



Cardiomyopathy^{UK}
the heart muscle charity

Our i♡pact

The difference we made in 2016 to people affected by cardiomyopathy

Hello.

Cardiomyopathy UK is the specialist national charity for everyone affected by cardiomyopathy. We provide support and information services, work to raise awareness of the condition, and we campaign for better access to quality treatment and promote research.

I am really proud of what we have achieved over the last year. We have been able to help people come to terms with their diagnosis, feel more informed, empowered and have the skills and support they need to cope with cardiomyopathy day to day. We have been a strong voice in Westminster, helped clinicians to improve the treatment they provide and made countless more people aware of cardiomyopathy and the impact it can have.

None of this could have happened without the fantastic work of our volunteers and supporters. We rely totally on their incredible generosity and we are truly thankful to all of them.

If you would like to know more about the charity and our work, or if we can help you in any way; please do just get in touch.



Alison Fielding

Alison Fielding
Chair of trustees

We're here for you

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



Cardiomyopathy UK
Facebook group



@Cardiomyopathy



Our support services

Our support services are here to help people feel more informed about cardiomyopathy and better able to cope with the condition. Living with cardiomyopathy can be a huge challenge, but speaking to our helpline nurses and to people who are going through the same thing can make the daunting seem manageable. That's why in 2016:

- ♥ We launched our new Live Chat service to enable people to connect to our nurses via their computer.
- ♥ We increased our capacity to provide practical support on welfare, benefits and rights.
- ♥ We recruited a paediatric nurse to provide specialist support to parents of young people with cardiomyopathy.
- ♥ We strengthened our network of local support groups and held **42** meetings throughout the country.
- ♥ We won support from the Big Lottery Fund to expand our support group network over the next three years.
- ♥ We monitored the diversity of people who use our services and are pleased to see that we were able to reach people from all communities.

“Thank you so much. I was so scared before I spoke to you, now it feels like I have got my wings.”

Kate

The types of issues we dealt with on the helpline in 2016



58%
Medical



18%
Welfare, benefits
and rights



9%
Emotional



7%
Accessing
treatment



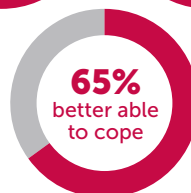
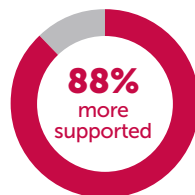
8%
Children and
young people



98%
of people
found service
'very helpful'

1,294 | Number of people our helpline team supported

How people felt after attending one of our support groups



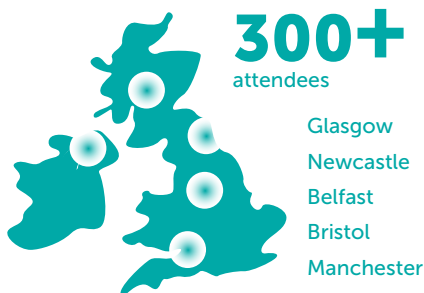


Providing clear and accurate information

If you, or someone you care about, have just been diagnosed with cardiomyopathy, or if you're just trying to live with the condition day to day then having clear and expert information is vital. The right information can help you to feel less scared and more in control. That's why in 2016:

- ♥ We produced a simple animated introduction to cardiomyopathy video. This video has been viewed over 40,000 times.
- ♥ We produced new simple factsheets on different forms of cardiomyopathy as well as on exercise and insurance.
- ♥ We held five local information days bringing together people affected by the condition and leading local and national experts.
- ♥ We held our first ever national conference in London with participants reporting that it helped them to feel more informed, more confident and better able to control their own treatment.
- ♥ We improved our website to make it easier to access information resources and read about other peoples' experiences with cardiomyopathy. We provided information both online and in print to **105,000** people.

Our information days around the UK



How people felt after attending information days and our national conference



“Excellent speakers and information that was informative and empowering.”

Shawn



Raising awareness and campaigning

Talking about cardiomyopathy saves lives. We know that there will be fewer avoidable deaths if more people recognise the symptoms of cardiomyopathy and can access the treatment they need. That's why in 2016:

- ♥ We built our case-study database of people ready to share their story with the media.
- ♥ We secured free coverage in a range of local and national print and broadcast media.
- ♥ We increased our social media activity to make sure that we could reach more people than ever before.
- ♥ We worked in partnership with other charities and health organisations to lobby for improved access to specialist services.
- ♥ We presented evidence to the All Party Parliamentary Group on Heart Disease and supported them in producing their heart failure enquiry.



Our media coverage reached over **600k** individuals



89

people signed up to our case study database



Social media following increased by

37%



Over

175,000

people visited our website

"The online forums and social media support has been a lifeline for me, a safe place, people who understand the little things that feel huge."

Ray



Educating and supporting healthcare professionals

It is a shocking fact that over **32%*** of people with cardiomyopathy are misdiagnosed in primary care and that even experienced cardiologists struggle to appropriately treat their patients with cardiomyopathy. That's why in 2016:

- ♥ We held a local training day for clinicians in the Midlands to help improve their ability to recognise and diagnose cardiomyopathy.
- ♥ We worked with University Hospital Morecambe Bay to deliver a specialist training day focusing on the dangers of peripartum cardiomyopathy.
- ♥ We held a national medical conference focusing on the detection of cardiomyopathy, rare diseases and the role of pathology.
- ♥ We worked directly with clinicians from across the Wessex region to identify service improvements in their area.
- ♥ We attended key medical conferences throughout the year to ensure that clinicians knew about the support that we can provide.

“ **Cardiomyopathy UK is a fantastic educational resource and is a vital part of our training.** ”

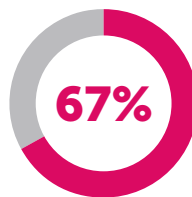
Dr Fraser, West Midlands

*Our national survey of patient experience

After attending our clinical training conference



of clinicians felt better able to treat and manage patients



said it would improve their ability to make a diagnosis



would recommend our medical conferences to colleagues





Supporting research and growing our understanding

The more we know about cardiomyopathy and the impact that it can have on individuals the more we can do to help people to live longer and more fulfilling lives. That's why in 2016:

- ♥ We undertook our own research into the emotional impact of cardiomyopathy and presented our findings to leading cardiologists and mental health professionals.
- ♥ We brought together our clinical advisory group, a group of leading cardiomyopathy experts, to discuss cardiomyopathy research priorities.
- ♥ We participated in the Heart Failure Research Forum to ensure that the needs of people with cardiomyopathy were understood by clinical researchers.
- ♥ We promoted opportunities for people with cardiomyopathy to be involved in research trials and invited researchers to attend our public information events.
- ♥ We worked with clinicians to develop research projects that would find new treatments for cardiomyopathy.

“ It seems many of us all over the world have the same feelings and experiences. Thank you for asking. ”

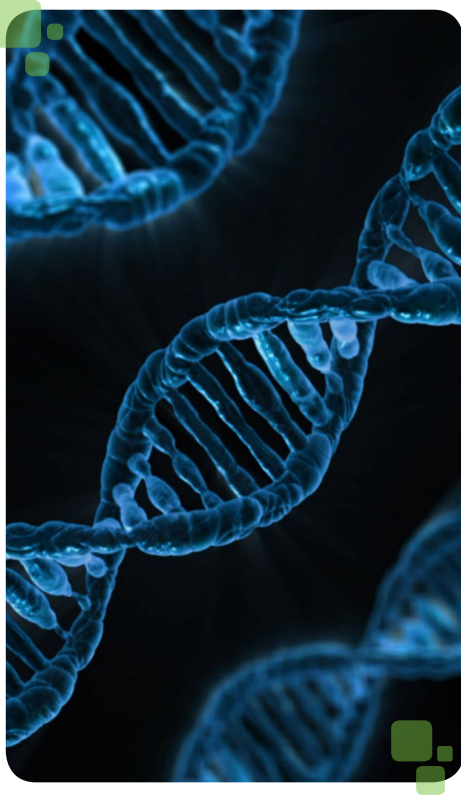
Janice, from our Emotional Wellbeing survey

Our social research

☐ ☒ **455**
☒ ☐ people contributed to our emotional impact survey



We presented our findings to **20** leading experts



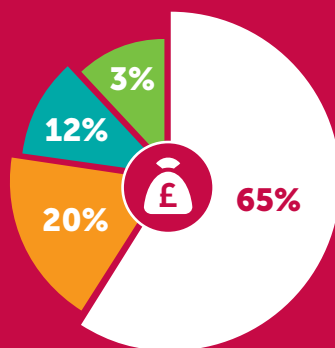
A bit about us


Although we are a small national charity we have been able to make a significant impact in 2016. We have achieved all this by bringing together people with cardiomyopathy, leading clinical experts and charity professionals. This gives us the unique ability to understand the needs of our community and have the policies, processes, network and skills to deliver great work with measurable results.

Our funding comes from the amazing support we receive from individuals up and down the country and from our fantastic fundraising volunteers. We receive no government funding and rely on these incredible people, and with their help, last year we raised **£652,000**.

Although 2016 was a great success, we still have much more to do. You can learn about our exciting plans for 2017 on our website, and see how we're going to help even more people with cardiomyopathy to live a longer and more fulfilling life. If you want to help us ensure that 2017 is a real success, then please get in touch.

How we raise our funds



-  Fundraising volunteers
-  Donations and legacies
-  Trusts and corporate supporters
-  Merchandise and conferences

Contact us

Helpline: **0800 018 1024**

Email: **contact@cardiomyopathy.org**

Office telephone number **01494 791224**

Address: **Unit 10, Chiltern Court
Asheridge Road, Chesham, Bucks HP5 2PX**

You can find us at **www.cardiomyopathy.org**

 Facebook  Twitter  Support in realtime via Live Chat

For details about supporting us, go to our website.

Cardiomyopathy^{UK}
the heart muscle charity

Cardiomyopathy UK, registered charity no 1164263