myInsight

Cardiomyopathy UK
the heart muscle charity

Living with cardiomyopathy

A state of the nation report from Cardiomyopathy UK



November 2025

Policy Summary

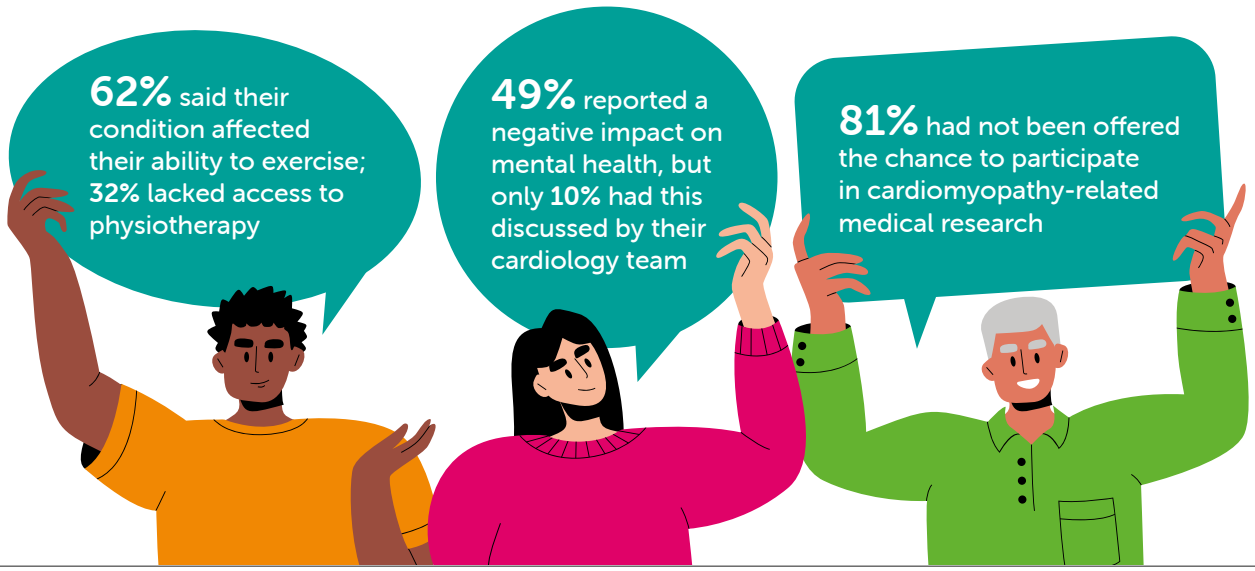
It is estimated that cardiomyopathy affects 1 in 250 people in the UK . While there is no cure, the correct diagnosis and treatment can reduce and manage the symptoms it causes in most people with the condition.

Following Cardiomyopathy UK's 2022 **state of the nation report**, our latest report, **Living with Cardiomyopathy**, published in November 2025, provides an updated stocktake of care across the UK. Drawing on findings from the associated MyInsight survey[2] of over 1,300 patients and carers, it identifies significant gaps across the cardiomyopathy care pathway and sets out targeted recommendations to ensure timely diagnosis and equitable access to high-quality treatment and care.

While the commitments set out in the NHS England 10 Year Health Plan – particularly around tackling cardiovascular disease and delivering person-centred care – are welcome, they must now be actioned with urgency. Our MyInsight survey shows that people affected by cardiomyopathy continue to face delays, inequities, and fragmented care, often having to navigate the system alone.

As the Modern Service Framework for cardiovascular disease is developed, it is vital that it reflects the full spectrum of cardiovascular conditions, including inherited and non-preventable diseases such as inherited cardiomyopathy. A truly inclusive approach will help avoid widening inequalities and ensure that all patients benefit from system improvements.

The report identifies three core priorities for the transformation of cardiomyopathy care in the context of NHS England: early diagnosis and timely access to genetic testing, where appropriate; holistic, person-centred care that reflects the full range of individual needs; and enhanced access to treatment alongside continuity of care.



1. Cardiomyopathy UK. **What is Cardiomyopathy?** October 2023
2. Details of the MyInsight survey methodology are included at the end of the **full report**

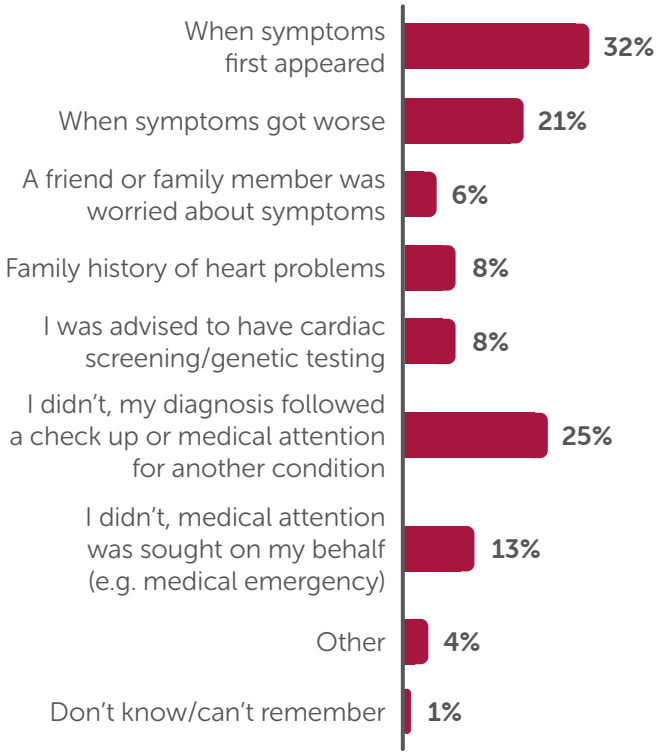


1. Early diagnosis and genetic testing

Timely and accurate diagnosis is essential for people with cardiomyopathy. Yet many individuals face delays, misdiagnosis, and missed opportunities for genetic testing. Many are not diagnosed until they experience severe symptoms or a cardiac event, such as heart failure. Symptoms are frequently missed or mistaken for other conditions, particularly among women. This is often due to limited awareness among non-specialist clinicians and the public about the signs and symptoms of cardiomyopathy.

As many types of cardiomyopathy are inherited, family history can play a crucial role in diagnosis. However, only **8%** of survey respondents were first prompted to seek medical attention before their cardiomyopathy diagnosis due to being aware of a family history of heart problems. In addition, **28% of respondents had not been offered genetic testing for themselves, and 38% had not been offered testing for their family members.**

What first prompted you to seek medical attention before your cardiomyopathy was diagnosed? (Please select all that apply) (n=192).



Policy recommendations

1. GP training and family history recording

Integrated Care Boards should work with Primary Care Networks (and Neighbourhood Health Services), charities and professional bodies (e.g. the Royal College of General Practitioners and the British Cardiovascular Society) to train and incentivise GPs to recognise the symptoms of cardiomyopathy and record family cardiac history.

2. Incentivising genetic assessment

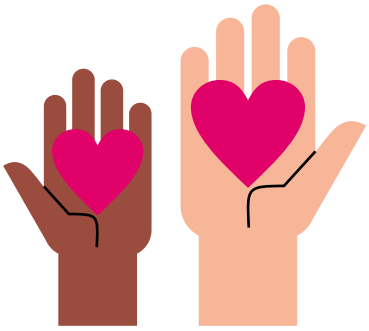
The Department of Health and Social Care should introduce Best Practice Tariffs to incentivise hospitals to assess people with cardiomyopathy and their families for genetic testing and ensure timely, standardised referral to inherited cardiac condition (ICC) centres. This must be supported by broader investment in ICC centres to manage any corresponding increase in demand.

3. Diagnostic capacity

The Department of Health and Social Care should support earlier diagnosis of cardiomyopathy by improving access to diagnostic services. This includes retention and expansion of the trained NHS echocardiography workforce.

4. Targeted screening

The UK National Screening Committee should embed cardiomyopathy within a stratified targeted screening programme, focused on individuals with known family history or other risk factors.



2. Holistic and person-centred care

Living with cardiomyopathy affects more than just the heart. It can impact mental health, physical wellbeing and everyday life. However, too many people report feeling unsupported and disconnected from the care they need. **76% of respondents said they did not have a care or treatment plan.** Those who did have a plan were more than twice as likely to report very good overall care compared to those without a plan **(14% vs 6%).**

The emotional impact of cardiomyopathy is also significant. Nearly half **(49%) of respondents with cardiomyopathy said their mental health had been negatively affected** in the last two years due to their diagnosis. Yet only **10%** reported that their cardiology team had discussed mental health and wellbeing with them during that time. A further **40%** said they wanted or needed this support but had not received it.

There is also uncertainty around nutrition, exercise and everyday health. For example, **62%** of MyInsight survey respondents said their condition had negatively affected their ability to exercise. Around a third **(32%)** were unable to access a physiotherapist or exercise physiologist, despite wanting or needing this support.

> **"I just got the diagnosis, was given pills and that's about it. I have never been advised of exercise, nutrition or any other everyday things that can affect my condition."**

Policy recommendations

5. Specialist cardiac care

The Department of Health and Social Care and Integrated Care Boards should ensure that the Modern Service Framework for cardiovascular disease provides people with ICCs, such as cardiomyopathy, with equal access to specialist cardiac care. This should be supported by integrated care plans and clear signposting to holistic support, including charity-led groups.

6. Mental health integration

The Department of Health and Social Care should support NHS regions and Integrated Care Boards to implement access to specialist mental health professionals in ICCs, as outlined in the European Society of Cardiology consensus on mental health and cardiovascular disease.

7. Tailored cardiac rehabilitation

The Department of Health and Social Care should develop clear commissioning guidance for ICC centres on the role of cardiac rehabilitation for people living with cardiomyopathy, reflecting the benefits of tailored physical rehabilitation services for people with cardiomyopathy.



3. Enhanced access to treatment and continuity of care

Continuity of care is essential for people with cardiomyopathy, yet many of our MyInsight survey respondents reported having to organise their own care due to poor coordination between services. This includes gaps between hospital departments, and between primary and secondary care. **28% felt the different healthcare professionals involved in their care do not work well together.**

Patients reported feeling abandoned, underscoring the urgent need to strengthen the network of care and ensure that all providers are equipped to deliver high-quality, coordinated support. The shift towards a networked model of care for amyloidosis, and growing interest in ICC 'hub-and-spoke' networks, makes continuity of care throughout the patient journey even more critical.

People with cardiomyopathy also face delays in accessing new treatments. Medicines approved by NICE are not always added to local NHS formularies in a timely way, creating a postcode lottery in access to care. Further, limited capacity in diagnostic services, particularly echocardiography, remains a persistent problem, affecting not only the diagnostic pathway but also treatment and ongoing management.

In addition, our survey findings highlighted limited opportunities for people with cardiomyopathy to take part in clinical research, representing a missed opportunity to involve those affected in shaping future care and innovation. Notably, **81% of respondents said they had not been offered the opportunity to take part in cardiomyopathy-related research or trials in the last two years.**

Policy recommendations

8. Seamless information sharing

The Department of Health and Social Care should expedite the implementation of the Single Patient Record to enable seamless information sharing across care settings for people with cardiomyopathy.

9. Treatment access and uptake

The Department of Health and Social Care should work with Integrated Care Boards, patient charities, and industry to ensure that newly approved cardiomyopathy treatments are not only accessible but actively prescribed. This includes developing implementation plans, facilitating clinician education, and monitoring uptake to ensure that innovations translate into improved patient outcomes.

10. Research investment

The Department of Health and Social Care and the Department of Science Innovation and Technology should work with the NHS, academia, patient charities and industry to invest in clinical researchers and research to enable earlier diagnosis, targeted treatments and improved quality of life for those in the UK affected by cardiomyopathy, in line with the James Lind Alliance priorities[3].

3. Cardiomyopathy Future Research | Cardiomyopathy UK

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