Irish Heart Foundation

The National Stroke & Heart Charity

Step by step through cardiomyopathy

A helpful guide for people diagnosed with cardiomyopathy, their families and loved ones

irishheart.ie

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Produced by the Irish Heart Foundation
This booklet is one of the publications in our patient information series. It is a guide for people living with cardiomyopathy, their families and their loved ones. It cannot replace the advice of your healthcare team.

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Bristol Myers Squibb has not had any editorial input into this resource.

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Introduction

This booklet is for people living with **cardiomyopathy**, their **families** and their **loved ones**.

If you have been told you have a sibling or relative with cardiomyopathy, this book is relevant to you, too.

This book will have the information you need to support you as you learn about cardiomyopathy. It has information about cardiomyopathy and how it might affect your everyday life.

You don't need to read the whole book.

➔ Start by reading **15 things to know about cardiomyopathy** on page 4.

➔ Use the **contents** page on page 8 to find any other information you need.

As you read this information, you can jot down your notes in the **notes** section.

The **appendix** contains other resources that may be helpful.

15 things to know about cardiomyopathy

1. Cardiomyopathy is a medical term used to describe diseases that affect your heart muscle. It can affect the **size, shape** and **thickness** of your heart muscle, making it difficult for your heart to pump blood around your body.

2. Many types of cardiomyopathy are **inherited**, but **it can also be caused by other conditions**. For some people, the cause of their cardiomyopathy is unknown.

3. There are several different types of cardiomyopathy. The 4 main types include **dilated cardiomyopathy**, **hypertrophic cardiomyopathy, arrhythmogenic cardiomyopathy** and **restrictive cardiomyopathy.**

4. In the early stages of cardiomyopathy, you may not have any symptoms. As the condition advances, **symptoms can start to appear**. Symptoms vary from person to person and the type of cardiomyopathy that someone has.

5. Treatment for cardiomyopathy aims to reduce symptoms and prevent any future complications. **Not everyone will need treatment**. Treatment will depend on the type of cardiomyopathy you have been diagnosed with.

6 Cardiomyopathy can be passed down through families. If you have been diagnosed, let your **first-degree relatives** (parents, siblings and your own children) know as they may need to be screened for the condition as well.

8 Fatigue, breathlessness and heart palpitations can be common with cardiomyopathy. **Speak to your doctor** if you have any of these.

9 It can be hard **coming to terms** with your diagnosis. Feelings of grief, loss, frustration, anger, guilt, depression and anxiety are normal.

10 A diagnosis of cardiomyopathy can feel overwhelming and scary, but with the right treatment, care, support and lifestyle changes, you can take care of yourself and **focus on living a full life**.

11 A **heart-healthy diet** can help reduce strain on the heart and manage symptoms. Talk to your dietitian or doctor for individual advice.

12 **Physical activity** has lots of health and wellbeing benefits for people living with cardiomyopathy. Speak to your doctor who can give you advice on how to **safely get moving** and how often you should exercise.

13. Your condition **may affect your work**. This depends on your symptoms and the severity of them, and on the kind of work that you do. See citizensinformation.ie for information about financial supports available to you.

14. There are **key social welfare supports** available that can help if you have been diagnosed with cardiomyopathy. For more information, see citizensinformation.ie.

15. Health and travel insurance are essential for peace of mind. It is important to get quotes from multiple travel insurers and carefully review what is covered in each policy. Some health insurers offer plans that provide **additional coverage** for people living with a heart condition.

Irish Heart Foundation cardiomyopathy supports

- Heart Support Network Facebook group
- Nurse Support Line

Visit irishheart.ie or contact our **Nurse Support Line** on **01 668 5001** for more information.

List of abbreviations

Below you will find a list of abbreviations used in this book.

DCM	Dilated cardiomyopathy
HCM	Hypertrophic cardiomyopathy
ACM	Arrhythmogenic cardiomyopathy
ARVC	Arrhythmogenic right ventricular cardiomyopathy
ATTR-CM	Transthyretin amyloidosis cardiomyopathy
ECG	Electrocardiogram
ECHO	Echocardiogram
MRI	Magnetic resonance imaging
DNA	Deoxyribonucleic acid
ICD	Implantable cardioverter defibrillator
GP	General practitioner
NDLS	National Driver Licence Service
DDAI	Disabled Drivers Association of Ireland
IWA	Irish Wheelchair Association

Contents

What is cardiomyopathy?

What is cardiomyopathy?

Cardiomyopathy is a medical term used to describe diseases that affect your heart muscle. It can affect the size, shape and thickness of your heart muscle, making it difficult for your heart to pump blood around your body. Over time, this can cause your heart to weaken and can lead to heart failure symptoms.

Many types of cardiomyopathy are inherited, but it can also be caused by other conditions. For some people, the cause of their cardiomyopathy is unknown. When this happens, it is called idiopathic cardiomyopathy.

Cardiomyopathy affects people of all ages, races and genders.

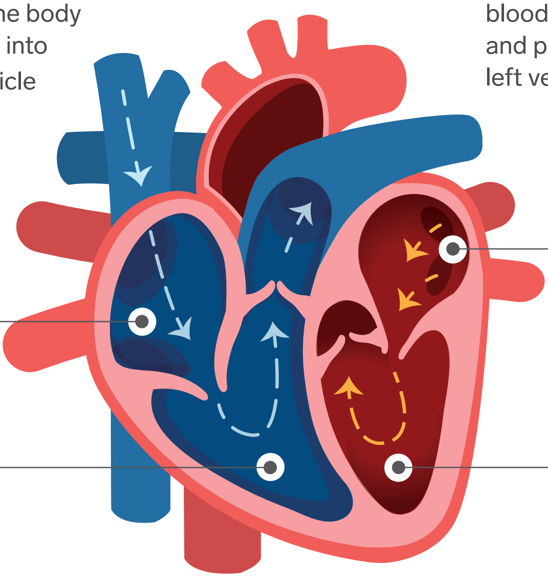
Types of cardiomyopathy

There are several different types of cardiomyopathy. The **4 main types** include:

1. Dilated cardiomyopathy
2. Hypertrophic cardiomyopathy
3. Arrhythmogenic cardiomyopathy
4. Restrictive cardiomyopathy

The human heart

The human heart is a muscle that pumps blood throughout the body, giving it the oxygen and nutrients it needs to function. The heart has 4 chambers, the **right** and **left atria**, and the **right** and **left ventricles**.



Right atrium
Receives oxygen-poor blood from the body and pumps it into the left ventricle

Left atrium
Receives oxygen-rich blood from the lungs and pumps it to the left ventricle

Right ventricle
Pumps oxygen-poor blood to the lungs to pick up more oxygen

Left ventricle
Pumps oxygen-rich blood to the body

🔵 Oxygen-poor blood

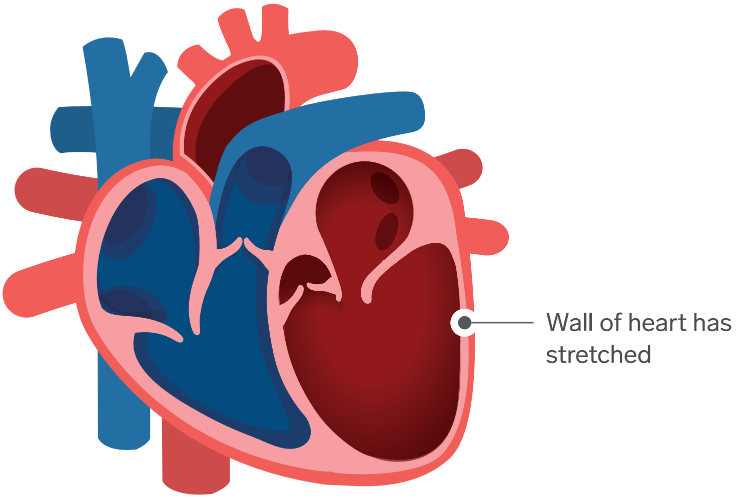
🔴 Oxygen-rich blood

Dilated cardiomyopathy

Dilated cardiomyopathy (DCM) is a disease that affects the chambers of the heart, causing the walls of the heart to get bigger, stretched and thin. This makes it difficult for your heart to 'squeeze' (or contract) and pump blood around your body. Over time, your heart weakens and, if left untreated, DCM can lead to heart failure symptoms.

DCM can be hereditary, which means it can run in families. It can also be caused by pregnancy and other conditions like uncontrolled high blood pressure (hypertension). In some cases, DCM can occur as a side effect from certain medications, infections, drinking too much alcohol or illegal drug use.

Many people with DCM may have no symptoms. DCM is the most common type of cardiomyopathy and usually occurs in adults under the age of 50.



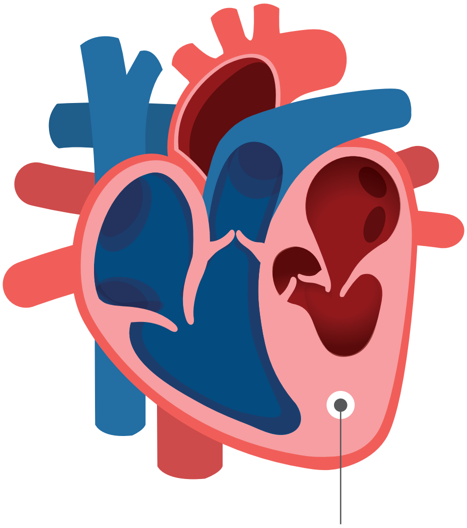
Hypertrophic cardiomyopathy

Hypertrophic cardiomyopathy (HCM) is a disease that causes the walls of your heart muscle to thicken, get bigger and become stiff. This makes it difficult for your heart to pump blood around your body.

HCM is diagnosed after excluding other causes such as high blood pressure and valvular disease which can also cause the heart muscle to thicken.

How much someone is affected by HCM depends on how thick their heart muscle has become and where the heart muscle has gotten thicker. Some people may have no symptoms. In general, people living with HCM notice that their symptoms may worsen as they get older and their heart muscle becomes stiffer. Many people get diagnosed with HCM in middle age when their symptoms start to appear.

HCM is a genetic condition which means that it can be passed down through families. People diagnosed with HCM are usually advised to have their first-degree relatives (parents, siblings and children) screened for the disease, so that they can receive timely care and treatment.



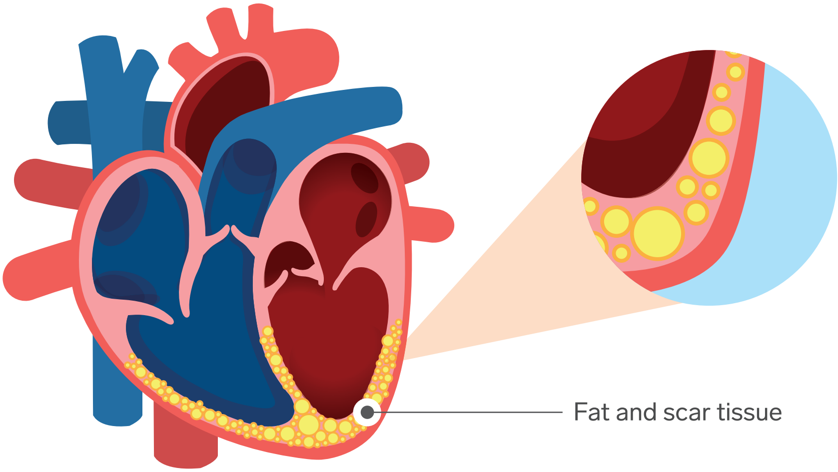
Heart walls have gotten thicker

Arrhythmogenic cardiomyopathy

Arrhythmogenic cardiomyopathy (ACM) is a rare condition that causes the structure of the heart to dilate causing it to stop working properly. With ACM, fatty tissue replaces normal heart muscle causing the walls of your heart muscle to thin. This makes it difficult for your heart to pump blood around your body. ACM may also affect the electrical signals in your heart which can cause irregular heart rhythms (arrhythmias).

ACM is usually a genetic condition, meaning it is passed down through families.

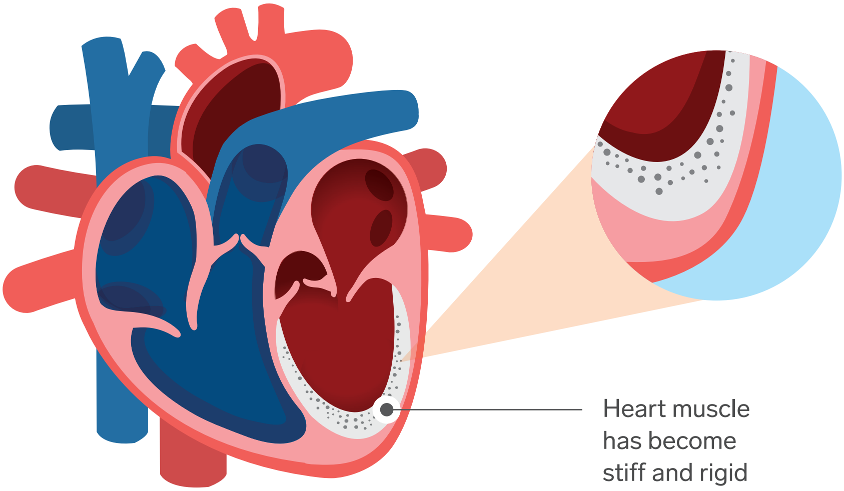
ACM used to be called arrhythmogenic right ventricular cardiomyopathy (ARVC) as it was thought to only affect the right ventricle chamber of your heart. It is now recognised that this disease can also affect the left ventricle chamber by itself or both chambers of the heart.



Restrictive cardiomyopathy

Restrictive cardiomyopathy is a rare condition. Usually diagnosed in children, it can develop at any age. With this type of cardiomyopathy, abnormal tissue (like scar tissue) replaces the normal tissue in the heart muscle. This causes the heart muscle to become stiff and rigid. This means that the chambers of the heart cannot relax and fill with blood like they normally would.

Restrictive cardiomyopathy causes a reduced flow of blood from the heart and, over time, can lead to heart failure symptoms and issues with heart rhythm. Sometimes it can be inherited but often the cause of restrictive cardiomyopathy is unknown. The common known causes of restrictive cardiomyopathy are amyloidosis, sarcoidosis and haemochromatosis.



Other types of cardiomyopathy include:

Peripartum cardiomyopathy	This is a rare type of cardiomyopathy that begins towards the end of (or after) pregnancy.
Transthyretin amyloidosis cardiomyopathy (ATTR-CM)	This is cardiomyopathy that happens due to deposits of abnormal proteins in the heart muscle.
Ischemic cardiomyopathy	This is cardiomyopathy that happens after a heart attack due to blockages in the coronary artery.
Takotsubo cardiomyopathy (also called ‘broken heart syndrome’ or ‘stress-induced cardiomyopathy’)	This type of cardiomyopathy often affects women more than men.
Chemotherapy-induced cardiomyopathy	This cardiomyopathy can be a side effect of certain chemotherapy medications used to treat cancer.
Alcohol-induced cardiomyopathy	This is cardiomyopathy that occurs due to excessive alcohol intake.

Other conditions that are associated with cardiomyopathy include:

- ✓ arrythmias or irregular heartbeats (for example, atrial fibrillation)
- ✓ diseases that can damage the heart (for example, amyloidosis)
- ✓ heart failure
- ✓ heart valve disorders
- ✓ high blood pressure
- ✓ diabetes
- ✓ coronary artery disease
- ✓ autoimmune conditions
- ✓ infections (for example, viral infections that cause myocarditis)

“I’d initially been discharged from hospital with anxiety. My bloods and ECG came back clear. A lot of the symptoms I’d been having were identical to ones I’d experienced before with my anxiety disorder – it was very easy to brush it off as just that, especially with doctors insisting that’s all it was. Thankfully I had a thorough GP who sent me for a separate echocardiogram...

...A few days after being discharged, my ECHO came back with some irregularities and I was diagnosed with cardiomyopathy soon after. I’d urge anyone who is being dismissed by their doctors to insist on getting an ECHO and push back when you feel something isn’t right. You know your body better than anyone.”

Siobhan, living with cardiomyopathy

What are the symptoms of cardiomyopathy?

In the early stages of cardiomyopathy, you may not have any symptoms. As the condition advances, symptoms can start to appear. These usually vary from person to person and the type of cardiomyopathy that someone has.

Symptoms may include:

- shortness of breath or trouble breathing during activity or while resting
- chest pain, especially after activity
- swelling of the legs, ankles, feet, stomach area and neck veins
- bloating of the stomach
- reduced appetite
- coughing or gasping while lying down
- fatigue and exhaustion, even after resting
- irregular heartbeats that feel rapid, pounding or like your heart is fluttering
- unexplained dizziness or feeling lightheaded
- fainting/collapse

Symptoms of cardiomyopathy usually get worse if they are not treated. For some people, this happens quickly. For other people, it can take a long time.

Speak to your doctor if you have any symptoms of cardiomyopathy. If you have trouble breathing, chest pain that lasts for a few minutes or gets worse, or if you collapse or faint, call **999/112**.

Diagnosis

Your doctor will ask you about your medical history and any symptoms you may be experiencing. Your doctor will also want to know if anyone in your family has been diagnosed with cardiomyopathy.

Diagnostic tests may include:

Blood test: Blood tests can check your kidney function to rule out issues like anaemia. They also measure the level of a peptide made in the heart called B-type natriuretic peptide (BNP). Your level of BNP might rise during heart failure, a common complication of cardiomyopathy. Blood tests can help diagnose your condition and monitor your progress.

Electrocardiogram (ECG): This test checks your heart for unusual rhythms and other abnormalities.

Echocardiogram (ECHO): An ultrasound of the heart that allows your doctor to check the size of your heart muscle and see how well it's working. It also assesses how well your heart valves are working.

Cardiac MRI: A scan that takes detailed pictures of your heart. This scan can show how well your heart is working and help your doctor to see if there are any signs of inflammation, scar tissue or other abnormalities.

Exercise test: You may be asked to walk on a treadmill or cycle on an exercise bike while your heart rate is monitored with an ECG. This test gives your doctor information about your exercise tolerance, your symptoms and any problems with your heart rhythm during exercise.

Holter monitor: This is a wearable ECG monitor that continuously records your heartbeat over a longer period of time. You may need to wear one for 1-5 days depending on your symptoms.

Treatment

Treatment for cardiomyopathy aims to reduce symptoms and prevent any future complications from the disease.

Not everyone will need treatment. Some people will be able to manage their condition with lifestyle changes. You can read more about lifestyle changes in the Living with Cardiomyopathy chapter.

Treatment will depend on the type of cardiomyopathy that you have been diagnosed with. You may be advised to make some lifestyle changes, be prescribed medications to manage your condition or need to have a procedure. Some people may need to have a device, such as a defibrillator or special pacemaker, fitted.

There is no cure for cardiomyopathy, but **with treatment you can manage your symptoms and lead a full life**.

> “Accept that cardiomyopathy is part of your life now like a constant, slightly annoying but familiar companion and work with any limitations it imposes to have the best life you can.”
>
> **Claire, living with cardiomyopathy**

Lifestyle changes

The following lifestyle changes can help:

- **eat well** and follow your doctor's advice when it comes to **physical activity**
- stop **smoking**
- aim for your **best weight**
- stop drinking **alcohol** or reduce your intake
- get enough **sleep** and **rest**
- manage your **stress** levels
- make sure any other **health conditions** you have are managed and well controlled

Medications

Your doctor may prescribe medications to:

- lower your blood pressure
- slow your heart rate
- prevent blood clots
- improve your heart’s pumping ability
- reduce the risk of fluid build-up in your body
- prevent abnormal heart rhythms

For more information read our booklet **Step by Step through Heart Medicines** or see irishheart.ie.

Procedures

If your symptoms are severe, your doctor may recommend a procedure. Any procedures recommended by your doctor will depend on the type of cardiomyopathy that you have. Procedures can include:

- ✓ an **angiogram** (or coronary artery assessment) to make sure there is no significant narrowing of the coronary artery that may be contributing to your cardiomyopathy
- ✓ **heart surgeries** such as a septal myectomy, aortic valve repair, mitral valve repair/replacement or an ablation for arrhythmias
- ✓ having an **implantable cardioverter defibrillator (ICD)** or **pacemaker** inserted to prevent life-threatening irregular heart rhythms

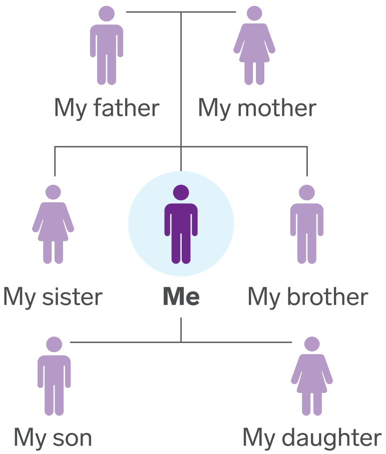
A heart transplant may be necessary, but this is usually only recommended as a last resort for people who have significant heart failure symptoms despite treatment.

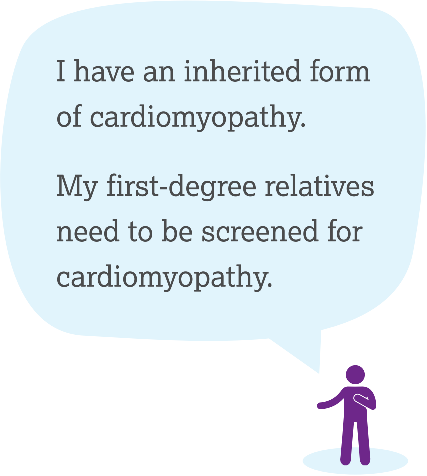
Notes...

Family and genetics

Family and genetics

Cardiomyopathy is often an inherited condition. This means that it can be passed down through families. Because cardiomyopathy can be caused by genetics, it's important to let your first-degree relatives (parents, siblings and your own children) know if you have been diagnosed as they will need to be screened for the condition as well.





I have an inherited form of cardiomyopathy.

My first-degree relatives need to be screened for cardiomyopathy.

When you receive your own diagnosis of cardiomyopathy, ask your doctor if your family needs to be screened for cardiomyopathy. Screening involves undergoing medical tests to check if they have the signs and symptoms of cardiomyopathy.

Ask your doctor to write a family letter that outlines the type of cardiomyopathy you have, your symptoms and how it may impact your family. You can then give this letter to your relatives, which can make it easier for them to access screening through their own doctor, if needed.

> “Embarking on a genetic testing journey may come against the backdrop of you having been diagnosed with a lifelong, perhaps critical, condition. You will already be anxious and stressed about your own diagnosis, so it is overwhelming to think about the possible implications for close family members… Remember that it isn’t all down to you to give difficult news to loved ones. Make sure that experts like consultants and counsellors do the heavy lifting. This is their job – not yours.”

Dermot, living with cardiomyopathy

Genetic testing

You can undergo genetic testing to find out if you have a gene variant that can be linked to your cardiomyopathy. If you have a gene variant that is causing your cardiomyopathy, your first-degree family members will need to undergo genetic testing too to see if they also have the gene variant.

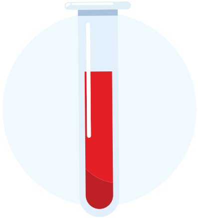
Starting the genetic testing journey can be a worrying and scary time. It is normal to feel frightened, stressed or guilty that you may have passed on cardiomyopathy to your family. But genetic testing can also be reassuring. By getting tested, your relatives can find out if they are at risk of developing cardiomyopathy. This can help them to know what symptoms to look out for and ensure they get treatment quickly.

Where do I go for genetic testing?

In Ireland, genetic testing services are provided by Cardiac Risk in the Young Ireland (CRY Ireland) and the Family Heart Screening Clinic at the Mater hospital in Dublin. Both of these services are delivered free but on the basis of need. See cry.ie or mater.ie/services/cardiac-subspecialities for more information.

You can access genetic testing and counselling as a private patient by asking your doctor to refer you to a specialist in genetic diseases. Some private health insurance plans will cover up to 70% of a private consultant. Speak to your insurer for more information.

How does genetic testing work?



Genetic testing involves giving a sample of your blood for testing. This sample will then be sent to a specialist lab for analysis to identify the gene that is causing your cardiomyopathy.

Once the gene has been identified, each first-degree relative will also have a blood test. Their samples will be tested for the specific gene.

During this process and waiting period, family members will be counselled by a genetic counsellor. Not all inherited cardiomyopathy has an identifiable gene, but new genes may be detected in the future.

What does a positive test result mean?

If a family member has a cardiomyopathy gene variant, it does not mean that they will go on to develop cardiomyopathy. It just means that they are at increased risk of developing the condition. It also means that they are aware of their risk and can be screened regularly going forward.

If a family member has the gene variant but not the symptoms of cardiomyopathy, they may be advised to have an ECG or an ECHO exam done on a regular basis (usually every 3-5 years) to check for the development of symptoms.

What happens if a gene is not identified?

If a gene is not identified, you may be cleared by your doctor and discharged safely. Speak to your doctor or genetic counsellor about whether you need to be screened again in the future.

Where can I find more information about genetic services for cardiomyopathy in Ireland?

If you are worried about cardiomyopathy, speak to your GP who will be able to refer you for testing.

Remember: It is possible to live a healthy life with a diagnosis of cardiomyopathy. By starting the conversation with your family, you can support each other and make informed decisions about your heart health together.

What is...

Screening is when a number of medical tests are carried out to see if you are experiencing symptoms that may be caused by cardiomyopathy. You may undergo a physical exam, an ECG test or an ECHO test. If a family member has cardiomyopathy which is being caused by a gene variant and if you are having symptoms of cardiomyopathy, you will be offered a genetic test.

Genetic testing is usually done with a blood test. This blood test is sent to a lab where specialists analyse your DNA and look for any changes in your genes that may be linked to cardiomyopathy.

Genetic counselling is a service where a specially trained genetic counsellor helps you understand the genetic testing process and how the results of your test may impact you or your family. A genetic counsellor can also offer advice on monitoring and managing your heart health if you have a positive genetic test result.

> “Be kind to yourself and be kind to your family, no matter how things work out. Use the professional supports available to communicate any difficult news.
>
> Remember, because you know you have an inherited heart disease, you can take action for yourself and the people you love”

Dermot, living with cardiomyopathy

Notes...

Effects of cardiomyopathy

Effects of cardiomyopathy

Cardiomyopathy does not just affect your heart. It also has an impact on how you feel physically and mentally. A diagnosis of cardiomyopathy can feel overwhelming and scary, but with the right treatment and support, you can take care of yourself and focus on living a full life.

Many people with cardiomyopathy start off with little or no symptoms and are able to have a good quality of life. Some people have symptoms that get worse over time. It is important to stay connected to your healthcare team. They can help you manage your symptoms.

The common **effects of cardiomyopathy** can be →

Fatigue

You may feel fatigued, especially when you do some physical activity. Fatigue is when you feel a kind of tiredness that does not get better with rest.

Fatigue can be caused by cardiomyopathy, but it can also be caused by the stress and emotional upheaval you might be feeling since the diagnosis. Lack of sleep can also contribute to your feeling of tiredness. Some medications can also have side effects that cause tiredness. These effects may wear off as your body adjusts to the new medicines. So, keep taking your medication.

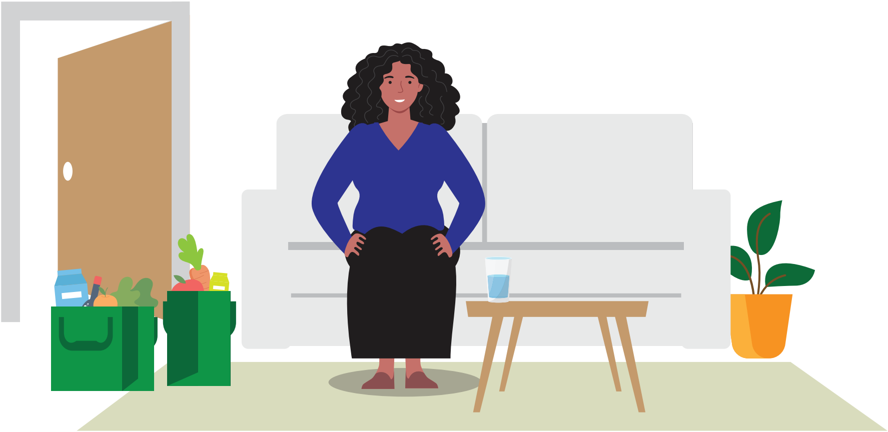
Fatigue can affect your quality of life and can be difficult, as family and friends may not understand how exhausted you are.

You can help reduce fatigue by:

- ✓ **Taking it easy**. Allow yourself plenty of rest. Have regular periods of rest and play.
- ✓ **Schedule your activities** for when you feel most energetic.
- ✓ **Talk to your family** and **friends** about how you are feeling.

> “Over time I’ve learned to trust my judgement. I go at my own pace and can do most things, but I do have to build in time off for anything we plan, to rest and recoup afterwards.
>
> I feel like the bunny in the Duracell ad years ago, the one that’s on the cheaper battery and runs out of energy sooner.”

Claire, living with cardiomyopathy



Breathlessness

Breathlessness is a common effect of cardiomyopathy.

You may:

- feel like you are struggling to breathe after a bit of **physical exertion**
- **wake up in the night** feeling breathless
- feel **breathless lying flat** or on your side
- struggle to breathe **bending down to tie your shoelaces**, for example
- have **sleep apnoea** which means that you have periods of paused breathing during your sleep

Breathlessness can also be a **symptom of heart failure**. So always speak to your doctor about your breathlessness. In some cases, breathlessness may be due to a build-up of fluid and you may need to have your **medications** adjusted.

Your doctor can also teach you **breathing techniques** (abdominal breathing, paced breathing, pursed lips breathing) to help you manage your breathlessness.

How to cope with breathlessness:

- Work out which activities make you most breathless. Pace yourself, make yourself comfortable and remember to take breaks.
- Sit and raise your leg to put on your shoes. Bending can make you more breathless.
- Sit down to prepare food instead of standing.
- Raising your arms can cause you to feel breathless so ask for help.
- Have your family place chairs at relevant places in the house so you can rest while walking between rooms.
- Use lukewarm water when bathing. Hot water can make you breathless. Open a door or a window to stop the room getting steamy.

- If your **symptoms are new**, **seek medical advice**.
- It is important to **make sure you take your medication**.

What is heart failure?

Heart failure happens when your heart doesn't pump blood as well as it should.

Heart failure is often called heart inefficiency or cardiac insufficiency, and can cause symptoms like shortness of breath, weight gain, swelling in your ankles, exhaustion and fatigue, dizziness, loss of appetite and low mood.

The Irish Heart Foundation has a range of supports available to people living with heart failure. For more information read our booklet **Step by Step though Heart Failure** or see **irishheart.ie**.

Heart palpitations

Heart palpitations are when you feel your heart pounding or beating very fast. This is common with cardiomyopathy. Palpitations mean that your heart is speeding up to compensate for its inability to pump blood around your body normally.

If your heart palpitations last a long time, get worse or make you feel dizzy or lightheaded, **see your doctor immediately**. You can get treatment for them, or you may need to change your medication.

Emotional effects

It may be hard coming to terms with your diagnosis. It is natural to feel overwhelmed. You may have the following feelings:

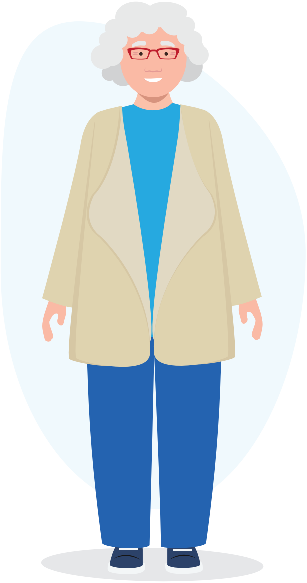
- ✓ **Grief** and a **sense of loss** about all the changes in your life.
- ✓ **Frustration** and **anger** about the impact your condition is having on your life and your relationships.
- ✓ **Guilt** about not being the parent or partner you'd like to be.
- ✓ **Depression** or **anxiety** about your future and the future of your loved ones. You may feel sad or down, lose interest in things you enjoy, feel empty or numb. You may have **trouble sleeping**. Talk to your GP if you feel this way.

You may also feel sad when you find your symptoms getting worse or when you go through treatment. You may be anxious about pushing yourself too much. And you may worry about your family members if you have an inherited type of cardiomyopathy.

Try to accept your new reality. Acknowledge the changes in you and try not to be hard on yourself. Over time you will be able to trust yourself to go at your own pace – making time for rest and play.

Meanwhile, there are things you can do to feel less overwhelmed:

- Talk to family and friends about how you are feeling and how much you can do. This will help them understand your situation. They will be able to support you.
- Practise mindfulness.
- Take part in physical activity that is in line with your abilities.
- Contact our **Nurse Support Line** on **01 668 5001** for information on support services available for you.



> “One of the things that helped me was to look back each year and see how far I had come - from having zero energy and sitting for 10 minutes after a shower before I was able to dry myself, to being able to walk for 10 minutes. Celebrate the little steps. After all, you are still here and alive”

Jocelyn, living with cardiomyopathy

Notes...

Living with cardiomyopathy

Living with cardiomyopathy

Living with cardiomyopathy can be challenging, but you can still live a full and meaningful life. With the right treatment, care and lifestyle changes, it is possible to manage your symptoms. After your diagnosis, it is important to focus on living well, making lifestyle changes that help you feel good and enjoying life with your family, friends and loved ones.

Healthy eating

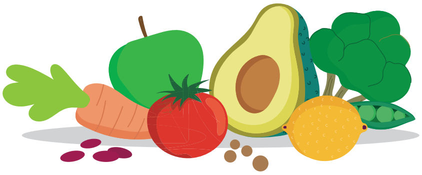
A heart-healthy diet can help reduce strain on the heart and manage symptoms.

Build a balanced meal:

- ✓ Aim to fill half your plate with vegetables, salad or fruit.
- ✓ Aim to fill a quarter of your plate with high-fibre, starchy foods like oats, brown rice or wholegrain bread.
- ✓ Aim to fill the remaining quarter of your plate with heart-healthy, high-protein foods like beans, lentils, fish, lean poultry or meat.

Have at least 5-7 portions of fruit and vegetables every day:

- ✓ Fresh, frozen, tinned and dried all count.



Cut down on salt:

- Limiting salt to no more than 5 grams per day can help to reduce the workload on your heart and lower your blood pressure.
- Choose fresh, unprocessed foods where possible and limit salty, ultra-processed foods.

Choose heart-healthy fats:

- Include olive oil, rapeseed oil, unsalted nuts, plant-based spreads and nut butter.
- Include oily fish like salmon or mackerel in your diet twice a week.
- Limit sources of saturated fat such as coconut oil, butter, cream, fried foods and processed or fatty meats.

Be mindful of alcohol and caffeine:

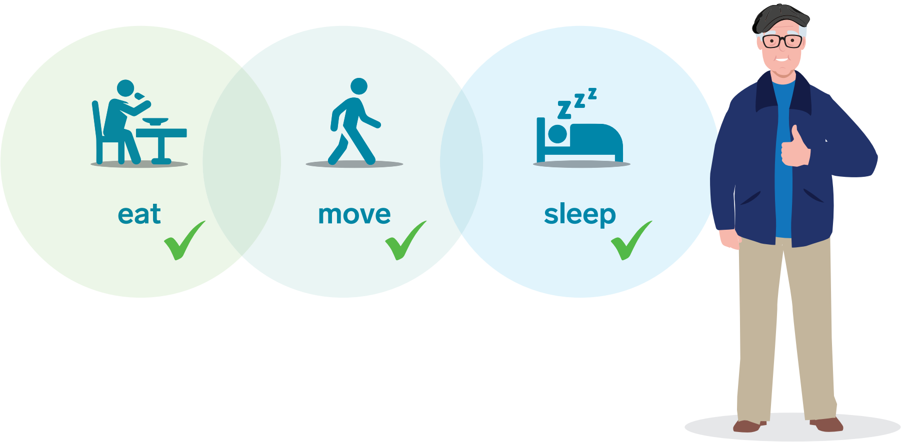
- Alcohol can raise your heart rate, cause irregular heartbeats (arrhythmias), damage your heart and stop certain medications from working properly.
- Speak to your doctor about your alcohol intake. Some people with cardiomyopathy may be advised to stop drinking completely.
- Caffeine can also cause changes to your heart's rhythm and some people living with cardiomyopathy may be sensitive to caffeine. Speak to your doctor about your caffeine intake and if you need to reduce it.

Individual needs can vary. Talk to your **dietitian** or **doctor** for individual advice.

For more information on a heart-healthy lifestyle, see irishheart.ie/how-to-keep-your-heart-healthy.

> “My mantra is now: **eat, move and sleep**. It sounds silly but I feel if I can just focus on those three things as my core ‘job’, especially if I’m feeling fatigued, then I’ll come out the other side for another spell in the sunshine.”

Dermot, living with cardiomyopathy



Physical activity

Physical activity has many health and wellbeing benefits for people living with cardiomyopathy. However, you may be concerned about the risks of moving more.

How you approach physical activity will depend on:

1. how bad your **symptoms** are
2. the **type** of cardiomyopathy you have
3. any **other medical conditions** you may be living with

Before starting any kind of physical activity after your diagnosis, it is important to speak to your doctor. They can give you advice on how to safely get moving, and how often you should exercise. Your doctor will also advise you on what you should do if you notice your symptoms getting worse with movement.

Your **doctor** may also refer you to a cardiac rehabilitation programme where your exercise can be monitored by healthcare professionals.

Cardiac rehabilitation

Cardiac rehabilitation (also called ‘cardiac rehab’ for short) is a programme of exercise, education and support. It has been specially designed for people living with heart conditions like cardiomyopathy. It is an important support available to cardiomyopathy patients.

The benefits of cardiac rehab

Empowers you – Cardiac rehab helps you to play an active role in managing your condition. By going through the programme, you will build your confidence and feel empowered to take care of your health.

Shows you how to exercise safely – Cardiac rehab involves supervised exercises that have been tailored to you and your symptoms. During cardiac rehab you will learn how to exercise safely and how to recognise any warning signs that your symptoms are getting worse.

Teaches you about heart health – During cardiac rehab you will get support for making heart-healthy lifestyle changes. For example, you will learn how to eat a heart-healthy diet and manage your stress levels.

Supports you – It can be difficult living with cardiomyopathy. You may struggle to know what supports are out there to help you. Cardiac rehab can signpost you to supports like counselling services or support groups in your local area.

Speak to your doctor about cardiac rehab and how it can help you.

Cardiac Rehab for All is a programme for people who have had a cardiac event and are doing cardiac rehab. A collaboration between the Irish Heart Foundation and the Irish Association of Cardiac Rehabilitation, it includes videos and a patient booklet on improving cardiovascular health. Visit **irishheart.ie/support-for-you/heart-support-services.**

Work

Your condition may affect your work depending on your symptoms and the severity of them. It also depends on the kind of work that you do. If your symptoms are manageable, you should be able to continue to work. But you may not be able to do work that involves strenuous physical activity.

Speak to your healthcare team about the work you do and whether you can continue doing it. You may be advised to take some time off work until you recover. Be kind to yourself. Give yourself time to follow any treatment or rehabilitation therapy you have been given.

What if I can’t go back to work?

If you have been advised that you will not be able to go back to a paid job, that can be very hard to adjust to. Not being able to work can make you feel like you have lost your identity and your ability to contribute. You may worry about your family’s financial circumstances.

You can use this time to re-evaluate what you want out of life. You may want to:

- do some volunteering
- develop new hobbies
- return to education
- start your own business

You can also receive **financial support** from the government if you can’t go back to work.

Benefits you may be entitled to

Here are some of the key social welfare supports available that can help if you have been diagnosed with cardiomyopathy. For more information on supports and benefits, contact your local social welfare office or visit citizensinformation.ie.

Illness Benefit – This is a weekly payment you may get if you can't work due to your illness. In order to get Illness Benefit, you must have enough PRSI contributions.

Supplementary Welfare Allowance – If you do not qualify for Illness Benefit, you may be able to get a Supplementary Welfare Allowance. You may also be able to get this if you are waiting to find out if you qualify for Illness Benefit.

Partial Capacity Benefit – This payment is available to people who have been receiving Illness Benefit for a minimum of six months. It offers support to people who cannot return to full-time work because of their illness, but who have been medically cleared to work part-time. You will need to be medically assessed for this benefit. For details, visit citizensinformation.ie.

Invalidity Pension – This support is available for people who cannot work due to a long-term illness or disability. You must have enough PRSI contributions for this support.

Carer's Allowance/Carer's Benefit – If you need a lot of support from a family member, they may be able to get Carer's Allowance or Carer's Benefit.

Medical Card/GP Visit Card – Depending on your medical situation and your income, you may be able to qualify for a Medical Card or a GP Visit Card. Both of these supports are means tested.

Drug Payment Scheme – This support limits the cost of medications for you and your family to €80 per month, making costs easier to manage. Anyone living in Ireland can apply and there is no means test for this support. You can apply online at **mydps.ie.**

Returning to work

If you have had to take some time off work and you are now thinking of returning to work:

- ✓ Contact your employer to discuss options for a gradual return to work. You may not want to work full-time.
- ✓ Returning to work may impact on any social welfare payments and entitlements you receive. Contact your local Social Welfare Office, Citizens Information or your Employee Assistance Programme, if you have one.

- ✓ Contact our **Nurse Support Line** on **01 668 5001** for information on returning to work.

Relationships and managing them

You may worry about how your relationships with your family and friends will get affected. Being around your loved ones can help you with your emotional wellbeing. Managing your relationships can be easier when you have explained to your loved ones what you are going through. Here are a few things that will help you manage your relationships:

- ✓ Let your family know how best they can support you with your emotional and physical wellbeing.
- ✓ Involve them in your care, for example let them help you with your medication or ask them to remind you every day to check in on your symptoms.
- ✓ Try to organise regular activities with your loved ones – making them aware of how much you can do.

Driving

The National Driver Licence Service (NDLS) has specific guidelines about driving and cardiomyopathy. These guidelines will depend on the type of cardiomyopathy you have, how severe it is and the symptoms you may be experiencing.

It is important that you speak to your doctor and ask them if it is safe for you to return to driving. You will also need to inform the NDLS of your condition.

The NDLS offers an overview of driving with heart conditions on their website. Visit **ndls.ie/medical-fitness**

If you need it, you can apply for a disabled person's parking card. This is a permit that allows you to park in disabled parking spaces. You can contact the Disabled Drivers Association of Ireland (DDAI) and the Irish Wheelchair Association (IWA).

Air travel

If your condition is under control and you feel well, it is usually ok to go on holiday. Check with your doctor if it's safe for you to go.

- ✓ Get a letter from your doctor explaining:

    1. your condition
    2. what medicines you need and why
    3. if you have any medical devices like an implantable cardioverter defibrillator (ICD)

- ✓ Carry phone numbers of your doctor and family members
- ✓ Make note of local emergency numbers and how to get medical help in your holiday destination
- ✓ Make sure you bring all the medicines you need to last you throughout the holiday - keep them in your hand luggage

Airport assistance

If you have reduced mobility as a result of your cardiomyopathy, you can ask your airline about mobility assistance while you travel.

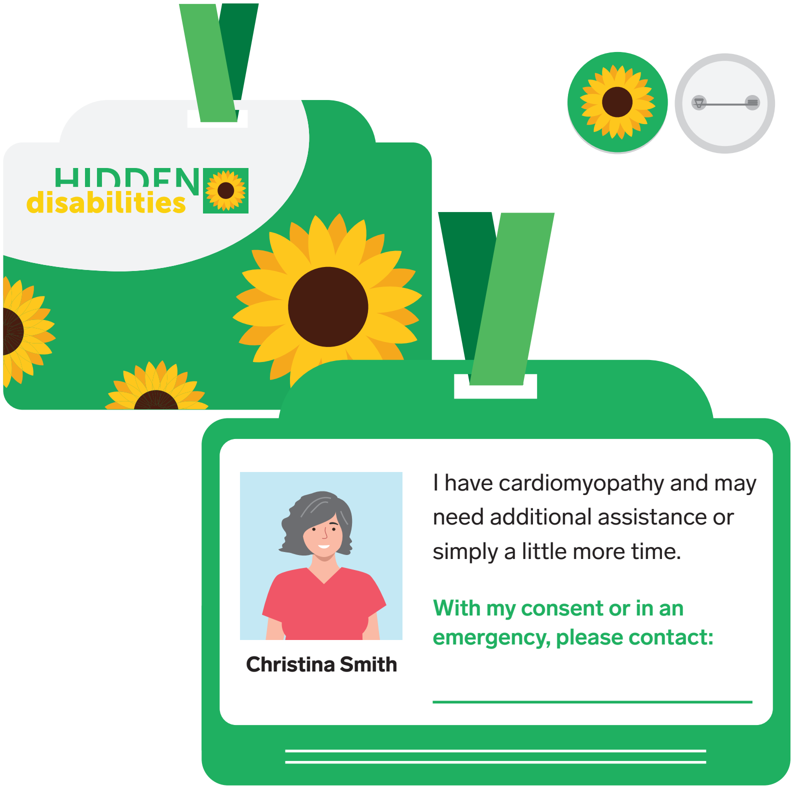
It is also a good idea to contact your departure/arrival airport and ask about their mobility assistance supports.

Most airports will be able to provide support for passengers with reduced mobility, although you will need to give notice before you travel to ensure you can access the type of assistance you need.

Hidden Disabilities Sunflower

The Hidden Disabilities Sunflower is a discreet symbol that someone has a hidden or non-visible disability and may need extra help.

The lanyard has become widely recognised in airports, on public transportation and in public spaces. Staff in participating locations are trained to recognise the lanyard and offer assistance. See hdsunflower.com/irl.



Travel insurance

Travel insurance is essential for peace of mind when travelling with cardiomyopathy. It's important to get quotes from multiple travel insurers and carefully review what is covered in each policy.

You should also ask your doctor for a letter of diagnosis as the insurance company may ask you for one as part of your application.

If you have a European Health Insurance Card, it's important to note that while this card grants public healthcare access in EU countries, it doesn't replace travel insurance.

> "I have always liked travelling, but as someone living with HCM and an ICD, it was important for me to research and find the health and travel insurance deals that worked for me. In recent years, the support and learnings from the Irish Heart Foundation's Heart Support Network Facebook page have been very beneficial. Travelling is still an option with cardiomyopathy."

Christina, living with cardiomyopathy

Health insurance

Some health insurers offer plans that provide additional coverage for people living with a heart condition.

When you are diagnosed, speak to your doctor about the types of treatment you are likely to need in the future.

Once you know the types of treatment you are likely to need, it's a good idea to get multiple quotes from different insurers. Compare what each of them is offering and if it suits your personal situation before you sign up.

You should also ask your doctor to give you a letter of diagnosis. You may need to give this to the insurance company as part of your application.

You can also access care through the public health system. In emergency situations, your care will be prioritised but routine management of your cardiomyopathy and accessing diagnostic tests or screening may be impacted by long waiting lists.

Making the most of your medical appointments

Medical appointments can be stressful. Here are some **tips** to help.

Keep a notebook for your cardiomyopathy
This will act as a record of your condition and help you keep track of your appointments, the questions you asked and what you spoke about with your doctor. You can also make note of questions you want to ask your doctor at your next appointment.

Make a plan
Before your appointment, write down any questions you have about your treatment, symptoms, medication or how to manage your condition day-to-day. This will help you stay on track.

Bring a support person to your appointment
A support person can be a loved one or a friend. They can help you remember what you discussed with your doctor.

Be honest during your appointment
Talk to your doctor about any changes you've noticed in your condition, any side effects you've had from your medication and how you've been feeling. Don't be afraid to talk to your doctor about the impact your cardiomyopathy has had on your emotional and mental health. Cardiomyopathy is a complex illness and by being honest with your doctor, they can advise the right treatments and supports for you.

Ask and repeat

If you don't understand something your doctor says, ask them to explain it in a way that's easier for you to understand. It's also a good idea to repeat what your doctor says back to them – this will help you remember their advice.

Ask about the next steps

Before you finish your appointment, ask your doctor to clearly explain what the next steps are for you. This will give you a chance to ask about follow-up appointments or if you need any tests or referrals to other specialists.

Take notes

Take notes in your notebook during your appointment (or ask your support person to do this for you). Also ask your doctor to send you a copy of the summary they will issue to your GP. This will help you to keep a record of your care and make sure you remember any key points.

> “In the early days, when you have doctor or consultant appointments, I would suggest having someone with you if possible. You won’t understand or process everything being said and sometimes a second person will hear things you miss.
>
> I always bring a notebook and before an appointment I try to list any points I want to mention as I will forget when I go in”

Claire, living with cardiomyopathy

Notes...

Appendices:

My journey with cardiomyopathy

My diagnosis

I have been diagnosed with this type of cardiomyopathy (**tick the one** that applies to you):

☐ Dilated cardiomyopathy

☐ Hypertrophic cardiomyopathy

☐ Arrhythmogenic cardiomyopathy

☐ Restrictive cardiomyopathy

☐ Peripartum cardiomyopathy

☐ Transthyretin amyloidosis cardiomyopathy (ATTR-CM)

☐ Ischemic cardiomyopathy

☐ Takotsubo cardiomyopathy (also called 'broken heart syndrome' or 'stress-induced cardiomyopathy')

☐ Chemotherapy-induced cardiomyopathy

☐ Alcohol-induced cardiomyopathy

☐ Left ventricular non-compaction (LVNC)

☐ Other: ______________________________

____

____

What questions should I ask my doctor?

Cardiomyopathy is a complex condition and it’s important to understand the type of cardiomyopathy you have and what treatment options are available to you. Here are some questions you may like to ask your doctor.

- What type of cardiomyopathy do I have?
- How bad is my condition?
- What caused my cardiomyopathy? Is it inherited? Do my family members need to be tested for it?
- What symptoms should I monitor?
- What can I do if my symptoms get worse?
- When do I need medical attention if my symptoms are bad?
- What are my treatment options?
- Do I need to have any surgery?
- Will I need an implantable device in the future (for example a pacemaker or implantable cardioverter defibrillator)?
- What medications are you prescribing me?
- What should I do if I have any side effects from these medications?
- Are there any other conditions associated with cardiomyopathy that I need to be aware of?
- Is it safe for me to exercise?
- What kinds of exercise should I do?
- How much exercise should I do on a daily basis?
- Do I need to change what I eat?

My healthcare team

Write down the names of the members of your healthcare team (for example, cardiologist, hospital nurse, public health nurse, general practitioner (GP), psychologist, occupational therapist (OT), dietitian, etc.)

Healthcare professional	Name and contact details

Healthcare professional	Name and contact details

My timeline of medical appointments and procedures

Medical appointments, procedures and other interactions with healthcare	Date
Example: I had an ICD fitted	

My medicine list

Name of medicine	
What is it for?	
Dosage (amount to be taken)	
Frequency (number of times in a day)	
Prescribed by?	

Name of medicine	
What is it for?	
Dosage (amount to be taken)	
Frequency (number of times in a day)	
Prescribed by?	

Name of medicine	
What is it for?	
Dosage (amount to be taken)	
Frequency (number of times in a day)	
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Frequency (number of times in a day)	
Prescribed by?	

Name of medicine	
What is it for?	
Dosage (amount to be taken)	
Frequency (number of times in a day)	
Prescribed by?	

Useful addresses and websites

Aware

A national organisation providing free support, education and information services to people impacted by anxiety, depression, bipolar disorder and related mood conditions.

Aware support line: 1800 804 848

web: aware.ie

British Heart Foundation

A UK-based charity that supports people living with heart and circulatory diseases.

web: bhf.org.uk

Cardiomyopathy UK

A UK-based charity that supports people affected by cardiomyopathy.

web: cardiomyopathy.org

Citizens Information Centres

Offers information on your rights and entitlements.

web: citizensinformation.ie

Croí

A heart and stroke charity with a particular focus on the west of Ireland.

web: croi.ie

email: info@croi.ie

Cardiac Risk in the Young (CRY Ireland)

CRY Ireland is a charity that helps to raise awareness of sudden cardiac death in Ireland. It offers free clinical assessment and management to all families of a young person living with an inherited cardiac condition or who has suffered (or is at risk of) a sudden cardiac death.

web: cry.ie

Dillon Quirke Foundation

The Dillon Quirke Foundation aims to fund widespread cardiac screening for young people (aged 12-18) who are involved in sport.

web: dillonquirkefoundation.com

Disabled Drivers Association of Ireland

The Disabled Drivers Association of Ireland (DDAI) is a national organisation that supports people with disabilities who drive or who need mobility assistance. They provide a range of services and resources aimed at improving access, independence and mobility for disabled drivers and passengers in Ireland.

web: ddai.ie

ICU Steps

ICU Steps is a group set up to provide supports to patients affected by critical illness and their relatives. The group aims to promote a positive outlook for people in recovery. Support is offered via a drop-in Zoom call one evening every month. In these calls, patients, relatives and ICU nurses can connect and share experiences.

web: icusteps.ie

email: information@icusteps.ie

Irish Association for Counselling and Psychotherapy
The largest counselling and psychotherapy association in Ireland. Offers information and contact details for accredited practitioners.

web: iacp.ie

Irish Association of Cardiac Rehabilitation
Offers resources and useful information about cardiac rehabilitation.

web: iacronline.ie

Irish Wheelchair Association
One of Ireland’s leading representative organisations and service providers for people with physical disabilities.

web: iwa.ie

The Mater Family Heart Screening Clinic
The Mater Hospital’s Family Heart Screening Clinic has been set up to cater for families affected by unexplained Sudden Cardiac Death in a young person. They also assess other family members and patients who have or have a family history of an inherited cardiac condition. Access to the clinic is by GP or self-referral.
web: mater.ie/services/cardiac-subspecialities

The Samaritans
Charity offering emotional support 24-hours a day, 365 days a year, to anyone who is in distress, lonely, struggling to cope or feeling suicidal.

web: samaritans.org
email: jo@samaritans.org

Samaritans’ 24-hour Helpline
116 123

Notes...

Irish Heart Foundation

The National Stroke & Heart Charity

The Irish Heart Foundation is a community of people who fight to protect the cardiovascular health of everyone in Ireland.

Irish Heart Foundation
17-19 Rathmines Road Lower,
Dublin 6, D06 C780.

☎ 01 668 5001

✉ info@irishheart.ie

Follow us on

CHY: 5507 CRA: 20008376 CRO: 23434

irishheart.ie