myLife

The magazine for people affected by cardiomyopathy and myocarditis

Issue 28/Winter 2021

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Cardiomyopathy^{UK} the heart muscle charity Highlights from the London Marathon Pages 14 - 15

Contact us

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

Call or write to us



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• Helpline

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Social media

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Front page image: Highlights from the London Marathon

Designed by Hi Top Design

Welcome to the autumn issue of My Life.

With the beauty of the trees changing colour and a spell of good weather recently, thankfully more of us are beginning to venture out a little more.



At this time of the year we have lots to look forward to, especially for children and families with Harvest Festivals, Halloween, Bonfire Night, Rosh Hashanah, Chanukah, Diwali and Christmas celebrations to name just a few. Talking of Christmas, head to **pages 20-21** and check out our selection of festive cards, available on our online shop!

In this edition, we look at what it means to be empowered. The launch of our professional CPD e-learning course, MedEd, is just one of the many exciting ventures that we've been working on (pages 18-19). We hear from Ali Thompson (Head of Services), on how we can help and support you, and the incredible work of our Services Team. (Pages 11-12) Plus, we have news about our new resources developed to help children and young people better understand their condition. The first of their kind in the UK, these resources have been put together thanks to funding from BBC Children in Need.

I must give a special mention to our Marketing Team, who have done a fantastic job creating our new website. The new site makes it easier for people to access the information and support they need to help them live well with their cardiomyopathy. You can see what's new on page 10 or by visiting www.cardiomyopathy.org.

In this edition we shine a spotlight on our fabulous fundraisers, showing our incredible team of 46 marathon runners, each one of them with a personal story to tell on how cardiomyopathy has impacted on their lives. (Pages 14-15). On pages 22-23, Steph Mackenzie shares her story with us, after being diagnosed with dilated cardiomyopathy (DCM) in 2015. Plus, there are lots of exciting events to look forward to in 2022!

Stay safe and stay well.



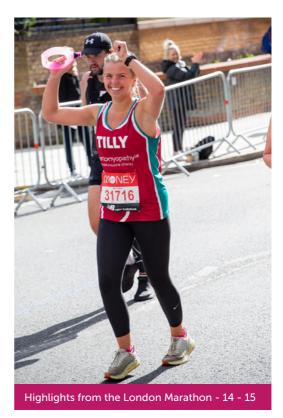
Rita Sutton, Chair

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Introducing MedEd - 18-19





What is cardiomyopathy?

Cadomyopathy is a disease of the heart muscle: 'cardio' means heart, 'myo' means muscle and 'justry' means disease.

It len's a kingle condition, but a group of conditions that affect the structure of the heart and engagement on the body. Around in 250 people in the UK are affected.

New Website - Page 10

ESC Guidelines Update

Richard Mindham's Story

n 2008, my diagnosis came as a complete surprise at the age of 50. I went to the doctor with fatigue and four hours later I was told I had heart failure & myocarditis. If I was lucky my situation would improve, if not then I would need a heart transplant by Christmas.

Within a few days of my diagnosis I spoke for an hour to Robert Hall, (former CEO), and he was immensely helpful. I cannot thank Robert enough for the time he spent talking to me as he sat in a lay-by on his way north. He was a rock.

In an attempt to understand my condition and begin to come to terms with my new life, I attended two information days and was greatly supported by the charity. It was a mine of useful information, and a place where people understood what I was going through.



How did you get involved with developing guidelines?

After a while, Robert told me there was a patient representative role available on the NICE (National Institute for Health and Care Excellence) heart failure guidelines board, and that I should apply for it. I got the role and my relationship with Cardiomyopathy UK began. This developed to the extent that Robert asked me to speak about the guidelines at the September AGM and to become a key point of contact.

I remained close to the doctors on the NICE Guideline board and they asked me to speak about my experiences at their annual gathering and later to sit on the English & Welsh Heart Failure audit. Through this I got the charity a stand at their conference, and subsequently I took over the running of the West London Support Group.

The guidelines were created by a group of some thirty experts drawn from the membership of the European Society of Cardiology (ESC), a membership organisation of 100,000 cardiac specialists. They are designed to help clinicians worldwide with their treatment and prescribing decisions. They also present and recommend what should be the ideal treatment pathway for people with heart failure.

When we developed these guidelines, we spent 18 months looking at fresh evidence for treatments that reduce the risk of death, reduce illness and improve quality of life. Looking back, it was a great experience and I learnt a lot. I was pleased that the guidelines pushed recommendations for helping patients after diagnosis with rehabilitation; including education on their condition and psychosocial support for the patient and family.

If the patient is not receiving the level of care that the guidelines recommend, they may be getting poor treatment. The guidelines offer a reference point for patients to understand (though the guidelines are very technical) whether they are on the best treatment and



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what questions to ask their cardiologist/nurse specialist if they feel they aren't receiving this.

What about the latest updates? What do they mean for patients?

These latest updates include changing the primary drug treatment for patients whose ejection fraction is down (compared to the last NICE guidelines of 2018.)

Instead of taking three types of medication, patients with reduced ejection fraction are now recommended to take four drugs to improve the symptoms of their condition, reduce risk of death and improve their quality of life. These drugs are:

- Beta Blockers (e.g. bisoprolol)
- ACE inhibitor* (e.g. Ramipril) or ARNI (Entresto)
- Mineralocorticoid receptor antagonist (MRA) (e.g. spironolactone)
- SGLT2 inhibitor (e.g. dapagliflozin).

*(An ARB (Angiotensin receptor blocker, e.g. Cadesartan) may be prescribed for people intolerant of ACE.)

What are you looking forward to?

I am very positive, and I feel very lucky to enjoy the health that I have; especially when I look back on how I felt when I was first diagnosed. I plan to continue advising as a patient on heart failure as I feel that this will really benefit patients.

I am looking forward to a world with lower COVID risks so that I can do some travelling. The first stop will be skiing in January!

The Burdett Trust

he Burdett Trust for Nursing was established in 2002; awarding charitable grants to support the nursing contribution to healthcare.

This funding will help provide ongoing support to our nurse team and help them to continue to do their job to the best of their ability. This is essential to our nurses for their professional development, and also for the charity as a leading provider of best and current clinical practice and expertise.

They fund three key areas:

Building nursing research capacity and capabilities

Building nurse leadership capacity and capabilities

Supporting local nurse-led initiatives

In response to COVID-19, Barts NHS trust received a grant from the Burdett Trust supporting Resilience in the Nursing workforce 2020. Nurses will receive:

- Shared learning and peer support
- Counselling supervision
- Skilled helper coursebespoke to Inherited Cardiac Conditions nurses

The funding was secured by our trustee and clinical fellow nurse, Tootie Bueser and will enable the charity to develop stronger networks with cardiac nursing teams in the community. This will enable us to better support our service users and share learning with the clinicians involved in their care.



Jayne Partridge Cardiomyopathy UK Support Nurse said,

"Specialist nurses working in isolation need to have robust support networks where they can share experiences, reflect on their practice, share best practice and knowledge to enable them to continue to provide the best possible care for those in our community who need our advice, quidance and support, especially during these difficult and challenging times."





Reaching out, reaching further

More people affected by cardiomyopathy than ever contacted our helpline during the Spring and Summer of 2020. Many of these people had never heard of us or used our services before the pandemic.

We understand that although we support thousands of people each year, there are still many more who for different reasons do not access our services. The charity remains committed to being the UK's leading third sector provider of information and support services to people affected by cardiomyopathy.



Looking at the data we capture each year we can see that we need to reach more young people, more people who identify with a heritage other than White British and people who are unable to access the information and support they need.

This is why we are now developing an outreach project, to ensure we are accessible to everyone who needs us. Our aim is to spread awareness and promote understanding about how to live well with their condition.

This project is overseen by a committee made up of volunteers, trustees, service users and clinicians. Our task is to look at and implement ways in which we can make our services more well-known and accessible to communities; who might not necessarily consider us as an option for help.

If you would like to know more about this innovative new project or to find out more, please contact Ali at Alison.thompson@cardiomyopathy.org



Not taking medication that has been prescribed to you at the correct times and/or missing a dose can sometimes result in your symptoms getting worse. Keeping up with taking your medication is important.

If you are concerned about experiencing any possible side effects, speak to your cardiac nurse, GP or pharmacist. They may be able to suggest an alternative or change of dose which might help. If you are experiencing side effects, sometimes altering timings of your medication may help, but this should only be done after seeking advice from a qualified professional who knows your clinical history and list of medications

You may be feeling overwhelmed with the amount of complex medication regimes you now have to take day to day. Your cardiac nurse or GP may be able to request a dosing box or write a simple list that could help you remember when to take your medications. You may want to arrange regular check-ups to see how things are going.



Nurse Jayne



How can I feel empowered looking after a child or young person with cardiomyopathy?

Although empowerment is described in different ways, it can be defined as a sense of power that gives the ability to influence people, organizations, and environments, and it also gives one control over one's life. Increased parental empowerment has a positive impact on well-being, self-efficacy, and levels of stress, and it is associated with an improved ability of parents to make adequate choices regarding their children's treatment.

Sometimes having an inherited cardiac condition can feel like things have been taken out of your hands, you can feel powerless. Particularly if it affects a child.

We know cardiomyopathy can accompany a child throughout their lifetime, and in addition to the child, it affects other family members and even the community, it is imperative that we empower parents and the child properly to control their own cardiomyopathy journey.



Nurse Emma



My cardiac nurse advised me to see my 'Community pharmacist' how can they help me?

Community pharmacists are located within your local pharmacy, there should be a local pharmacy within the equivalent of a 20 minute walk for 95 % of people. Pharmacists are experts in medicines, it takes 5 years to qualify. Pharmacists check prescriptions, dispense medicines safely and accurately to patients. They also provide health advice and if you need any advice about your medications or are starting a new medication make sure you know how to take it correctly.



Nurse Caryl

They might also offer other NHS services such as stopping smoking, blood pressure checks, weight management and the flu vaccination. Pharmacists are available to speak confidentially about any health concerns and can advise about over the counter medications. Around 10 % of GP pharmacists prescribe medicines to treat long term conditions.

Speak to your pharmacist if you are finding your medications expensive as they will be able to discuss pre-payment schemes with you.

Cardiomyopathy UK

New Website

Throughout the pandemic we've been busy working behind the scenes on our website. With more visitors coming to our site than ever before from across the globe, our ambition is to be the authority for all leading information and research about cardiomyopathy and heart muscle disease.

We are delighted to share the launch of Cardiomyopathy UK's new website with you.

We've refreshed the style and feel, with a simplified look which is easier to navigate. Our website has also been updated for a better experience when accessing information on mobiles and different browsers or devices.





What can you expect?

- It is now much easier to access information about the different types of cardiomyopathy, with dedicated pages for each condition and resources you can download to read in your own time.
- Information to empower yourself to live well with cardiomyopathy, including advice on practical support such as benefits, insurance, families, your emotional health and more.
- All our latest news, plus a new dedicated section written by our Nurses with their tips and advice.
- Lots of opportunities to find the perfect fundraising challenge or activity for you.

www.cardiomyopathy.org/

Please note, all our old website links will still link to the new site.

Resources

For children and young people



They say knowledge is power, yet for children and young people access to age-appropriate sources of information about cardiomyopathy are extremely limited. As part of our grant from BBC Children in Need, we decided to fix this by

creating some new, accessible resources for children and young people.

My Activity Pack

For our youngest children, we have created an activity pack which has the dual purpose of keeping them entertained during long hospital waits and providing a space to learn and share a bit about cardiomyopathy and their experiences.

My Cardiomyopathy and Me

For young readers, or young children with the assistance of a parent or caregiver, we have created an interactive information booklet to demystify cardiomyopathy and provide a safe space to learn, question and express thoughts and feelings, which can then be shared with a trusted adult. The focus is on the child as an individual, reflecting on the physical, mental and social impact which cardiomyopathy may have.

Cardiomyopathy and Me

Finally, for older children and teenagers, we have created a booklet which puts the reader at the centre of the information and decision making. As well as simplified explanations of cardiomyopathy and what to expect from testing and treatments, there is a focus on the mental, physical and social adjustments of a life with cardiomyopathy and how the young person can reach out to a wider network of support from peers and professionals.

Cardiomyopathy

and Me

Our hope is that these resources will empower children and young people affected by cardiomyopathy, through knowledge, support and self-expression. They are available in all main children's hospitals and paediatric cardiology clinics, as well as on our website where they can be downloaded or ordered. If you are a parent or care giver do let us know what you think. Email Sade at sade.mccarthy@cardiomyopathy.org

Empowerment in Action Our Services



Ali Thompson shares how our Services team can support you in understanding your (or a loved one's) diagnosis of cardiomyopathy.

You might have come across the word "empowerment" quite often lately, but what does it actually mean- and how does it translate to someone affected by cardiomyopathy?

A dictionary definition of empowerment is, "The process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights".

DID YOU KNOW?

- Our information resources are fact checked every year to make sure that the information we provide you is the most up to date and accurate.
- Our closed, moderated Facebook groups are available day and night (nurses are available in these groups during helpline operating hours only these are Mon-Fri 8.30 am – 4.30pm).

We support you so that you feel better able to cope with cardiomyopathy; and to become more confident to access the help, guidance and support you need to live well.

Cardiomyopathy UK offers a huge range of services which can support people to get the clinical advice they need. You can:

- Talk to one of our specialist nurses on our helpline
- Chat to one of our trained peer support volunteers in confidence
- Meet others similarly affected and who know what you're going through
- Attend a support group and hear from a range of expert speakers. Our support groups cover all condition specific cardiomyopathies (ARVC) to Heart Failure.

Plus, if you're aged 18 or under, we've got our youth support services and Youth Panel. (You can read more on our world exclusive Children in Need resources, page 11)

There is always a safe space for you to share and discuss how you are feeling and any concerns you might have.

We understand that living with a long-term condition can be challenging and sometimes sharing with someone who knows how this feels can help us feel less alone.

Together we are more knowledgeable about how we can manage our condition on a daily basis, and what we can expect from the healthcare system, and how to speak out if we feel something isn't right or working for us.

Many of our trustees and volunteers have the condition themselves so they understand first-hand how cardiomyopathy can change over time and how people can sometimes feel differently towards their condition.

Our services for our community are constantly evolving and growing. We want to reach out to those who aren't always represented, and offer involvement, advice, guidance and support.

Finding our voice to question our care and understanding better how our cardiomyopathy affects us physically, emotionally, psychosocially and with regards to our employment are all ways in which the charity can help and support you.

If you would like to learn more about our services or there is a service you feel the cardiomyopathy community could benefit from that we don't currently have, please contact me at alison.thompson@cardiomyopathy.org or any of our services team.

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London Marathon

On Sunday 3 October, 46 Team Cardio runners completed the London Marathon. They ran for themselves, in support of friends, family and colleagues, and in memory of loved ones lost.

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So far, their efforts have raised over

£130,000 for people affected by cardiomyopathy.

When our runners lined up at the start line, it had been 2 years and 6 months, that's 889 days, since the London Marathon last took place in its full glory along the streets of London.

Due to cancellations and postponements because of the pandemic, some of our runners had been waiting since 2019 for this memorable day. We were delighted to finally meet and thank runners as they each arrived at our post-race reception to a round of applause. It was an emotional day, and we were so pleased to be able to share it with our runners and their families.



THANK YOU!

Our London Marathon runners were cheered on by our fantastic volunteer cheer point at mile 17.



We'd also like to say a special thank you to our supporter, Tyndall, who has done a bucket collection on the day of the London Marathon for Cardiomyopathy UK for the past 14 years!





Here are some of our runners celebrating at the after party







Charity places on Team Cardio for the London Marathon 2022 are now available. We have a limited number of places so apply today at www.cardiomyopathy.org/london2022

Dates for your diary in 2022

Join Team Cardio 2022

We have many more challenges available on our website. Our Challenge Events Fundraiser, Becky, is here to help you find the right event for you and support you every step of the way.

To sign up or find out more visit www.cardiomyopathy.org/find-a-challenge or email fundraising@cardiomyopathy.org

Skydives

Take on the ultimate adrenaline challenge! Experience an amazing, once in a lifetime opportunity and help us raise vital funds by taking part in a tandem skydive.



January

29 & 30 - London Winter Walk

March

20 - Hampton Court Palace Half Marathon 27 - Cardiff Half Marathon

May

22 - Hampton Court Palace 10k 28 & 29 - Edinburgh Marathon Festival (range of distances available)

June

11 & 12 - Nightrider London 25 to 26 - Cotswold Way Challenge

August

5 to 7 - UK Coast to Coast Cycle 10 to 14 - London to Paris Bike Ride

September

9 - Thames Moonlight 10 11 - Great North Run

October

- 2 TCS London Marathon
- 9 Royal Parks Half Marathon

Our strong and empowered community



By Joel Rose, our Chief Executive

or some people, a diagnosis of cardiomyopathy can come with a sense of powerlessness and a feeling of no longer being able to control your life.

We know how devastating this can be, and so our support services are focused on helping people who may feel this way to reassess their situation by developing the knowledge, skills and motivation to feel more in control.

But while individuals may sometimes feel like they are becoming powerless, I have no doubt that the cardiomyopathy community, as a whole, is becoming increasingly empowered. We have seen this over the last year with our Change Maker project and the work we have been doing to shape research.

Our Change Maker volunteers are now operating across the country and using their voice to shape cardiomyopathy services so that more people with the condition are able to access the support and treatment that they need. Over the last few months, we have brought together focus groups and have run a national survey, the results of which have played a significant part in shaping research projects so that they are focused on the issues that matter to people with cardiomyopathy.

Next year we are planning to do even more by increasing the number of Change Maker volunteers and working with more researchers. Our strong voice will be heard by all policymakers and health service providers. At the same time of course, our fantastic support services will keep ensuring that nobody with cardiomyopathy feels powerless.

But while individuals may sometimes feel like they are becoming powerless, I have no doubt that the cardiomyopathy community, as a whole, is becoming increasingly empowered.

Introducing Med Ed Med Ed Part Med Ed Part



Adrian Taylor, Education and Information Manager

We caught up with Adrian Taylor, Education and Information Manager to hear about the launch of our new e-learning courses for healthcare professionals.

Designed to support cardiac specialist clinicians, we have developed a series of free CPD accredited courses, starting with the two most common types of cardiomyopathies: hypertrophic and dilated cardiomyopathy (which affect an estimated 1 in 250 people in the UK).

"It has been a pleasure to work with some of the world's leading cardiologists to share their knowledge and experience on a dedicated

learning platform that is free to healthcare professionals.

We know just how busy clinicians can be, so we've designed the platform as a place where you can just drop in to look up a specific topic; or work through a full course to gain 15-hours of accredited learning."

Adrian Taylor

Each course contains an extensive range of medical images and research, videos from patients living with the condition and interviews with leading cardiologists. We intend to add more courses in the near future.



But what does that mean for patients?

Our aim is to increase medical knowledge and expertise, so that clinicians are more confident in recognising and managing cardiomyopathies. We hope this will lead to quicker diagnoses and a better care pathway for anyone diagnosed with the condition; potentially saving lives and improving quality of care.

Joel Rose, CEO says: "We are delighted to be launching our new medical education platform. It will play a significant part in helping to ensure that medical professionals have the knowledge they need to provide timely and accurate diagnosis so that more people with cardiomyopathy can get the support and treatment they need." www.cardiomyopathy.org/healthcareprofessionals



Knowing more saves lives.



For Professionals

There is no time limit, you can study subjects in any order and you can access the materials from any device.

Read more about how we can support professionals on our website: www.cardiomyopathy.org/healthcare-professionals

Interested in receiving resources for your hospital or GP surgery? Order our wide range of resources via our website form here: www.cardiomyopathy.org/order-hospital-resources

For more information contact Adrian.taylor@cardiomyopathy.org

Christmas Cards

online shop at www.cardiomyopathy.org/online-shop

There's nothing quite like the personal touch of receiving a hand-written card in the post.

Show your loved ones that you're thinking of them this festive season.

Why not gift a stylish Cardiomyopathy UK hoodie this Christmas- as modelled by our staff! Every purchase raises funds so that we can continue to give support, raise awareness, campaign for change and provide hope for the future for people affected by cardiomyopathy.



Spread some joy with a card this festive season





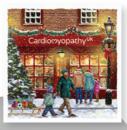


















Please note that some designs may only be available in multi packs, contents may vary. One pack contains 10 cards of varying styles, sizes and designs.

Steph Mackenzie

My story

Retired dental nurse Steph shares her story after being diagnosed with dilated cardiomyopathy in 2015. She lives in Scotland with her husband and two sons aged 21 and 16.

My symptoms started mid September in 2015. I felt sick, had no appetite with pressure in my chest and a rasping cough. I was feeling breathless when lying down, and I had fluid retention around my abdomen and legs.

An ECG and bloods were taken at the doctors, and when the ECG showed an abnormal reading, I was transported to hospital in an ambulance. Within 24 hours, I had a chest X-ray, an echocardiogram (a scan to look at the heart and blood vessels), an angiogram and an MRI.

The echo showed I had dilated cardiomyopathy and I was in hospital for 10 days until I was stable. I had pneumonia. I was treated



with heart failure medication and then reviewed for having an ICD fitted. After I was discharged from hospital, I was placed under the care of the local heart failure nurse, Rita.

My diagnosis came as a shock to both me and my family. Having worked as a dental nurse I had a bit of medical experience but had never come across anyone with cardiomyopathy. I knew about heart disease but thought it was a lifestyle thing linked to having an unhealthy diet, drinking and smoking.

Now, I generally feel so much better, I have the odd day when I feel some arm pain, and then I know I have to slow down. The medication has improved my EF (Ejection Fraction) and I no longer need an ICD fitted.

The consultant thought the condition may have come from a virus, but I'd kept healthy and never really had any cold or flu symptoms, so I underwent genetic testing and it was discovered that I had the DCM gene. All my family have been tested now except for my sons who are just getting screened. It was found that my father, brother, two aunties and one cousin carry the gene.

I was advised against doing anything that would put pressure on my heart or cause stress, such as high intensity exercise, drinking alcohol in moderation and not to have any more children! I miss doing cardio workouts and cleaning the house is now done day by day as I get so tired.

The support of my family gets me through the daily challenges, and walking my dog daily gave me the confidence to get out and exercise again!

Now, I generally feel so much better, I have the odd day when I feel some arm pain, and then I know I have to slow down. The medication has improved my EF (Ejection Fraction) and I no longer need an ICD fitted. I will always remember the head nurse in CCU saying to me if I kept positive about my condition, I would rarely be admitted to hospital. From then on, my mantra has been: keep your head up and keep your heart strong. I do believe maintaining a positive outlook is why I've only been in hospital once since.

My heart failure nurse has been great, she is only a phone call away if I need her. Cardiomyopathy UK has helped me with advice on medications, symptoms and general heart health. The charity is a great support.

I feel positive going forward. I take each day as it comes, there are new medications and new trials, plus medical knowledge has grown in the last six years. Personally, we have just taken on the challenge to build our own house and downsize. I cannot wait to oversee the project with my husband and enjoy the views!



Cardiomyopathy UK has helped me with advice on medications, symptoms and general heart health. The charity is a great support.





