

Our national plan for cardiomyopathy

- how we can improve the diagnosis, treatment and long-term care of cardiomyopathy -



Cardiomyopathy^{UK}
the heart muscle charity

Background Information

Cardiomyopathy is a disease of the heart muscle. It is a group of conditions that affect the structure of the heart and reduce its ability to pump blood around the body. It is thought that around 160,000 people in the UK have the condition.

The condition is primarily inherited and so genetic testing and taking a full family history play an important part of the diagnosis process along with other heart imaging techniques.

Although it cannot be cured there are treatments that aim to control the symptoms of cardiomyopathy and reduce the risk of a cardiac arrest. These include medication and implanted devices.

Cardiomyopathy UK is the national charity for people affected by cardiomyopathy. The charity provides support and information services, raises awareness of the condition amongst the public and healthcare professionals, supports research and campaigns for wider access to quality treatment.

Over the last year, the charity has been working with its service users to gather more information about their experiences of their own diagnosis care and treatment. This information was gathered from face to face meetings, feed-back from service users and a national survey that received over 750 responses.

The charity has also been talking to NHS leaders and members of its Clinical Advisory Group, which represents leading experts in the field of cardiomyopathy, to get their views on what improvements could be made and the barriers that they face in providing appropriate care and treatment.

This document is written for anybody who cares about cardiomyopathy. It brings together the views and ideas of a wide range of stakeholders to define the main problems that people with cardiomyopathy face and makes practical suggestions for improvements to the healthcare system.

The charity believes that by working alongside clinicians, health care providers and policy makers we can make these suggested improvements and so achieve a real and lasting difference to the lives of people with cardiomyopathy.

1500
in

Minimum number of people thought to have cardiomyopathy in the UK

15

Recommended actions that can make a difference to them

Early detection

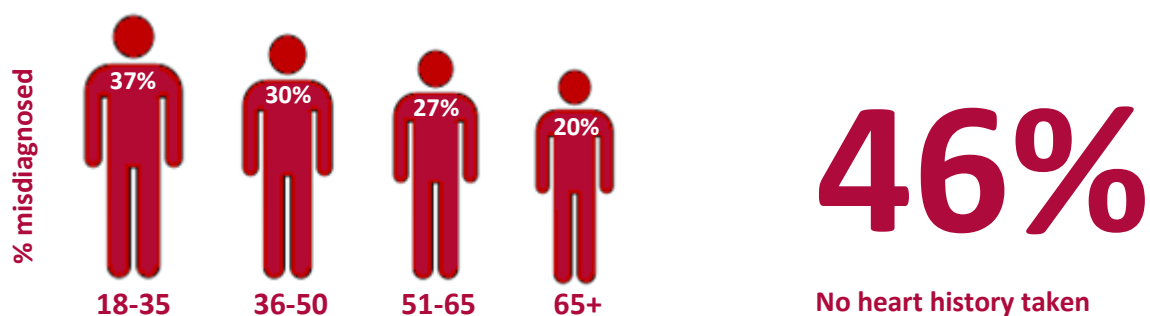
The problem

People with cardiomyopathy often struggle to receive an appropriate diagnosis and spend too long in primary care being treated inappropriately.

Overall, 28% of respondents to our national survey stated that they were initially treated for something else before their GP suspected a heart problem. Typically this was asthma, stress and anxiety.

One of the key ways to differentiate cardiomyopathy from other illnesses is to ask a patient about heart problems in their family. 46% of respondents to our survey told us that this heart history was not taken.

Inappropriate diagnosis was more common in younger people. This is likely due to the fact that GPs tend not to associate heart problems with younger people.



The reasons for improvement

Cardiomyopathy can be managed through appropriate medication and the use of implanted devices. Early detection of cardiomyopathy and speedy intervention can therefore reduce the risk of sudden cardiac death and can improve outcomes for patients.

Appropriate diagnosis first time around will also reduce the costs associated with unnecessary GP visits and prescribing ineffective medication.

"My diagnosis was protracted, and confusing. I went to the doctor with because I was feeling breathless, my heart was racing and I had put on lots of weight. I was told it was anxiety and given medication.

After two years of this I was rushed to A&E and spent a further two months in hospital before being told that I had dilated cardiomyopathy and heart failure. I could have coped much better if I had known about all this from the start and I am sure that I would be much better now if I had gotten the right help sooner." - Katie

What we want

Increased knowledge in primary care

The charity wants GP's to have a better understanding of the signs of cardiomyopathy and who is at risk of having the condition. We don't expect GP's to be the ones making a diagnosis of cardiomyopathy but we do want many more to recognise that a patient may have a heart problem and refer them for further testing.

Improved access to testing

Cardiomyopathy can be detected through the use of electrocardiograms (showing how the heart is beating by measuring the flow of electricity through it) and echocardiograms (using sound waves to make an image of the heart).

Both these tests are relatively cheap but do require experts to carry them out and interpret the results. We want to ensure that these tests are more widely available to GPs.

Increased targeted screening and testing

Cardiomyopathy is often an inherited condition. We want to make sure that when a person is diagnosed with cardiomyopathy their immediate family are considered and appropriate screening undertaken. Where necessary, genetic testing and pathology should be used to determine at risk family member and make a quick diagnosis.

We also want coroners to play a part in identifying sudden cardiac death and work with pathologists to diagnose cardiomyopathy and communicate their findings back to family members.

What we will do and who we will work with

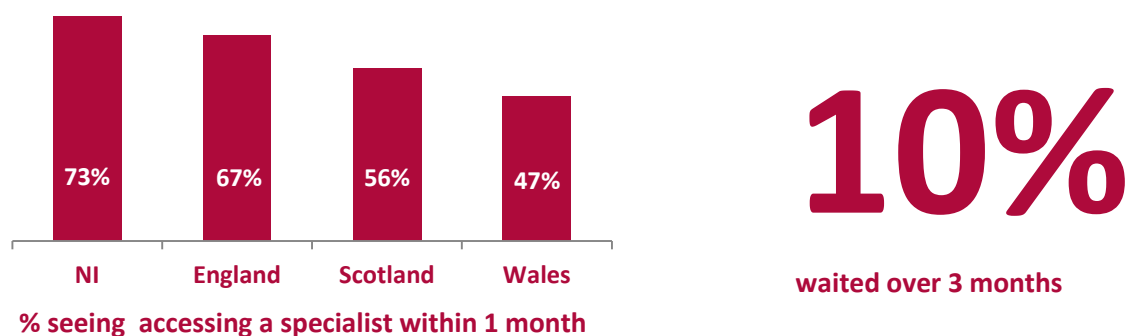
- 1.** Create a simple GP card for patients to take with them to appointments.
- 2.** Offer short online GP training and work with the Royal College of General Practitioners to promote GP resources.
- 3.** Work as part of the Alliance for Heart Failure and in partnership with the British society of Echocardiology to lobby for improved access to testing nationally.
- 4.** Bring together the Association of European Cardiovascular Pathologists, the UK Cardiac Pathology Network and leading coroners to identify how they can improve detection and communication of cardiomyopathy amongst their colleges.
- 5.** Work with the British Heart Foundation as part of their steering committee to help direct their work to increase access to genetic testing in hospitals nationwide.

Accessing quality treatment

The problem

Once diagnose, a person with cardiomyopathy can still struggle to get the treatment that they need. For some people this is due to the need to wait for appropriate care. Only 60% of the people we surveyed were able to see a cardiologist within one month. Worryingly, there was a good deal of regional variation with people in some areas of the UK having to wait much longer.

One significant problem is that clinical centres with a high level of knowledge of cardiomyopathy are few and far between and expertise tends to be focused in a limited number of sights, mainly in London. This is especially the case when it comes to services that are the most able to treat children and young people.



The reasons for improvement

The National Institute of Health and Care Excellence have produced guidance on how best to treat cardiovascular disease and heart failure. This guidance clearly recognises the importance of specialist care in improving outcomes for patients.

Having expertise to concentrated in one area disadvantages large sections of the population and restricts the learning and development opportunities needed to train the next generation of cardiomyopathy experts.

"My experience has been very patchy. Like many people it took me a long time to get the help I needed and I ended up going to a number of different hospitals being passed from department to department.

I can't stress enough how important it is to be seen by a specialist. It makes all the difference to not only the treatment that you get but also how you feel in yourself. I felt I could get through this and was much more confident when the person I saw knew what they were doing." - Annette

What we want

Improved spread of expertise

We want to make sure that more cardiologist can develop an expertise in cardiomyopathy and that infrastructure is in place to enable cardiomyopathy experts to support and share knowledge with their cardiology colleges.

Improved access to specialist care

The charity believes that it is the duty of local NHS commissioners to ensure that specialist care is available in their region and that a clear care pathway is in place so that people with cardiomyopathy know what care they can expect to receive. We also want local NHS services to acknowledge a person's right to choose their treatment even if this means getting help from outside of their local area.

More information on outcomes

We know that one of the main drivers of improvements in treatment and care in hospital is accurate outcome measuring. We want to work to ensure that the treatment and the outcomes that people with cardiomyopathy experience are properly recorded and that this information is made public.

This will also give people with cardiomyopathy the information that they need to make informed decisions about their care and treatment.

What we will do and who we will work with

- 6.** We will work with cardiologist and commissioners in local areas to help them to agree local care pathways and create the infrastructure they need to share knowledge.
- 7.** We will provide learning opportunities for cardiologists nationwide enabling them to access and network with leading cardiomyopathy experts.
- 8.** We will work as part of the Alliance for Heart Failure to give evidence to the All Party Parliamentary Group on Heart Disease that shows the value of specialist care and treatment.
- 9.** We will work with the Health Quality Improvement Partnership to ensure that cardiomyopathy specific data is collected and reported on as part of their national audit of cardiac services. We will also work to persuade the British Society of Heart Failure to include cardiomyopathy specific data in their public reports.
- 10.** We will support efforts to develop patient centred outcomes measurements that can give a really useful indicator of how well a person have been treated and how their life has changed following treatment.

Long-term care and support

The problem

People with cardiomyopathy often need support to adapt to their condition and long-term care in order to stay well. For some this will be six monthly or annual check-up or a change of implanted device for other more regular help will be needed.

Many people also need support to cope with the psychological impact of being diagnosed with and living with cardiomyopathy. Cardiac rehabilitation services throughout the country are ill equipped to provide this support and are increasingly only focused on helping people who have had a heart attack.

Young people with cardiomyopathy have a unique set of needs that often change as they develop and these needs are not being met at present. It is also important to remember that cardiomyopathy does not just effect the individual with the disorder; it also can have a massive impact on their family.



The reasons for improvement

Good quality services help an individual to adapt to and cope with their cardiomyopathy and understand the lifestyle changes that they need to make. This can make a significant difference to their long-term outcomes and reduce the need for further help.

Most of the support that can be given to people to help them to live with cardiomyopathy can be delivered outside of the hospital environment by a range of professionals, volunteers and by Cardiomyopathy UK.

"I often feel that it is the emotional impact of having cardiomyopathy that has the biggest impact. I think that this is probably due to it being a hidden illness, people look at you and can't see that there is anything wrong and you have to fight harder to get the help you need.

The impact is not just on me, my young son had to see me collapse at home and I know that he still feels the effects of this." - Kerry

What we want

More psychological support

We want to see improved access to psychological support for people with cardiomyopathy so that they feel better able to come to terms with their condition. For some people, it will be appropriate that this support comes from mental health professionals. For most however, this emotional support can be delivered by other NHS professionals such as heart failure nurses and through the work that we do at Cardiomyopathy UK

Better use of technology

Many people with cardiomyopathy could take advantage of advances in device technology and tele-medicine to avoid unnecessary hospital visits for regular check-ups. By giving people with cardiomyopathy appropriate training and the necessary equipment they will also feel more in control of their own condition.

A joined up system

We want the NHS to be able to help people with cardiomyopathy throughout their life and in a range of different settings, not just hospitals. This means providing continuity of care for young people as well as making greater use of the excellent network of heart failure nurses throughout the country.

What we will do and who we will work with

- 11.** We will bring together patients, clinicians and experts in the field of mental health to develop clear guidance on how best to support the emotional needs of people with cardiomyopathy.
- 12.** We will work to grow the network of local cardiomyopathy support groups throughout the country and demonstrate the impact of these groups in helping individuals to cope with cardiomyopathy.
- 13.** We will work to develop support services for young people, especially those who are moving into adulthood so that they can make the appropriate lifestyle and attitudinal changes they need to help them live with cardiomyopathy.
- 14.** We will work with the British Association for Nursing in Cardiovascular Care and the British Society of Heart Failure to provide education support to heart failure nurses so that they can better understand the needs of people with cardiomyopathy.
- 15.** We will encourage people with cardiomyopathy to participate in local health decision making organisations and forum to help ensure that the long-term needs of people with cardiomyopathy are considered and that the voice of people with cardiomyopathy is heard.

The Wider context

It is important to acknowledge the wider environment in which we work and how other initiatives, trends and developments in heart disease and heart failure can help us to deliver our national plan.

We want to make sure that as a charity we work with a range of people and play a part in these wider trends and developments while at the same time always ensuring that the unique voice of people with cardiomyopathy is heard.

NHS initiatives

Over the last few years the NHS in England and Wales has been working to enabling people to choose where they receive treatment. This right to choose is now part of the NHS constitution and means that you can tell your GP where you want to be referred to for your first appointment with a specialist.

✓ *This helps us to argue that it is important that people with cardiomyopathy have the information that they need to make an informed choice about their treatment*

Another NHS and Department of Health initiative is to focus on prevention and reducing inappropriate and unnecessary use of the NHS.

✓ *This makes it easier for us to argue for the need for improved access to heart failure nurses and psychological support.*

Trends in screening and genetics

Our understanding of the value of targeted screening has increased over the last ten years and the vast majority of academics as well as the UK National Screening Committee agree that efforts must be focused on targeted screening of first degree relatives.

As well as this, initiatives such as the 100,000 Genome Project have led to an increase in our understanding of the role of genetics in cardiomyopathy and will continue to enable clinicians to use genetic testing quickly and more accurately.

✓ *This makes it easier for us to persuade local NHS organisation to provide quick and effective family screening.*

Technological developments

Advances in telemedicine and self- monitoring equipment are making it easier for individuals to manage and monitor their own condition and avoid unnecessary hospital visits.

✓ *This will make tele-medicine devices and software more available nationwide.*

A summary of Action points

We believe that we can make a real and lasting difference to the lives of people with cardiomyopathy if we undertake to carry out these specific actions;

- 1.** Create a simple GP card for patients to take with them to appointments.
- 2.** Offer short online GP training and work with the Royal College of General Practitioners to promote GP resources.
- 3.** Work as part of the Alliance for Heart Failure and in partnership with the British society of Echocardiology to lobby for improved access to testing nationally.
- 4.** Bring together the Association of European Cardiovascular Pathologists, the UK Cardiac Pathology Network and leading coroners to identify how they can improve detection and communication of cardiomyopathy amongst their colleges.
- 5.** Work with the British Heart Foundation as part of their steering committee to help direct their work to increase access to genetic testing in hospitals nationwide.
- 6.** We will work with cardiologist and commissioners in local areas to help them to agree local care pathways and create the infrastructure they need to share knowledge.
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10. We will support efforts to develop patient centred outcomes measurements that can give a really useful indicator of how well a person have been treated and how their life has changed following treatment.

11. We will bring together patients, clinicians and experts in the field of mental health to develop clear guidance on how best to support the emotional needs of people with cardiomyopathy.

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13. We will work to develop support services for young people, especially those who are moving into adulthood so that they can make the appropriate lifestyle and attitudinal changes they need to help them live with cardiomyopathy.

14. We will work with the British Association for Nursing in Cardiovascular Care and the British Society of Heart Failure to provide education support to heart failure nurses so that they can better understand the needs of people with cardiomyopathy.

15. We will encourage people with cardiomyopathy to participate in local health decision making organisations and forum to help ensure that the long-term needs of people with cardiomyopathy are considered and that the voice of people with cardiomyopathy is heard.

A timetable for action

The charity will aim to deliver all these action points within 3 years. We feel that this is a realistic timeframe and are confident that our team of volunteers, staff and supporters can work together to deliver these actions that will make a real and lasting difference to the lives of people effected by cardiomyopathy.

The charity's trustees will be responsible for overseeing progress on these action points and we will be producing an annual update that will track our achievements as well as highlighting any new developments or changes that we need to make to our plans.