

Cardiomyopathy^{UK}
the heart muscle charity

We're here to help

How we helped people affected by cardiomyopathy in 2017



Every heart has a story...



...do you know yours?

#MyHeartStory



Hello.

Looking back at 2017, there are a few things that really stand out to me. We saw a huge increase in the number of people helped through peer support. This is where people with personal experience of cardiomyopathy or of supporting someone with the condition, volunteer to help others in clinics, over the phone or at one of our local support groups. We were also able to increase the amount of money raised to support our work and to deliver a national media campaign.

All this has been possible thanks to our volunteers and staff working hard to deliver services, raise awareness, improve treatment and ensure that the charity has the funds it needs to grow.

It has been because of their fantastic efforts that 2017 has been such a success and we have been able to reach more people than ever before, something that all the team at Cardiomyopathy UK are very proud of.



Joel
Joel Rose
CEO

Cardiomyopathy UK is the national charity for anyone affected by the heart muscle disease, cardiomyopathy. We provide support and information services, raise awareness of the condition and campaign to improve access to quality treatment.

As you will see, 2017 was a big year for the charity and I am proud that our work continues to make a real and lasting difference. None of our successes could have been achieved without the fantastic work of our volunteers and supporters; we rely on their incredible generosity and are truly thankful to all of them.

If you would like to know more about what we do or if you think that we can help you in any way then please get in touch.



Alison
Alison Fielding
Chair of trustees

Remember we're here for everyone affected by cardiomyopathy so if you need any help or advice please don't hesitate to contact us.



www.cardiomyopathy.org



Helpline 0800 018 1024



Live Chat via our website



Cardiomyopathy UK



Facebook group



@Cardiomyopathy



@cardiomyopathyuk



Our support services

Cardiomyopathy can have a huge impact on a person's life and that of those around them. We want people to feel better able to cope with this impact, and more confident that they can live as full a life as possible. One of the ways we do this is by providing medical advice and support on our helpline and opportunities to meet other people.

It is really important that our services can help as many people as possible, including young people, and that we can be there for them at all stages of the cardiomyopathy journey. That's why in 2017 we:

- launched a new service to provide peer support to individuals in hospital, many of whom had just been diagnosed with cardiomyopathy;
- brought together a young person's panel to provide support to people aged 14-25 and help design services and materials for young people; and
- continued to strengthen and expand our network of support groups opening 9 new groups and holding 65 meetings during the year.

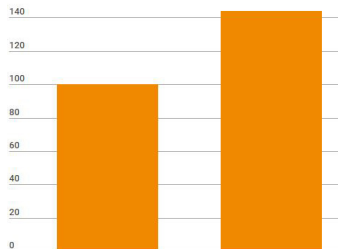
"You've made me smile and laugh for the first time in days, thank you. It's good to be able to speak to someone about my condition."

Geoff, helpline caller

The difference our helpline makes



1,865 people were helped

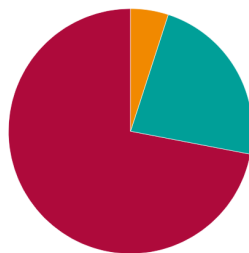


that's **44%** more than 2016



99% of callers found the service helpful or very helpful

What people call about



72% call with medical questions



23% call about practical aspects



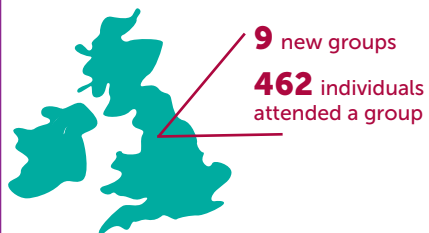
5% call about the emotional impact of cardiomyopathy

"It's a fantastic service where I can call and speak to an actual person with a wealth of knowledge. Thank you. Ahmed, in clinic"



Location of our face-to-face groups
(plus we have virtual groups)

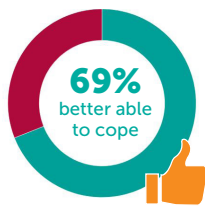
The difference our peer support makes



260 people received peer support by phone or in clinic



4,544 members on our facebook group

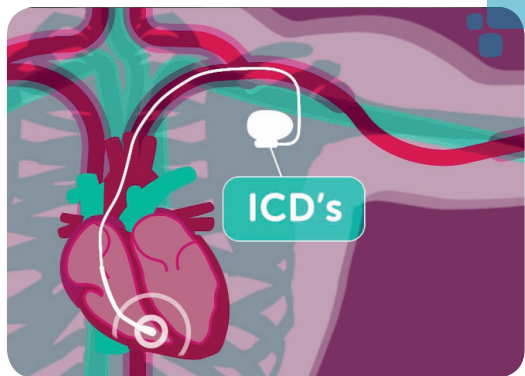




Providing clear and accurate information

Clear information can make all the difference, it can make you feel less scared about your diagnosis and more in control of your life. We want to make sure that our information is easy to access and covers all aspects of cardiomyopathy and related conditions. That is why in 2017 we:

- created a new animated video explaining treatments for cardiomyopathy and 16 new factsheets to give a clear and simple explanation of all aspects of cardiomyopathy;
- developed new resources for parents of young people with cardiomyopathy and information to help people cope with the emotional impact of the condition; and
- held six local information days aimed at underrepresented communities as well as a national conference covering all aspects of cardiomyopathy.



How we reached out through information



465

People attended an information event

People who attended an information event...



202,000

visitors to our website



15%
on last year



"I have more knowledge now. It helps me make decisions and ask for help when required."

Cheryl, Facebook



Raising awareness of cardiomyopathy

We believe that by increasing awareness of cardiomyopathy we can save lives by reducing misdiagnosis and enabling people with the condition to get the help they need sooner.

Our general awareness work aims to ensure that more people are aware of the signs and symptoms of cardiomyopathy and challenges some of the misconceptions around the condition. Improving awareness nationally is a big challenge, but one that we are determined to meet. That is why in 2017 we:

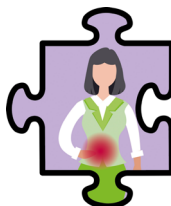
- ran our #MyHeartStory campaign highlighting the need to know about any family history of heart disease;
- grew our social media presence to reach a wider and more diverse audience; and
- secured local and national media coverage throughout the year.

The impact of our #MyHeartStory campaign



25

national and local media ran our #MyHeartStory campaign



241million

audience for all media coverage of the campaign



13%

increase in our social media following

Cardiomyopathy^{UK}
the heart muscle charity



"I knew nothing of this condition until I was diagnosed. Your website and support group has been very helpful."

Campaign survey respondent



Improving treatment and diagnosis

We want to see more people with cardiomyopathy receiving a quick and accurate diagnosis and to be able to access the most appropriate treatment. This is so that they can live as long and as fulfilling a life as possible. This means ensuring the clinicians have the skills that they need and that local and national NHS organisations have the resources they need to provide high quality care. That is why in 2017 we:

- ran a national medical conference with the theme of “hidden in heart failure” to improve clinicians’ ability to diagnose and treat cardiomyopathy;
- worked as part of the heart failure research hub to help clinical researchers explore new clinical research priorities; and
- collaborated with the Alliance for Heart Failure to ensure that the politicians and key health policy makers were aware of the specific needs of people with cardiomyopathy.

After attending our clinical training conference



“Very good presentation and good speakers. Very informative.”

Clinician, attended 2017 clinical conference



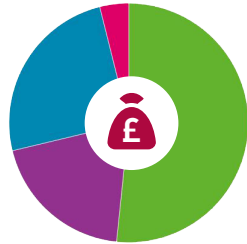
A bit about us

All of the team at Cardiomyopathy UK are proud of the impact that we have made in 2017. Our success is down to our unique ability to bring together leading clinicians, people affected by the condition and charity professionals. By working in this way we know that that we have a full understanding of the challenges of cardiomyopathy as well as the skills, knowledge and resources to meet these challenges.

It may be a surprise for you to know that we made such a big impact in 2017 despite being only a small charity and one that relies entirely on the generosity, determination of our donors and volunteers. Their support helped us to raise £681,000.

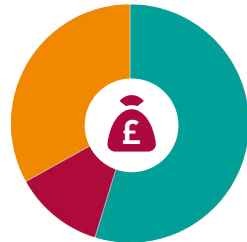
We want 2018 to be even more successful. You can learn more about our plans for 2018 on our website and "my life" magazine. As you will see, we think that we can do even more to reach the people who need us. As ever, we need as many people as possible to help us continue to be successful so if you think that you would like to join our team then do please get in touch.

How we raise our funds



- Community fundraising
- Donations & legacies
- Trusts & corporates
- Merchandise & conferences

How we raise our funds



- Administration
- Fundraising
- Charitable activity

Contact us

Helpline: **0800 018 1024**

Email: contact@cardiomyopathy.org

Office telephone number **01494 791 224**

Address: **Unit 10, Chiltern Court**

Asheridge Road, Chesham, Bucks HP5 2PX

You can find us at www.cardiomyopathy.org

 Support in realtime via Live Chat

 Facebook  Twitter  Instagram

For details about supporting us, go to our website.

Cardiomyopathy^{UK}
the heart muscle charity

Cardiomyopathy UK, registered charity no 1164263