

Cardiomyopathy^{UK}
the heart muscle charity

Three Year Plan
January 2021 – December 2023

Contents

Part 1: Introduction

- About this document
- About cardiomyopathy
- Related conditions
- Our vision
- Our values and ambitions
- Our team

Part 2: Outcomes

- Objects and outcomes
- Coping with cardiomyopathy
- Helping healthcare professionals to detect and treat cardiomyopathy
- Getting more people to seek medical help
- Making it easier to get treatment
- Helping to develop better treatment options and support services
- The challenge of the next three years

Part 3: Activities

- Activity plan
- Providing support and information
- Working with healthcare professionals
- Raising awareness of cardiomyopathy
- Campaigning for improved access to quality treatment
- Research

Part 4: Making it happen

- Growing our income
- Developing volunteers and staff
- Making full use of digital
- Monitoring and reporting on progress

Part 1: Introduction

- **About this document**

This three year plan sets out our work and objectives from January 2021 to December 2023. The purpose of this plan is to set measurable objectives for each year with the confidence that all activities work towards achieving our vision. Having a three year plan also enables us to plan ahead and ensure that resources can be properly managed.

This three year plan has been developed by our Trustees and staff, with the valued input of volunteers, members and beneficiaries of the services we provide. It has been written for all of the Cardiomyopathy UK team and anyone who has an interest in our work.

- **About cardiomyopathy**

Cardiomyopathy is a disease of the heart. It is not 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. It is thought to affect around 1 in 300 people. For simplicity, when we use the term “cardiomyopathy” in this document we are referring to all forms of cardiomyopathy and related conditions.

The function of the heart is to pump blood around the body, carrying oxygen and nutrients to ‘feed’ the cells and organs. So when the heart doesn’t work properly or as efficiently as it should the cells and organs don’t get enough oxygen and nutrients. This can lead to tiredness, breathlessness, swelling in the abdomen and ankles, dizziness or fainting and palpitations.

Some types of cardiomyopathy are caused by a pathogenic variant or genetic change 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. Cardiomyopathy can also have a significant impact on the emotional wellbeing of a person with cardiomyopathy and on their loved ones.

Cardiomyopathy can be managed through medication, implanted devices, surgery or in some cases a heart transplant. While there is no cure for the condition, it is possible to live a full life with cardiomyopathy. You can find out more on our website (www.cardiomyopathy.org)

We believe in targeted screening for cardiomyopathy. With the majority of heart conditions, including cardiomyopathy, being inherited, it is most efficient for screenings to be focused on families where we know cardiomyopathy to be present or where there is a history of sudden unexplained cardiac death. This way, we can strategically focus on diagnosing those who are most likely to have, or develop, heart conditions. The National Screening Committee has shown that un-targeted screening would not work. This is because it only provides a snapshot of an individuals’ heart at that moment and heart conditions, such as cardiomyopathy, can develop at any time.

To allow for changes in heart health, screenings would have to occur regularly, which the NHS cannot realistically provide without taking up a great deal of resources that would be better used elsewhere.

- **Related Conditions**

Myocarditis is an inflammatory disease of the heart muscle that can lead to dilated cardiomyopathy and in some cases, sudden cardiac death. The charity includes myocarditis in its support and information services and the work that it does to educate healthcare professional.

Heart Failure is a broad term used to describe a state where the heart is not able to pump enough blood around the body. Heart failure can occur as a result of a number of different conditions including cardiomyopathy. It is most commonly caused by coronary heart disease.

Amyloidosis is a rare condition where the body produces too much of a protein called amyloid. This can have a serious impact on a number of organs in the body including the heart. When amyloid protein builds up in the heart this is called Amyloid Cardiomyopathy.

- **Our vision**

Our vision is that everyone affected by cardiomyopathy should live long and fulfilling lives. We believe that this is achievable for most patients if we work in a strategic and focused way and in partnership with healthcare professionals, the government and other stakeholders.

- **Our values and ambition**

We are a charity that is focused on meeting its objectives and measuring its outcomes. But, at the same time, we want to make sure that we act in accordance to our own set of values. We think that there is a right way to act, a view that we share with our supporters and stakeholders. Our core values are;

Caring:	We are devoted to supporting those affected by cardiomyopathy
Dedicated:	We are committed to giving information, advice & support across the UK
Responsive:	We reach out to anyone who needs us
Collaborative:	We work with others to benefit those affected by cardiomyopathy
Expert:	We provide up to date specialist knowledge about cardiomyopathy
Realistic:	We are honest about the impact of cardiomyopathy

We are a relatively small charity and cardiomyopathy is a big problem. In order to have the impact that we want, we need to be ambitious and continue to “punch above our weight”. This means not being afraid to set challenging goals, try new ideas or work with others.

- **Our team**

We believe that the problem of cardiomyopathy is best addressed by bringing together people affected by the condition, healthcare professionals and charity professionals. By working in this way

we have the insights, clinical knowledge and skills we need to deliver our work and meet our objectives.

Our team of trustees bring with them a wide range of skills including research and financial expertise, organisational leadership in the NHS and third sector, marketing and IT. They have all been touched by cardiomyopathy in some way either as people with the condition, carers or as someone who sadly has lost a loved one. They are always working to meet best practice in charity governance and take the lead in monitoring our progress against plans to ensure that we deliver great work.

Our clinical advisory group is made up from the leading healthcare professionals and researchers in cardiomyopathy. They come from across the UK and represent a range of specialisms. The clinical advisory group helps the charity to ensure that its work is clinically relevant, they advise on changes in clinical practice and NHS services and enable us to extend our network of healthcare professionals.

Our volunteers play a significant role in helping us to deliver our services and to spread the word about cardiomyopathy. We have volunteers willing to share their story with the media, to run support groups and help others to deal with the emotional impact of cardiomyopathy. We have volunteers who give up their time to help out at events and in our office and volunteers who take on truly inspiring fundraising challenges to ensure that we have the ability to fund our work.

Our staff team bring with them a considerable amount of professional and clinical experience. They share a commitment to our cause and work hard to ensure that while we are only a small team, we can make a significant impact. You can find out more on our website (www.cardiomyopathy.org)

We recognise that we need to work harder to improve the diversity of both our organisation and the beneficiaries of the service. We will incorporate actions in each of our activity areas to address this and seek support in improving our practice.

Part 2: Outcomes

- **Objects and outcomes**

Our constitution sets out the charity's broad aim which is referred to officially as its "objects". This is a statement of the overall purpose of the charity; "to relieve people affected by cardiomyopathy and related conditions."

We use the term "people affected" because we recognise that the impact of cardiomyopathy is not only limited to the person with the condition but also their loved ones. For this reason, we ensure that all our services, whether it's our helpline service or an information day, are able to provide support to family and carers.

Our leadership team remains committed to this original object but such a broad statement needs to be translated into something more tangible and specific. Outcomes are the specific things that we want to happen as a result of our work. They define the difference that we want to make and are used to measure our effectiveness. Our outcomes for 2021-2023 are;

- **Coping with cardiomyopathy**

We want to improve the ability of people affected by cardiomyopathy to cope with the condition. This means that they feel better able to manage the emotional, practical and physical impact that cardiomyopathy has. We want to make sure that the support we offer covers all parts of the cardiomyopathy journey including, for some, end of life care.

We believe that the best way to help someone to cope with cardiomyopathy is to give them the information that they need to understand their condition, help them to develop a personal support network and give them the skills and motivation to manage their own care.

Because "coping" means different things to different people, there is no objective way to measure this outcome and so we ensure that all the activities that we do that aims to meet this objective will have processes in place to gather service user feedback.

- **Helping healthcare professionals to detect and treat cardiomyopathy**

We want to improve the ability of healthcare professionals to diagnose and treat cardiomyopathy and related conditions. We know that people with cardiomyopathy often have difficulties in getting an appropriate diagnosis and being referred to appropriate treatment. We want to make sure that healthcare professionals have the right skills to be able to identify cardiomyopathy in general practice and treat it appropriately.

In our experience the best way to do this is through educational programmes for healthcare professionals at all levels. Educating healthcare professionals can be very expensive and there are a large number of companies and other charities competing for their attention. In order to be successful we will need to make use of our partnerships and networks to reach the right audience

and use digital education as much as possible.

We will measure our success in this area by counting the number of healthcare professionals who we work with and asking them whether they feel more informed about cardiomyopathy and better able to make a diagnosis or support a person with the condition after accessing our educational events and materials.

- **Getting more people to seek medical help**

We want more people who may have cardiomyopathy to seek medical treatment. A person with cardiomyopathy who has not been treated is at a greater risk of experiencing a cardiac arrest.

The best way to do this is to raise public awareness of the condition and the signs and symptoms that may indicate cardiomyopathy. It is especially important to highlight the hereditary nature of some cardiomyopathies and how a history of heart problems or sudden unexplained death can increase the risk of having the condition.

We will measure the effectiveness of this work by tracking our media profile, and where possible identifying cases where individuals have sought medical help because of our awareness work.

- **Making it easier to get treatment**

We want to make it easier for people with cardiomyopathy to access appropriate treatment in a timely fashion. We hear a great deal about the frustration that people with cardiomyopathy have in accessing treatment near to them. The delay in getting the right help leads to peoples' condition deteriorating and can increase the chances of cardiomyopathy impacting on emotional wellbeing.

The best way to increase access to treatment is through highlighting inequality where it exists as well as celebrating best practice. We also believe that in order to make an impact in this area of work we will need to work in partnership with other organisations.

Towards the end of 2020 the charity launched its ambitious new "Change Makers" project. As part of this project we will be working with all stakeholders to update our National Plan for Cardiomyopathy document that was originally published in 2016. We will be setting out updated best practice, the argument for the need to improve access to treatment and the steps that we believe should be taken. We will also be recruiting volunteers and providing them with the skills, knowledge and support to effect change in their local area. We hope that this groundbreaking new project will help us to have a significant positive impact on the support and treatment provided to people with cardiomyopathy throughout the UK especially at a time when services are being redesigned to manage the impact of the COVID-19 pandemic and its aftermath.

We will use service user feedback to assess whether we have been able to make any improvements in this areas as well as an objective on-going audit of service availability.

- **Helping to develop better treatment options and support services**

We believe that the charity can play an important part in helping to developing new treatments for cardiomyopathy and better ways of providing support. We can do this by sharing our insight and knowledge with relevant professionals, helping researchers to focus their efforts on work that will ultimately lead to real benefits for people with cardiomyopathy and encouraging as many people as possible to participate in relevant research trials.

We will be able to monitor our success in this work by counting the number of individuals who we have encouraged to sign up for clinical trials and the number or research projects we have been able to share our knowledge.

We have developed these outcomes on the basis of evidence from our national survey in 2015, a survey on emotional impact of cardiomyopathy in 2016 as well as the feedback from all our service users over the past year. We have also included the ideas of our clinical advisory group and other key stakeholders. When developing these outcomes, we have also given a lot of thought to what other organisations are doing and the general trends that we see in society that will affect our work.

- **The challenges of the next three years**

We have seen the number of people who use our services increase every year but this is still a small proportion of the total number of people who could benefit from our help. We are also aware that in some areas of our work, the people who use our services do not reflect the diversity of the wider community. In the next three years we are challenging ourselves to change this. We want to see more people coming to the charity for support and a better representation of all communities involved in our work. We will achieve this through increasing our outreach work and making it easier to access our services through our website and digital platforms.

Cardiomyopathy UK is unique; there is no other charity like it in the world. This is why we see a large number of people from outside the UK use our online services. Over the next three years we want to be able to support more people from outside the UK and play a part in creating and supporting a worldwide cardiomyopathy community of supporters and healthcare professionals. We believe that being part of a worldwide community benefits everyone as we can share knowledge and information more widely. We want to make sure that we can do this work without any negative impact on the support that we currently give to our service users in the UK.

The global pandemic has had a considerable effect on the charity. Income has been impacted due to the limitation imposed on community and challenge events while at the same time 2020 saw a 400% increase in the number of people contacting us for support and information. The pandemic has also prompted us to provide more support services online meaning that the work we do is accessible to more people. The long-term impact of the pandemic is not yet known but it is likely that while the charity will be facing a challenging fundraising environment, there will be new and exciting opportunities to broaden our work and reach more people who need us.

Part 3: Activities

- **Activity Plan**

The tables below show the activity that we will be undertaking over the next three years, what we want to achieve and how we will measure our success. The work that the charity does is split into five areas of activity. We use these areas of activity in our annual accounts and in our budgeting. These areas of activity are;

Providing support and information

This area of activity includes our nurse led helpline, national conference, information resources, and website. It also includes the work we do with young people and the peer support we offer through our support group network, over the phone and in hospitals.

Working with healthcare professionals

This area of activity includes our healthcare professional education events and our online education for healthcare professionals.

Raising awareness

This area of activity covers our national media campaigns and the work that we do to spread awareness by traditional and social media.

Campaigning

This area of activity covers the work that the charity does to improve access to treatment and highlight regional inequalities in the support that people with cardiomyopathy and related disorders receive from the NHS.

Research

This area of activity includes the work that we do to help shape research by providing insight from people with experience of cardiomyopathy. It also includes the research the charity undertakes for itself to gain a detailed understanding of the impact of cardiomyopathy and related condition on people's lives and their experienced of accessing treatment. As funds and opportunities arise, we do offer occasional research funding. This is typically in partnership with another funding partner.

- **Providing Support and Information**

	Activity	Outcome/s
Helpline Service	Provide support and advice online and over the phone covering all aspects of cardiomyopathy and related conditions.	Coping with cardiomyopathy
Young People	Provide online peer support opportunities for young people (14-25).	Coping with cardiomyopathy
	Create age appropriate information materials designed for young people under 14 and educators	
	Provide opportunities for young people to meet each other	
Support groups	Provide high quality regular peer support via our support group network	Coping with cardiomyopathy
Peer support	Provide high quality one to one peer support to individuals over the phone	Coping with cardiomyopathy
Information resources	Provide up-to-date and accessible information resources on all aspects of cardiomyopathy and related disorders	Coping with cardiomyopathy
Hospital volunteers	Provide peer support volunteers in cardiomyopathy clinics	Coping with Cardiomyopathy Making it easier to get treatment
Supporting the whole family	Provide support and learning opportunities for parents, carers and siblings of people with cardiomyopathy and related disorders	Coping with Cardiomyopathy

- **Working with healthcare professionals**

	Activity	Outcome/s
Providing learning opportunities	Provide thought leading medical education events for healthcare professionals.	Helping healthcare professionals to detect and treat cardiomyopathy
Campaigns	Run national education campaigns to reach GPs and other primary care professionals.	Helping healthcare professionals to detect and treat cardiomyopathy
On line learning	Provide online learning opportunities	Helping healthcare professionals to detect and treat cardiomyopathy

- **Raising awareness**

	Activity	Outcome/s
Awareness campaigns	Run UK wide awareness campaigns to increase appropriate diagnosis and reduce the incidence of misdiagnosis of cardiomyopathy and related conditions	Getting more people to seek medical help
Media activity	Seek all opportunities to secure free coverage in national and local media	Getting more people to seek medical help
Reaching all communities	Promote and monitor diversity across the organisation and consider the need to reach all communities when planning any new activity	Getting more people to seek medical help

- **Campaigning**

	Activity	Outcome/s
Shaping services	Develop our Change Maker network of local volunteers to influence cardiomyopathy services in their area	Making it easier to get treatment
Setting Standards	Update the charity's National Plan for Cardiomyopathy to ensure that it remains relevant	Making it easier to get treatment
Working with others	Continue to collaborate with other relevant charities and professional bodies where this will enhance services and treatment for people with cardiomyopathy and related disorders	Making it easier to get treatment
Building an international community	Play a role in helping to build an international cardiomyopathy community where ideas, best practice and research can be shared more widely	Making it easier to get treatment
Tracking NHS services	Work with other agencies to ensure that cardiomyopathy outcomes and the availability of cardiomyopathy services in the UK are audited appropriately	Making it easier to get treatment

- **Research**

	Activity	Outcome/s
Improving our understanding of the impact of cardiomyopathy	Undertake social research projects amongst supporters and service users and where appropriate, seek to co-author research studies	Helping to develop better treatment options and support services
Sharing our findings	Produce and distribute research finding to a wider audience	Helping to develop better treatment options and support services
Supporting research and increase research co-production	Act as special advisor and provide patient insight to relevant clinical research projects. Encourage service users to engage with research projects and both case studies and co-producers	Helping to develop better treatment options and support services

Making it happen

- Growing our income

In order for us to be able to deliver our ambitious programme of activity over the next three years, we need to increase the amount of money that we raise and the variety of sources of that income. In particular, we will need to increase the support that we receive from individuals, charitable trusts and companies. We also need to ensure that our fundraising practice is appropriate and meets all the relevant regulation and guidance.

We calculate that the charity's expenditure will reach £1million per year by 2022 and we have put in place a fundraising strategy that will enable us to meet this increased expenditure.

- Developing volunteers and staff

We rely on a fantastic team of volunteers to deliver our work and over the next three years, we will need to grow this team and ensure that each one of them has the appropriate training and support to do their work. We want our volunteers to feel appreciated and enthusiastic about the contribution that they make and to stay with us for a long time. We also want to make sure that we are supporting our staff and that they have the opportunities to grow and develop whilst they work for the charity.

The charity will invest resources each year to fund staff and volunteer training and ensure that the right staff and volunteer management processes and policies are in place.

We will also seek to develop ways to encourage people from underrepresented groups , particularly people from the Black and Minority Ethnic community, to join us as staff and volunteers. We will provide development opportunities so that they can move into positions of leadership including becoming trustees.

- Making full use of digital

At present, the charity supports more people online through its website, Facebook group and live chat services than it does face to face or over the phone. It is clear that more people are choosing to get our help and support online. We also recognise that if we want to reach as many people as possible to tell them about cardiomyopathy and about the work we do, then we need to have a strong digital presence.

The charity will update our separate digital strategy that shows how we plan to make full use of technology and social media across all of our areas of activity.

- Monitoring and reporting on progress

We think that it is important that we keep everyone up to date with our progress. We will continue to do this via our My Life magazine, annual report and accounts, events and an annual impact report.

How we will review and change our strategy

This document is designed to guide our activity over the next 3 years. As the environment changes, the plan will continue to be reviewed and updated to ensure that it still offers the right direction for the charity. Our response to COVID-19 showed that we can change rapidly whilst still keeping true to our core purpose. Trustees are charged to ensure that this approach will continue as we change, adapt and grow over the next decades. For 2021-2024, this will be by 6 monthly board reviews in addition to monthly reports from the CEO and staff team.
