

Cardiomyopathy^{UK}

the heart muscle charity

The difference we made in 2015

Over the last year we've been able to do more than ever to support people affected by cardiomyopathy and help ensure that healthcare professionals are able to spot cardiomyopathy and provide appropriate support and treatment. We changed our name, our look and launched our new website, all with the aim of helping more people affected by cardiomyopathy.

"Your help and advice were brilliant - it was so helpful. Before I felt lost and that no-one believed me - now I feel in control and am adapting my life to live with the condition". **Simon, helpline caller**

Providing information

Good quality information is vital. Finding out that you have cardiomyopathy is a frightening experience and one that can leave you feeling confused and uncertain about the future. Our information resources give people the clear and simple information that they need to fully understand their cardiomyopathy and the treatments available so that they can regain control.

"Everything I know about the condition I found out from you and your website. It's amazing, I got home from the doctor's and didn't know anything, and found you online". **Nicola, Cardiomyopathy UK website user**

In 2015 we were able to meet our objective of ensuring that more people affected by cardiomyopathy feel better informed, know what their next step is and feel more able to cope.

My Life magazine

Our new 'My Life' magazine was launched. We send out nearly 12,000 copies of each edition to individuals, doctor's surgeries and hospital waiting rooms.

Booklets

As well as three booklets (on hypertrophic, dilated and arrhythmogenic right ventricular cardiomyopathy) In 2015 we also produced a brand new booklet - 'Living with Cardiomyopathy' - offering vital advice and information on many aspects of life with cardiomyopathy. In total we sent out over 5,000 of our booklets last year.

Information days

We had seven cardiomyopathy information days last year across the UK; with over 450 attendees in total.

Website

Our website has always been a vital source of information and support for people affected by cardiomyopathy and in April last year we updated the website in order to make the important information easier to find and to give better access to our services.

As a result we had over 200,000 unique visitors to our website.

Working with healthcare professionals

It is taking far too long for people to be diagnosed with cardiomyopathy and when they are, often they face a struggle to receive the treatment that they need. We know how important it is that clinicians develop their own understanding of cardiomyopathy and the latest developments in treatment, which is why we are in regular contact with over 2,200 medical professionals.

"I now have the confidence and skills I need to really help my patients". **Rita, clinician**

We want clinicians to be better able to diagnose cardiomyopathy and to support their patients in the most appropriate way. During 2015 we made great progress towards this vital goal.

Medical conferences

In 2015 we had over 321 healthcare professionals attend our 4 medical conferences and the vast majority told us that they felt better able to support a person with cardiomyopathy after attending.

Growing networks

2015 saw the launch of our Clinical Advisory Group. We brought together leading clinicians and academics across the country to help ensure that our work is appropriate, that we can reach even more clinicians and we can develop our research and campaigning plans.

Offering support

Living with cardiomyopathy can have a huge impact on all aspects of life. We know that getting the right support can make the difference between feeling overwhelmed and feeling like you can cope.

"As a family, we have lost a lot because of cardiomyopathy. I have had major open heart surgery, but we will never give in. Talking with others makes me feel better." **John, Support group member**

Helpline

Our nurse helpline offers the chance for people affected by cardiomyopathy to get personal support and advice from a trained nurse. In 2015 our nurses helped over 1,500 people.

Support groups

Sharing personal experiences can make a person with cardiomyopathy feel less isolated. In 2015 we had 17 active support groups and over 40 meetings held.

Online community

In 2015, we grew our already active online community, giving people the chance to interact with and support people affected by cardiomyopathy wherever they are in the world. Our private Facebook group was particularly active with around 1,000 new members signing up. We also launched our brand new forum - which had over 500 members by the end of 2015.

Improving access to quality treatment

One of the best ways to make a real difference to lives of people affected by cardiomyopathy is to work with other charities and organisations to raise the standard of treatment by developing best practice guidance and lobbying for better access to services.

In 2015 we played a key role as a member of the Alliance for Heart Failure and we were able to push for a parliamentary inquiry to assess inequality in treatment and make recommendations for change. We also worked with the National Institute for Health and Care Excellence (NICE) to review its guidance on heart failure and ensure it meets with the needs of patients.

Thanks to you!

We couldn't have achieved any of our success in 2015 without the help of our wonderful supporters.

"I found Cardiomyopathy UK on facebook one day and they offered me the support I needed when my husband was diagnosed with hcm... I wanted to give something back". **Jen, #teamcardio marathon runner**

340 fundraisers took on runs, baked cakes, climbed mountains and flipped pancakes and went the extra mile for us this year, raising over £400,000.

Our supporters bought over £12,000 of Christmas cards and Cardiomyopathy UK merchandise this year.

Over 1860 people chose to make a donation to our work.

The difference we will make in 2016

We know the impact we made last year but we also know that we need to do much more. We have ambitious plans for the year ahead and in particular we will be focusing on:

Supporting you all the way

In 2016 we will be working with young people to develop services for them and recruit a paediatric specialist, who'll offer support to parents of young people with cardiomyopathy. We know that our local support groups play a vital role so we'll be working with our current group leaders to make their groups the best that they can be and to help establish new groups nationwide. We are also planning to make it easier for people to reach our helpline nurses by launching a new "live chat" service.

Increasing Diagnosis

In 2016 we aim to increase the amount of clinical education events we provide nationwide and to work with clinicians to develop and promote simple guidelines for GP's. We'll also be working with government, the NHS and others to make it easier for relatives of people with cardiomyopathy to access genetic testing.

Getting specialist help

In 2016 we'll be doing more to highlight inequality in accessing treatment and we will be calling on local health organisations and the government to make it easier for people to get specialist care. We also want to ensure that psychological support for people with cardiomyopathy is made available. We'll aim to develop an individual advocacy service to help people navigate the complex NHS system to secure the referral and treatment that they need.

Developing treatment

In the coming year, the charity will be working with researchers to help ensure that their work really meets the needs of people with cardiomyopathy through greater involvement in research boards. The charity will also do more to encourage people to participate in research trial and to disseminate the outcomes of new research