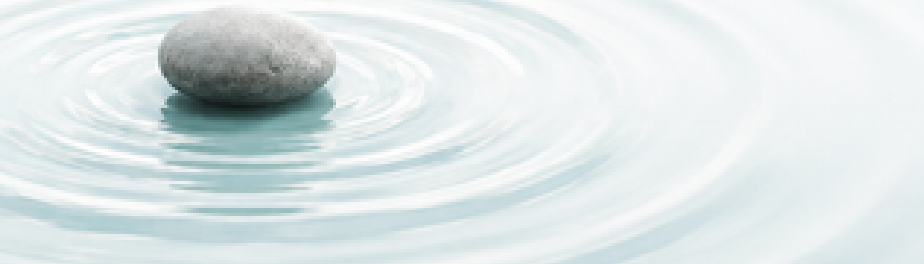
North Thames Family Support Guides

Cardiomyopathy

Supporting families after a sudden cardiac death



Before you begin

First of all, I am so sorry that you and your family are going through this.

Losing someone you love is overwhelming. It is completely understandable if this guide feels like more information than you can take in right now.

Some of the information in this guide may be new to you. You do not need to understand everything straight away. If you have questions, or something does not make sense, you can ask your healthcare team to talk it through with you.

There is no expectation that you read it all today. You may find it helpful to come back to different sections over time.

This guide explains why we may recommend cardiac screening, why DNA may sometimes be stored, and what happens next.

It is here to support you.

Understanding your loved one's condition

Cardiomyopathy is a condition that affects the heart muscle. It can change the structure of the heart and how well it works.

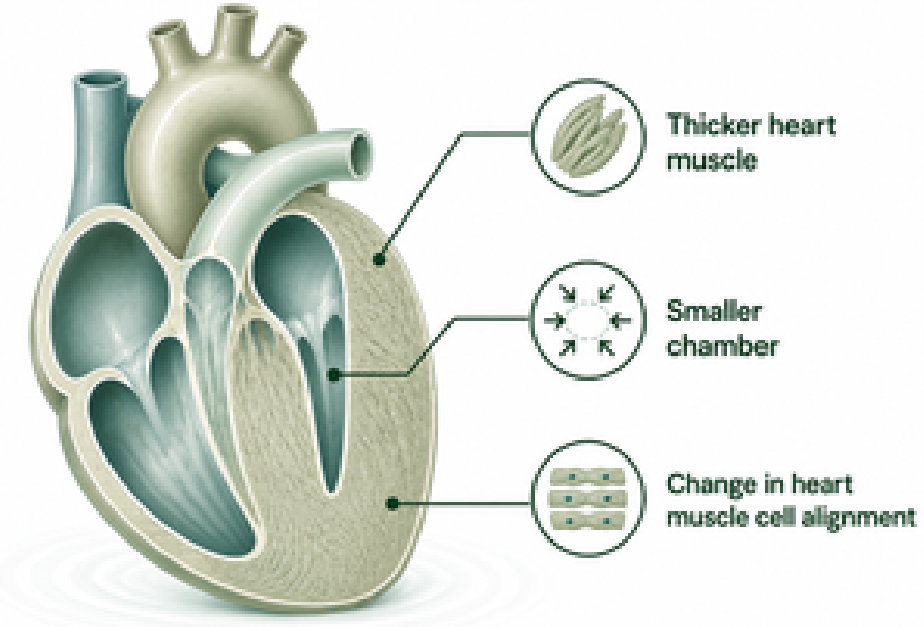
There are different types of cardiomyopathy. Some can be inherited, meaning they can run in families.

Because of this, we may recommend cardiac screening for close relatives.



Hypertrophic cardiomyopathy

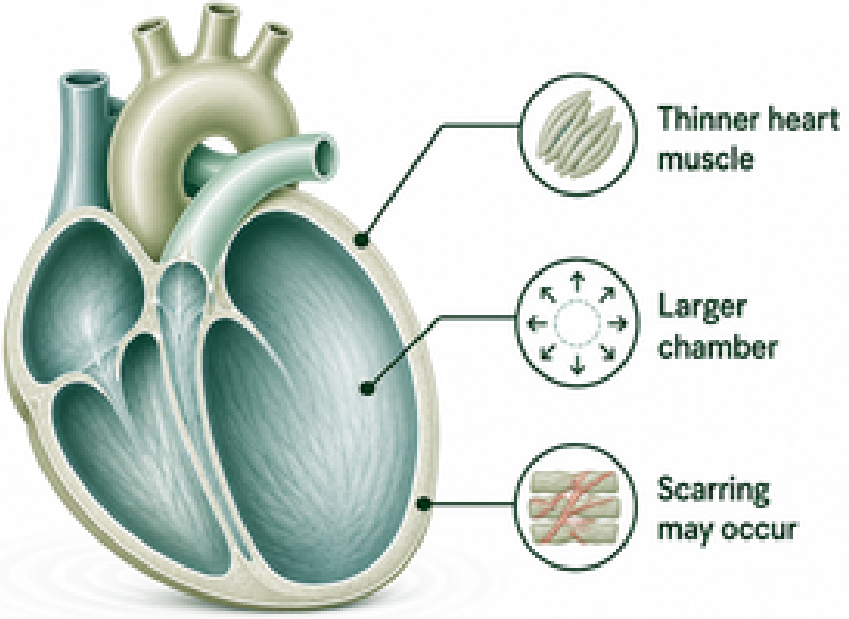
In hypertrophic cardiomyopathy (HCM), the heart muscle can become thicker, reducing the space inside the main pumping chamber. The heart muscle cells may also become less organised.



These diagrams show typical changes. Cardiomyopathy can look different in each person.

Dilated cardiomyopathy

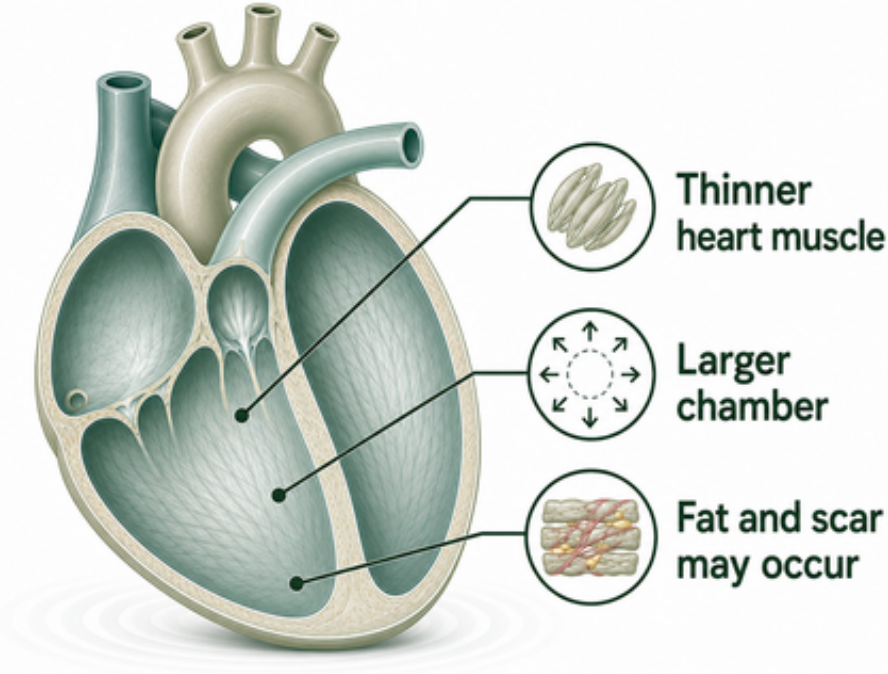
In dilated cardiomyopathy (DCM), the heart muscle can become thinner and weaker, increasing the space inside the main pumping chamber. This can make it harder for the heart to pump blood effectively. Scarring may also occur within the heart muscle.



These diagrams show typical changes. Cardiomyopathy can look different in each person.

Arrhythmogenic cardiomyopathy

In arrhythmogenic cardiomyopathy (ACM), the right ventricle, left ventricle or both can become enlarged, and the heart muscle wall can become thinner. Fat and scar may also occur within the heart muscle.



These diagrams show typical changes. Cardiomyopathy can look different in each person.

What symptoms can cardiomyopathy cause?

Some people with cardiomyopathy have no symptoms and may feel completely well. Others may experience:

- Breathlessness
- Palpitations - feeling your heart racing, pounding or skipping beats
- Fainting or feeling faint
- Chest pain or discomfort
- Tiredness or reduced ability to exercise

Symptoms can vary depending on the type of cardiomyopathy and from person to person.

What does this mean for my family?

Some cardiomyopathies can be inherited, meaning they can run in families. A relative may therefore have the same condition, even if they feel completely well.

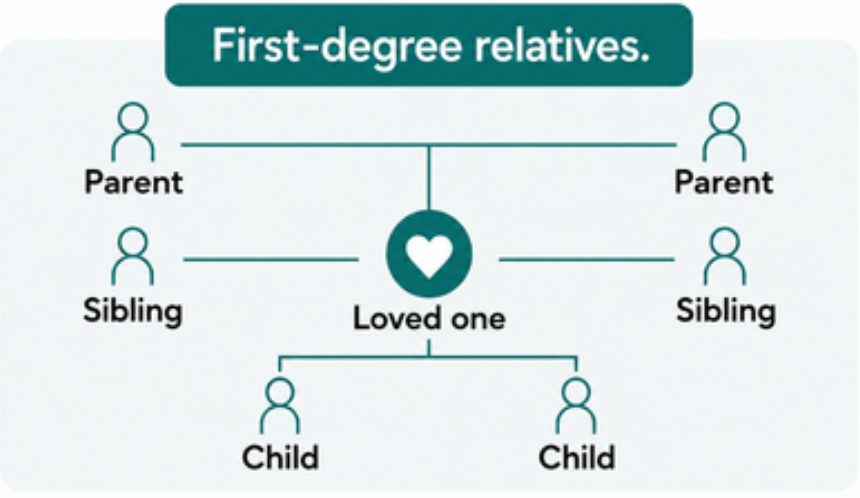
This is why we recommend cardiac screening for close relatives.

Who should have cardiac screening?

We usually begin by offering cardiac screening to your loved one's first-degree relatives.

Screening may then be recommended for other relatives, depending on the results and what we learn about the family.

If your screening is normal, relatives on your side of the family will not usually need cardiac screening.



What does cardiac screening involve?

Cardiac screening involves a number of tests that look at the structure and electrical activity of your heart.

These tests are routinely used to help us build up a complete picture of your heart. Most people find them straightforward, and most are painless.

You may not need every test, and they do not always need to happen on the same day.

ECG
Stickers are placed on your chest and connected to a machine that records the electrical activity of your heart.

Echocardiogram
An ultrasound scan of your heart that looks at its structure and how well it is working.

Cardiac screening continued

Heart monitor

A small wearable monitor may be used to record your heart rhythm over one or more days, usually while you go about your normal activities.

Cardiac MRI

A scan that takes detailed pictures of your heart. This may not be needed for everyone and is not usually performed at the first appointment.

What happens next?

The first step is usually to ask your GP for a referral for cardiac screening **(or take the letter I provided to your GP).**

GP referral

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Cardiac tests

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Clinic appointment
Discuss your results and questions with the cardiac team.
This may be on the same day as your tests or on a different day.

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After screening
The team will explain whether you need any further tests or follow-up.

What happens after my screening?

Once your tests are complete, the cardiac team will explain the results and what they mean for you and your family.

If your screening is normal

This is reassuring. **Screening may need to be repeated** because some cardiomyopathies become apparent with age.

The cardiac team will advise you if and when you need to be screened again.

If your screening shows something

Sometimes screening identifies signs of a heart condition that needs further investigation.

The cardiac team will explain what the results mean for you and your family.

If a heart condition is found

If further investigations confirm that you have cardiomyopathy, your cardiac team will talk to you about what this means for you.

Not everyone will need treatment. Depending on the type of cardiomyopathy and your individual circumstances, you may be offered:

- regular heart checks and follow-up
- medicines to help your heart work better or treat abnormal heart rhythms
- advice about exercise and physical activity
- in some people, a device such as an implantable cardioverter defibrillator (ICD)

Some people may need other treatments or procedures. Your cardiac team will explain what is recommended for you.

Any treatment or follow-up will be tailored to you and the type of cardiomyopathy that is found.

• Storing DNA

A tissue sample may have been stored after your loved one died. DNA can be extracted from this sample and stored in case genetic testing may be helpful now or in the future.

DNA can be stored for many decades. Storing it does not mean that genetic testing has been carried out.

Keeping DNA stored simply keeps this option open for your family.



DNA extraction and storage usually takes around **6–8 weeks.**

• Will genetic testing be carried out?

No. Genetic testing is not carried out automatically.

The cardiac and genetics teams will consider the post-mortem findings, family history and results of cardiac screening when deciding whether genetic testing may be helpful.

If genetic testing is recommended, we will give you a separate guide explaining genetic testing, what the results may mean, and what this could mean for your family.

Things I don't want to forget

You can use this page to write down questions, things you would like to talk about, or anything you want to remember.

Support and resources

You may find these sources of information and support helpful.

SADS UK – sadsuk.org
Bereavement support for families affected by sudden cardiac death.

Cardiomyopathy UK – cardiomyopathy.org
Information and support for people and families affected by cardiomyopathy.

British Heart Foundation – bhf.org
Information and support for people and families affected by heart conditions.

Amber's story
A parent shares her experience after loss.
NT GMS website: 'Highlighting our Sudden Cardiac Death project'.

The Ripple

A family member once described the impact an inherited condition can have on a family as being like a stone dropped into a pond. The ripples spread outwards, touching every member of the family in different ways.

Those words have stayed with me ever since.



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This guide has been developed to support families following a sudden cardiac death.

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