

myLife

The magazine for people affected
by cardiomyopathy and myocarditis



National Conference
2024




Nurses Q&A

Jaana's Story

Contact us

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




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Find us online

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-  contact@cardiomyopathy.org
-  **Live chat**
www.cardiomyopathy.org
8.30am-4.30pm, Monday-Friday

Social media

-  [/cardiomypathyuk](https://www.facebook.com/cardiomypathyuk)
-  [@cardiomypathy](https://twitter.com/cardiomypathy)
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Welcome to the summer edition of MyLife.

Having just returned from a week away, I am now playing catch-up with the numerous tasks I need to complete, but I'm also making the most of the warmer weather and enjoying the uplift that summer brings.

We appointed new auditors this year and I am pleased to say that our audit was completed well ahead of the submission deadline, and that our finances continue to be in good shape. The Annual Report 2023 provides a comprehensive review of our achievements during the year. See page 6 for an overview.

Our National Survey as detailed on Page 18 is key to shaping our research work and enabling us to represent and take forward your views and needs. Please take the time to complete and return the survey, as always, your views and experiences are important to us.

This year we had a record number of keen runners and volunteers participating in the London Marathon. Well done and thank you to each and every one of you that took part and completed the course and thank you to everyone who supported our team and or made a donation, helping to lift the spirits of our runners and raise funds for the charity. Turn to page 14. Who knows, you might be inspired to enter next year.

Our conference planning team have been hard at work with arrangements for our 2024 National Conference. Save the date: Saturday November 16th and join us for what promises to be an informative day. With a wide variety of topics and many renowned speakers in the field of cardiology, there promises to be something for everyone. I look forward to seeing you there. Further details on Page 4.

I wish you and your families an enjoyable summer.
Stay safe and stay well.

Rita Sutton, Chair of Trustees

Rita



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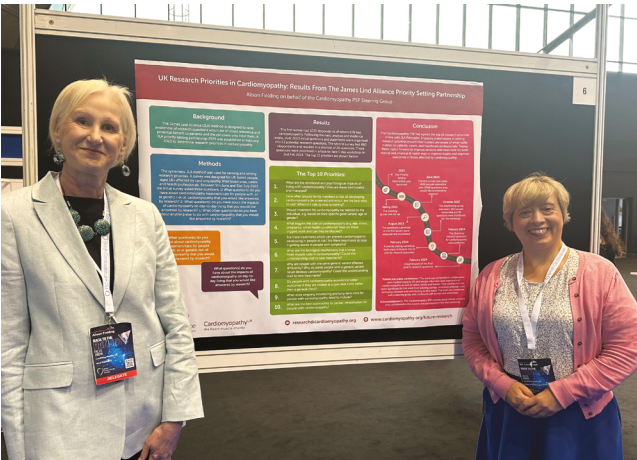
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National Conference 2024

Saturday 16 November

The annual Cardiomyopathy UK conference brings together people affected by cardiomyopathy with health and social care professionals. Our conference provides you with the information and networks needed to give you support, wherever you are on your cardiomyopathy journey.

On Saturday 16 November we'll be welcoming leading clinical speakers to present on cardiomyopathies, as well as other health and social care professionals that will explore the wider impacts of cardiomyopathy and how to live well with the condition.

The theme this year is 'Comprehensive Care; The Whole Person Approach'. We're focusing on addressing the practical, emotional and psychological impact of cardiomyopathy. We'll cover the needs of those that are newly diagnosed and cover topics relevant to individuals that have been living with the condition for some time. We'll connect you with actively recruiting clinical trials and other people affected by cardiomyopathy. We'll explore pharmacy and medication, women's health, genetics and family planning, lifestyle and much more.

Following continued positive feedback in 2023, we'll be returning to our London venue, which you told us had excellent facilities and catering. We look forward to providing you with the information, support and networking opportunities that will help you to develop your knowledge, improve your confidence and discuss the practical challenges of living well with cardiomyopathy.



To learn more about this year's conference, and grab your tickets, scan the QR code or visit:

www.cardiomyopathy.org/cardiomyopathy-conference



| Cardiomyopathy UK Conference 2024: Comprehensive Care – The Whole Person Approach | | | | |
|---|---|--|--|---|
| 📅 16 November 2024 📍 155 Bishopsgate, London | | | | |
| 🕒 9:30-9:55 | Registration & breakfast | | | |
| 🕒 10:00-10:05 | Welcome | | | |
| 🕒 10:05-10:25 | Key Note 1 - The State of the Art in Cardiomyopathy | | | |
| Cardiomyopathy Specific Sessions | | | | |
| 🕒 10:30-11:25 | Room 1 | Room 2 | Room 3 | Room 4 |
| | Dilated Cardiomyopathy - DCM | Hypertrophic Cardiomyopathy - HCM | Arrhythmogenic Right Ventricular Cardiomyopathy -ARVC | Restrictive Cardiomyopathy and Amyloidosis RCM/Amyloid |
| | Room 5 - Round table discussions on: Takotsubo, LVNC (LVH), and Myocarditis | | | |
| 🕒 11:30-11:55 | Morning Break | | | |
| Topic Sessions 1 | | | | |
| 🕒 12:00-12:55 | Room 1 | Room 2 | Room 3 | Room 4 |
| | Diet, Nutrition and Lifestyle | Welfare and Benefits, Insurance and Pensions | The Journey Through Advancing Illness | Understanding Diagnostic Tests |
| 🕒 13:00-13:55 | Lunch Break | | | |
| Topic Sessions 2 | | | | |
| 🕒 14:00-14:55 | Room 1 | Room 2 | Room 3 | Room 4 |
| | Pharmacy and Medication | Research and Clinical Trials | Women's Health | Devices and Surgery |
| 🕒 15:00-15:25 | Afternoon Break | | | |
| Topic Sessions 3 | | | | |
| 🕒 15:30-16:25 | Room 1 | Room 2 | Room 3 | Room 4 |
| | Genetics and Family Planning | ICC Services; Centres of Excellence | Acceptance and Commitment Therapy (ACT) for People with Cardiomyopathy | Acceptance and Commitment Therapy (ACT) for Carers & Supporters |
| 🕒 16:30-16:50 | Your Role in the Cardiomyopathy Community | | | |
| 🕒 16:50-17:00 | Closing Remarks | | | |
| 🕒 17:05-17:30 | Networking session | | | |



Our review of 2023

2023 was another great year for the charity, and we are pleased to say that we achieved a huge amount thanks to the continued dedication of our supporters, fundraisers, volunteers and staff team. Here are just some of the highlights.

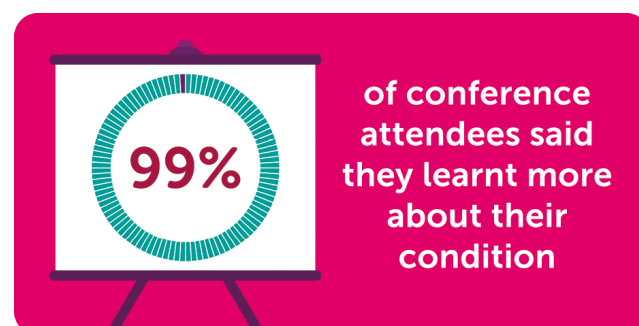
Providing support and information

We continued to provide a mixture of online and face-to-face support groups providing opportunities for individuals affected by cardiomyopathy to meet others in a supportive environment. These groups, led by our team of fantastic volunteers, held over 220 meetings during the year.

As well as our online and face to face support groups, our peer support volunteers spoke to 265 people during the year and our Facebook volunteers helped to ensure that this unique source of support remained a safe, informative and supportive forum for over 2,000 active members.

Our Cardiomyopathy UK Specialist Nurses continued to be busy on the Helpline supporting people over the phone and online. Feedback from service users continues to be overwhelmingly positive.

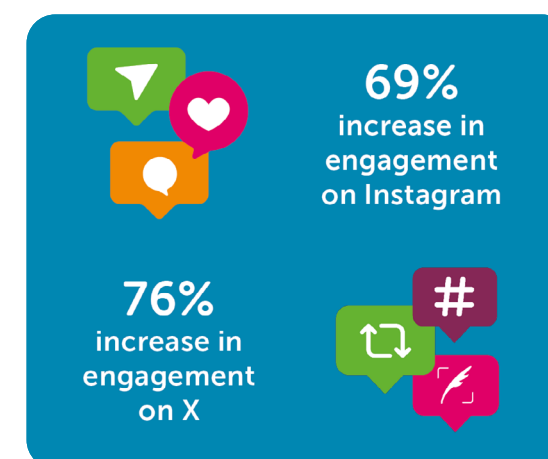
Feedback from our national conference was overwhelmingly positive. We were especially pleased that so many attendees told us they felt more confident about living with their condition after attending the meeting.



Raising awareness

During the year we once again joined with cardiomyopathy charities from around the world as part of an international awareness campaign. This campaign focused on the role of genetics in cardiomyopathy and the importance of knowing the history of heart disease in your family. Work as part of this international campaign enabled us to reach more people than ever before.

As well as joining in with international campaigns, we continued to create and share personal stories of people living with cardiomyopathy on our website, in our MyLife magazine and across our social media channels. This approach proved to be popular with more people engaging with and sharing our important awareness messages.



Promoting Research

In 2023 we built on our work to promote research that aims to make a real and lasting difference to the lives of people affected by cardiomyopathy. We worked with the James Lind Alliance on a priority setting partnership, bringing together our community, researchers and other stakeholders to identify and agree the top ten research priorities. The results of this work will be used to set our future research strategy so that as we take our first steps to become a funder of research, we can make sure that the work that we support addresses the needs of our community.

Advocating for people affected by cardiomyopathy

Our team of Change Maker volunteers continued to work hard during the year to help improve care and treatment for people affected by cardiomyopathy. We are incredibly thankful for their hard work in ensuring that the needs of people with cardiomyopathy are recognised by those who manage and deliver care for our community.

We also played an important role in the process of choosing which medications are available to people through the NHS. We provided evidence to the committees reviewing Mavacamten, for hypertrophic cardiomyopathy with obstruction and Tafamidis for amyloidosis cardiomyopathy. We are pleased to say that both these drugs have now been approved and, for the first time ever, medication specifically for people with certain types of cardiomyopathy is now available.

Thank you

"On behalf of all the team at Cardiomyopathy UK, I would like to say a huge thank you to all those who have been involved in making 2023 such a success. With your continued support, I have no doubt that 2024 will see us go further and do even more for our community."

Joel Rose, Chief Executive

To read our annual report in full, scan the QR code or visit:

 www.cardiomyopathy.org/about-us/our-impact





Jaana's Story

Jaana was diagnosed with hypertrophic obstructive cardiomyopathy (HOCM) in May 2017. Jaana has shared her cardiomyopathy journey with us to help others who may be going through a similar experience.

The diagnosis

Before my diagnosis, I was experiencing more cold/flu type illnesses than before, but I assumed it was just a bad year for them. I am at an age now where I thought this was common, so it was easy to discredit these symptoms as normal as I didn't go to my GP every time I had a cold or a flu. I was having trouble breathing, walking, and getting up the stairs. As these symptoms worsened, I went to my GP.

My GP found a murmur and the results of my ECG were unusual, so I was referred to the hospital where I was eventually diagnosed with HOCM. I was put on medication and had an ICD implanted which helped at the beginning.

At the time of my diagnosis, I was aware of some heart problems in my family history, but I didn't know anything specific. I'm from a generation where things like this weren't discussed as openly as they are today. I was told after tests that I was found to have a 'genetic spelling mistake' with my MYBPC3 gene, meaning my HOCM did have a genetic cause.

Receiving my diagnosis felt unreal, I was shocked and scared. You read all these stories in the papers about things like this, but you never think it'll happen to you. It left me thinking about how much my life is going to change, and what might happen to me in the future. Before my diagnosis, I have always been aware that lots of people have hidden disabilities. People can carry many kinds of disabilities without others knowing. Some people get comments like 'you look so well; nothing can be wrong with you', it goes to show you never know what struggles other people are going through, and you should never judge a book by its cover.

Living with cardiomyopathy

I have always been a very active and independent person. I love sports, fitness, and I have done martial arts for most of my adult life at a high level. I took part in a lot of cycling, walking, skiing, and ice skating. We have an allotment that requires a lot of physical work and I used to do all kinds of DIY. My entire life has been sports orientated and I absolutely love it. It was a difficult adjustment post diagnosis, learning my limits and knowing what I can and can't do, as my active lifestyle has always been very important to me.

At first, I was managing my condition well with medication and my ICD. I left the extreme sports behind, but I continued to do a reasonable amount of walking, cycling and water exercises. Unfortunately, I went into ventricular fibrillation in 2020, and my condition started to deteriorate in 2021. My breathing had got worse, and walking was becoming more difficult. I couldn't do much at all and even jobs around the house were difficult to complete. It was a challenging time, I was frustrated and worried about everyday life and felt like I had an unpredictable future. Life was like a slow-motion movie, and it was like being trapped in a vicious cycle with no way out. I did my best to stay busy and not let things get too negative. I ended up needing surgery, having a septal myectomy, mitral valve repair and an appendage clip, which I benefitted from greatly.

Since my surgery I feel a lot better. I can do much more and things became a lot easier. I found household chores easier again, I didn't need to think about it too much or stop between jobs, I could just get on with things again.

"There is always a fighter in you, however bad things may look, there is always hope. Staying positive definitely helps me."

- Jaana



I have reintroduced exercise back into my life, with long walks, cycling and gardening. It took time to get back to normal after the surgery, I think it's important to let your body heal and not rush things.

At the moment, I can make plans in life, even long-term plans, and things all look more promising and positive. I don't have any major symptoms, and I am increasing my strength little by little. There is always a fighter in you, however bad things may look, there is always hope. Staying positive definitely helps me.

To read Jaana's story in full, scan the QR code or visit:

 www.cardiomyopathy.org/news-blogs/latest-news/jaanas-story





Research Roundup

It's a significant time for cardiomyopathy research, with work to understand the condition starting to translate into new treatments.

Cardiomyopathy UK has a vital role to play though partnering on projects and ensuring people affected by the condition are at the heart of research. We also track and share the latest developments from around the world. **Follow us on X: @cardiomyopathy.**

Potential new treatment for hypertrophic cardiomyopathy

A recent phase three clinical trial showed new drug aficamten improves symptoms, with fewer side-effects than existing medication, in people with obstructive hypertrophic cardiomyopathy (HoCM). Regulatory approval will be needed before it can be made available to people with the condition.

Our research partnerships

CureHeart

As reported in the Spring 2024 edition of MyLife, we're part of the £30 million British Heart Foundation (BHF) funded CureHeart project which is developing genetic therapies for inherited cardiomyopathies. A few months back we asked you to complete a questionnaire for the CureHeart Patient Perspectives study. Thank you to everyone who took part and helped the team reach over 1200 responses! Now they're analysing the results and will start inviting a sample of respondents to take part in the interview part of the study. You can sign up to receive updates about CureHeart at: cardiomyopathy.org/cureheart-updates

SMASH-HCM

We're supporting this cutting-edge European study which is investigating using 'digital twins' to improve the diagnosis and management of hypertrophic cardiomyopathy (HCM). The condition can be caused by different genetic changes and people with HCM are affected differently – from the symptoms they experience to how quickly they progress. The team are developing computer models of unique variations of HCM with the aim of personalising treatment.

Promoting our research priorities

We presented a poster at the British Cardiac Society (BCS) conference in June highlighting our top 10 priorities for the future of cardiomyopathy research. People with lived experience of cardiomyopathy and healthcare professionals created the list through our 'priority setting partnership' led by the James Lind Alliance. Find out more on our website: cardiomyopathy.org/future-research



Join our research network

If you'd like to keep updated on the latest research news and find out about opportunities to get involved in cardiomyopathy research, you can subscribe to our research network newsletter at: cardiomyopathy.org/form/research-network-subscribe

If you have any questions about cardiomyopathy research or how to get involved contact us at: research@cardiomyopathy.org

Advocacy and campaigns roundup

Our calls to the new Government

At the end of spring, a general election was called for early July. We shifted our priorities in quick response to publish a Cardiomyopathy Manifesto. This drew on our previously published priorities, particularly the Change Agenda, as well as manifestos and reports published by coalitions that we work alongside, given our shared aims.

Calls in the Cardiomyopathy Manifesto:

1. Early detection and diagnosis
2. Mental health support for people living with long-term conditions
3. Access to specialised care, treatment and drugs
4. Reduce heart failure deaths by 25% in 25 years
5. Investment in life sciences

To read our calls to Government in further detail, please go to: cardiomyopathy.org/general-election

We asked you to engage with your parliamentary candidates to highlight our manifesto in relation to your own experiences of living with cardiomyopathy. Thank you everyone who took the time to do this. It is still too early to know the impact of our engagement; however, this does help us to build relationships with the newly elected MPs. This should put us in a good position to continue building our parliamentary engagement going forward. Should you have any links with parliamentarians and be able to facilitate an introduction, please get in touch at: policy@cardiomyopathy.org

The Manifesto will also form our calls on the new Government. We will be asking our community to take part in other influencing activities over the coming months. Our Change Maker network plays an active role in advocating for improved services and support for people with cardiomyopathy, on an ongoing basis. Keep your eyes out for the launch of the next phase of the Change Maker network later this year – and please consider joining.

To read our manifesto in full, scan the QR code or visit:

 www.cardiomyopathy.org/general-election



Q&A

with our nurses

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



Helpline

0800 018 1024
(free from a UK landline)
8.30am-4.30pm, Monday-Friday

Q. I've got Cardiomyopathy and want to go abroad for a holiday, what do I need to consider?



Nurse Emma

Once you've decided where you're going, do get appropriate travel insurance, making sure they are aware of your diagnosis. If you have a long flight, consider wearing flight socks and move about as much as possible, to avoid risk of blood clot. It would be sensible to check out the area that you're travelling to and identify the nearest hospital with cardiology care, in case you need to seek some medical attention. We advise travelling with your latest clinic letter and ECG so that you can show any clinician treating you about your condition. Also travel with a good supply of your medications in your hand luggage, in case of lost luggage. If there's a significant time difference work out when you are going to take your medications, making sure they are spaced out properly. If you have a device implanted, remember to carry your device ID card so that you can inform airport security staff. Remember that hydration is really important, especially if you're going to a hot country. Make sure you drink plenty and stay in the shade as much as possible. If you suffer with any sickness or diarrhoea whilst on holiday it's vital you re-hydrate well. Consider taking some oral rehydration sachets (such as dioralyte) with you.

Most importantly enjoy yourself!

Q. My specialist told me about a new medication which might help treat my cardiomyopathy called tafamidis, can you tell me more about it?



Nurse Jayne

Tafamidis is prescribed to treat Amyloidosis cardiomyopathy a rare condition caused by a build-up of an abnormal protein in the body called Amyloid. ATTR-cardiomyopathy is caused by a protein called transthyretin, or TTR, that changes its shape and forms into fibrous clumps. Clumps of misshapen protein are deposited into various organs including the heart and peripheral nerves, which can cause them to function abnormally.

Symptoms are often similar to heart failure. Symptoms may include:

- Fatigue
- Leg, ankle, or abdominal swelling
- Shortness of breath with activity
- Sudden drop in blood pressure upon standing
- Trouble breathing when laying down
- Irregular heartbeat (arrhythmia)

Tafamidis is a transthyretin stabilizer, it works by preventing the formation of transthyretin deposits in the heart. It is approved in Scotland for patients with ATTR-CM, as the first ever treatment for this type of cardiomyopathy. In England and Wales approval by NICE (National Institute for Health and Care Excellence) is awaited.

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



London Marathon 2024

In April, we had 72 incredible and inspiring members of #TeamCardio run the iconic London Marathon. Some were running for themselves, some in support of friends and family who have cardiomyopathy, and some who took on the 26.2 miles in memory of loved ones.

We were so pleased to be able to share the amazing day with our Team Cardio and their families. We loved cheering on our incredible runners at our mile 17 cheer point, and it was amazing to meet and thank so many of the team at our post-race reception. So far, over £190,000 has been raised through the London Marathon to support individuals and families affected by cardiomyopathy.

Thank you to our 2024 team!



"I cannot thank Cardiomyopathy UK enough for giving me the opportunity to take part in the marathon. I knew I always wanted to do a marathon, but to be able to do it for a charity that is so important to me was just perfect."
- Luke

"The support was great, and the post marathon party with showers and massages, food and drink was very welcome and fantastic!"
- Richard



"I loved meeting other members of Team Cardio during the course and seeing the charity banners in the hardest part of the race - I felt very supported."
- Barbara



Cheer point!

Our staff, volunteers and runner's loved ones cheered the London Marathon team on at mile 17 this year.



A huge thank you for Tyndall, who collected through the streets of London on race day for Cardiomyopathy UK, for the 17th year in a row. Tyndall raised £932.70 at this year's London Marathon.

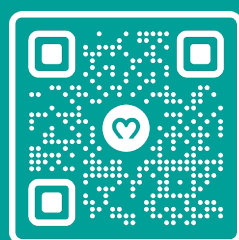


Post race

It was great meeting some of our Team Cardio runners at this year's post-race reception!

Paris Marathon

13th April 2025

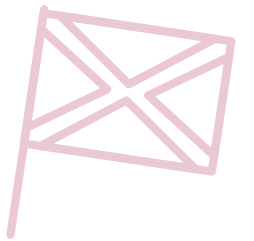


Join #TeamCardio

Limited charity places left

bit.ly/teamcardio-paris

* Just 7 places left. Registration £35, minimum fundraising target of £850 *



Working in Scotland

In our recently published five-year strategy we highlighted our aim to ensure that we can support people affected by cardiomyopathy throughout the UK.

In our recently published five-year strategy we highlighted our aim to ensure that we can support people affected by cardiomyopathy throughout the UK.

People from right across the country already use our helpline, information, website and peer support services and anyone who has ever been to our national conference will know that people come from far and wide to be part of this empowering event.

You will also have seen that over the last few years we have been doing more to influence the health and social care policies as well as the NHS services that impact on people affected by cardiomyopathy. To do this, we work with a wide range of stakeholders including other charities, clinicians, NHS organisations and politicians.

If we want this work to be effective, we need to recognise that there are important variations in the NHS structures, decision making processes and devolved powers in different UK regions. That is why in Scotland, for example, we work with the Health and Social Care Alliance Scotland, the Scottish Heart Failure Alliance, the Network of Inherited Cardiac Conditions Scotland, Public Health Scotland's Cardiac Audit Programme and other key stakeholders.

The process for deciding which drugs are made available via the NHS in Scotland is also different to the rest of the UK. Last year we worked with the Scottish Medicines Consortium to support its work in assessing the suitability of new drugs Mavacamten and Tafamidis, both of which have now been approved for people in Scotland.

Another big difference that impacts our ability to support people in Scotland is that Scotland has its own register of charities. This means that any charity that wants to increase its presence in the country needs to be registered with Scottish charity regulator (OSCR) even if they are already registered with the Charity Commission in England. Because of our plans to do more in this region, trustees decided to apply for charitable status in Scotland. I am pleased to say that our application has now been accepted.

So now we can forge ahead with our plans to increase the number of local Scottish support groups, and work more closely with the Scottish government, NHS Scotland, Public Health Scotland, and other important stakeholders in the region.

Over the coming year we will take a similar approach in Northern Ireland and in Wales. I look forward to updating you on our work in these regions and on our progress towards meeting the goal of supporting people throughout the UK.

Take part in our national survey




We need your help to make MyInsight, the 2024 Cardiomyopathy UK national survey, better than ever.

Every two years we carry out a survey to understand the experiences of people affected by cardiomyopathy. The results help us target our campaigning work and services to the issues that matter most to you. The 2024 MyInsight survey is taking place this summer.

Make this our best survey yet

This year we're working with Picker, an experienced research organisation who regularly carry out surveys for the NHS and other charities. When developing the survey, they interviewed people with a range of experiences of cardiomyopathy to ensure we're asking the right questions. They will also be helping us to interpret and share the results.

To maximise the impact of our findings we need as many people as possible to respond. We want to hear from people who have or care for someone with any type of cardiomyopathy from:

-  different age groups and backgrounds
-  across the UK
-  newly diagnosed to living with the condition for a while

Over 600 people completed the survey in 2022. This year we want that number to be even higher. This is the first time we're also working with clinics to try and reach people who are not known to Cardiomyopathy UK.

Your voice matters

In 2022 you told us the wellbeing needs of people with cardiomyopathy were not being met. Now we're advocating for improved mental health provision on the NHS and building on our existing services.

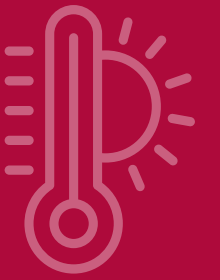
Your responses also gave us evidence to present to the UK medical regulators in support of mavacamten - the first drug of its type to be approved that specifically improves symptoms in people with obstructive hypertrophic cardiomyopathy (HoCM).

"Our survey plays a crucial role in our work to advocate for improvements in health services and wider sources of support for people affected by cardiomyopathy."

Katharine McIntosh, Head of Research and Policy at Cardiomyopathy UK

myInsight | & Picker

The 2024 MyInsight survey is taking place this summer. If you are signed up to our newsletter, you will receive the survey via email, and if you are signed up to receive post, you will receive a paper copy of the survey.



How to manage in hot weather

Anyone can find the hot weather difficult to cope with, but if you have a heart condition you might find the heat can affect you more.

When the weather is warm, your heart needs to work harder to pump blood to the surface of your skin to assist with sweating to cool your body. When you sweat to cool down you lose more fluid than usual from your body, which can lower your blood pressure and make your heart beat faster. It is important to always check with your GP or cardiologist for advice if you are on a fluid restriction and you're concerned about your fluid intake during a period of hot weather.

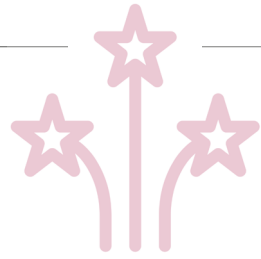
Otherwise, try to take frequent sips of fluids like water, and try to reduce caffeine-based drinks, as they can make you more dehydrated. You might also find that you need to rest more during warmer weather because your heart is working harder to keep you cool. Try to find a cool room and wear light comfortable clothing. Sometimes medications for heart conditions can reduce the body's ability to cool when it is warm. It is advisable to try to reduce the time you are outside in the sun, try to keep indoors and as cool as possible.

You may need to speak to your GP or heart nurse if you are taking diuretics and you are concerned about safe levels of fluid intake during a period of hot weather. The main risks during a heatwave (when the daytime temperature reaches 30 degrees) and hot weather are, dehydration, overheating, heat exhaustion and heat stroke.

10 tips for managing in warmer weather

1. Try and stay out of the sun and don't go out between 11am and 3pm if you are vulnerable to the effects of warmer weather.
2. Shut your windows and keep curtains, blinds or shutters closed when it is hot outside. You can open the windows for ventilation during the cooler parts of the day.
3. Try having slightly cooler water in your shower or bath. Sometimes splashing yourself with cool water can help to cool your skin.
4. Drink cooler drinks regularly, such as water or diluted fruit juice. Try to avoid drinking alcohol and drinks high in caffeine or sugar.
5. Plan ahead to make sure you have enough supplies of drinks, food and any medications you need.
6. Identify the coolest room in the house so you can go there to keep cool.
7. Wear loose clothing, a hat and sunglasses if you go outdoors. Sit outside during cooler hours and try to remain in the shade.
8. Limit physical activity during the hottest parts of the day and do light exercise during the cooler hours.
9. Eat light meals; avoid hot heavy meals and reduce the use of your oven to keep your rooms cooler.
10. Some medications can increase your risk for heat stress, ask your pharmacist if any of your medications could increase your risk.

Our fundraising superstars



Football Match

In May, Old Pond FC held their annual football match in memory of Lisa Freeman. Lisa sadly passed away in 2005 aged 30 from hypertrophic cardiomyopathy. Since her passing, the Hove Edge community have been raising money for Cardiomyopathy UK. This year's event raised an incredible £630, with nearly £20,000 now raised in Lisa's memory.

One of the day's organiser's, Denise, said "It was a beautiful day which brought many spectators both at the game itself and at the Old Pond pub afterwards for a raffle and other games. Many thanks to the footballers past and present and local people for their support! We have now raised just short of £20,000 in the years we have been doing this and that is down to our wonderful local community."



Golf Day

In March 2024, the 8th annual James Stephenson Memorial Golf Day was held, raising £520 for Cardiomyopathy UK. After James tragically passed away in 2015, his loved ones wanted to find a way to remember James whilst supporting his favourite charity. Since then, the golf day has gone ahead every year, and James' family have already got a date in place for 2025.

James' Father-in-Law, Chris, says "Over 70 golfers took part in this year's golf day, which was blessed with fine weather and an excellent golf course. Many of the regular attendees were present together with some new supporters to raise money. We support Cardiomyopathy UK as James' mother has Cardiomyopathy and James had been diagnosed as a carrier."

Ben Nevis

In April, Becki's friends took on the challenge of walking up Ben Nevis in her memory. The event raised £4220, contributing to the total raised in Becki's memory of nearly £7000!

"Becki was truly and honestly, THE best person I have ever known or will ever know. I feel so honoured and privileged to call Becki a best friend. She had the most wonderful personality, so happy and bubbly, the one who would light up the room and make you feel happy. As much as she had so much softness, empathy, and loving, she had a strong sense of justice and strong morals, she could absolutely be assertive if necessary. It is these attributes that led her to being a sister in ICU (which was her dream role as a student nurse)

Becki led a healthy and active life, there were no symptoms in the lead up to the cardiac arrest, other than feeling lightheaded. There were no signs of what was to come.

Following the cardiac arrest, which happened as Becki was sleeping, she went on to be a patient on her own ICU unit. The love and care she received at Blackpool Victoria Hospital was truly outstanding. It was evidently one of the most horrendous set of circumstances staff could be faced with to care for one of their own, but they did so with so much love and compassion. They are truly amazing, and I know Becki would be so proud of her team!

I was the organiser of the Ben Nevis Hike. My thinking around this was that, in the most difficult time, it would give some motivation both physically and mentally. It was a positive aim whilst we were faced with so much sadness. Personally, having this to aim for has helped me manage grief massively. I've had an aim and it's all for Becki! In all honesty, I've felt very flat and sad the event is over. But in respect of Becki, I feel I should make best efforts to remain healthy and never take my health for granted! I owe that to Becki.



The climb itself was a beautiful and emotional experience. There was a complete sense of togetherness. We were all there for Becki. We came together and effortlessly moulded through our love of Becki. It was a truly amazing experience for me! (to explain, Becki and I are best friends, but live very far apart) there were so many who made an extra special effort to travel from Lancashire to Fort William!

It's worth mentioning the picture of the boots are Becki's at the summit of Ben Nevis - ICU staff took them and Becki went to the summit several times as we set different paces!

After the climb I said never again...however I'm climbing Ben again on the anniversary of Becki's passing, and I'm aiming for sunrise."



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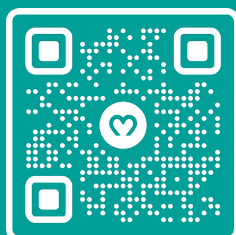


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