

The State of Cardiomyopathy Care

National Cardiomyopathy Report 2023



Cardiomyopathy^{UK}
the heart muscle charity

Introduction

In June 2022 we launched a national survey asking people living with cardiomyopathy, and their loved ones, about their experiences of accessing care and treatment in the UK. Our aim was to develop a clear understanding of the current state of cardiomyopathy care and treatment and identify areas of inequality and gaps in service provision.

This report outlines our key findings. We will use the evidence in this report to advocate for the needs of people affected by cardiomyopathy, and their loved ones, and help ensure that they are able to access the support and treatment that they need.



632 people responded to the survey from across the UK



566 were people with cardiomyopathy themselves



66 were partners or carers of somebody with cardiomyopathy

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About cardiomyopathy

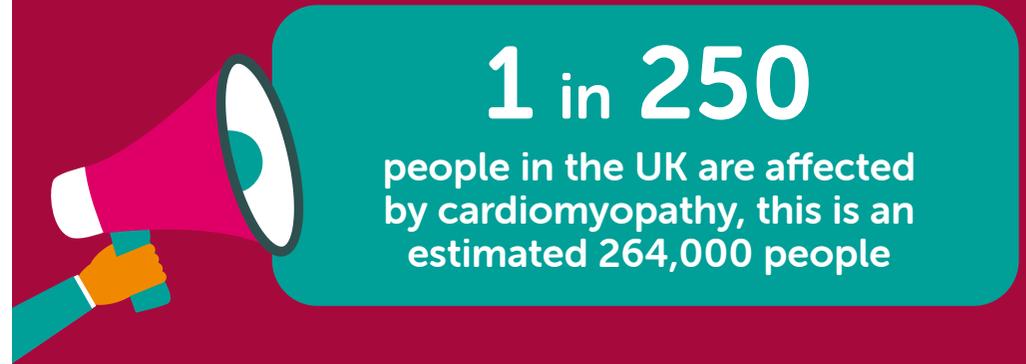
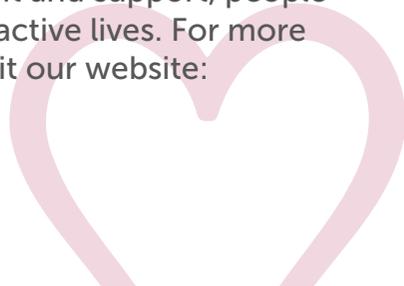
Cardiomyopathy is a disease of the heart muscle affecting 1 in every 250 people – an estimated 264,000 people in the UK. It isn't a single condition, but a group of conditions that affect the structure of the heart and reduce its ability to pump blood around the body. Cardiomyopathy can affect anyone at any age and sadly is the main cause of sudden cardiac death in under 35-year-olds. Cardiomyopathy is incurable. For people living with cardiomyopathy, their condition can impact many aspects of life, physically and psychologically, as well as having practical implications for work, finances, and their personal life.

The main symptoms of cardiomyopathy include tiredness, breathlessness, swelling in the abdomen and ankles, palpitations, pain in the chest, and dizziness or fainting. It can be difficult to diagnose cardiomyopathy as these symptoms can occur in other conditions and some people may have no symptoms at all in the early stages.

There are many possible causes of cardiomyopathy. Some types are genetic, caused by a mutation in the person's DNA which affects how their heart develops. Genetic conditions may be inherited so cardiomyopathy sometimes runs in families. Often if one person is diagnosed with cardiomyopathy it is recommended that their close family members are tested for the condition too. Other causes of cardiomyopathy include viral infections, autoimmune diseases and some medications used to treat cancer.

Although a diagnosis of cardiomyopathy can be life-changing, with early diagnosis, the right treatment and support, people with cardiomyopathy can live full and active lives. For more information about cardiomyopathy visit our website:

 www.cardiomyopathy.org



1 in 250
people in the UK are affected
by cardiomyopathy, this is an
estimated 264,000 people

What are the symptoms?



swollen ankles
and/or tummy



chest pain



dizziness and/or
fainting



breathlessness



tiredness



palpitations

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Our Findings



Diagnosis

Early diagnosis reduces the risks of sudden cardiac death. It means that people with cardiomyopathy can receive the protection, care, and treatment that they need sooner. It was clear from the survey that there are significant delays in the diagnosis and specialist referral for cardiomyopathy. **In particular, the survey showed that:**

GPs struggle to diagnose cardiomyopathy

53% of people who first went to their GP with cardiomyopathy symptoms were diagnosed initially with a non-heart related condition. It was disappointing to see that only 29% of people were asked by their GP about the history of heart disease in their family.

“I was told, on several visits by several different GPs, I was too young to have a heart problem and I was having a panic attack. No tests done, no referral, nothing. Nothing was done until I almost died!”

Where you first go for your care affects how long it takes to be diagnosed

Of the people who went to accident and emergency (A&E) first, 92% were immediately diagnosed with a heart related condition and 76% saw a cardiologist within 3 months. This is compared to 51% of people who went to their GP first.

“No one seemed interested in taking my concerns seriously or willing to investigate symptoms further.”

Where you live can also make a difference

The time it takes to get a confirmed diagnosis once you have sought help differs depending on which UK nation you live in. 46% of people with cardiomyopathy in Wales waited less than sixth months for a formal diagnosis. In comparison more people in Northern Ireland (60%), England (63%) and Scotland (68%) were diagnosed within 6 months.



There have been some significant changes since the pandemic

The proportion of people who go to their GP with symptoms first, compared to those who go straight to A&E has changed since the pandemic. 11% of the people in our survey who were diagnosed before the pandemic told us that they went to A&E first compared to 42% of people who were diagnosed in the last two years. At this stage we do not know exactly what has caused this change but believe that it may be due to people being unable to access their GP, or unwilling to go to their GP, until their symptoms worsen, and they need emergency care.

We can also see the impact that the pandemic has had on how long it takes from first seeking help to receiving a diagnosis. 63% of people took less than 6 months to be diagnosed pre-pandemic, during the pandemic this dropped to 52%.

What our Change Agenda says about diagnosis

People with cardiomyopathy need:

- GPs to ask, and have on record, a detailed family cardiac and medical history, for potential cardiomyopathy symptoms to be identified in this context.
- 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.
- The referral process for diagnostic tests in hospital, through whichever point of entry, to be effective and timely.
- 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.

Care plans and involvement in treatment



Over the last ten years, the NHS and other health related agencies have shifted the focus of patient care to ensure that the voices of patients are heard, and that patient preferences are uppermost in the minds of health professionals. ¹

Having an agreed treatment or care plan enables a person with cardiomyopathy to have a better understanding of their condition and a clear idea of the support and treatment that they should expect. Plans help people know where they are in the NHS system and feel more in control of their lives. The best care and treatment plans include not only details on the treatment of an individual's condition but also highlight their mental health needs and the support they require for day to day living.

There is strong evidence that care and treatment plans lead to better outcomes. The King's Fund has called for a 'shared responsibility for health' between patients and clinicians, over the next five years and for the NHS to ramp up support for people to manage their own health. ²

Most people with cardiomyopathy have no care plan and many feel unheard.

Only 36% of people surveyed said that they had a plan in place for their cardiomyopathy care. The rest either had no plan (44%) or did not know if they had a plan in place (20%).

42% of respondents did not feel that they had a say in what their treatment should look like or that their personal views were heard by the clinicians.

People who did not have a care plan are less satisfied with their care

It was evident that those individuals without a plan in place were "less than satisfied" with the care they received. 77% of those people with a care plan were either satisfied or very satisfied with their cardiologist compared to 54% of people who had no agreed plan in place.

"Any complaints about medication were greeted with a 'just take what we prescribe' attitude."

"I have to really push to be listened to sometimes."





Care plans and involvement in treatment

The content of care plans varies

Most of the care and treatment plans that respondents had received contained information about the condition, drug treatments and a plan for regular monitoring. Few plans contained information on wellbeing support (9%), nutrition (6%) or accessing cardiac rehabilitation (12%). All of these issues are important to people with cardiomyopathy.

Quality information on diagnosis makes a big difference

38% of respondents received a diagnosis letter without any further information about their condition. Those individuals who were given Cardiomyopathy UK information on diagnosis reported being more satisfied with their treatment and had a greater understanding of cardiomyopathy.

Some people reported feeling that the lack of information on their condition led them to leave their appointment unsure about their diagnosis and having to use the internet to find out what condition they had. Some said it was the worst part of their care, and that it had impacted their mental health.

"I think people should be referred to Cardiomyopathy UK when diagnosed so that they only get the correct current information ...which might help to alleviate the stress and depression caused from the initial diagnosis and then looking online for information that may well be false or at the very least well out of date."



What our Change Agenda says about care plans and treatment

People with cardiomyopathy need:

- 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.
- 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.



Family screening and genetic testing

Family screening and the use of genetic testing are the best ways to identify people who are most at risk of cardiomyopathy and ensure that they have access to the support and treatment they need. We asked people living with cardiomyopathy about their experiences of family screening and genetic testing.

The use of genetic testing is increasing

While genetic testing is still not at the level that we would wish to see, it should be noted that the use of genetic testing is increasing. In our 2019 survey, 38% of people had been offered genetic testing, in our 2022 survey this had increased to 56%. It should also be noted that this level of testing is well above the US and European averages.

There is a lack of genetic counsellors

Although a large number of respondents had been asked about a family history of heart disease once diagnosed, only 38% had been asked to draw up a detailed family tree; a more thorough process that is completed with the support of a genetic counsellor. In our 2019 survey, 58% of people had completed a detailed family tree.

There is clear evidence that a lack of NHS funding is impacting the number of genetic counsellors available to support patients through the genetic testing process. In 2022 there were only 300 genetic counsellors in the NHS across the UK covering a range of conditions not just cardiac conditions. [3](#)

Location and type of cardiomyopathy affects access to genetic testing.

54% of respondents were offered genetic testing in England versus 62% in Scotland. People presenting with hypertrophic cardiomyopathy were more likely to be offered genetic testing (71%) than people with dilated cardiomyopathy (42%).

“My direct family members have taken a test. I’m unsure if the wider family have taken up the offer of testing. Following advice and much discussion, we have chosen to test my 7-year-old daughter when she is older.”



What our Change Agenda says about family screening and genetics

People with cardiomyopathy need:

- 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.
- Genetic test results to be delivered, with all the implications explained, family testing initiated where indicated, and a point of contact established.

Mental health and wellbeing support



Cardiomyopathy has a significant impact on an individual's mental health and wellbeing. Mental health support must be part of the care offered to people with cardiomyopathy to help them feel better able to cope with their condition.

The wellbeing needs of people with cardiomyopathy are not being met

Over 50% of respondents felt that they struggled to cope emotionally over the last 6 months due to their cardiomyopathy and 46% of people felt having access to counselling and therapy would help their emotional wellbeing. However only 9% of people with cardiomyopathy had been offered mental health support as part of their care.

"I find it hard sometimes to not do what I used to do and my close family find it hard too. I try to be philosophical and appreciate what I can do though. It's difficult when out and about and I can't walk as far as others or go upstairs easily - some disabilities are hidden"

"I live alone and I get very scared about my condition and how to cope with it. Also I feel anxious a lot of the time as I never know what will happen next in my body."

Only 3% of people surveyed had seen a counsellor, social worker or psychologist as part of their cardiomyopathy care. Further research is needed to examine what the emotional support needs are for people who are living with cardiomyopathy, how these needs change in relation to different stages of their journey and how the charity can fill some of the gaps that the health services are unable to provide.

"I've become severely depressed at the total change this condition has done to my daily life, I used to be out and about most days but now I'm so exhausted some days I'm too tired to even eat. I've lost a lot of weight and this condition has aged me 10 years, it's made me feel very frail and depressed."

Loved ones also need support

When we asked the loved ones of people with cardiomyopathy about their experience, they told us that they were also struggling emotionally with the impact of cardiomyopathy. 60% of respondents said that they found it hard to cope and 28% believed that counselling could help their emotional wellbeing. None of the loved ones who responded to the survey had been offered any professional support over the last 6 months.



What our Change Agenda says about mental health and wellbeing

People with cardiomyopathy need:

- 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.
- The cardiology team to signpost newly diagnosed patients to Cardiomyopathy UK for further support.

Conclusion

Our survey shows that there is still a great deal that needs to be done to improve the diagnosis, care and treatment that people with cardiomyopathy receive.

Perhaps the most concerning trend since our last survey in 2019 has been the increase in the time it takes from first seeing a healthcare professional to being diagnosed. It is especially concerning to see the persistent high level of misdiagnosis by GPs. Getting things right in primary care must be a priority for the cardiomyopathy community.

Another area of significant concern is the inconsistent and under use of care and treatment plans. At a time when diagnosis is delayed, services stretched, and health systems at breaking point, it is more important than ever for people with cardiomyopathy to have an agreed and co-produced plan to navigate what can be a chaotic care and treatment journey.

While the overall picture remains challenging the survey did highlight a positive development; the 18% increase in the use of genetic testing. As our understanding of the genetic basis of cardiomyopathy improves and more cardiomyopathy associated genes are discovered, genetic testing will become increasingly important. However the health system still needs to adapt to fully realise the benefits that genetic testing can bring

and start by reversing the decline in the number of genetic counsellors who play a vital part in the testing and family screening process.

Our survey underlines why it is so important that we continue to advocate for the needs of the cardiomyopathy community and work with all stakeholders to deliver the improvements detailed in our Change Agenda, which you can read [here](#).

Over the coming year we will be undertaking further research, focusing on people's experience of accessing family testing and genetic testing. We will also be looking closer at the emotional health and wellbeing impact of cardiomyopathy and the lack of mental health support for people with cardiomyopathy and their loved ones.

A more detailed report, containing all the data collected from the survey is available on request. If you would like to use our findings for further research or advocacy work, then please email:

 contact@cardiomyopathy.org

Finally, we would like to thank all those who took time to respond to our survey. Your insight has been incredibly valuable and will help us to strengthen our voice and our ability to advocate for improved access to quality treatment.

About Cardiomyopathy UK

Cardiomyopathy UK is the specialist charity for people affected by the heart muscle disease cardiomyopathy. Our vision is that people affected by cardiomyopathy should live a long and fulfilling life.

We work towards this vision by providing a range of support and information for people affected by cardiomyopathy to help them feel more informed about their condition, less scared and better able to cope day to day. We also educate healthcare professionals so that they are better able to detect and treat the condition and we work to raise awareness of the signs and symptoms of cardiomyopathy among the general public, so that more people seek help. In addition to this, we campaign for improved access to quality treatment through the NHS and work with the research community to ensure that their efforts meet the needs of people with cardiomyopathy.

Cardiomyopathy UK is at the centre of the cardiomyopathy community. We bring together the patient community, leading clinicians, researchers, policy makers and other key stakeholders to work collaboratively on tackling the issues that people affected by cardiomyopathy face now and in the future.

1. [NHS Long Term Plan » 3. People will get more control over their own health and more personalised care when they need it](#)
2. Ham, C., Charles, A. & Wellings, D. (2018) Shared responsibility for health: the cultural change we need. The King's Fund. <https://www.kingsfund.org.uk/publications/shared-responsibility-health>
3. Middleton, A. et al. (2022) The genetic counsellor role in the United Kingdom European Journal of Human Genetics; 31: P. 13 <https://doi.org/10.1038/s41431-022-01212-9>
4. Five Year Forward View for Mental Health (2016) A report from the independent Mental Health Taskforce to the NHS in England [NHS England » Mental health](#)

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