

Our impact

The difference that we made in 2019



“So reassuring I have someone to speak with that understands, it’s such a relief to finally feel we have somewhere to turn.”

Helpline caller

“I couldn’t have faced all of this without you.”

Helpline caller

“When you’re diagnosed with cardiomyopathy you feel like you are dumped on a desert island not knowing how to survive. You eventually find others on the island who are going through the same thing. Without the group you’re on your own.”

Support group attendee

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Hello

2019 was a year of transition and learning. We continue to evolve how we provide services to suit the needs of patients.

We have continued to take our services away from a focus on telephone helpline, paper resources and face to face information events and to a more digital service with social media, chat, web services and email. We piloted some online support groups in preparation for a new focus in 2020. There is still a place for a friendly face and our peer support services continue to grow. The in-clinic support is particularly important as we reach those who may not otherwise approach us.

Part of our role is to raise awareness of cardiomyopathy and myocarditis in order to save lives. Each year, we run a large awareness campaign focussed around our research. In 2019, the focus was on myocarditis and how to recognise possible symptoms. We were delighted by the media response generated for both the data and our case studies. The reach was many millions of people. Our vision is that one day people will have heard of cardiomyopathy or myocarditis before they are given it as a diagnosis.

Alison Fielding, Chair



Alison

.....

2019 has been another great year for the charity and I am especially pleased that we were able to reach out to more people and make a deeper and longer lasting impact on their lives.

In our 30th anniversary year, it is amazing to think how far we have grown and I am proud that while the range of our work and the number of people we support has increased greatly since our early days, we still remain rooted in the community that we support and have kept true to our core belief that everyone affected by cardiomyopathy should lead long and fulfilling lives.

As ever, we could not do any of this without our generous supporters, volunteers, and staff who continue to show their amazing commitment to our work. Thanks to them, I am sure that the charity will continue to go from strength to strength.

Joel Rose, Chief Executive



Joel

Helpline

The charity's helpline aims to help people to manage the huge impact that cardiomyopathy and myocarditis have on a person's life and the lives of their family and loved ones.

Our nurses can give all the time that a person needs to talk through their concerns and offer clear and accurate information as well as practical and emotional support.



1,532

people supported on our helpline in 2019

Call types



26%

Practical



24%

Emotional



50%

Medical

What condition did our callers have over the last year?

Dilated
Cardiomyopathy



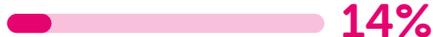
Hypertrophic
Cardiomyopathy



Undiagnosed



Other



In 2019 our helpline was able to support 1,532 people over the phone, via email and online. We ask callers how they feel after speaking to one of our nurses and we know that the vast majority of people feel better informed about their conditions, better able to cope with their situation and know what steps they need to take.



Outcome



of callers felt more informed and better able to cope



of callers described the helpline as "very helpful"

This year we have helped even more people challenge their unsuccessful applications for Personal Independence Payments (PIP) when their payments had been reduced stopped or denied. We also helped a small number of people access the blue badge scheme after their application was unsuccessful.

Benefits

47 PIP cases taken on...



refusals overturned

19 Blue Badge cases taken on...



refusals overturned



Helpline team

"You have been very helpful and have given me lots of information and guidance which I can go away and think about - thank you."

Helpline caller

Peer support

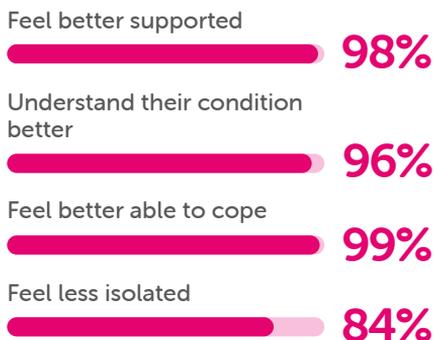
Local groups

Peer support is all about giving people the opportunity to share their thoughts and concerns with someone who really understands what they are going through.

2019 was the final year of our support group expansion project funded by The Big Lottery Fund. Thanks to their support and the fantastic work of our support group volunteers we were able to open up 27 new groups and launch new online support groups for rarer cardiomyopathies and for people who would not be able to attend a group meeting. We are really pleased that in 2019 we held 71 meetings across the country.



People who attended our groups said that it helped them...



Hospital volunteers

Our hospital volunteers are there to offer peer support at cardiomyopathy clinics often speaking to people who have just been given their diagnosis and are still in a state of shock. They are there to let people know that they are not alone and that there is a fantastic support network ready to help them. In 2019 our volunteers were able to support 496 people when they needed it most.

Peer support over the phone

Some people just don't feel ready to join a group or are not comfortable in a group situation so the charity also offers people the chance to speak to people with experience of cardiomyopathy one-to-one over the phone so that they can still get the benefit of peer support. In 2019, thanks to our volunteers, we were able to help 116 people in this way.

Support usage



1,120
support
group visits



894
Facebook
group users



116
helped by
peer support
volunteers



496
helped by
hospital
support
volunteers

More to come

In 2019 we were delighted to secure funding from the National Lottery Community Fund to help us expand our community peer support volunteers, opening up new local support groups and placing more volunteers in hospitals up and down the country.



Young people

2019 saw our first ever youth gathering, bringing together young people with cardiomyopathy and myocarditis. Our youth panel continues to work hard supporting other young people with the condition.



"When I was first told I had cardiomyopathy I had no idea what it was and didn't know anyone who had it. Joining a group had given me knowledge, understanding, friendship and mutual support."

Support group member

Providing information

Good quality information makes a huge difference especially to people coming to terms with a diagnosis of cardiomyopathy.

Our regional information events are designed to help people feel less scared about their condition and better able to cope with the day to day challenges that it causes. In 2019 we welcomed 386 people to our regional information days and national conference; our biggest yet. We also saw a big rise in the number of people accessing our website and information resources and were able to provide quality information to over 313,000 people.



felt more confident about managing and living with cardiomyopathy after attending our national conference

"It was really helpful meeting other people with my condition and my husband now understands more about how I feel."

Conference attendee



Working with healthcare professionals

In 2019 we continued to provide information and training events for healthcare professionals across the range of roles that play a part in diagnosing, treating and caring for people with cardiomyopathy and myocarditis.

The aim of these events is to ensure that participants are better able to provide the care and treatment that people with cardiomyopathy need.

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

Improved their confidence in detecting and treating cardiomyopathy



Greatly improved their knowledge of cardiomyopathy and related conditions



"Fantastic that it was free and still great quality."

"Extremely useful day, appropriately pitched."

"Good study day with great content."

Comments from clinician

Clinical advisory group

In 2019 the charity worked with its clinical advisory group, a network of cardiomyopathy experts from across the UK, to help ensure that its work remains effective, our knowledge is up to date and that we are able to shape and influence clinicians understanding of the impact that cardiomyopathy has on an individual and their loved ones.



Improving our knowledge

Supporting research

In 2019 the charity worked with a team of researchers at Imperial College London to launch The Heart Hive, bringing together researchers from across the country and people with cardiomyopathy and myocarditis who are keen to participate in research initiatives. The charity was able to fund this project through its Alexander Jansons Fund. Over 250 people signed up to the site within the first few months of it going live and more are set to join in 2020.



Undertaking research

As well as funding research, in 2019 the charity undertook its own research project looking at the experience of people with cardiomyopathy in accessing screening and genetic testing. Our work, published in national cardiac journals showed that;



Only 25% of people with cardiomyopathy are diagnosed on first visit to GP or Hospital



Only 10% were offered family screening or genetic testing

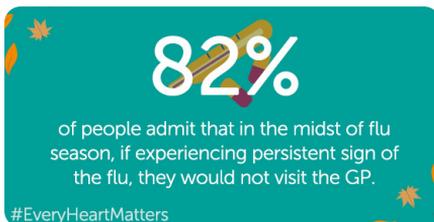
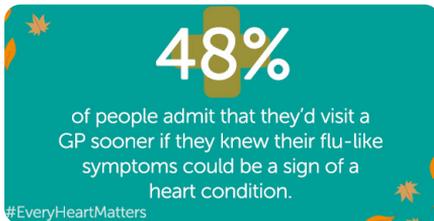
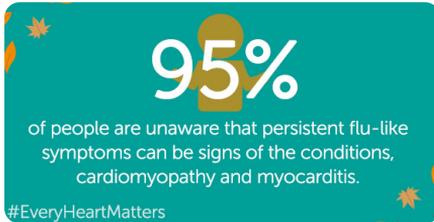


Only 9% of people with cardiomyopathy experienced the ideal diagnosis and treatment journey

Awareness that saves lives

The charity believes that when more people know about cardiomyopathy then fewer people die. That's why our national awareness raising work is so important. In 2019 we ran a national media campaign in the middle of flu season. We wanted people to know how cardiomyopathy and myocarditis can be masked by flu like symptoms. We were really pleased with the coverage that we received;

Images from the campaign



55

pieces of media coverage during the year



Social media

Throughout the year we were able to grow our social media presence to make sure that we were able to reach as many people as possible.



26%

increase in social media followers



290,000

visitors in 2019



22%

increase in website visitors

Fundraising

It goes without saying that we would not be able to do any of our work without the support of #teamcardio, our fantastic community of fundraisers. We had 178 community fundraisers and 143 challenge event fundraisers, a big increase on last year. Their support means that people affected by cardiomyopathy can get the help they need. In 2019 we were delighted to see more people sign up and take part in an increasing range of fundraising activity including our new 30 day challenge. We are always so impressed by our fundraisers' passion and dedication as well as some of the incredibly creative ideas that they come up with.

Community events



Challenge events



Corporate events



Income & expenditure

You may be surprised to know that the charity is able to make such an amazing impact on so many peoples' lives despite having no government or NHS funding and we relying entirely on the generosity and dedication of our supporters and our corporate and trust donors.

Income

Merchandise & events

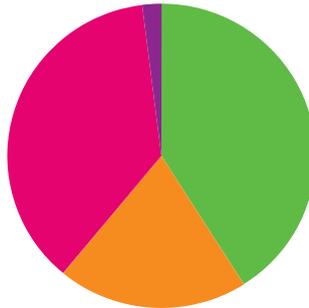
2%

Companies & trusts

37%

Total income:

£850k



Community and challenge event fundraising

41%

Donations & legacies

20%

Charitable expenditure

Campaigning

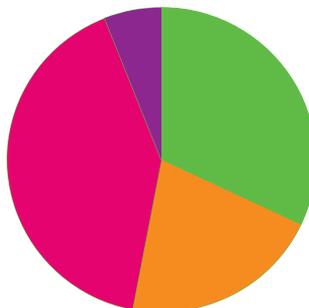
6%

Research

41%

Total expenditure:

£1.1million



Providing direct support

32%

Public and healthcare professional education

21%

In 2019 our expenditure exceeded our income as we used the extra funds that we received at the end of 2018 to fund research projects. We were pleased that during the year we were able to keep our administrative costs to 9% of total expenditure meaning that we had more funds to spend on direct charitable activity.

Thank you

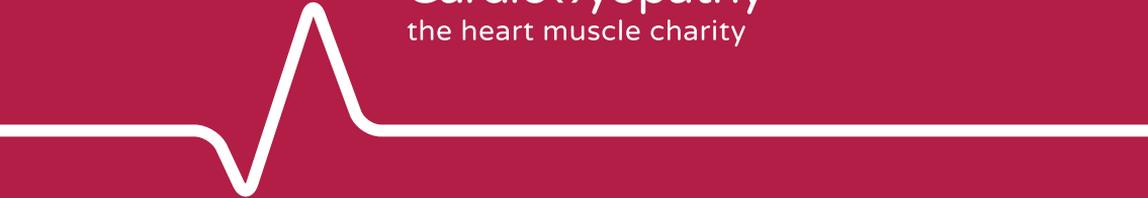
Governance

Cardiomyopathy UK is a unique charity. We bring together leading clinicians, people affected by the condition and charity professionals so that we fully understand the challenges of cardiomyopathy and myocarditis and have the skills, knowledge and resources that we need to meet these challenges. Our trustees have overall responsibility for the work of the charity. They have the range of skills that we need to be a successful charity as well as a deep and personal understanding of the impact of cardiomyopathy and a real dedication to our cause.

Volunteers

The Cardiomyopathy UK team would like to thank all of our volunteers, their hard work and dedication has made 2019 a real success. If you would like to know more about how you can volunteer and support our work in 2020 then please visit www.cardiomyopathy.org or just give us a call. We would love to welcome you to our family.





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the heart muscle charity

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Get real time support live chat via our website

Helpline: **0800 018 1024**

Office telephone number: **01494 791 224**

Email: **contact@cardiomyopathy.org**

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Asheridge Road, Chesham, Bucks HP5 2PX

For details about supporting us, visit our website

www.cardiomyopathy.org

Cardiomyopathy UK is registered in England and Wales as a charity, no 1164263