

Emotional wellbeing & mental health

Living with the impact
of cardiomyopathy

Contents

What is 'mental health' or 'emotional wellbeing'?	page 5
Elis' story	page 8
Mental health conditions	page 10
The impact of long-term conditions	page 13
Tina's story	page 14
Emotional wellbeing and cardiomyopathy	page 16
Looking after your emotional wellbeing	page 21
When to look for support	page 23
Dawn's story	page 24
Services and support	page 26
Your support networks	page 27
Talking to other people	page 28
Support groups	page 29
Helplines	page 30
Online support	page 32
Meditation and mindfulness	page 34
Self-management courses	page 36
Counselling, psychological therapies and IAPT	page 37
Community mental health services	page 39
Support for carers	page 40
Jasmine's story	page 42
Useful resources and further reading	page 44
Resources used in this booklet	page 46

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Quotes in **purple** are from people with cardiomyopathy, and those supporting them.

About this booklet

Living with cardiomyopathy is more than just managing symptoms and taking treatment. It can affect all areas of your life, including how you feel physically, how you manage practically, and how you feel emotionally and deal with the impact it has on your life.

Cardiomyopathy can also have a significant impact on the lives of the family, friends and carers of the individual with the condition.

This booklet is about the emotional impact of cardiomyopathy on the lives of those living with it: people diagnosed with the condition, and those close to and supporting them (their family, friends and carers). It includes information about mental health, and lists sources of help, support and self-management strategies. It also includes the stories of people affected by cardiomyopathy: the impact of the condition on their emotional wellbeing, and how they have sought help from various services.

While this booklet cannot cover all aspects of mental health and emotional wellbeing, it aims to highlight some of the issues people living with cardiomyopathy may experience, and suggest some services and strategies that other people feel they have benefitted from. It also signposts to further information if you would like to find out more for yourself.

You may have picked up this booklet because you have cardiomyopathy, or you are supporting someone who does. You may recognise that cardiomyopathy is having an impact on your emotional wellbeing, or you may be looking for sources of help and support. Don't feel that you have to read this booklet straightaway, or from front to back. You can dip in as and when you want to, and the contents on page 2 can help you find the information you are looking for.

“There is a stigma around mental health. People do not know how common mental health problems are and that they can take many different forms and affect anyone.”
Individual with cardiomyopathy

‘Mental health’ or ‘emotional wellbeing’?

There are many different terms used to refer to ‘mental health’, including ‘psychological health’ and ‘emotional wellbeing’.

When preparing this booklet we asked people their views about mental health, including what term they prefer to use when referring to it. In an online survey, people with cardiomyopathy, and family, friends and carers, preferred the term ‘emotional wellbeing’ to describe mental health. For this reason we include the term ‘emotional wellbeing’ as people felt that this was more positive, and less stigmatising, than ‘mental health’. However, many services and charities refer to ‘mental health’ and so we use this term too, where appropriate.

“People are seen in a negative light... perhaps if we spoke of ‘wellbeing’ it would be better.”

Carer of someone with cardiomyopathy

Throughout this booklet we also use the word ‘cope’. Although some people avoid this term as the opposite, ‘not coping’, is often seen as negative and as ‘failure’, it is also a widely accepted way of asking if people are ‘OK’. We use this as a positive term to mean when people find a way to ‘deal with’ and ‘manage’ what is happening.

“There should be more support for dealing with the psychological aspects.... To understand and manage the maelstrom of emotions you can have, by talking to someone about it, would be very beneficial. A positive mental attitude can help you to feel better physically too.”

Individual with cardiomyopathy

What is 'mental health' or 'emotional wellbeing'?

Just as we all have physical health, we all have mental health too. Mental health refers to our psychological or emotional health and wellbeing. It is about how we think, how we feel, how we behave, how life affects us and how we cope with it, how we engage with others, and the choices we make. When we are in 'good' mental health, we feel that we can cope well and respond positively to life, and we can be involved in relationships, activities and our environment and community.

Our mental health is affected by our biology (our genes and how our body reacts to situations) and our life experiences (what we experience and how this affects us).

We can all probably recognise times when we feel 'down' or 'stressed'. Sometimes there is a clear reason why we are feeling this way and, with time, these feelings pass. Mental health, and how we respond to events in our life, varies from person to person: some people cope and adjust positively, some find certain aspects of life challenging at certain times, and some find it hard to cope with and engage with many aspects of life.

Like physical health, an individual's mental health can vary over time: moving between being able to cope sometimes to feeling unable to at other times. This may change as our life, perspectives and experiences change. This can be in the shorter or longer term: you may find that sometimes you can manage whatever life hands you, yet on other days even the 'simplest' things feel overwhelming. Or it might be that it depends on the situation, for example, being able to manage at work but experiencing difficulties in your personal life.

Some people experience few, if any, mental health problems. Some may have periods of mental ill-health which may be temporary or fluctuating, and others may have longer-term or persistent difficulties. Some people have mental health conditions that can be recognised and diagnosed. These conditions are usually not ‘passing’ feelings but are more long-lasting, more debilitating, and have an impact on the person’s day-to-day life. They can lead to feelings of isolation and, in severe situations, result in people self-harming or having suicidal thoughts.

“I think people are so focussed on the physical symptoms of cardiomyopathy that they forget the emotional impact.”

Individual with cardiomyopathy

The impact of a mental health problem can be as important as a physical health condition.

“My mental health has affected me twice as much as my heart condition.”

Individual with cardiomyopathy

Talking about mental health

“There is still shame attached to mental health problems. People feel they should ‘pull themselves together’ or are told they should.”

Individual with cardiomyopathy

Mental health conditions can be difficult to talk about, and they are often poorly understood or misunderstood. Some people have particular ideas about what mental health conditions mean, and how someone with a condition will be affected by it.

“This is often to do with lack of knowledge and understanding and if people have not experienced depression/anxiety/mood disorders it is hard for them to really grasp what it is like.”

Individual with cardiomyopathy

Many people feel that there is a stigma around mental health, and are reluctant to raise the issue. Maybe they are worried about themselves, or someone they know, but don't know who or how to ask for help. Unless their healthcare professionals ask them about it, many people don't feel able to raise the subject themselves. This can be a vicious cycle with people feeling uncomfortable or unable to talk about it, which makes it harder to raise the issue.

“Just a simple question, such as ‘How are you coping’ or ‘How does that make you feel?’ would mean so much to us...”

Individual with cardiomyopathy

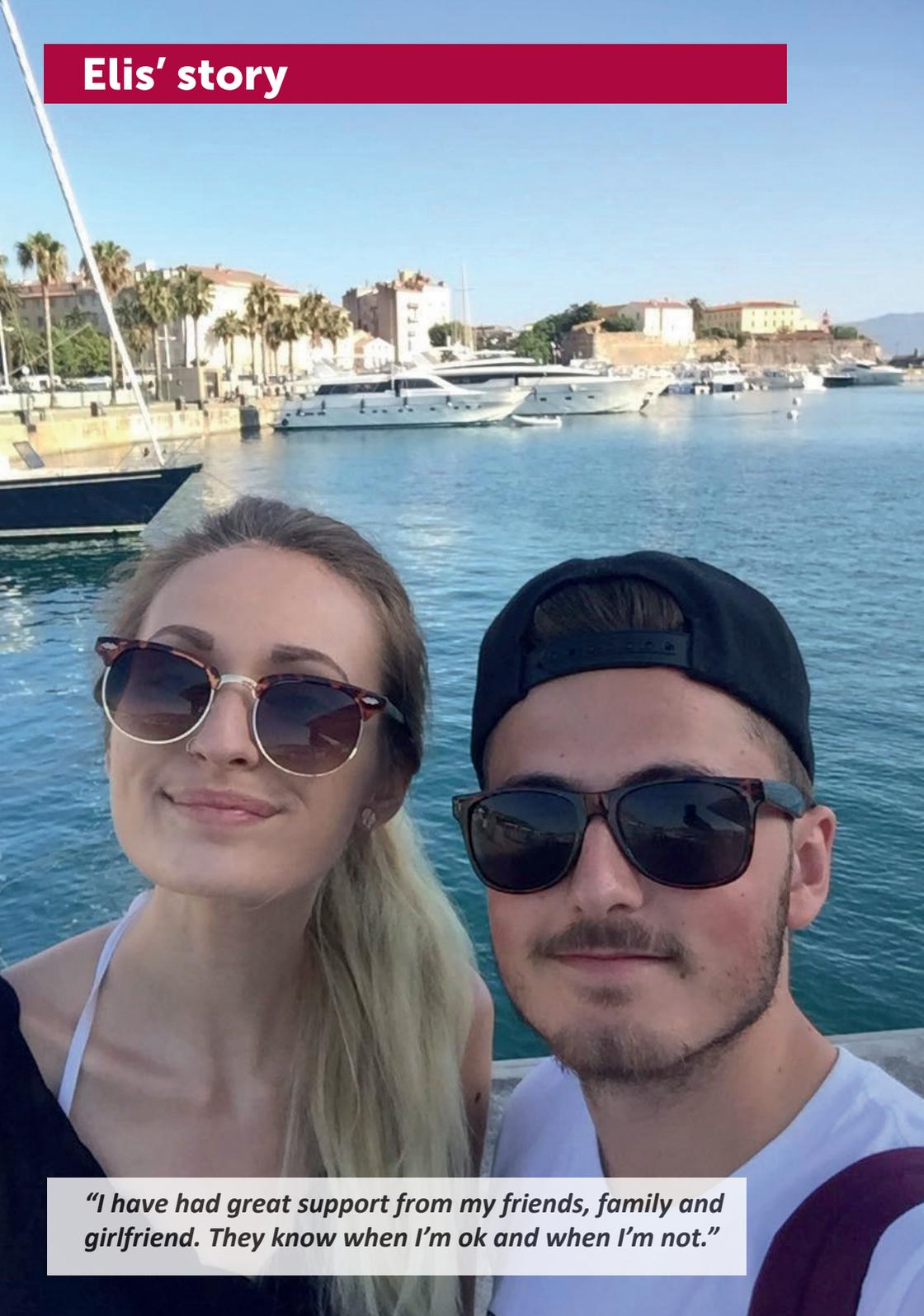
Being able to talk about mental health, and find strategies to cope, may help you to feel more empowered around managing your condition. Later on this booklet we look at various services and support available (see page 26).

“At first I worried about my diagnosis... but I quickly decided what a waste it would be to look back at 85 and think about all that time spent worrying which you never get back. I know not everyone can be this positive but if they can look at things this way then they will get the most out of life.”

Individual with cardiomyopathy



Elis' story



"I have had great support from my friends, family and girlfriend. They know when I'm ok and when I'm not."

Adjusting my goals

I was diagnosed with hypertrophic cardiomyopathy after years of screening and testing. The condition was found to be in my family after my father passed away unexpectedly. The hours I have spent in the hospital not knowing whether I had the condition or not was extremely stressful. Initially, being diagnosed made me really scared. I was 22, all I could think about was how my father was 30 when he died and I thought that I may only have a limited time left.

Thoughts go through my head on a daily basis: 'do I want to have children' as it is a genetic condition, and 'will I be able to work when I'm older' in case I get quite ill. I'm 23 now and have recently got a job after university. I question whether my life will ever be 'normal' (even if it isn't a stereotypical 'normal' like my friend's).

I have been told I can't play rugby (which for a Welsh boy is awful), I can't play squash, I can't lift heavy weights - all things my friends do. Knowing that I can't join in with certain activities and having to be careful in the gym can be quite disheartening. It's hard psychologically that you can't do the same as everyone else, but it is important to find other activities rather than completely stopping everything you used to do. I still go to the gym, but instead of lifting heavy weights and pushing myself to the limit, I stick to weights I know don't put too much strain on myself, and keep an eye on my heart rate with my Fitbit. I do football training, but play in goal rather than outfield. I go for jogs and have recently got into hiking. Along with a healthy diet to keep my heart as healthy as possible, this allows me to keep fit and active, and not focus on the fact I can't play the sports I used to.

My mother is a retired cardiology nurse, and is great at explaining things about the heart and making sense of things at hospital appointments. My girlfriend has been extremely important in keeping me psychologically healthy.

I would recommend accessing information and support if you feel mentally or physically unwell and don't know who to talk to.

Mental health conditions

Mental health conditions are not uncommon. It is estimated that over 10 million people in England have a mental health condition¹.

1 in 4 people will have a mental illness at some point in their lives².
Rethink Mental Illness

There are many mental health conditions. The number of people living with them, and how they are affected by them, varies. Some conditions, such as anxiety and depression, are more common: anxiety affects around 5 in 100 people, depression affects around 3 in 100 people, and around 8 in 100 people have both anxiety and depression. Others, such as bipolar disorder and OCD (obsessive compulsive disorder) are less common³.

On the opposite page are some examples of mental health conditions. Not everyone will fit easily into a definition of a mental health condition, and the difference between conditions can be subtle.

Some people have mental health conditions in isolation, and some have them alongside other health conditions. The Department of Health estimates that more than 15 million people in England have at least one long-term condition⁴ (a condition that cannot be cured but can be treated). And people with long-term conditions are more likely to have mental health conditions than people without long-term conditions⁵. In fact, it is estimated that 30% (or 1 in 3) people with a long-term condition also have a mental health condition⁶.

Some mental health conditions, such as anxiety and depression, may be more common in people with cardiomyopathy than other mental health conditions.

"I feel unless people have been affected by this themselves, either personally or family, friend, the understanding isn't there."
Individual with cardiomyopathy

Anxiety – where you feel worried or fearful, and this feels overwhelming and it is hard to overcome the feelings. This can cause problems with being able to sleep, not eating, palpitations (feeling your heart beating), and feelings of panic.

Bipolar disease – where you have extremes of mood, such as feeling very ‘high’ (sometimes called mania) and very low (depression). This can be very distressing or overwhelming, and can affect everyday life.

Depression – where your mood is low for a long period of time, and affects your day-to-day life. You might experience feelings of despair and hopelessness. It might feel hard to be motivated to do anything, or enjoy things in life you used to take pleasure in. It can lead to severe feelings such as suicidal thoughts.

OCD (obsessive compulsive disorder) – this is a type of anxiety disorder which causes obsessions (such as unwanted and persistent thoughts that can be worrying or distressing) and compulsions (repetitive actions that you feel an urge to complete).

Schizophrenia – where you may experience hallucinations (for example seeing or hearing something that is not there) or delusions (believing something that is not real), your thinking is disorganised, you may feel unconnected to how you feel and feel differently towards people.

Postnatal depression – this is a type of depression that can happen following the birth of a baby. It is more common in women, but can affect a man too, and usually starts within a year from the birth. It can include persistent feelings of sadness, low mood, lack of engagement with others or losing interest in things, and problems concentrating.

PTSD (post-traumatic stress disorder) – this is a type of anxiety disorder caused by very frightening, stressful or upsetting experiences (such as serious accidents and abuse). It can affect people who have experienced the event, or have seen an event happening to someone else. It can cause vivid flash-backs which can be distressing, and cause feelings of isolation or problems sleeping and concentrating.

These are simplified explanations. You can find out more about mental health conditions from the organisations listed on page 44.

How are mental health conditions managed?

Different mental health conditions have different forms of treatment and ways of managing them. Some treatments are medications, and others focus on psychological interventions (such as types of therapy).

If you are concerned that you may be experiencing a mental health condition, you might like to contact your GP or specialist (if you have one) to talk about this. The organisations listed on page 44 can give you further advice on this.

What is the impact of mental health conditions on physical health?

Mental health conditions can affect all aspects of life, and can affect how you feel, how you think and your behaviour. It can also have a big impact on your physical health. For example, it can cause problems with sleep or affect your eating, you may not feel like being active, and it may affect your concentration, memory or ability to make decisions. It can also cause problems such as sweating, headaches, breathlessness and palpitations (where you are aware of, and can feel, your heart beat).

Over the next few pages we look at how having a long-term condition, cardiomyopathy in particular, can affect your mental health and emotional wellbeing.

“I had two very understanding doctors who showed great compassion towards me when I was at my lowest ebb.”

Individual with cardiomyopathy

“For the first 18 months after diagnosis I had regular appointments with a heart failure nurse. He was brilliant! I could have discussed emotional well-being with him, but at the time I was so focussed on getting better physically that I didn’t consider emotional wellbeing.”

Individual with cardiomyopathy

The impact of long-term conditions

Having a long-term condition can cause many challenges. This can include the physical impact of the condition (such as causing pain or limiting activities), practical limitations (such as managing medication and side effects) and lifestyle issues (such as driving, work and leisure). It can also affect friendships, family dynamics, and intimate relationships. A diagnosis can also have a significant impact on someone's mental or psychological health. This can be for many reasons, which may include the following.

- Loss of the life you were expecting and adjusting your expectations to life with a long-term condition. Some people describe this as a bereavement – the loss of the life they were expecting to have.
- Limitations that a condition can place on your activities, including your social life and interactions with others. This may mean you feel excluded or isolated.
- Feeling that you are now 'unwell' or are worried that people will see you as a 'poorly' person.
- Concerns and worries about how the condition will impact you, now and in the future. This might include your health, being able to work, your family life and worries about your life expectancy.
- Changes to relationships and family dynamics, particularly if you need to rely on others when previously you didn't have to (for example, to drive you around, or do the shopping or housework).
- The impact of, or on, any other medical condition or disability that you have.
- For some, the condition may lead to developing a mental health condition such as anxiety and depression. For someone who already has a mental health condition, developing a long-term condition can have an impact on this, or can affect how an individual copes with their new condition.
- People often strive to feel a sense of 'normality', which can be difficult with a condition that can cause great changes to their lifestyle.

Tina's story



"I am now very much in control and live a rich life. I have two beautiful children, drive, work and exercise. I am steadily fulfilling my hopes and dreams!"

Fulfilling my hopes and dreams

In 1994, out of the blue, I suffered a cardiac arrest. I was fortunate that my husband was on hand to resuscitate me. I was diagnosed with cardiomyopathy and our world as we knew it was changed irrevocably.

It was a relief to have a diagnosis: at least we had some idea about what we were up against. At the same time we felt fear, anxiety, disbelief, anger, sadness and so much uncertainty about the future. We were setting out on married life with so many hopes and dreams. Would these be fulfilled? Would my life expectancy be reduced? So many unanswered questions.

At the same time I had to stop driving, decrease my hours at work, stop the exercise that I love and start on life-long medication: big unexpected lifestyle changes. I struggled to cope and felt out of control. My fatigue meant that my husband had to take on more, giving him little time for his hobbies. When asked how he was doing he would reply 'OK'. However, he wasn't really: he was just putting on a brave face and being strong for me.

I was very fortunate to be put in contact with Cardiomyopathy UK. To be given reliable and accurate information and talk to a knowledgeable nurse was so reassuring. I have now become an expert patient and am very proactive in managing my condition. This is something that I have found to be very empowering. Peer support, talking to others with cardiomyopathy who can empathise and 'get it', has really helped me.

I've had counselling on several occasions and have found this invaluable. As a diagnosis of cardiomyopathy is a life-changer, being offered counselling at diagnosis would have been so beneficial. I would have liked to have been offered cardiac rehab after I was given my ICD. I've had shocks from my ICD. This is both reassuring (it literally saves my life) but psychologically traumatic at the same time. After a shock is also another time I'd have liked to be offered counselling.

I've also undertaken a Mindfulness Based Stress Reduction course and Expert Patient Programme. Both have been very beneficial and enable me to live in the here and now and worry less about the future.

Being a 'can do' person I am now very much in control and live a rich life. I have two beautiful children, drive, work and exercise. I am steadily fulfilling my hopes and dreams!

Emotional wellbeing and cardiomyopathy

Our Cardiomyopathy UK survey asked for people's thoughts and experiences about mental health and emotional wellbeing. We asked people with the condition to complete a survey, and also people who support someone with the condition (family, friends and carers).

The following information is feedback from the survey and represents what people have told us. This may or may not be your own personal experience, and that of people around you, but it identifies some of the ways in which cardiomyopathy can affect emotional wellbeing, at what stages people felt it affected their wellbeing, and what would have helped them to cope.

Does having cardiomyopathy affect emotional wellbeing?

"My confidence has been shattered and I do not function as well as I would normally."

Individual with cardiomyopathy

Most people, both with the condition and supporting someone with the condition, felt that cardiomyopathy has some impact on their mental health and emotional wellbeing, either some or most of the time. The impact makes parts of life more challenging.

"I have all the tools as a coach to stay emotionally well and practise those. Despite all of these tools, the medical aspects of the condition make staying positive and emotionally well a massive challenge."

Individual with cardiomyopathy

For some people with cardiomyopathy, the impact of the condition on their emotional wellbeing can be as great, if not greater, than the impact of living with the medical condition.

"It has affected me in the past for several weeks, a few months at a time."

Individual with cardiomyopathy

Emotional wellbeing and the course of cardiomyopathy

For many people, when their cardiomyopathy is well-managed it has less impact on their emotional wellbeing. However, there may be times where their condition changes, and this can have a greater impact on emotional wellbeing. Some people cope well until their condition changes, and this can throw everything up in the air again, possibly bringing back feelings of worry and uncertainty.

Although everyone's experience will be different, as the course of their condition will be unique to them, the following are examples of when cardiomyopathy affects emotional wellbeing, and when people feel they need support.

When symptoms first start to happen

This can be a worrying time, particularly when symptoms can come and go. Symptoms of a heart condition, such as palpitations and feeling very tired, can be very worrying.

At the time of diagnosis

For some people a diagnosis may be a relief: they know what the condition is and that treatment can be started. However, for others a diagnosis can be a huge shock and very upsetting. It can be a time of very mixed emotions, and can be confusing or worrying. It can also be difficult to take in new information at this time, which can add to any worry or confusion someone is feeling.

“When I was first diagnosed I took it hard... Basically I turned in on myself, I wouldn't talk to anyone about it.”
Individual with cardiomyopathy

When the condition or its symptoms get worse

When a condition is stable it may start to reduce its impact on someone's life as they come to terms with it. When this changes, it can bring up worries. Sometimes it can feel like being diagnosed all over again, or it can bring up new feelings and concerns about what these changes mean.

When a device is needed and implanted (an ICD* or pacemaker)

Needing to have a device implanted can be difficult. Devices are used to help the heart work, improve symptoms and reduce the risk of complications. However, needing to have a device can often mean facing the reality of the seriousness of the condition. And having a device can cause anxiety: some people are extremely worried that the device will go off at some point, particularly an ‘inappropriate shock’ from an ICD (where the device gives a shock by accident).

“Recently I received my first shock from my ICD, there was nobody to talk to who understood my emotional feelings...”

Individual with cardiomyopathy

When heart failure symptoms develop

Many people with cardiomyopathy develop symptoms of heart failure: where the heart struggles to meet the demands of the body. Although there are many effective treatments to help someone with heart failure, the term ‘heart failure’ itself can be worrying as ‘failure’ sounds very scary and as if the heart is about to ‘stop’.

“My heart had not ‘failed’, it still beats, still pumps, though not quite as effectively as I would like it to have done.”

Individual with cardiomyopathy

When genetic testing is considered

Cardiomyopathy is often a genetic condition: caused by an altered or ‘mutated’ gene. Where it *is* genetic, it can be inherited (passed from parent to child) and so often runs in families. For this reason, if someone’s cardiomyopathy is genetic it is recommended that close (first degree) family members (parents, siblings and children) are tested to see if they have the same genetic mutation, and therefore could develop cardiomyopathy. Having genetic testing can be a worrying time, and people can have conflicting feelings about it. Some people feel scared or guilty that they might have passed on the gene to their children, and worry about what this means. Genetic testing also looks at the family history and whether any family members have the condition, and this can also be upsetting.

*A form of treatment that shocks the heart if it is in a dangerous arrhythmia.

What might help at these times?

Both people with the condition, and those supporting them, felt that talking to someone with similar experiences, sharing experiences in a group, and seeing a counsellor, would be helpful during these times. As conversations can be difficult to start, speaking to someone who shares similar experiences can be particularly helpful.

Talking about mental health with healthcare professionals

“Healthcare professionals should take a holistic approach and ask about emotional wellbeing at appointments, not wait until there is a problem.”

Individual with cardiomyopathy

Most people hadn't started a conversation with their healthcare professional about the impact of their condition on their emotional wellbeing. And for most people, their healthcare professionals have never brought up the subject.

For people with the condition, often this is because appointments are too short to raise the subject or they felt embarrassed to. Having the right sort of relationship with a healthcare professional, or if the professional brought up the subject, would help people to feel able to talk about it. If people do start a conversation about this, this is usually with their GP, rather than a nurse or cardiologist.

“I feel I should not have a problem so feel guilty that I do and should not bother the busy health professionals.”

Individual with cardiomyopathy

Family, friends and carers don't start a conversation because they don't want to talk about their own feelings in front of the person with the condition, or they feel guilty having these feelings when they don't have the condition. Having the right sort of relationship with a healthcare professional, or having an appointment to focus on their own needs, would help them feel able to talk about this.

“I am afraid to mention this to anyone in my work life or to my doctor. I also find it very difficult to talk about.”

Carer of someone with cardiomyopathy

Talking to family and friends

Although people with the condition often speak to partners or spouses, and to friends, about their emotional wellbeing, almost 1 in 3 haven't spoken to *anyone* about it. This is similar for family, friends and carers, with many speaking to partners and friends, but 1 in 3 haven't spoken to anyone about this. This is because people are embarrassed to bring up the subject or they don't know how to start the conversation.

How should support services be offered?

Although their needs change over time, most people said that they would like support services to be offered. We asked *what sort* of support people would like to be offered around their emotional wellbeing. People with cardiomyopathy would prefer peer-support by speaking to someone with similar experiences, to share experiences within a group and to meet, informally, face-to-face. They also prefer online support such as through social media.

"The thing that really helped me was talking to another person who had been through the same experience. She reassured me that I was not alone in having the psychological struggles."

Individual with cardiomyopathy

Those supporting someone with cardiomyopathy would prefer to speak to someone with similar experiences, to meet face-to-face informally, to attend a course, and to speak to a counsellor.

"At different times, different things are needed, but it would be good to know they can be accessed in different ways."

Carer of someone with cardiomyopathy

We offer various types of support through our peer-support services, support groups, helpline and Live Chat service, our online support and information events. See page 26 for more detail.

♥ *For more information about practical help and emotional support for family, friends and carers see our factsheet 'Support for carers'.*

Looking after your emotional wellbeing

Like our physical health, there are often things we can do to support our emotional health and wellbeing. This may be helpful for anyone, not just someone with a long-term condition. The following are some suggestions of ways to look after your emotional health and helping you to feel a sense of control over your life.

It may help to talk about how you are feeling with someone you trust and who will understand. This might be a family member or friend, a healthcare professional, or you might like to talk to someone from a support group, helpline or through online support services.

Look after your physical health

Looking after your physical health can have a positive impact on your emotional health. Eating a healthy, well-balanced diet, helps to keep your body healthy and can help with weight management. This can help with some of the physical symptoms of cardiomyopathy as it reduces extra pressure on the heart.

Exercise can help improve overall health and fitness, and can reduce the impact of some physical health conditions. It is also recognised as helping with mental wellbeing by reducing stress and depression. It can also be beneficial for the heart by improving blood circulation and strengthening the heart muscle. Some people with cardiomyopathy are concerned about the type and level of exercise that is safe for them.

 *See our factsheet 'Cardiomyopathy and exercise'.*

Take time for yourself

Taking 'time out' to look after your emotional wellbeing might feel like a strange thing to do, or it might feel self-indulgent. But taking time to have a break, do something you are good at and enjoy, and get away from your normal routine can have positive effects on your mental health and reduce stress. Doing something you enjoy helps with self-confidence as well as giving you time to focus on something positive. This might be a few minutes a day to sit somewhere quiet and meditate, doing a regular hobby, to a break away from home.

Be kind to yourself

It can be all too easy to tell ourselves ‘pull yourself together’ or to ‘stop feeling sorry for yourself’ when we are feeling low or struggling to cope. But often the feelings we are having are a natural and automatic response to what is happening. Telling ourselves we shouldn’t be feeling this way often has the opposite effect to what we want, making us feel worse because we feel that we ‘cannot cope’.

“Most people just think that you’re in a bad mood for some reason and expect that you can just snap out of it... It’s not that simple.”

Individual with cardiomyopathy

Sometimes it is helpful to think ‘what would I say to a good friend, if they were feeling this way?’ Often we are kinder to those we love than to ourselves. Treat yourself as you would a friend. Acknowledging your feelings as natural and not a ‘weakness’ may allow you to move forward and refocus on positive ways of coping with these feelings.

Ask for help

As cardiomyopathy can be a ‘hidden’ condition (it is not obvious who has it by looking at them), people may not understand the symptoms someone with cardiomyopathy experiences. People might ask “how are you?” but may not be prepared to hear how someone *actually* feels. Sometimes it is easier to just say “I’m fine”.

It can be difficult to ask for help, whether it is from a friend or family member, or from a health professional. It can feel like admitting that we are ‘not coping’ and that it is a weakness. But asking for help can be a strength and can be positive: a sign that we acknowledge how we feel, and want to develop ways to cope with what we are feeling.

The mental health foundation has several useful resources.

♥ *Visit www.mentalhealth.org.uk and search ‘look after your mental health’.*

There are several charities that provide detailed information on mental health conditions, services and support. See page 44 for details.

When to look for support

If you have cardiomyopathy, or you are supporting someone with it, the right time to look for support depends on you and what you need. There may be times when you feel that you don't need to look for support, either because you have networks in place already, or you don't need any additional support at this time. But there may also be times when you feel the need for support deeply or urgently.

As your need for support may change over time, so might the type of support you would find helpful. This may depend on what is happening with your condition, and what coping strategies you have in place.

If and when you need it, there are a variety of different services available. This could be anything from having time out with a friend over lunch, meeting and sharing experiences in a support group, signing up to a meditation or self-management course to finding a counsellor. Some are things you can do yourself including help you can ask for and services you can sign up to. Others are services that you may need a referral to access, such as from your GP. The next section of this booklet will focus on services to support your mental health and emotional wellbeing.

Please note: on the following pages we refer to services and support for emotional wellbeing and mental health. If you are concerned that you may be experiencing a mental health condition, contact your GP or specialist (if you have one) to talk about this, as additional treatments or therapies might be appropriate.

Dawn's story

Taking each day as it comes

My partner Paul was ill for almost a year before he was finally diagnosed with DCM (dilated cardiomyopathy). In all that time I didn't really believe that it was anything serious because he had always been so strong and apart from having PTSD (post traumatic stress disorder) he was never ill. His angiogram result was quite shocking and it meant that he was going to be referred to hospital in Newcastle.

His first echo showed an ejection fraction* of 17-22% and hasn't ever improved over the 10 years he has had the condition despite all his medication. We went from being a normal couple running our own business and getting out and about to something very different. Paul didn't have the energy to run a business anymore and decided to work for someone else as a driver which didn't sit well at all. I decided to give up work and be there for when he came home.

I think the hardest part for me was finding the balance of being a carer and trying not to wrap him up in cotton wool. He gets very frustrated when I do things that he wants to do. I've had to learn to let him do what he can and not be too bothered if things take longer than I could do myself (he has to stop a lot and rest). I've also had to learn to slow down and take life at his pace and not get too het up if something we plan doesn't come off because he doesn't feel well. I'm not the most patient of people and some of these things have taken time. I'm not a natural carer and will be the first to admit it.

One difficulty is his mental health. He already had PTSD but his lack of energy has really got him down. I have to have an outlet which is mine. I think this is important for all carers. I'm doing a degree as well as developing my painting which is very important to me. When he finally gave up work three years ago (at 45, which is far too young) he became depressed. Then things got trickier because I felt I had to stay even stronger.

It took some time to get into a new routine but I think the trick is not to dwell on what might be or could be but just take each day as it comes and where possible let the grumpy outbursts slide by as much as possible.

*Ejection fractions measure the amount of blood pumped out (or 'ejected') from the heart when it beats.



"I have to have an outlet which is mine. I think this is important for all carers. I'm doing a degree as well as developing my painting which is very important to me."

Services and support

Over the next few pages you can find information about different types of services and support. These include services that other people with cardiomyopathy, or their family, friends and carers, have told us they have used and found helpful.

There are many other sources of help and support around mental health and emotional wellbeing available other than what we can cover here. You may like to talk to your GP or specialist about what services are available and what might be helpful for you.

If you have, or think you may have, a mental health condition, we would recommend that you consult a healthcare professional.

“I don’t think anyone really appreciates how difficult it can be to seek out and ask for emotional support. All the responsibility lies with us.”

Individual with cardiomyopathy



Finding time to do something you enjoy, like a hobby, can be rewarding.

Your support networks

Support doesn't always need to be something 'formal', or to come from professionals, organisations or charities. Sometimes it comes from those around you: your family and friends.

You may not feel comfortable or able to ask for 'help' or for people 'to listen'. Or maybe you have particular people that you turn to when you need to talk things through. Perhaps there is someone who knows you and understands what you are going through, who listens and offers help and support. Sometimes you might need just a listening ear so you can off-load: you might not need someone to do anything else. Or maybe you would prefer just to meet and do something nice together, rather than focusing on how you are feeling, perhaps taking your mind off things that are worrying you.

Whether it is a chat on the phone, meeting for a cup of tea, or taking a walk in the park together, meeting friends can help you to feel supported and positive.

"I would not want to worry my family and feel that I should carry on."
Individual with cardiomyopathy

Spending time with friends can help you feel supported.



Talking to other people

Many people with cardiomyopathy find it helpful to share experiences with other people. Often referred to as 'peer support', this might be through support groups and online support, meeting at conferences, reading personal stories in magazines, and having one-to-one contact online or by phone.

What peer support offers

Peer support provides help and support through sharing experiences. It can help people feel understood, less isolated and that someone really empathises on a personal level with what they are going through. It also helps to have a different perspective and discuss what strategies and support might be helpful. It is worth being aware that everyone's experiences are different, and that what works for some might not work for everyone.

Availability and how to access services

There are different ways of accessing different types of support.

Useful contacts

Cardiomyopathy UK

We can put you in contact with other people through our support groups (page 29), online support (page 32), and information days and conferences. We have Peer Support Volunteers who you can speak with by phone, text or email. This includes people with the condition, younger people, and family members. Contact us to find out more.

01494 791 224

www.cardiomyopathy.org

Read personal stories at www.cardiomyopathy.org/supporter-stories

Meet our young people panel at www.cardiomyopathy.org/cypya-panel

"There have been times when I have been so depressed I could not speak to anyone. Having an excellent volunteer with lived experience who chatted on the phone with my carer when I was unable to, was invaluable and kept us both going at even the worst times."

Individual with cardiomyopathy

Support groups

Support groups are opportunities to meet other people and share experiences. They are often set up by organisations and charities, and may be run by volunteers. They usually meet regularly, and you may have to 'join' to attend (although they are usually free to attend).

What support groups offer

Most support groups meet in person (rather than online) and provide peer support: meeting and sharing experiences with people with similar conditions. Some groups have guest speakers at meetings, and may meet for social gatherings as well as more formal meetings.

Availability and how to access services

How often support groups meet will vary from one group to another. There is usually a group leader who will arrange the meetings, who can keep members up to date with information about meetings. Some groups also have Facebook pages where they will advertise meetings and where members can keep in touch between meetings.

Most support groups do not need a referral to use them, although they may be recommended by a professional. You can find details by contacting individual charities that run groups, or your GP surgery may have information on groups.

"The support group was a lifeline."
Carer of someone with cardiomyopathy

Useful support groups

Cardiomyopathy support groups

You can meet other people with cardiomyopathy, and family, friends and carers, to find out about the condition and share experiences. Contact 01494 791 224 or www.cardiomyopathy.org/support-groups for details of our local groups.

"My local cardiomyopathy group have given me so much support and information I would be lost without them."
Individual with cardiomyopathy

Helplines

There are various helplines available, for example:

- for specific health conditions or disabilities;
- for mental health concerns and support for individuals with emotional needs; and
- for practical issues such as housing, benefits, employment or money issues.

What helplines offer

Helplines vary in what they offer including information, advice, emotional support, counselling, practical help, referrals and advocacy. It can be helpful to find out more about the service before you call. Helplines will usually describe the service they offer, who it is available to, and any cost (including call costs). You can usually find this on the organisation's website or promotional materials (such as helpline cards or posters advertising their services).

Availability and how to access services

Helplines are usually telephone lines, but some also offer email and online access such as Live Chat (through a website). The cost will vary. Online services usually have no cost but using a helpline may: some are standard rate calls, others may be low-cost or free numbers from a landline. If you call from a mobile you may be charged for this.

Opening hours will vary. Some are open only during usual office hours, and others are available 24 hours a day. Some may offer an answerphone or call-back service.

Most helplines do not need a referral to use them (although they may be recommended to you by a healthcare professional). Local helplines can be found through local services such as a library, community centre, health centre or social services. Details can also be found through the Yellow Pages and online searches.

Useful helplines

Cardiomyopathy UK helpline

Through our specialist helpline you can talk to our nurses for medical information and support, and to our advisers about benefits, housing and your rights at work. The helpline is there for you if you have the condition yourself or you are supporting someone who has it.

0800 018 1024 (Monday – Friday 8.30am – 4.30pm)

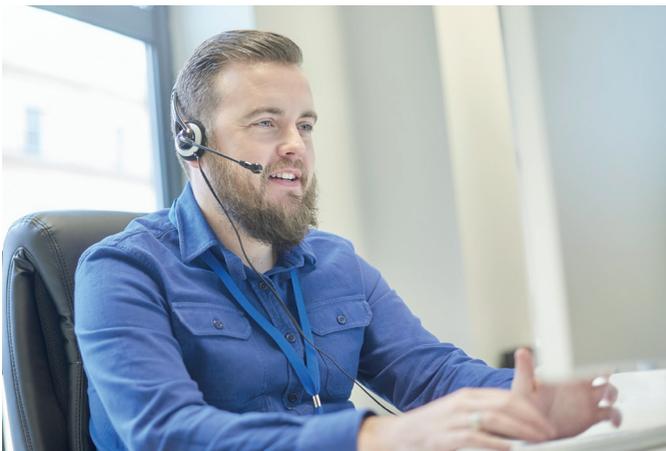
Free from a UK landline, mobile costs may vary.

Live Chat at www.cardiomyopathy.org

See also the organisations listed on page 44.

“I have learnt to seek out the right people for advice: GP for medical advice, private counsellor for emotional therapy, helplines have been absolutely invaluable for practical advice which then assists my emotional wellbeing.”

Individual with cardiomyopathy



Helplines can give you time to explore how you are feeling, in a safe environment.

Online support

Online support includes forums and social media sites such as Facebook and Twitter, as well as email and Live Chat.

What online support offers

Online support may be from professionals, such as health and mental health professionals, or from 'peers' (people with lived experience). Many people get a huge amount of support by connecting with others online. Groups can be incredibly welcoming and supportive, help people to share experiences, and feel connected and part of a group. They also connect you to people who you would otherwise never meet.

However, it is important to remember that people's experiences are personal and may be very different to your own. People may be very honest and share experiences that are unhelpful or worrying. And some people may give what they feel is helpful 'advice' but without being qualified to do so. Some people also give medical advice which might be inaccurate or misleading. Some sites are 'moderated' which means that they have 'ground rules' which everyone has to agree to, and moderators will keep an eye on what people are saying and remove any upsetting or harmful posts.

Availability and how to access services

Online support is generally available 24 hours a day, 7 days a week via the internet, although email and Live Chat may only be available at certain times. Online support is free to access, although you may have to join, or request permission to join, some groups.

"My biggest support has been through the Cardiomyopathy UK Facebook site as this has helped me to realise how many others are experiencing problems and helped me to believe that I am not 'faking' my illness."
Individual with cardiomyopathy

Useful online groups

Cardiomyopathy UK Facebook page and closed group

The Facebook page is available to use by anyone but you will need to ask to join the closed group.

www.facebook.com/cardiomyopathyuk

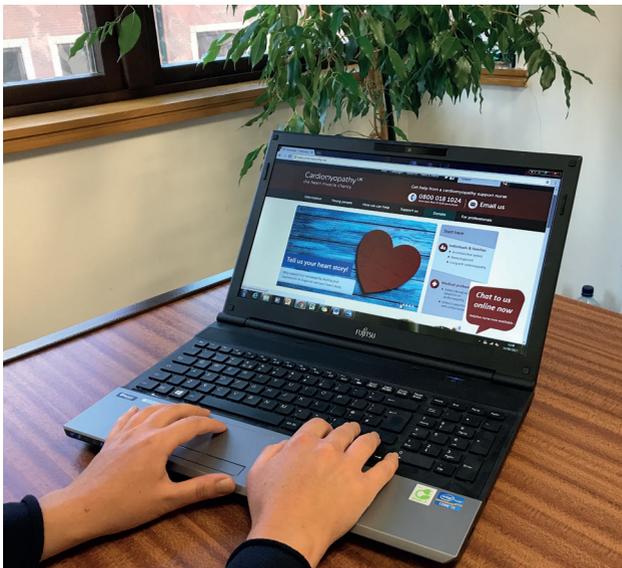
Cardiomyopathy UK children, young people and younger adults Facebook page and closed group

The Facebook page is available to use by anyone but you will need to ask to join the closed group. This is only available for young people aged 14 – 25 years.

www.facebook.com/1425cardiomyopathyuk

“The online forums and social media support has been a lifeline for me, a safe place, people who understand the little things that feel huge. It is crazy to think that people I have never met and probably never will, understand me better than those close to me...”

Individual with cardiomyopathy



Online support gives you the opportunity to share experiences with people in similar situations.

Meditation and mindfulness

Meditation and mindfulness are practices that promote relaxation and wellbeing by calming and focusing the mind. They can also help people to develop ways to deal with stressful thoughts and experiences.

What meditation and mindfulness offers

Meditation is about ‘thoughtful awareness’. Although there are many different techniques, it focuses on clearing the mind, promoting a feeling of calm and relaxation, and aims to help with emotional wellbeing. Some forms of meditation are linked with particular religions or groups. Some people use objects such as candles, incense or prayer beads to help them meditate. Some use chants or music, focus on their breathing, or use ‘guided meditations’ (where another person talks them through a meditation. This might be in person or a recording such as a CD, MP3, podcast or mobile app).

Mindfulness is the practice of being aware of, and paying attention to, the present moment in time: your thoughts, sensations and the environment around you. Some people refer to this as ‘being in the moment’. It is a way of focusing on the present, rather than thinking about the past or worrying about the future. It can help people be more aware of their thoughts and feelings, identify ways in which negative thoughts come up and how they react to them, and find ways to change how they think and feel about their experiences. Some people use other techniques, such as tai-chi or yoga, as part of their mindfulness practice.

“Mindfulness apps’ have helped me.”
Individual with cardiomyopathy

Availability and how to access services

There are many free online courses, resources and apps. You can buy booklets and CDs or downloads of meditations for your personal use.

You can find out about local courses online and through your local library. Courses might also be listed through local adult education centres or holistic therapy centres. You can also ask your GP or health centre if they know about any courses. Most courses will have a cost, and details should be available from the organisation or person running the course. You don't need to be referred to these courses.

Useful organisations and apps

BeMindful

A website about mindfulness, including online learning.
www.bemindful.co.uk

Buddhify app

This is a meditation app, offering custom-made meditations for mindfulness.

There is a one-off cost of £2 – £5 to download this app, depending on your device. Search your device app store for 'Buddhify'.

Headspace mindfulness app

This meditation and mindfulness app is available from Headspace. It is free to download but there is a cost for some of the content. Search your device app store for 'Headspace'.

Insight Timer app

This app offers over 6,000 free guided meditations.

This app is free to download. Search your device app store for 'Insight Timer'.

NHS Choices

Has information about meditation and mindfulness.

www.nhs.uk and search 'meditation' or 'mindfulness'.

There are lots of different apps available. Search your device's app store for details.

Self-management courses

Self-management courses aim to help people develop the skills and confidence to actively manage their health condition. This includes managing the condition itself as well as the impact it can have.

What self-management offers

Self-management aims to give people skills and tools to manage their health condition, feel in control of their treatment, and the confidence to work with their healthcare professionals. Courses are also an opportunity to meet and share experiences with others. They are run for people with long-term health conditions and disabilities.

Some self-management courses are specifically for carers of people with long-term conditions, and focus on helping the carer to manage their own health and psychological needs.

Availability and how to access services

Self-management courses are usually run by specific organisations and charities, or through local CCGs (Clinical Commissioning Groups).

You can ask your GP or local hospital if there are courses running in your area, as you may need to be referred to a course. You can also look online on your local council's website (try searching 'health and wellbeing').

Useful courses

Self-management UK

Self-management courses throughout the country for people with long-term conditions and for carers.

www.selfmanagementuk.org

*"While not explicitly about emotional wellbeing it does come into it.
I found this course really useful and helpful."*

Individual with cardiomyopathy

Counselling, psychological therapies and IAPT

Counselling or psychological therapy is a type of therapy offered by trained counsellors (also called therapists), psychologists and psychotherapists. It is often offered to people with mental health conditions such as anxiety and depression, or anyone who has emotional issues that they want to work through. It is also helpful for people with long-term conditions if they are having difficulty managing the emotional impact of their condition.

The Improving Access to Psychological Therapies (IAPT) service makes counselling and psychological therapies available through the NHS, workplaces, educational settings and some voluntary organisations.

What counselling and psychological therapies offer

Counselling and psychological therapies give you a confidential space to talk about and explore your feelings, particularly any difficulties, with someone trained to listen and to help. It aims to help you to identify ways in which you can come to terms with any issues, and develop coping strategies for the future.

There are different types of counselling and psychological therapies which offer different approaches. What is suitable for you will depend on what you want to get out of counselling. This is something that you can discuss with a counsellor when you are arranging counselling.

Availability and how to access services

Counselling and psychological therapies are usually offered as a number of sessions. They can be one-to-one or in a group, and can be offered face-to-face, although some counsellors might offer sessions by phone.

“I spoke to my cardiac nurse who organised a course of counselling.”
Individual with cardiomyopathy

Your GP may be able to refer you for counselling or psychological therapy through the NHS, and this will be free of charge. You can also arrange to see someone privately, and there will usually be a cost for this (although some counsellors will offer a sliding scale of charges depending on your financial situation).

In many parts of England you can refer yourself to IAPT services, and in some areas IAPT services specifically for people with long-term conditions are available.

♥ *Read more about IAPT services and how to find them from NHS Choices at www.nhs.uk and search 'IAPT'.*

When looking for a counsellor privately it is important to look for someone who has a formal qualification and is registered with BACP (see below), to ensure that they follow ethical standards.

“Basically I turned in on myself, I wouldn’t talk to anyone about it. I eventually spoke to my GP and a counsellor which helped immensely.”
Individual with cardiomyopathy

Although not available everywhere, Clinical Health Psychology may be available. This is provided by psychologists who have specialist knowledge of physical health problems, such as heart conditions. You can ask your cardiologist, specialist nurse or GP if this is available in your area.

Useful organisations

British Association for Counselling and Psychotherapy (BACP)

A professional body that sets standards for counselling and psychological therapies in the UK. It has information on the website and details of registered qualified counsellors.
www.itsgoodtotalk.org.uk

“I visited my local depression and anxiety team who gave me helpful CBT exercises.”*
Individual with cardiomyopathy

Community mental health services

Community mental health services (CMHS) are services provided by Community Mental Health Teams (CMHTs) to people in the community. These services are for people with serious mental health problems, and are provided by health and social care professionals such as psychiatrists, psychologists, psychiatric nurses and social workers.

Children and adolescent mental health services (CAMHS) are available for people up to the age of 18 years. CAMHS is an NHS service which is available throughout the UK. These services are for young people with mental health problems, provided by professionals including psychologists, therapists and support workers.

What these services provide

These services offer specialist assessment of your needs, and work with you to identify suitable treatment and support options. This may include treatment such as medication or psychological therapies.

Availability and how to access services

These services are usually offered in GP surgeries or health centres, and some services may be offered at home. You need to be referred to CMHS by your GP or specialist, social services or IAPT service (see page 37). CAMHS are accessed by a referral from a GP, teacher, parent or the young person themselves.

Useful organisations

Rethink mental illness

Provides information about mental health conditions, including CHMS.
www.rethink.org

Young minds

Provides information on CAMHS and how to access them.
www.youngminds.org.uk

NHS Choices

Provides information on various aspects of mental health services.
www.nhs.uk

Support for carers

A carer is “anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support” (Carers Trust). Being a carer can have a significant impact on a carer’s life, both practically and physically. And the emotional impact of being a carer can also be significant.

Not everyone who supports someone with cardiomyopathy considers themselves to be a ‘carer’, but some may recognise themselves in this role more easily. It can be helpful to recognise when you are a carer, as there may be help and support available to you.

What help is available

There are various sources of help and support for carers, and some entitlements. To qualify for some of the services below you will need to meet certain entitlement criteria. Services include the following.

- A carer’s assessment from your local authority supports any physical or emotional needs you have, and provides information on respite care and carer’s breaks.
- Carer’s Allowance is a benefit for people over 16 and under retirement age who give at least 35 hours of care a week to someone who gets certain benefits.
- Carer’s Credit is for people who give at least 20 hours of care but don’t receive Carer’s Allowance.
- There are also sources of psychological support and counselling, peer support and self-management courses (see previous pages).

Some areas have carer’s centres, which offer practical help and advice and can signpost you to further sources of help.

Availability and how to access services

There are a number of national organisations that provide information, help and support. Local areas will differ in what is provided locally, for example through the local authority or social services. Some services are only available for people who provide a certain number of hours of care a week.

♥ For more about emotional and practical support for carers, see our carers factsheets at www.cardiomyopathy.org/carer-impact and www.cardiomyopathy.org/carer-help

"I didn't want to focus on me when I didn't have the serious condition."
Carer of someone with cardiomyopathy

Useful organisations

Carers Trust

Support and services for carers and young carers, including grants and local sources of practical and emotional help.

www.carers.org

Carers UK

Advice on all aspects of caring, including help, entitlements and a forum. Adviceline 0808 808 7777

www.carersuk.org

Citizens Advice

Details of support and benefits for carers, including eligibility criteria.

www.citizensadvice.org.uk

Cruse

Emotional support for people who have been bereaved.

www.cruse.org.uk

GOV website

Information from the Government on carer's rights and entitlements.

Carers Direct helpline on 0300 123 1053

www.gov.uk

NHS choices

Information about carer's rights and the Care Act, as well as other entitlements including respite care and carer's breaks.

www.nhs.uk

You can also contact your local council or visit their website to see what help is available locally.

"It took the Carer's centre to help ... They were brilliant..."
Carer of someone with cardiomyopathy

Jasmine's story

Adapting through understanding

My name is Jasmine and I am 20 years old and from South Wales. I have not been diagnosed with cardiomyopathy, but it has certainly had an impact on me.

My partner, Elis, was diagnosed with hypertrophic cardiomyopathy at 22 years old and has had to adapt his lifestyle since. As well as Elis, I have also had to adapt through understanding what cardiomyopathy is and how to support someone who has been diagnosed with the condition.

I hadn't heard of cardiomyopathy before meeting Elis, so to go from not knowing about the condition to now supporting someone with it, as well as being part of Cardiomyopathy UK's children, young people and young adult (CYP&YA) panel, has been a big responsibility to take on board. Elis was diagnosed in 2015 and was quite taken aback when he had discovered that he had the condition. I was by his side as he was diagnosed, which gave me the opportunity to try and reassure him that he will not be on his own going through this, and that he will have support from his family, his friends and myself.

Understandably, Elis had a very negative approach towards his condition when he was first diagnosed. As he was the only individual out of his friends to be diagnosed with a heart condition he felt very alone and different from everyone else. A few months later he decided that it would be best for him to attend the national cardiomyopathy conference in London to hear other individuals approaches to their diagnosis and some of the leading doctors in cardiomyopathy. This was very reassuring for Elis, it made him realise that he was not alone with his condition. He was able to meet others who are diagnosed with a heart condition, he had opened up and began to start talking about it more and he was also able to hear how their diagnosis changed their lives like it did with his. This is exactly why the CYP&YA panel has been organised, to help those who have been diagnosed meet other people within their age range who would listen and discuss about their difficulties coming to terms with it and experiences.

I have always said to Elis that I will never understand what it is like to be diagnosed with a heart condition, but that I will always be as supportive as I can be with it (and more)."



"I will never understand what it is like to be diagnosed with a heart condition, but that I will always be as supportive as I can be with it (and more)."

Useful resources and further reading

Mental health

Mental Health First Aid England (MHFA England)

Provides mental health awareness training to a variety of organisations, businesses and communities, and aims to increase the population's mental health literacy and reduce the stigma around mental ill health.
www.mhfaengland.org

Mental Health Foundation

Provides information on mental health and tips for looking after your mental health. They also focus on preventing mental health problems.
www.mentalhealth.org.uk
Also has a website about mindfulness at www.bemindful.co.uk

Mind (for better mental health)

Provides information about mental health conditions and advice, advocacy and support services. Local Mind services provide drop-in centres, counselling and befriending services.
www.mind.org.uk
supporterservices@mind.org.uk
0300 123 3393 or text 86463, 9am – 6pm, Monday – Friday.

Rethink Mental Illness

Provides information and advice on mental health problems, practical, legal and welfare issues. Provides services and support groups.
www.rethink.org
0300 5000 927, 9.30am – 4pm, Monday – Friday.

Samaritans

A Freephone helpline. Although known as a service for people who feel suicidal, Samaritans are there for anyone who wants to talk.
116 123, 24 hours a day, every day.
www.samaritans.org

Young minds (for children and young people)

Has information about mental health and services, including children and adolescent mental health services (CAMHS).
www.youngminds.org.uk

Self-management

Self management UK

Self-management courses throughout the country for people with long-term conditions and for carers.

www.selfmanagementuk.org

Books

‘Living with the enemy – coping with the stress of chronic illness using CBT, mindfulness and acceptance’ by Ray Owen, Routledge Press.

♥ *Read our review: www.cardiomyopathy.org/living-with-the-enemy-book*

Articles on emotional wellbeing

A series of articles on emotional wellbeing and coping strategies, written by consultant clinical psychologist Graeme Gillespie, can be found on the Cardiomyopathy UK website at:

www.cardiomyopathy.org/emotional-health

Apps

Headspace mindfulness app

A free meditation and mindfulness app available from Headspace (see www.headspace.com).

Search your device app store for ‘Headspace’.

Insight Timer app

This app offers over 6,000 free guided meditations.

This app is free to download. Search your device app store for ‘Insight Timer’.

Buddhify app

This is a meditation app, offering custom-made meditations for mindfulness.

There is a one-off cost of £2 – £5 to download this app, depending on your device. Search your device app store for ‘Buddhify’.

♥ *You can also find more helpful resources on our website at www.cardiomyopathy.org/emotional-health-resources*

Resources used in this booklet

Many resources have been used in this booklet, including websites and leaflets, feedback from people living with cardiomyopathy and their families and carers, and health and social care professionals working in both cardiomyopathy and mental health services.

Some of the organisations that have been used include the following.

Mind – for information about mental health conditions.

Visit www.mind.org.uk

Rethink Mental Illness – for statistics about mental health conditions.

Visit www.rethink.org

MentalHealth.gov – for information on ‘What is mental health’.

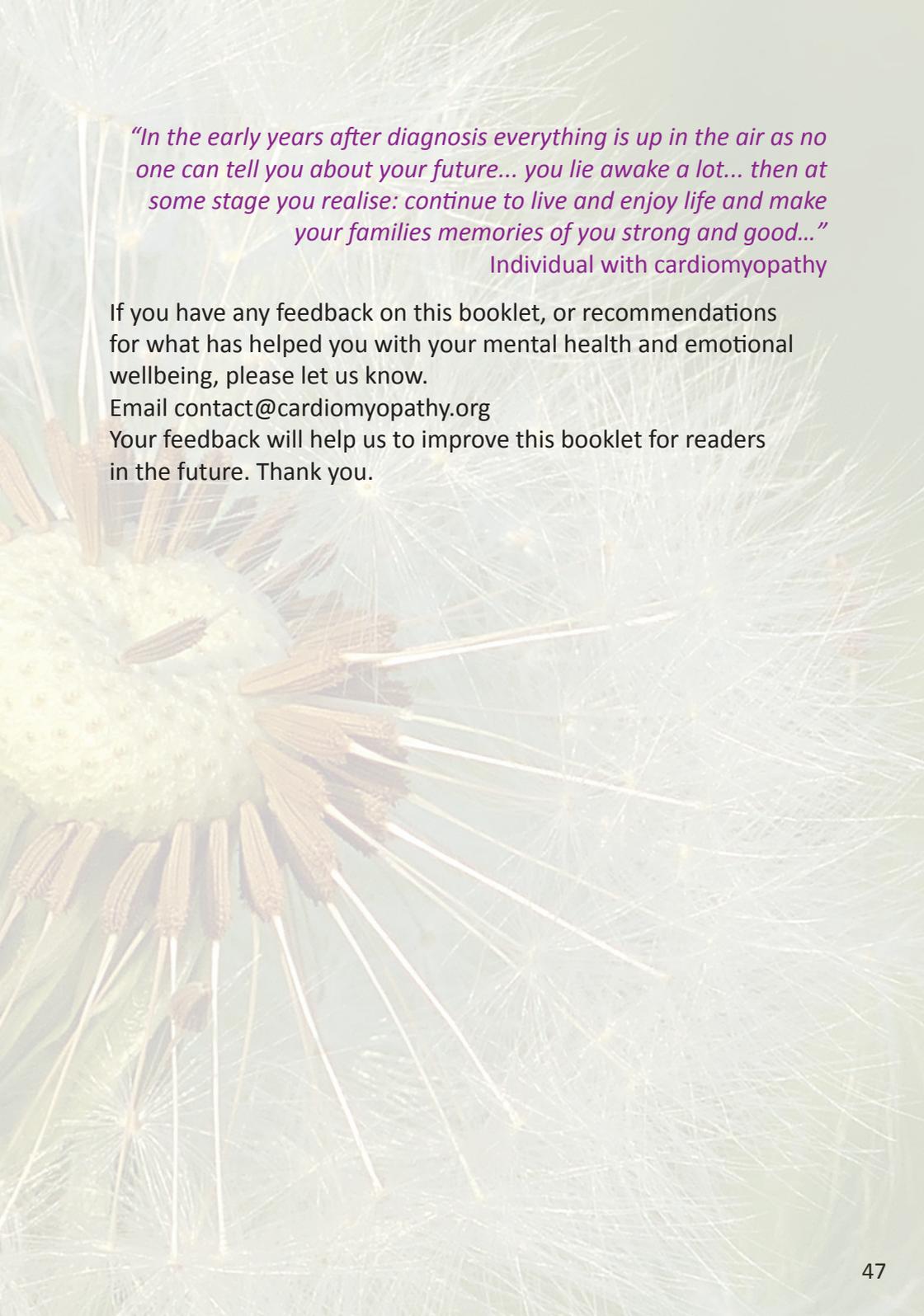
Visit www.mentalhealth.gov

There are many other sources of valuable help and information available. See the organisations listed on page 44.

Specific references for statistics listed on page 10

1. The Kings Fund. Long-term conditions and mental health - the cost of comorbidities. See www.kingsfund.org.uk
2. Rethink Mental Illness. See www.rethink.org
3. Mind, Mental health facts and statistics. See www.mind.org.uk
4. Department of Health, Policy paper: 2010 to 2015 government policy: long term health conditions. See www.gov.uk
5. The Kings Fund. Long-term conditions and mental health - the cost of comorbidities. See www.kingsfund.org.uk
6. The Kings Fund. Long-term conditions and mental health - the cost of comorbidities. See www.kingsfund.org.uk





"In the early years after diagnosis everything is up in the air as no one can tell you about your future... you lie awake a lot... then at some stage you realise: continue to live and enjoy life and make your families memories of you strong and good..."

Individual with cardiomyopathy

If you have any feedback on this booklet, or recommendations for what has helped you with your mental health and emotional wellbeing, please let us know.

Email contact@cardiomyopathy.org

Your feedback will help us to improve this booklet for readers in the future. Thank you.

This guide to emotional health and mental wellbeing is for anyone affected by cardiomyopathy: those with the condition and those supporting them.

It has been put together from using insights shared by people with cardiomyopathy, and their families, friends and carers, through an online survey, focus group and a reader panel.

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helpline: 0800 018 1024

e: contact@cardiomyopathy.org

w: cardiomyopathy.org

f facebook.com/cardiomyopathyuk

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

We rely on donations to fund our work supporting people affected by cardiomyopathy. For details about supporting us, go to our website www.cardiomyopathy.org

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