class and practising the Chi Kung energy-building exercises most days, Jane began to get more energy and now rarely needs an afternoon sleep.

She also attends a seated yoga class, which helps to reduce her stress levels, as well as improve her flexibility, and still walks every day, enjoying finding new 'flat and downhill' routes for variety.

Living in stunning countryside near the sea, she is spoilt for choice. "But I do have to pace myself," she admits, "and try to alternate a physical activity with something more sedentary."

The physical and psychological benefits of singing are well known and as a member of two local choirs, Jane is a walking testament to its positive effects.

"I find the weekly rehearsals are an uplifting highlight of my week and I further indulge my lifelong passion for music and regularly play the piano.

"I also enjoy socialising with family and friends and being involved in the local community."

Jane also tries to adhere to an unprocessed diet to maximise good nutrition as part of a holistic approach to her wellbeing.

"I was sleeping two hours a day on top of six to seven hours' uninterrupted sleep at night. But being on the waiting list for an implant gave me time to learn about my condition and about how doing little things each day can really help. Now my life is deeply fulfilling and each day, very precious."



By Sanjay Prasad  
Consultant cardiologist  
at the Royal Brompton

### What is myocarditis?

Myocarditis means inflammation of the heart muscle.

### What are the causes?

It can affect anyone at any age and is usually related to recent viral infection. The virus may have gone, but the immune system over-reacts causing inflammation that can persist in the heart. Other causes include bacterial infections, certain medications, toxins and auto-immune disorders.

### What are the signs and symptoms?

Symptoms are diverse and include chest pain mimicking a heart attack, difficulty breathing due to weakened heart muscle, palpitation due to electrical rhythm disturbances, fever and abnormal fatigue.

### How is myocarditis diagnosed?

Diagnosis is challenging with no specific blood test and taking a biopsy of the heart is definitive, but high-risk. In practice, diagnosis is made on the basis of a raised troponin blood test, normal coronary angiogram and where available, a cardiac MRI scan. In some centres, a heart muscle biopsy may also be performed.

### How is myocarditis treated?

Most patients get better without any specific treatment apart from rest and anti-inflammatories whilst the heart recovers. There are no specific therapies to tackle the underlying viral infection. However, in a third of patients, the heart can become weaker and enlarges (dilated cardiomyopathy).

### What is the future of myocarditis?

Early detection and better treatment are key priorities - researching new blood tests ('biomarkers') for diagnosis, advances in cardiac MRI mapping technology and greater understanding of genetic testing to predict why most patients recover whereas some experience complications. Our hope is to find better treatments, enable much earlier diagnosis and better identification of patients who may be at risk.

# Lights, camera, action for Sam

Cardiomyopathy UK and the Alexander Jansons Fund joined forces in 2018 and Sam Hinton tells My Life how the AJF charity helped him to start a career in video production

I was diagnosed with myocarditis in my second year of university in 2012.

I woke up around 3am to frightening, thumping pains in my chest that felt like I was being kicked in the chest every 30 seconds.

Unfortunately, on my first trip to hospital, my problem was misdiagnosed as the convulsions were due to a supplement I was taking.

After being released, it happened again a couple of days later. After this second attack, I think it was clear that something else was wrong and after further tests, it was shown that I had an elevated amount of a particular enzyme that is usually present after someone has had a heart attack.

After a week or so of recovery, I came down with severe tonsillitis, thought to be related to the same viral infection. It was about one month in total before I felt back to normal.

After being so fortunate to recover, I have lived a relatively normal life.

Follow-up echocardiograms reveal that my heart looks in good shape. The only after-effects I experience are a little fear and anxiety about sudden feelings or pains around my chest and I also hate being startled.

There is a sudden rush of feeling that goes straight through my heart and I can't help but instantaneously become very angry. It's very embarrassing after a moment or two,



but an interesting side-effect I would not have predicted.

My partner Emma found the Alexander Jansons Foundation (now the Alexander Jansons Fund) shortly after its launch via Facebook.

Emma showed me and I instantly wanted to get in contact and offer any help. The charity's founder Andy Jansons and fundraiser Patricia Dean were so welcoming and soon after, I started taking photographs and filming fundraising events they hosted.

At this time, I hadn't long left university and I not only got to meet a bunch of amazing people and make lifelong bonds with other sufferers, but working with the charity allowed me to gain experience in my field of work.

It soon followed that I was offered a job as a direct result of the help from the foundation.

I am now a freelance video producer and wouldn't be where I am without their help.

Today, although the stated minor residual effects linger, I think it's accurate to say, that had I not found the AJF, I would still be very fearful of living with myocarditis.





# Ready, steady, bake

Raise vital funds for families affected by cardiomyopathy by holding a Tea and Heart-shaped Biscuits event this spring

We're teaming up with top chef Ian Human, for a fundraising challenge you can really get your teeth into.

Ian, (right), has come up with four mouth-watering heart-shaped biscuit creations exclusively for Cardiomyopathy UK. What's more, he's used healthy ingredients such as coconut oil, honey and low-fat margarine to develop four delicious new recipes:

- Cinnamon and pecan nut shortbread
- Oat and cranberry cookies
- Lemon drizzle sablé biscuits
- Gluten-free chocolate brownies

The recipes are easy to follow, fun to make and the flavours and toppings can easily be adapted to suit your preferences.

Sign up via our website and we'll send you a fundraising pack, including four free recipe cards to kick off your own get-together.

Tea and Heart-shaped Biscuits is an event that's easy to organise, perfect for bringing people together and a great way to help families affected by heart muscle disease. All you need are a few ingredients, an oven, some hungry guests and a pot for your donations.

Why not host a tea party at home with friends, at work with colleagues, or at your local members club?

Children and grandchildren can also get involved by holding a bake sale at their schools. They'll love adding a personal touch to their biscuits with colourful and imaginative toppings and you never know where the next budding chef might be! Send us photos of your creations and we'll feature a selection on our website and social media.

Email our Community Fundraiser Christie Jones at [christie.jones@cardiomyopathy.org](mailto:christie.jones@cardiomyopathy.org) for more details.



To request your free recipe cards and fundraising pack, go to [www.cardiomyopathy.org/biscuits](http://www.cardiomyopathy.org/biscuits)

## The beat goes on for actor Becky

In February 2017, Rebecca Shorrocks was diagnosed with ARVC, aged 34.

"I've always been someone who exercised regularly and took care of myself, so my diagnosis was a real bolt from the blue, especially as I was the first in my family to have any heart problems," says Becky.

But after understanding that she was "incredibly lucky to be alive" - as 80% of cases like Becky's are found post-mortem - she began to research her condition.

"ARVC is quite a rare condition," she adds.

"Not many people are diagnosed and because of that, they are still learning about it. Like all forms of cardiomyopathy, it affects each person differently and everyone's journey is unique."

Aware how a diagnosis can often leave people feeling lost and isolated and that the ICD implanted in her chest could lead to anxiety and depression, Becky was inspired to put her talents to good use in a bid to raise awareness and help others going through the same experience.

The Beat Goes On is a brand new piece of theatre, which will be devised and performed by women with heart conditions.

Becky was unable to secure Arts Council funding, but My Life readers can help make her vision a reality, by donating to, or simply sharing, her Just Giving page:

<https://www.justgiving.com/crowd-funding/thebeatgoeson>

Becky adds: "The aim is to embark on a UK theatre tour, raising awareness and challenging perceptions."

● The Beat Goes On is calling for **#hearthelpers!** The team is particularly, (but not exclusively), looking for young women, who are in some way affected by heart conditions to give feedback and share experiences that will help to shape Becky's theatre project.

For details, email: [thebeatgoesonuk@gmail.com](mailto:thebeatgoesonuk@gmail.com) or head to [www.thebeatgoesonuk.com](http://www.thebeatgoesonuk.com) and @thebeatgoesonuk on Instagram, Twitter and Facebook.



# Taking a microscopic view

Regular exercise is important to help reduce cardiovascular disease and hearts can change in shape and function after only a few hours of exercise per week.

These changes are usually physiological and normal, (athletic heart).

However, hearts can change in shape and function as a result of damage from many conditions, including myocardial infarction, or due to inherited cardiac conditions eg. dilated or hypertrophic cardiomyopathies.

Echocardiography is commonly used for assessing cardiac structure and function because of its ease of application, non-invasive nature, safety and ability to provide a vast amount of information.

For many decades, measurement of 'ejection fraction' (percentage of blood volume leaving heart) has been used as the main determinant of left ventricular systolic function (contraction).

Although modern echocardiography techniques have

improved the accuracy of assessing ejection fraction, this may still not correctly assess left ventricular function, especially when subtle cardiac dysfunction is present.

Picking up subtle changes in cardiac function has been difficult in the past, but newer echocardiographic techniques now give us a microscopic view of the heart.

The heart is made up of layers of cardiac fibres, which are orientated in different directions around the heart.

Ejection fraction is predominantly a measure of radial function (inwards motion).

However, a great proportion of cardiac function is determined by longitudinal function (vertical movement apex towards valves), similar to the action of an accordion.

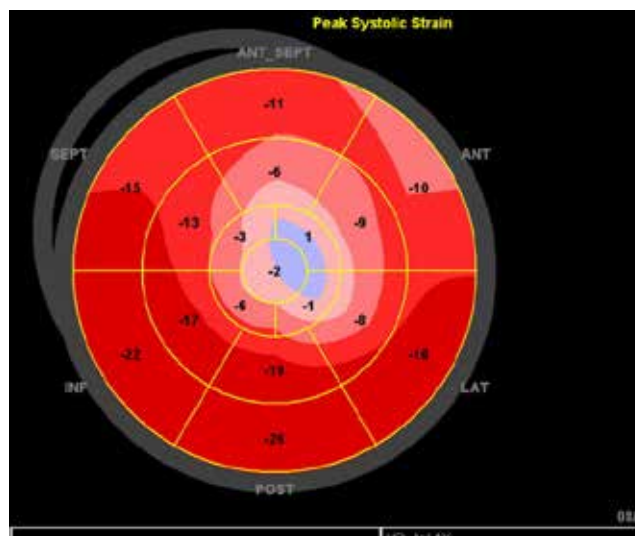
It is important to measure longitudinal function, as this may be one of the first markers of cardiac disease, before changes in ejection fraction. Speckle-tracking echocardiography, which looks at the way small areas of the heart (speckles) move in different directions, is an innovative method of assessing cardiac function or 'myocardial strain'.

It can precisely measure the heart's longitudinal function and also radial and circumferential strain rather than just in one direction (which ejection fraction measures).

Detailed assessment can be made of specific areas of the heart, or a global assessment can be made (global longitudinal strain



**Cardiomyopathy specialist and consultant cardiologist to Liverpool FC, Professor John Somauroo, (left), says assessing longitudinal strain is an exciting new technique in the diagnosis and treatment of many cardiac diseases**



**Speckle-tracking echocardiography measures the heart's longitudinal function and is an innovative method of assessing cardiac function or 'myocardial strain'.**

**Left: The normal heart is red, but the damaged part of the heart is light pink/blue**

= GLS). Initially, these measurements were time-consuming, but advances in technology mean this is now practical enough to apply in a busy NHS clinic.

Results are often comparable to cardiac MR scans, but much quicker

and no contrast agent is required as with cardiac MR.

GLS may detect subclinical left ventricular dysfunction in a wide range of cardiac disorders, including ischaemic heart disease and valve disease before impact on the ejection fraction, so that patients can be offered early valve surgery.

Patients with hypertrophic cardiomyopathy often have normal ejection fractions, whereas the longitudinal function may be reduced due to areas of damage (fibrosis).

This is especially useful in differentiating athletic heart from cardiomyopathies. Patients being treated with chemotherapy (e.g. Herceptin in breast cancer) may have their treatment stopped if the ejection fraction falls too low. However, GLS can correctly identify those that do not have a true reduction in cardiac function allowing them to continue with chemotherapy.

Ejection fraction has been a useful tool in assessing cardiac function in the past, but the use of speckle-tracking to assess longitudinal strain is an exciting new technique and a game-changer in diagnosis and treatment of many cardiac diseases.



Today's portable laptop echocardiography machines use sophisticated electronics



**Have a word with your cardiologist to see if assessing the longitudinal function of your heart is something that would be useful for you**



# Q&A



Head of Services Ali Thompson and Support Nurses Robert Hall, Jayne Partridge and Emma Greenslade answer your questions

**Q: I've heard that people with cardiomyopathy should avoid caffeine. Is this correct?**

**Support Nurse Robert says:** Coffee is the first thing people often think about when caffeine is mentioned, whereas of course it's also contained in tea, some soft drinks, chocolate and nuts.

Caffeine has various actions on the body; it acts as a stimulant to the nervous system which can lead to an increase in the heart rate, it releases free fatty acids into the blood stream and can increase fluid loss by increasing the production of urine.

Research has been done to assess the effect of caffeine on the heart and the results have been inconclusive.

In general, a moderate intake doesn't appear to cause problems, such as abnormal heart rhythms, in the majority of people.

It's not thought necessary for everyone to totally avoid caffeine, however, it does appear some people may be more sensitive to its effect than others.

Moderation is key, and particularly for anyone who is sensitive, drinking caffeine-free coffee and tea, and avoiding items high in caffeine, (such as energy drinks, strong coffee and high cocoa content chocolate), may be helpful. If you're unsure, as there is an individualised response to caffeine, check with your doctor on specific guidance for yourself.

**Q: I struggle daily with my son's diagnosis and worry about him constantly. How can I cope better?**

**Support Nurse Emma says:** Sometimes you may feel overwhelmed and it's okay to ask for help!

Get professional help from cardiologist/paediatricians, nurse specialists and psychologists to form a care team for your child.

Be open, honest, available and

supportive with your son, but consider his maturity and development to judge how much information to share with him.

Teach your child to manage their own condition. For example, when going for hospital check-ups, let him choose which arm he wants blood taken from today, and allow him to choose what social activities he is able to do.

Help your son find things he enjoys by emphasising strengths and encouraging new things.

Maintain structure, discipline and daily routines to normalise the whole family and schedule one-on-one time for your son with other children.

Most importantly, find time for yourself by building rest and relaxation into your schedule and get support from family and friends.

**Q: I have just been turned down for a benefit I applied for. What can I do now?**

**Head of Services Ali Thompson**

**says:** To challenge a decision about a benefit you have had from the DWP (Department for Work & Pensions) you will need to apply for a mandatory reconsideration - this is where you ask the DWP to look again at your original claim for benefit.

A decision-maker will look at the claim and make another decision whether to afford you the benefit or uphold the original decision.

You must request a mandatory reconsideration within one month of the date given on your decision letter.

There's no special form to fill in, you just need to write a letter. If the decision notice does not include reasons for the decision, you have the right to ask for one. You must ask the office that made the decision to look at it again. The contact details will be on the decision letter. I would advise sending your letter recorded delivery.



If you have questions you would like us to answer, email them to:  
[contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org)

## How to deal with tiredness

By Jayne Partridge  
Cardiomyopathy UK  
Support Nurse



There can be various reasons you may feel tired when you have cardiomyopathy - both physical and emotional.

If your heart is not able to pump blood to your body, which includes your muscles, then this can make you feel fatigued, especially after exercise.

Medications, such as beta-blockers and blood pressure treatments, can also cause tiredness. It is also possible you could be suffering with an underactive thyroid or anaemia that can make you feel more tired or lethargic.

And reduced sleep or interruption in sleeping pattern could cause you to feel more tired during the day.

Some people with heart conditions can feel emotional stress, coming to terms with living with a heart condition and dealing with changes in their condition.

If the cause of emotional stress can be reduced, then this can in turn, reduce the resultant feelings of tiredness.

Reducing the amount of alcohol you drink, not smoking, maintaining a healthy weight and eating a healthy diet can all help to reduce feelings of tiredness and lethargy.

Discussing how you feel with family members and friends can also help and if you are concerned that you feel unduly tired or fatigued then tell your GP, cardiac nurse or consultant, who may want to investigate further.

Schedule things to do at times of the day when you feel most energetic and allow yourself periods of rest throughout the day.

Positive lifestyle changes - including exercise - can help people with cardiomyopathy to manage their condition and lead long and fulfilling lives.

Exercise has a number of health and wellbeing benefits, but many people have concerns about the risks and benefits

A diagnosis of cardiomyopathy can come as a huge shock to anyone who has previously enjoyed an active lifestyle and leave them fearful that continuing to exercise will place too much exertion on their heart.

Although there is little evidence to say what the appropriate level of exertion for people with cardiomyopathy is, the general advice is that intensive or competitive exercise is not recommended, but you can still find an activity that is safe and good for your heart.

Cardiomyopathy UK's Support Nurse, Robert Hall, says: "The issue is complex, but we should never get the idea that exercise is bad.

"It's always about looking at the individual and at how cardiomyopathy affects them.

"People need to balance the risks and benefits in order to make an informed decision - alongside a discussion with their cardiologist - about what type of exercise is advisable for them to do.

"Each person's condition will inform that decision and then how they can self-manage their exercising in a responsible way."

### What exercise is recommended?

During exercise, our bodies need more oxygen to power our muscles and the speed and depth of our breathing increases to meet these oxygen needs.

As more blood needs to get to the muscles, our heart rate increases (number of beats per minute) and the amount of blood that is pumped through the heart with each heartbeat increases (called 'stroke volume').

# Blood, sweat

## Balancing benefits and concerns



All of this means extra work on the heart.

In cardiomyopathy, the heart can be under greater pressure to meet the normal demands to pump blood and provide oxygen to the body.

These demands are increased during exercise and can be even harder for a heart that may already be struggling.

General recommendations for people with cardiomyopathy are:

- To participate in 'recreational' (for fun) exercise
- To avoid exercise that involves sudden bursts of exertion (such as weight lifting, sprinting)

International guidelines classify sports and activities by how much exertion they need, based on their 'static' (non-moving) and 'dynamic' (active) components.

Suitable types of exercise include walking, jogging, easy cycling, swimming, skipping, golf and non-strenuous hiking, tennis, bowling and low-impact aerobics.

For more information and advice about the topic of exercise, please get in touch - at [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org) or by calling 01494 791224 and speaking to one of our Support Nurses.

# and fears rns around exercise



## Fitness and trackers apps

We have a new factsheet on fitness trackers and apps (as we often get requests for information on this and have had feedback from people with the condition about what they use).



Health and fitness trackers are designed to help you monitor and manage your overall health and well-being. Some include heart rate monitors that some people with cardiomyopathy find helpful. There are many available, so it is worth thinking about what you want to get from them and finding out more about each one to make sure it meets your needs.

For more information, go to: [www.cardiomyopathy.org/trackers](http://www.cardiomyopathy.org/trackers)

### What is the BORG scale?

The BORG scale, which looks at the effort (or 'exertion') needed to do different types of exercise is another way of deciding what amount and type of exercise is recommended.

However, the BORG scale applies to the general population and not specifically to people living with cardiomyopathy.

- Green: no exertion to extremely light exertion. You can sing without getting out of breath.
- Yellow: very light to light exertion. You can't hear your breathing and you can talk easily.

For example, you are walking or jogging, but you can still hold a conversation.

- Orange: somewhat hard to hard exertion. You feel tired but can carry on, it is harder to talk and you

The Borg scale	
Green	easy ▶ minimal effort
Yellow	very light ▶ light
Orange	somewhat hard ▶ hard
Red	very hard ▶ extremely hard

start to hear your breathing whilst doing it.

- Red: very hard to extremely hard exertion. You are very tired and breathing is challenging.

In the general population, the level of exercise shown to have most health benefits is within the green and yellow zones (light exercise).

It is suggested that most people with cardiomyopathy exercise within the green or yellow zones and intense exercise (orange or red) is not recommended for people with cardiomyopathy because it places too much exertion on the heart.

Always discuss the results with your cardiologist to decide what exercise may be suitable for you.

## 'I fight daily to overcome the symptoms'

John Kinnaird, (pictured right, centre), was diagnosed with dilated cardiomyopathy in 2008 and responded to our Facebook post about exercise.

"It brought back vivid memories of my diagnosis and the support Cardiomyopathy UK gave me on my return to exercise at high level," says John, 47.

"As someone who had always enjoyed sport and exercise, I was devastated to be told that I would no longer be able to exercise, play sports and indeed would be lucky to continue to work," he recalls.

"Luckily for me, I found myself a fantastic cardiologist and an amazingly supportive GP.

"Through their innovative and ground-breaking medical intervention, as well as their physical, mental and emotional support, I have defied that initial prognosis.



"I have found exercise to be a decisive subject these past 11 years, but it is not what I achieve that is the point, but how I approach it and its use in goal-setting, which everybody can do.

"From my first day in hospital of not being able to walk down the corridor, I have basically just slowly, carefully - and never forgetting my condition - just seen what I am capable of.

"I fully accept I have limitations, but can control them with careful

planning and understanding of them."

Every time I set a goal - be it a triathlon, John O'Groats to Lands End cycle, or my last physical achievement of a two-mile swim in Loch Lomond in 2016, I had days in training where I couldn't do anything, but accepted it.

"If I felt I was pushing too hard, I stopped.

"Every time I achieve a physical goal, I fully understand that I need to go back to the beginning for the next one and need to review and plan carefully again as my condition needs that respect.

"The point is, it gives me something positive to aim for and fight daily to overcome the symptoms I of course constantly have.

"I live a full, happy and positive life and want to encourage other heart-failure patients to do the same."





# Do Androids dream of electric bikes?

Ian, 70, from Whitley Bay, thought his days of riding bikes were over, until he tried an ebike

Before I was diagnosed with HCM in 2015 and had an ICD fitted, I loved cycling. When I went back to it months later, I found it too tiring and gave up.

I thought I might never cycle again when a friend suggested I try his ebike. I knew nothing about ebikes, so my first ride in the streets around his home was a revelation - I was hooked and I bought my own shortly afterwards.

It has made such a difference to me that I thought others with cardiomyopathy might be interested.

An ebike is just a bike with a small (under 250W) electric motor powered from an on-board battery. The motor is located either in one of the wheelhubs or the pedal crank. In the latter position, a torque sensor measures the input from the rider and delivers power from the motor to match.

So riding an ebike under power feels rather like having another cyclist pedalling in tandem with you. You still have to pedal, but nothing like as energetically as you might otherwise.

Batteries vary, but you can often get 30-40 miles on one charge and recharging takes 3-4 hours from a domestic supply. Ebikes come in four basic styles; folding, road, mountain and hybrid in a range of models and frame sizes.

The choice is surprisingly wide with almost any style suitable for people with cardiomyopathy.

Folding, road and hybrid may be best for commuting and general leisure use and mountain for off-road.

Legally, you can ride an EAPC at 14 in England, Scotland and Wales and don't need a motorcycle licence, nor do you need to register it, tax it, carry compulsory third party insurance, have an MOT or wear a motorcycle crash helmet! In Northern Ireland, the law is more strict.

Ebikes typically cost between £500 and £3,000, depending on quality, but specialised machines cost much more.

You can insure your ebike as an extension of your house contents. If it's worth more than a few hundred pounds, your insurers will charge and may also want to impose security conditions when the ebike is unattended.

There are specialist insurers online who offer better deals on dearer ebikes, but they also impose security conditions.

You can buy new ebikes from the internet and many big bike retailers also have a small selection.

I found a specialist local dealer who had a good range and offered sound advice. He also does repairs and servicing.

If like me you haven't cycled for a while because of your cardiomyopathy, but are medically fit to do so, an ebike might suit.

You will get exercise and fresh air and cycling can be sociable too.

I often go out with cyclists who do not have heart conditions and keep up with them without difficulty. So why not take a look yourself?

An ebike is more properly known as an Electrically Assisted Pedal Cycle [EAPC]

# Time to talk peer to peer

By Ali Thompson  
Head of Services

One of the charity's most popular services is the peer to peer helpline service that we offer to children, young people and adults, who have a diagnosis of cardiomyopathy, are being screened for the condition or support someone who has the disease.

Cardiomyopathy UK understands that sometimes people just want to know what 'real life' is like living daily with cardiomyopathy and that the best people to provide this insight are those with lived experience of the condition.

The most common requests from helpline callers wanting to speak with a peer support volunteer are because they have been recently diagnosed; they have been advised to have an ICD fitted; or they are having emotional difficulties surrounding the condition.

The helpline provides clinical advice and advice regarding benefits and welfare rights - but not everyone wants or needs this type of information.

As caller Geoff, 47 put it: "I just wanted to know what it's really like, you know, to live with it (cardiomyopathy) as



my doctor couldn't tell me that. It's not the same asking questions of someone who hasn't got the condition."

Peer support can often provide that vital link between formal clinical intervention and advice.

No one can understand the condition better than someone who has the condition and that is why we offer the peer support service.

Wherever possible, we try to match the caller to a peer supporter of a similar age and experience. For example, our young people and younger adults offer support to peers who are within the 14-25 age range.

The peer support service allows callers to talk in

confidence about issues or concerns they have that they might not feel able to discuss with close family and friends. It also reassures the caller that they are not the only person with the condition.

Sandra, 35 called the helpline to speak to a peer support volunteer about having an ICD fitted: "I was really frightened when my consultant mentioned the possibility of me having a device fitted. I really didn't want one.

"I called the helpline and spoke to someone who had an ICD and they made me realise that it was to help me and could save my life. They

were doing really well with theirs and explained all about the operation and what it was like afterwards."

Given the proven benefit of offering service users peer support, we have further developed the service by offering similar within certain cardiac clinics.

If you have the condition or support someone with cardiomyopathy and are interested in learning more about the service, please contact me for more information at [alison.thompson@cardiomyopathy.org](mailto:alison.thompson@cardiomyopathy.org)

## Reaching out with our online groups

By Jo Franks  
Support Group Manager

We currently have 26 support groups, comprised of online and face to face groups.

Since the autumn last year, we have launched a number of online support groups to help address more niche needs.

These groups are run a bit like webinars and can be accessed via phone, pc, laptop, tablet and iPad, which allows participants to communicate via chat, webcam or verbally.

The hosts are able to share information via presentations and participants are able to share and learn from others.

We started with online groups for those affected by ARVC, who often find it more difficult to meet others with their type of cardiomyopathy.

Our group for supporters and carers of adults with cardiomyopathy provides a confidential, safe place to share with others in similar situations without feeling a burden to those they are supporting.

This year, we have created an online rural isolation group

for those whose location makes it harder for them to travel and addresses issues such as coping with delays in accessing medical care and ensuring medicine supplies are maintained where services are limited.

Our paediatric support nurse Emma is starting a group during school hours for parents and carers with children and young people affected by cardiomyopathy. Whilst we recognise online groups are not a replacement for face to face meetings and don't suit everyone, they are an innovative way of increasing accessibility.

If you have an idea for a potential new online group, do get in touch with me: [jo.franks@cardiomyopathy.org](mailto:jo.franks@cardiomyopathy.org)

After collecting more extensive information from our support group attendees since 2017, we are in a stronger position to identify groups who are currently under-represented in accessing our service, notably those from black and minority ethnic backgrounds and the under-35s.

We have launched an 18-35 year old group in Birmingham, which will be supplemented with online sessions. We are also seeking to extend our geographical reach by launching new groups in Cambridge and Chelmsford during May.



## Maddy's story

Maddy Orford was just 18 when she was diagnosed with dilated cardiomyopathy and severe heart failure in November 2016.

A fit and healthy young woman who regularly played football and enjoyed exercise, Maddy had a real zest for life.



At the time she first became unwell, Maddy was busy visiting prospective universities and had ambitions to become a forensic scientist in the future.

Maddy's diagnosis was sudden, and so was her deterioration in health.

In the nine short months after she was diagnosed she had two heart transplants that sadly failed, and she tragically died of dilated cardiomyopathy in August 2017.

Her heartbroken family are determined to raise awareness of cardiomyopathy and are working with us to make more people aware of the signs and symptoms of the condition.

Read Maddy's story on our website at [www.cardiomyopathy.org](http://www.cardiomyopathy.org)

## WCDs study

Future trials could influence UK guidelines for the use of wearable cardioverter defibrillators (WCDs) after a new study found they reduce the overall risk of early death for heart attack survivors – but not the risk of sudden cardiac death.

There are no current guidelines for use in the UK at present.

WCDs can sound an alarm if medical care is needed and deliver a shock to restore a normal heart rhythm if a life-threatening abnormal heart rhythm is detected.

Read the story in full online, at [www.cardiomyopathy.org](http://www.cardiomyopathy.org)



## Joining the pack

### Rugby player Lee supports Cardiomyopathy UK

Former Bath and England rugby player Lee Mears was forced to retire from the game at the age of 34 when he was diagnosed with hypertrophic cardiomyopathy in 2013.

Since retiring from the sport, he has thrown himself into various ventures determined to live his life to the fullest.

With two Rugby World Cups, 43 international rugby caps for England and a British and Irish Lions tour under his belt, he is now involved in coaching teams around the world.

Lee supported our 2017 national campaign #MyHeartStory that

encouraged families to have open conversations about their family heart history, as well as raising awareness to recognise signs and symptoms of the condition.

Lee said: "People often have very set ideas of what a 'typical heart patient' looks like, so often cardiomyopathy can go undetected or misdiagnosed.

"Despite being a professional sportsman, my diagnosis forced me to retire from competitive rugby.

"It can affect anyone at any age and often runs in families, so it's important for people to find out their own family history."

## Plans for our 2018 campaign

By **Priya Manek**  
PR & Communications  
Manager

Our campaign for 2017 highlighted the need for people to find out if there was a history of heart disease within their family.

The campaign was a success with thousands of people learning about #MyHeartStory through various media – online, in print and broadcast.

Part of the campaign focused on our information-gathering survey, which we targeted at our supporters and service users. We asked them



about their experiences of being diagnosed; their journey through treatment and the acceptance of living with cardiomyopathy.

Cardiomyopathy UK is now looking ahead to this year's campaign, where we will be looking at and challenging some of the more common myths and misconceptions that surround cardiomyopathy.

We are confident that our voice will be even louder and further-reaching in 2018, so we can continue to raise more awareness of the condition.

Watch this space and please get involved with your own experiences.



# 'There's always a person wrapped around the heart'

**Graeme Gillespie is a consultant clinical psychologist at the Northumbria Healthcare NHS Trust**



## How did you become a clinical psychologist?

After completing a first degree in psychology at Manchester University, I came into clinical psychology through an unusual route.

I taught in secondary education prior to training and worked as an educational psychologist, before completing a doctorate in Clinical Psychology in 1996, then working in North Wales in a Child Development Centre.

There, I became increasingly interested in the links between physical health and psychological wellbeing.

That led me into working as a clinical health psychologist and a move back home - to the wonderful north east of England.

## What does your work involve?

My work is quite varied and includes direct and indirect clinical work, training, management/supervision, service development and research.

Clinical work is usually with people referred by cardiac rehabilitation/community cardiology teams, as well as

from hospital-based cardiology colleagues.

## What methods do you use to help patients?

Effective psychological help is collaborative, so I always start by finding out what patients feel would be most useful to talk about.

Often (but not always) the starting point is a history of their medical journey and how this experience has affected them.

We work together in order to reach a shared understanding of the difficulties they are currently struggling with and want help to manage.

But of equal importance is identifying their internal strengths and qualities, as well as the range of possible sources of support they have drawn on throughout their lives.

My work is informed by various psychological therapies, which I use flexibly to suit the needs and preferences of the individual patient.

## How does your work help people living with cardiomyopathy?

Often patients report the process of describing their experiences, thoughts and feelings is helpful in itself.

Rather than give advice, I usually try to help patients find the best ways forward for themselves, by focusing on actions that reflect what's most important to them.

Healthcare, particularly involving the heart, can be dominated by the language of symptoms, diagnosis and treatments, but there is always a thinking, feeling person wrapped around the heart and we need to pay attention to their psychological, as well as physical wellbeing.

## Do you have any advice for My Life readers?

People with cardiomyopathy face a wide range of challenges and stresses that can affect them psychologically - in positive, as well as negative, ways.

Cardiomyopathy UK's information booklet on emotional health and wellbeing is a great resource and a very useful starting point for anyone who would like further support.



Download or order our booklet **Emotional wellbeing and mental health - living with the impact of cardiomyopathy** online at [www.cardiomyopathy.org](http://www.cardiomyopathy.org) or call 01494 791224.

# Cardiac rehab - the first step to a more active life

Following a diagnosis of heart failure, participating in cardiac rehab is one of the best things you can do for your heart health, says Lucy Girdler-Heald (Heart Failure Nurse Specialist) and Claire Gray (Cardiac Rehabilitation – Assistant Practitioner)

Cardiac rehabilitation programmes will help you to:

- Understand your condition.
- Make changes to your lifestyle that will help improve your heart health.
- Reduce the risk of further heart problems.
- Help to regain confidence, test abilities and learn what is achievable in a safe environment.
- Enable you to take control of your condition and feel positive.
- Programmes are fun, relaxed and enjoyable.

The programme usually involves going to several sessions, each lasting an hour or two, either once or twice a week. Some programmes may have shorter or longer sessions and vary in the number of weeks.

At the beginning of your programme you may be invited to an assessment appointment with a cardiac rehab specialist. You can agree a programme of goals and activities that are best for you.

Programmes are usually run in a hospital, or in a community or leisure centre.

## Cardiac rehab programmes usually include one or more of the following:

- Physical activity  
Structured physical activity is an important part of your rehabilitation. It will help with your recovery, boost your confidence, improve your fitness, strength and general wellbeing.  
You will be encouraged to start slowly and gently and to increase your exercise gradually over the programme working within your limitations.  
Even a small amount of activity can be helpful in regaining your confidence.



- Education on healthy lifestyle choices, such as sticking to a healthy diet and how to take your medicines.
- Relaxation – Some programmes teach you different relaxation techniques so you can find one that suits you. This can help in reducing and managing stress levels.
- Psychological support.

After you have finished your programme, it is important that you continue on with regular physical activity and a healthy lifestyle in the long term.

This may be your own exercise that you enjoy, or cardiac rehab staff can refer you to exercise classes that are run in leisure centres with specially-trained instructors who can help you.

Go to **[www.cardiac-rehabilitation.net](http://www.cardiac-rehabilitation.net)** to find out where your nearest cardiac rehabilitation programme is.

## What is cardiac rehab?

Cardiac rehabilitation is a supervised programme that helps improve the health and well-being of people with heart problems. It includes exercise training, healthy living information and support to reduce stress and help people return to an active life.

# #teamcardio highlights

2018 has got off to a flying start with our incredible fundraisers already raising thousands of pounds for #teamcardio through a variety of community and challenge events.



Please get in touch with our fundraising team at [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org) or visit our website [cardiomyopathy.org/support-us](http://cardiomyopathy.org/support-us)

The **Cardiomyopathy UK fundraising team** (right), bounced their way through 5k of inflatable obstacles in the 2018 Gung-Ho this March. Thank you to everyone who got involved, same again next year?



Incredible scenes displayed from **James England** who trekked a fantastic 5,000-miles, on a solo expedition from Cartagena to Patagonia, raising over **£2,200**. Amazing job, thank you so much.



Thanks to all of our inspirational fundraisers who braved the cold sunny shores of Brighton for the half marathon, including our own Community Fundraiser **Christie Jones!**



Our Trustee **Ivor Adair** donned his tux for Sweetwoods Park Golf Club's annual awards dinner where he was presented with a cheque for **£11,782.25**.

Huge thanks to ladies captain Marion Gatland and everyone at the club for their unbelievable dedication to our cause.

## Supporting Cardiomyopathy UK with the click of a button

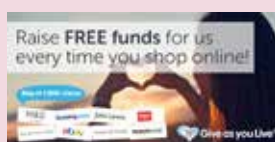
Whether you're at home, or out and about, raise funds for us with the click of a button - at no extra cost to you.



### Amazon Smile

Amazon Smile is a quick and easy way for you to support Cardiomyopathy UK whenever you shop at Amazon.

Simply go to [smile.amazon.co.uk](http://smile.amazon.co.uk), where you'll find the exact same low prices and great choice as amazon.co.uk, with the added bonus that Amazon will donate 0.5% of the net purchase price to us!



Give As You Live Shop at over 4,200 of your favourite

stores, at home or on your smartphone, and raise free funds for Cardiomyopathy UK.

All your high street favourites are there, including Waitrose, who will now contribute up to £20 of free funds from your purchases!

Head to [giveasyoulive.com](http://giveasyoulive.com) or go to the App Store to find out more.



eBay for Charity eBay is a fantastic way to earn some

extra cash from your unwanted clutter, but did you know you can donate some or all of your final sale price to Cardiomyopathy UK? Head over to [charity.ebay.com](http://charity.ebay.com) to find out more.

### ChariTable Bookings

Whether it's a meal out, a night in a hotel - or both - you can raise £1 per head in free funds when you book with ChariTable bookings.

There are over 8,500 restaurants to choose from, and the list is still growing! Check out [charitablebookings.com](http://charitablebookings.com) or visit the App Store.





# Summer Raffle 2018 – be in it to win it!



Our Summer Raffle is back and once again, there are some big cash prizes up for grabs!

The draw takes place on 31 August, 2018, with the deadline for the return of cheques and counterfoils by 30 August, 2018.

**For more information, call 01494 791224 or email [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org)**



## Vitality London 10,000 2018

Run the route of Olympic champions this May and take on the 2018 Vitality London 10,000 - the London Marathon's little brother! Let this popular 10k inspire you, as you pass the crowds and iconic London landmarks in #teamcardio colours.

We will provide you with all of the support and guidance you need to help kick-start your fundraising and get you to that start line.

**Location:** St James Park, London  
**When:** 28 May, 2018  
**Distance:** 10k  
**Pledge:** £150



## Superhero Run 2018

Embrace your inner superhero and help save the lives of people with cardiomyopathy by taking on the 2018 Superhero run this spring for #teamcardio.

Whether you're a superman or super woman, you can choose between a 5km or 10km course in Regents Park, London and win prizes for the best-dressed superhero!

**Location:** Regents Park, London  
**When:** 13 May 2018  
**Distance:** 5k  
**Pledge:** £100



## Tough Mudder 2018

Run, jump or crawl your way through miles of muddy obstacles for Tough Mudder 2018.

This is the perfect team-building event for you and your friends or colleagues so why not join #teamcardio today?

**When:** April – September 2018  
**Location:** Throughout the UK  
**Pledge:** £350

## Ultra Challenges 2018

Whether you're a walker or new to endurance events, Ultra Challenge Series could be just the thing for you.

Choose from a 100km, 50km or 25km distance and push yourself to the limits this year.

**When:** Various dates  
**Location:** Throughout the UK  
**Distance:** 100km, 50km or 25km



To take part in any of the events listed, please email [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org), call 01494 791224 or visit our website [www.cardiomyopathy.org](http://www.cardiomyopathy.org)

We provide a free fundraising pack with a t-shirt or running vest – and can help you smash your target!

Wishing the best of luck to each of our incredible 51 London Marathon runners, braving the iconic 26.2-mile race for Cardiomyopathy UK. We can't wait to cheer them on and support our team on the day! See the next My Life for an update on how they got on.

# April

28th April, 2-4pm

## **Birmingham Support Group**

Jayne Partridge, Cardiomyopathy UK Support Nurse

The Lapworth Museum of Geology,  
Aston Webb Building, University of  
Birmingham, B15 2TT

28th April, 2-4pm

## **Dorset Support Group**

Emma Simmons, Heart Failure Nurse  
Specialist  
Best Western Hotel Rembrandt, 12-18  
Dorchester Road, Weymouth, Dorset,  
DT4 7JU

28th April, 3-5pm

## **North London Support Group**

Carys Barton, lead clinical nurse  
specialist for heart failure  
Finchley Memorial Hospital, Granville  
Road, London, N12 0JE

28th April, 9:30-12:30pm

## **Kent Support Group**

Julie Shannon, Psychotherapist  
emotional wellbeing, grief and loss in  
connection to cardiomyopathy.  
Maidstone Community Support  
Centre, 39-48 Marsham Street,  
Maidstone, Kent, ME14 1HH

28th April, 2-4 pm

## **ARVC Support Group**

Ellie Quinn, a genetic counsellor from  
Barts Hospital  
Northolt Methodist Church, 240  
Church Road, Northolt, Middlesex,  
UB5 5AE

### **Enquiries**

If you have questions about

- support groups
- how to register for one of our events
- how we help people affected by cardiomyopathy

phone us on 01491 791 224, email  
[contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org) or  
visit [www.cardiomyopathy.org](http://www.cardiomyopathy.org)

# May

6th May, 12-3pm

## **West Scotland Support Group**

Ross Marscheider, Senior  
Physiotherapist, on exercise  
Glasgow Royal Infirmary, Castle  
Street, Glasgow, G4 0SF

12th May, 2-4pm

## **Bridgend Support Group**

Moiras Ashton, Heart Failure Specialist  
Nurse  
Pencoed Welfare Hall, Heol-Y-Groes,  
Pencoed, Bridgend CF35 5PE

12th May, 3-5pm

## **Sussex Support Group**

Katherine Moore, a Cardiac  
Rehabilitation Nurse  
The Friendship Centre, Mayfield  
Avenue, Peacehaven, East Sussex,  
BN10 8PB

16th May, 7-9pm - New

## **Cambridge Support Group**

Robert Hall, Cardiomyopathy UK  
Support nurse will be giving a  
cardiomyopathy overview  
Meadows Community Centre, 1 St  
Catharine's Road, Cambridge, CB4  
3XJ

17th May, 7-9pm - New

## **Chelmsford Support Group**

Robert Hall, Cardiomyopathy UK  
Support nurse will be giving a  
cardiomyopathy overview  
Springfield Parish Centre,  
St. Augustine's Way, Springfield,  
CM1 6GX

17th May, 7-9pm

## **Cheshire and Merseyside Support Group**

Sarah Quinlan, Specialist Heart Failure  
Occupational Therapist will be giving  
advice on relaxation techniques  
Holiday Inn, Centre Island, Lower  
Mersey Street, Ellesmere Port, CH65  
2AL

28th May, 9:30 am to 4:30 pm

## **Exeter Information Day**

Mercure Exeter Rougemount Hotel,  
Queens Street, Exeter EX4 3SP



# June

23rd June, 9:30 am to 4:30 pm

## **Brighton Information Day**

The Old Ship Hotel, Kings Road,  
Brighton BN1 1NR

### **Online support groups**

25th April, 11-12:30pm

#### **Online parents & carers**

For those supporting children and  
young people with Emma,  
Paediatric Cardiomyopathy UK  
Support Nurse

23rd May, 7:30-8:30pm

#### **Supporters & carers**

For those supporting adults with  
cardiomyopathy with Jo Franks,  
Support Group Manager



Walk the walk this autumn with #teamcardio...

# Septe♥ber Stroll 2018



**Embrace the great outdoors and organise a September Stroll in your local countryside for Cardiomyopathy UK**

***For more details, call Christie Jones on 01494 791224  
or email [christie.jones@cardiomyopathy.org](mailto:christie.jones@cardiomyopathy.org)***