

2021

Cardiomyopathy

# Change Agenda



Cardiomyopathy<sup>UK</sup>  
the heart muscle charity

# Background information

Cardiomyopathy is a disease of the heart muscle and presents as a group of conditions that affect the structure of the heart, reducing its ability to pump blood around the body. Whilst it is thought that around 220,000 people in the UK have the condition, a lack of accurate data is also an issue.

Cardiomyopathy UK is the national charity for people affected by cardiomyopathy. We provide support and information services, raise awareness of the condition amongst the public and healthcare professionals, advocate for improved access to appropriate treatment and support research.

Previous work with people affected by cardiomyopathy has highlighted that only 9% of people with the condition received ideal care and treatment, with many patients not being informed about the potential genetic nature of their condition and not being offered genetic testing.

Campaigning for wider access to quality treatment is a priority, thus we have worked with our Change Maker volunteers, the wider Cardiomyopathy UK community and members of our Clinical Advisory Group, consisting of leading professional experts, to develop this patient-centred Cardiomyopathy Change Agenda. Supporting data has been gathered from our Service User Survey, which received 650 responses, and our National Survey that received over 750 responses.

This Change Agenda is for all who care about cardiomyopathy. It highlights what people affected by cardiomyopathy want at all stages of their healthcare pathway, from diagnosis and specialist treatment to genetics and family testing, and long-term care and support. The implementation of these priorities would ensure that the healthcare future and current patients receive, meets their needs fully, enabling patients to live well with the condition.

We believe that our Change Agenda is achievable. Our Change Maker volunteers will now work with the NHS, alongside clinicians, commissioners, professional organisations and more, to make a real and lasting difference to the lives of people affected by cardiomyopathy.

## Cardiomyopathy Change Agenda Priorities

# Early detection and diagnosis

Many cardiomyopathy patients have struggled to receive an appropriate diagnosis, spending too long in primary care being treated inappropriately.



73% of patients did not associate their symptoms with a heart problem at the time of diagnosis.



46%

46% told us that their heart history was not taken.



**A diagnosis of cardiomyopathy affects the whole family and often marks the beginning of a quest for answers. Why do I have it? What caused it? Will I pass it on? Am I going to drop dead suddenly? If, at that point, you're given reliable information, the opportunity to discuss concerns, and a plan to find answers, you have hope for the future. Without that, you are lost in a sea of uncertainty, misinformation and fear. //**

- Libby Jarman

### People affected by Cardiomyopathy want...

1. GP's to ask, and have on record, a detailed family cardiac and medical history, for potential cardiomyopathy symptoms to be identified in this context.
2. The use of a NT ProBNP blood test where the possibility of heart failure symptoms are apparent, and with guideline referral times to secondary care met when results dictate.
3. The referral process for diagnostic tests in hospital, through whichever point of entry, to be effective and timely.
4. To be seen by and cared for by a cardiologist, and if in hospital on a cardiology ward.
5. The cardiology team to deliver a specific cardiomyopathy diagnosis, where this is the cause of symptoms. This should be delivered in a sensitive manner, with the opportunity for further explanation available and a point of contact agreed.
6. The cardiology team to signpost newly diagnosed patients to Cardiomyopathy UK.

### Supporting the Change Maker's work, Cardiomyopathy UK will continue to:

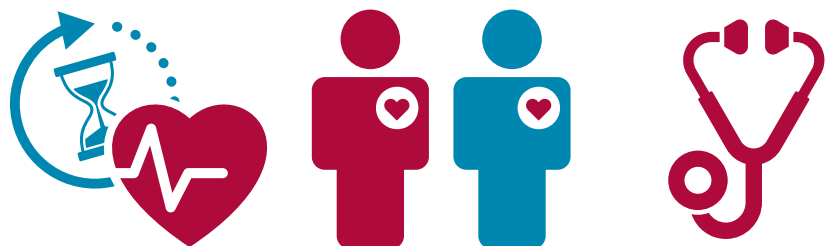
- Deliver national public awareness campaigns to highlight the signs and symptoms of cardiomyopathy and the importance of telling your GP about any family history of heart disease or sudden unexplained death.
- Work as an active member of The Alliance for Heart Failure, alongside other medical colleagues, charities and stakeholders to advocate for greater use of diagnostic testing in primary care and quicker and more efficient referral processes.

## Cardiomyopathy Change Agenda Priorities

# Improving specialist treatment

Once diagnosed, a cardiomyopathy patient can still struggle to get the specialist treatment and emotional and wellbeing support that they require. Patients often feel 'lost' in the system, confused about what is likely to happen next and how to access additional support.

The **top 3 improvements** to care and treatment that people want are:



quicker diagnosis, more emotional support and more practical support.

”

**Over a 10-year period with Dilated Cardiomyopathy I had repeated admissions through A&E, followed by discharge with changes to my medication. For weeks each time, I'd have a Specialist Nurse monitoring my progress, until the dreaded words "you're now stable; I'm discharging you to the care of your GP"... in reality meaning, "you're on your own, if (when) you need help before your next consultation, it'll have to be back through the dreaded A&E". Cue feeling abandoned, but for Cardiomyopathy UK and their support. "**

- Stephen Kirkham

## People affected by Cardiomyopathy want...

7. Mutually agreed 'Care Plans' encompassing their immediate and wider treatment plan, and indicating additional support arrangements, including devices. They want to be able to take these away and for them to be updated as required.
8. When newly diagnosed or actively symptomatic, Specialist Heart Nurses should explain and maintain care plans, as well as educate and enable patients to effectively self-monitor vital signs and symptoms.
9. Access to an integrated package of care appropriate to the needs of patients, covering the following areas: emotional and mental health support, sexual health and family planning clinics, prescription of tailored exercise, information on welfare rights and nutritional support.

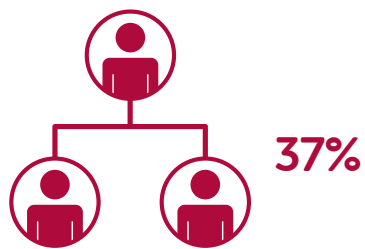
## Supporting the Change Maker's work, Cardiomyopathy UK will continue to:

- Work with Change Makers, cardiologists and commissioners in local areas to help them to agree local care pathways and create the infrastructure they need to share knowledge.
- Provide learning opportunities for cardiologists nationwide, enabling them to access and network with leading cardiomyopathy experts.
- Work with our Clinical Advisory Group to continually review best practice in cardiomyopathy management.
- Advocate for the inclusion of cardiomyopathy specific hospital outcome data to be included in the annual National Institute of Cardiovascular Outcome Research annual report.

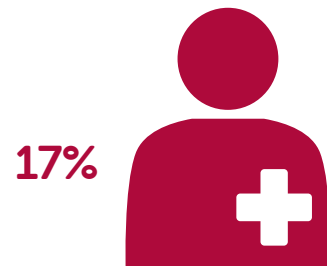
## Cardiomyopathy Change Agenda Priorities

# Accessing genetic and family testing

Cardiomyopathy is often an inherited condition. However, awareness of the genetic nature of the condition and access to appropriate screening or genetic testing, including for their immediate family varies considerably between regions and UK nations.



37% had not been offered genetic testing for their condition.



17% weren't informed by a health professional that their condition may be genetic.

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**Our whole family life was decimated when my sister, who had dilated cardiomyopathy, died from an out-of-hospital cardiac arrest, aged just 31. Grief for me, was interspersed with intense worry about what might happen to me. I wonder: is it worse not to know of the genetic nature of the condition, or, as in my case, to have the awareness but be told that there is no provision for genetic assessment where you live? //**

- Rachelle Barlow

### People affected by Cardiomyopathy want...

10. All patients diagnosed with cardiomyopathy to be considered for genetic assessment and to understand the implications, with every hospital having this ability, or a clear and timely process of referral to an existing Inherited Cardiac Conditions clinic.
11. Genetic test results to be delivered, with all the implications explained, family testing initiated where indicated, and a point of contact established to address future concerns.

### Supporting the Change Maker's work, Cardiomyopathy UK will continue to:

- Work with the Network of Inherited Cardiac Conditions Scotland and develop further contacts within the Association for Inherited Cardiac Conditions and genetic specialisms to strengthen their ability to advocate to improved access to genetic testing for people with cardiomyopathy and related disorders.

## Cardiomyopathy Change Agenda Priorities

# Ongoing care and support

Cardiomyopathy patients often need support to adapt their lifestyles and live well. Good quality services help individuals to understand their diagnosis, cope with the potential changes they need to make in their lives and support patients in doing so.



45%

45% applied for benefits and were initially or completely refused.



52%

52% of people with co-morbidities felt these impacted on their cardiomyopathy treatment.

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**I received little information about possible 'cardiac events' after my cardiomyopathy diagnosis. Nothing prepares you for the life-altering physical & mental impact of an out of hospital cardiac arrest. With access to the right care and rehabilitation (cardio and neuro-related), you and your loved ones can survive, grow, and live with cardiomyopathy.** ”

- Andy Smith

### People affected by Cardiomyopathy want...

12. Access to cardiac rehabilitation services when prescribed, and for these to be personalised to individual needs.
13. Those with complex cross speciality needs arising from their cardiomyopathy to be cared for in a coordinated and multidisciplinary way.
14. Patients with negative genetic test results to be actively considered for further testing as new gene panels are identified.
15. An established point of contact for concerns outside regular reviews, including risk and symptom assessment.
16. Advanced/advancing heart failure patients, caused by cardiomyopathy, to be carefully monitored and supported, to enable referral to a Transplant Centre for assessment and on-going care at the earliest opportunity. This support should include:
  - Assistance with frailty, including support to access disabled parking badge, occupational therapist support within the home and 'pre-hab exercise programmes', where available.
  - Palliative care with an advanced care package to run ahead of and in parallel with route into transplant.
  - Referral for end-of-life provision for those patients judged unsuitable for transplant of Left Ventricular Assist Device.

### Supporting the Change Maker's work, Cardiomyopathy UK will continue to:

- Further grow our network of local and specific cardiomyopathy support groups and in-clinic support volunteers throughout the country and demonstrate the impact of these groups in helping individuals to cope with cardiomyopathy.
- Further provide support services for young people, especially those who are moving into adulthood, so that they can make appropriate lifestyle and attitudinal changes they need to help them live with cardiomyopathy.
- Continue to share our own research into the impact of cardiomyopathy on all aspects of an individual's life and use this insight to help develop long-term support services.

# Get in touch

## Find us online

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 [www.cardiomyopathy.org](http://www.cardiomyopathy.org)

 [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org)

### **Helpline**

**0800 018 1024**

*(free from a UK landline)*

*8.30am-4.30pm, Monday-Friday*

## Social media

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 [/cardiomyopathyuk](https://www.facebook.com/cardiomyopathyuk)

 [@cardiomyopathy](https://twitter.com/cardiomyopathy)

 [@cardiomyopathyuk](https://www.instagram.com/cardiomyopathyuk)