British Heart Foundation

LIFE WITH DILATED CARDIOMYOPATHY

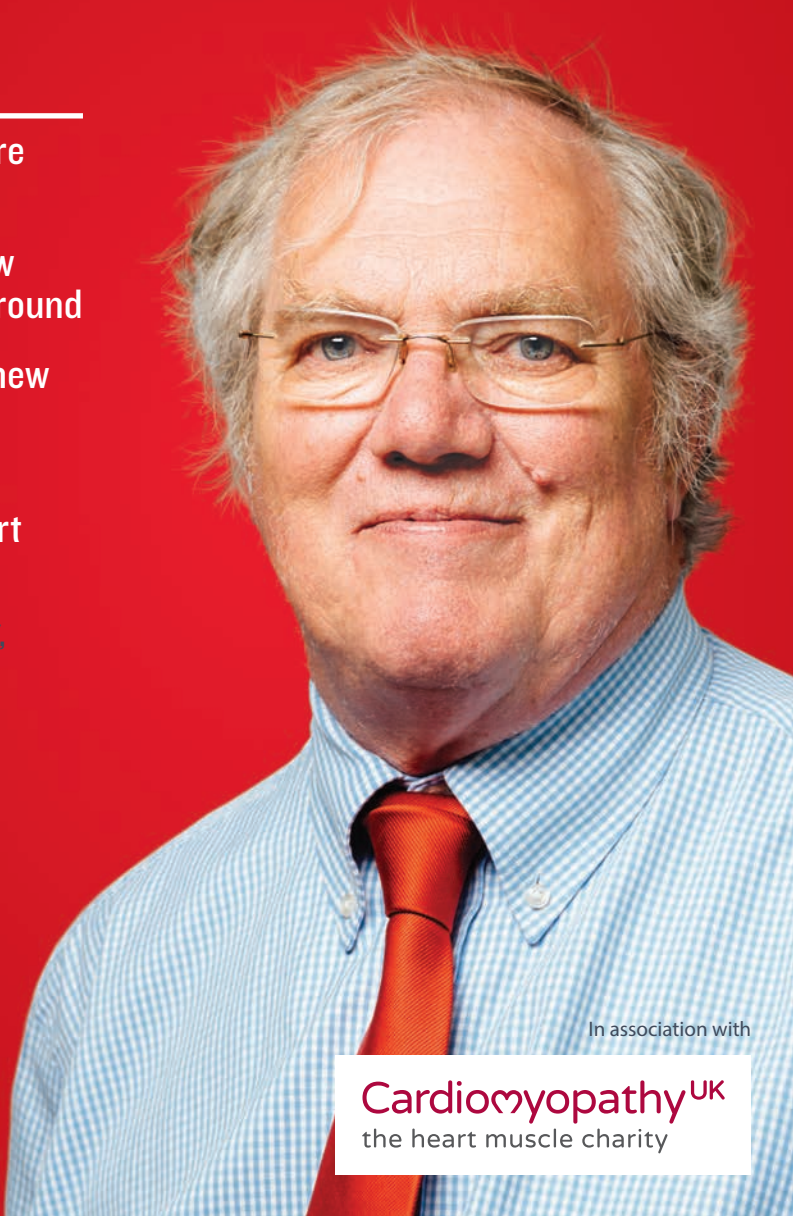
I like to explore new places

I've found new ways to get around

I'm planning new adventures

I live with an inherited heart condition

JEREMY'S STORY, PAGE 22



FIGHT FOR EVERY HEARTBEAT

bhf.org.uk

In association with

Cardiomyopathy UK
the heart muscle charity

This booklet has been developed from the original version inspired by the founder of Cardiomyopathy UK – Carolyn Biro. Published by the British Heart Foundation.

This booklet is not a substitute for the advice your doctor or cardiologist (heart specialist) may give you based on his or her knowledge of your condition, but it should help you to understand what they tell you.

The illustrations used in this booklet are artistic impressions and are not intended to accurately depict the medical material that they represent.

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You may be reading this booklet because you've been diagnosed with a heart condition called dilated cardiomyopathy. Or maybe someone else in your family has been diagnosed with the condition and your doctor has suggested that you should have some tests to find out if you've also inherited it.

Cardiomyopathy is a disease of the heart muscle. It can run in families and can affect one or more members of a family. Some members of a family may be affected more than others. Some family members may not be affected at all.

There are three main types of cardiomyopathy:

- dilated cardiomyopathy (DCM)
- hypertrophic cardiomyopathy (HCM or HOCM)
- arrhythmogenic right ventricular cardiomyopathy (ARVC).

This booklet is about dilated cardiomyopathy. For information on the other types of cardiomyopathy, see the other booklets in this series. See page 57 for details.

Some people with dilated cardiomyopathy may experience symptoms, and a small number could be at risk of dangerous abnormal heart rhythms and sudden death. It's important that families affected receive accurate assessment, diagnosis, treatment and support from specialists in a clinic for inherited heart conditions.

This booklet:

- describes how the normal heart works
- explains what dilated cardiomyopathy is and what can go wrong if you have the condition
- explains why it's important that close blood relatives of someone with the condition should have an assessment to find out if they've inherited the same condition
- describes the tests your doctor may ask you and your close family members to have
- describes the treatments you may need
- offers advice on how to live a healthy lifestyle if you have dilated cardiomyopathy.

We explain the medical and technical terms as we go along but, if you find a word you don't understand, look it up in the list of Technical terms on page 53.

This booklet has been produced with the help of doctors and other health professionals, and people who have dilated cardiomyopathy. We hope it will help you to understand your condition and come to terms with what it means for you and your family. This booklet is the result of a joint collaboration between the British Heart Foundation (BHF) and Cardiomyopathy UK.

At the British Heart Foundation we're fighting for every heartbeat. The research we fund has helped push the boundaries of our understanding of genetics, and given us tools we can use to find and help people at risk of dangerous heart conditions like dilated cardiomyopathy. Join the fight at **bhf.org.uk**

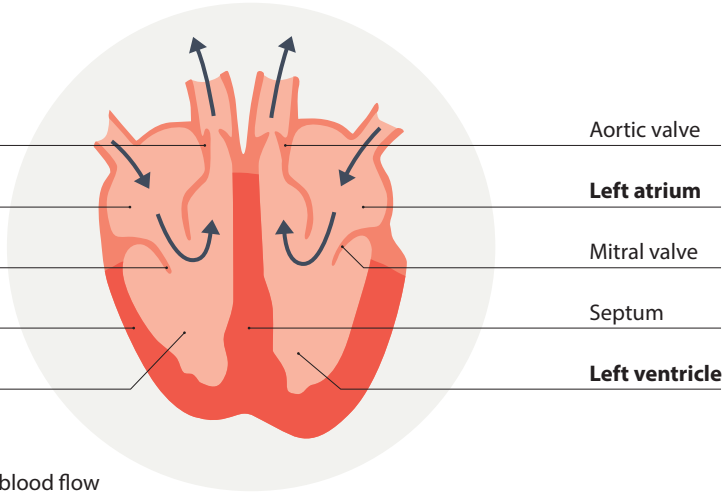
At Cardiomyopathy UK, we campaign for more heart checks and gene tests for affected families, to find those at risk and save lives. We help educate doctors about best practice in diagnosing and treating affected families so they get better care. You can help the fight against cardiomyopathy by supporting us at **www.cardiomyopathy.org**

UNDERSTANDING YOUR HEART

THE NORMAL HEART

The heart is a specialised muscle that contracts regularly and continuously, pumping blood to the body and the lungs. It has four chambers – two at the top (the atria), and two at the bottom (the ventricles). See the diagram below.

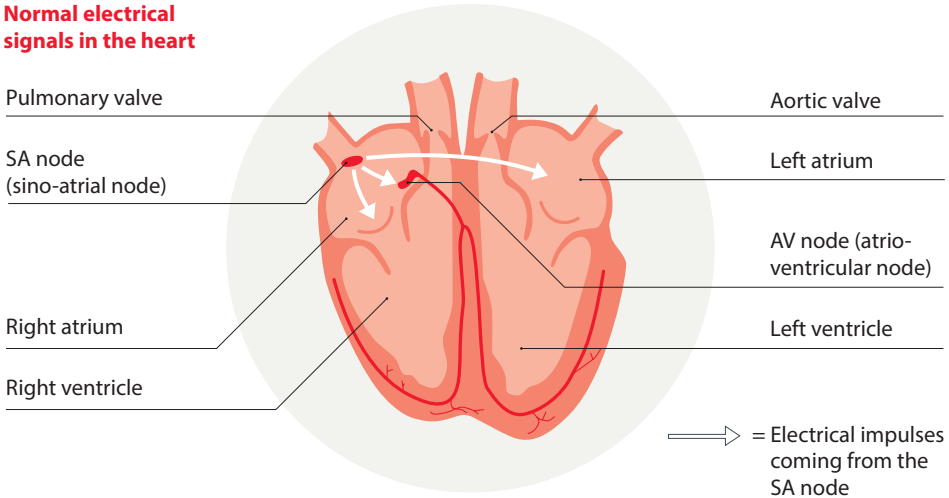
Normal heart



How the heart functions electrically
The pumping action of the heart is caused by a flow of electricity through the heart that repeats itself in a cycle. This is normally triggered by the heart's natural pacemaker, the SA node (sino-atrial node), which is in the right atrium (see the diagram below). The SA node sends out regular electrical impulses, which make the atria contract and pump blood into the ventricles.

The electrical impulse then passes to the ventricles through a form of 'junction box' called the AV node (atrio-ventricular node). This causes the ventricles to contract and pump blood out of the heart. The blood from the right ventricle goes through the pulmonary artery to the lungs, and the blood from the left ventricle goes through the aorta and then around the body.

Normal electrical signals in the heart



Structure of the heart
The heart is made up of three layers:

- the endocardium
- the myocardium
- the pericardium.

The endocardium is a thin layer on the inside of the heart, lining the chambers and valves.

The myocardium is the thick, muscular layer of the heart that contracts and squeezes the blood out of the heart. It's this layer that is affected by cardiomyopathy.

The pericardium is a thin, double layer that forms a protective sac around the outside of the heart. It contains a small amount of fluid – called pericardial fluid – which acts as a lubricant when the heart is contracting.

DILATED CARDIOMYOPATHY

I'm achieving my ambitions

I only do the things I enjoy

I love the challenge

I live with an inherited heart condition

SIMON'S STORY

My father had an enlarged heart and died when he was just 44 years old.

I was tested when I was younger, but I was fine back then.

It was a shock when I collapsed. I was rushed to the hospital and went through a lot of tests. I was diagnosed with dilated cardiomyopathy. They gave me a pacemaker and said they had caught my condition before something worse happened.

But my condition got worse and I collapsed again at work.

I went back to hospital and was given an ICD. Six months later, my ICD went off. My heart kept getting weaker and I ended up on the heart transplant waiting list. I remember the phone ringing at 11 o'clock at night. By 12 o'clock I was going into the theatre for the transplant.

The condition has devastated my family. I've lost my dad, uncle and sister. But thanks to research into better treatment and care - I'm the first person on my father's side of the family to have a 50th birthday in 150 years.

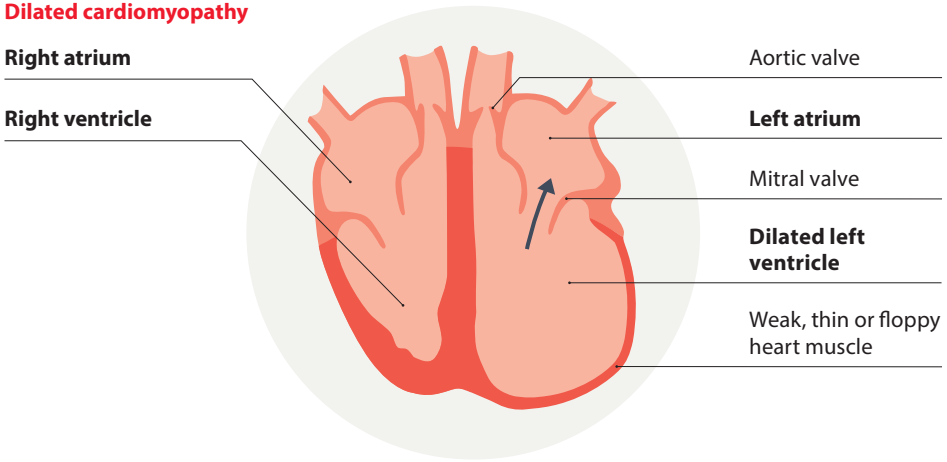
WHAT IS DILATED CARDIOMYOPATHY?

Dilated cardiomyopathy is a disease of the heart muscle. It is often a genetic condition. This means that it's caused by a change (known as a mutation) in one or more genes that can be passed on through families. We explain more about how cardiomyopathy is inherited on page 26.

How does dilated cardiomyopathy affect your heart muscle?

Having dilated cardiomyopathy means that the left ventricle of your heart becomes dilated (enlarged). When this happens, your heart can no longer pump blood efficiently around your body (see the diagram below). This can lead to fluid building up in your lungs, ankles, abdomen and other organs of your body and a feeling of being breathless. This collection of symptoms is known as heart failure. In most cases dilated cardiomyopathy develops slowly, so the heart can be quite severely affected before someone is diagnosed. In some cases, there may also be mitral regurgitation. This is when some of your blood flows in the wrong direction through the mitral valve, from the left ventricle to the left atrium.

Dilated cardiomyopathy



Other conditions can also cause your heart to become dilated and lead to the symptoms of heart failure, such as coronary heart disease, high blood pressure (hypertension), or heart valve disease. So, if you have symptoms of heart failure, your doctor will need to do tests to find out exactly what is causing your symptoms.

WHAT CAUSES DILATED CARDIOMYOPATHY?

Genetics

Research has shown that dilated cardiomyopathy can be linked to an individual's genetic make-up. Each one of us has our own genetic information that makes us unique. Your genes make you who you are, for example, what colour your hair is, your blood type and gender. This genetic information is held in your DNA, in the cells of your body. Your genetic information acts as a code from which a system of proteins can be created. These tell all of the cells in your body what their function should be.

If there's a mistake in a gene, your cells may not work as they should do. These mistakes are known as mutations. We explain more about genetic inheritance on pages 24-28.

In most cases, the exact reason for dilated cardiomyopathy is unknown and the condition is called 'idiopathic dilated cardiomyopathy'. Idiopathic means that there is no known cause.

Scientists have identified some gene mutations that are known to affect the development of heart muscle, and that may cause dilated cardiomyopathy. However, there are many other gene mutations that may also cause the condition. This makes genetic testing of individuals to find out if they have the condition more difficult (see page 27).

Some non-genetic factors are also linked to an increased risk of developing dilated cardiomyopathy. These include:

- viral infections
- auto-immune disease
- exposure to toxins (including alcohol) or certain medicines
- pregnancy.

In some people with dilated cardiomyopathy there may be more than one reason to explain their condition. For example, some people may carry a gene mutation that makes them more vulnerable to viral infections in the heart.

Viral infections
We're all exposed to many viruses every day. Normally, your body's immune system is very efficient at dealing with these viruses. However, sometimes a virus can affect the heart muscle of an apparently well person, even though the person has no other symptoms of having a virus. This is known as viral myocarditis.

Viral myocarditis is commonly caused by a number of different viruses. It is thought that dilated cardiomyopathy may occur when your heart muscle is badly damaged by the initial infection. Or it may be that the virus triggers your body's own defence system (the immune system) which then attacks and damages your heart muscle.

Auto-immune disease
Your body's immune system is responsible for defending your body against infection – for example, against viruses and bacteria. Sometimes your immune system breaks down and starts to attack your body's own tissues. This is called auto-immune disease. Some people who are diagnosed with dilated cardiomyopathy appear to have this condition.

Exposure to toxins or certain medicines
In very rare cases, exposure to certain chemicals can cause dilated cardiomyopathy. In these cases, we don't know if the person developed the condition because they already had a genetic tendency to develop it, or whether the toxins caused the cardiomyopathy.

Some anti-cancer medicines, such as anthracyclines, can cause dilated cardiomyopathy. These medicines are a very effective treatment for cancer, but they are toxic and can have harmful effects on your heart muscle, which can lead to dilated cardiomyopathy. The risk of this happening is usually related to the total dose of anthracyclines received.

If you've had treatment with anthracyclines, you should be seen by a cardiologist (heart specialist) at least once a year. If you know that you have a heart condition and that you will need treatment for cancer, you should discuss this with your cardiologist before you start the treatment.

In some cases, alcohol can be the cause of dilated cardiomyopathy. Over time, regularly drinking too much alcohol can weaken your heart by damaging your heart muscle. It can take years for dilated cardiomyopathy to develop and so the effects on your heart may not be seen immediately.

Pregnancy
In developed countries, up to one in every 2000 women may develop dilated cardiomyopathy during pregnancy. It can occur from mid to late pregnancy or soon after delivery and is known as peripartum cardiomyopathy. It's possible that, in these circumstances, some women may have already had dilated cardiomyopathy but it had not been diagnosed.

For most women, the dilated heart returns to normal within six to eight weeks of the delivery, provided they get the appropriate treatment. However, it's possible that the condition could develop again in subsequent pregnancies.

If you've had peripartum cardiomyopathy and have not fully recovered from it, your doctor may advise you not to have any more children.

Women who have dilated cardiomyopathy or peripartum cardiomyopathy should seek specialist advice before planning another baby or if they find themselves unexpectedly pregnant. This is particularly important if you're receiving medication for your cardiomyopathy, as this can affect the baby. See page 47 for more details.

WHAT ARE THE SYMPTOMS OF DILATED CARDIOMYOPATHY?

Most people who are affected by dilated cardiomyopathy remain well. Some people have a few symptoms and others may develop problems which need more complex treatment. Once the condition has been diagnosed, in most cases its symptoms can be controlled with medication or other treatments (see page 31).

The symptoms of dilated cardiomyopathy are similar to those of heart failure. Heart failure is a term used to describe a group of symptoms caused when your heart muscle becomes less efficient at pumping blood around your body.

The symptoms of heart failure include:

- shortness of breath
- swelling of your feet, ankles, abdomen and lower back
- tiredness.

Not everyone who has dilated cardiomyopathy goes on to develop all the symptoms of heart failure. The symptoms usually come on slowly, but sometimes they can come on suddenly, for example, in the circumstances described on page 13. We describe these symptoms below. See the More information section on page 57 to order our *Living with heart failure* booklet.

Shortness of breath
Breathlessness is very common and often happens because your lungs become congested with fluid. Some people are breathless only when they exert themselves, while others may be breathless when resting. When fluid collects in your lungs, it is known as pulmonary oedema (oedema means swelling).

Swelling
Oedema is a build-up of fluid in your body's tissues, known as water retention. It can accumulate in your feet and around your ankles or the small of your back causing swelling. Sometimes there can also be swelling in your abdomen (ascites).

Tiredness
The reduced blood supply to your body can lead to a feeling of heavy limbs and excessive tiredness, and can affect your ability to exercise.

Palpitations
Some people with dilated cardiomyopathy get palpitations. This is the sensation of your own heart beating and can feel like extra or skipped beats. In some cases, palpitations may start suddenly and feel very fast, and may be accompanied by sweating or light-headedness. Many people experience palpitations which are completely unrelated to a heart condition and are not a cause for concern. Palpitations can be caused by anxiety or stressful situations.

You may feel that your heart is beating too quickly (tachycardia) or too slowly (bradycardia). You may describe it as a feeling of fluttering, missed beats or 'thumps' in your chest or stomach area. Some people describe it as a thudding in their ears. See our booklet *Heart rhythms*. (To order our booklets see More information on page 57.)

HOW IS DILATED CARDIOMYOPATHY DIAGNOSED?

Your doctor may suspect that you have dilated cardiomyopathy because of your symptoms, because you have a heart murmur, or because of the results of an electrocardiogram (ECG) test. You may also be going for tests because someone else in your family has been diagnosed with the condition.

If your doctor suspects that you may have a dilated heart, you'll be sent to the hospital for a series of tests. Your doctor will also refer you to a cardiologist for specialist advice. The most common tests for dilated cardiomyopathy are:

- a physical examination
- an electrocardiogram (ECG)
- an echocardiogram
- exercise testing
- an angiogram.

We explain more about these and other tests on page 29.

IS THERE A CURE FOR DILATED CARDIOMYOPATHY?

At present there is no cure for dilated cardiomyopathy. However, treatment with medicines helps to control symptoms and reduce your risk of the condition getting worse or of getting new symptoms. Some people may need to have a pacemaker or an ICD (implantable cardioverter defibrillator) fitted. In some very rare cases, a heart transplant may be considered. We explain more about all these on page 31.

WHAT OTHER CONDITIONS CAN OCCUR AS A RESULT OF DILATED CARDIOMYOPATHY?

Some people with dilated cardiomyopathy can develop a number of other conditions.

We describe these conditions in this section, which include:

- arrhythmias
- blood clots
- angina
- heart murmurs.

Arrhythmias
When your heart muscle becomes dilated, it stretches the cells in the heart muscle and can cause scars to develop. These abnormalities can interfere with the way that the electrical impulses pass through your heart muscle and can lead to slow, fast or erratic abnormal heart rhythms known as arrhythmias.

Arrhythmias can cause a fall in blood pressure and lead to episodes of dizziness or cause blackouts. They can sometimes slow the flow of blood through your heart and lead to an increased risk of having a stroke. If this is the case, your cardiologist will prescribe anticoagulants for you to reduce that risk. We explain more about anticoagulants on page 34.

Some arrhythmias need to be corrected by delivering a controlled electric shock. This procedure is known as a cardioversion.

Arrhythmias are a common complication in people with dilated cardiomyopathy. We describe some of the common arrhythmias below.

Normally, your heart's natural pacemaker (the SA node) sends out regular electrical impulses from the upper chambers of the heart (the atria). In atrial fibrillation – an abnormal heart rhythm – these impulses are sent from different places in the atria in a disorganised way. This makes your heart beat uncontrollably and often very fast. It can lead to feelings of palpitations or fluttering in your chest. The condition can usually be controlled with medication (see page 33).

Ventricular tachycardias are arrhythmias that affect the ventricles, the lower pumping chambers of your heart. Electrical signals in the ventricles become disorganised and take over the heartbeat independently from the SA node. This leads to a rapid heartbeat. Ventricular tachycardias can be controlled with medication (see page 33), but they can sometimes lead to more life-threatening arrhythmias and the risk of sudden death.

Ventricular ectopics usually occur as single extra beats, originating in the ventricles. They should be investigated to rule out a serious arrhythmia, but they normally don't need any further treatment. They can be found in healthy people too.

Heart block can occur in a small number of people with dilated cardiomyopathy. This is when the electrical impulse travels down to the ventricles slowly, or may even be completely blocked. This affects the way that your heart contracts, and often causes your heart to beat too slowly. For information on treatment for heart block, see page 38.

For more information and to order our booklets on abnormal heart rhythms, see More information on page 57.

Blood clots
People with dilated cardiomyopathy have an increased risk of blood clots forming in the heart, because the blood flows through the heart more slowly than normal. The formation of clots increases the risk of having a stroke. Some people with dilated cardiomyopathy will be prescribed anticoagulants to reduce this risk. For more information on anticoagulants see page 34.

Angina
Angina is usually caused by a narrowing of the coronary arteries, the blood vessels that supply blood to your heart muscle, and causes symptoms such as chest pain. If a coronary artery becomes completely blocked, it can cause a heart attack. However, in people with dilated cardiomyopathy, angina is usually caused by the high pressure on the dilated wall of the left ventricle. This pressure reduces the supply of blood to your heart muscle, causing chest tightness or pain. Treatment for this is usually medication to reduce the pressure and widen the arteries. See page 31 for information about medication.

If you experience chest tightness or pain that is not relieved by your medication, or if you think you are having a heart attack, you should call 999 immediately.

Heart murmurs
Heart murmurs are extra or unusual sounds from your heart that can be heard through a stethoscope. In most people, there is no known cause for them and they do not need treatment. In other people, however, they may be caused by a structural problem in the heart such as a leaking valve. If your doctor hears a heart murmur, they may send you for an echocardiogram (see page 29) to check the structure of your heart.

Is there a risk of sudden death?
Dilated cardiomyopathy is a common condition, and the majority of affected people remain well and have few or no symptoms. Research has shown that, with proper treatment and follow-up, most people with the condition live a normal life. However, because there is a very small risk of developing a life-threatening arrhythmia, a small proportion of people with dilated cardiomyopathy are at risk of sudden death.

Some arrhythmias can cause your heart to beat too fast and chaotically, eventually causing your heart to stop beating. This is a cardiac arrest and can lead to sudden death. This is different to a heart attack, which happens when one of the coronary arteries that supply your heart with blood becomes blocked and the heart muscle which it supplies may be starved of oxygen. For information on treatment for people with dilated cardiomyopathy who may be at risk of sudden death, see page 38.

TESTING, TREATMENT AND YOUR FAMILY

I like to explore new places

I've found new ways to get around

I'm planning new adventures

I live with an inherited heart condition

JEREMY'S STORY

I've been treated for dilated cardiomyopathy for nearly 20 years now.

I take 23 tablets a day. Although the medication has been great for my heart, I've had to come off some of my tablets due to the side effects. But I've managed my condition all this time with medication.

After my diagnosis, we traced back the family history to see if I had inherited my condition. I knew my mother had died young from heart failure. Now my daughter Nancy is screened every three to five years. She gets an ECG and an echocardiogram and has been taught about recognising the warning symptoms. So far, thankfully, she's clear.

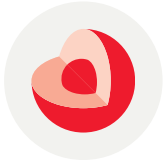
I've been offered a pacemaker in the past and now I'm being assessed to have one fitted. From what I've heard, not many people with my condition have gone this long without a pacemaker. Some days are bad days, but I've learnt to work around my condition and continue doing the things I enjoy.

IMPLICATIONS OF A DIAGNOSIS OF DILATED CARDIOMYOPATHY

How can you inherit a condition?
Your body is made up of trillions of cells. Each cell has a nucleus, which contains information that makes each one of us unique. This information is your genes. We each have between 20,000 and 25,000 different genes. Genes give the instructions that are needed for development and growth of all the cells in your body, and they determine things like hair colour, eye colour, height and blood type.

Genes are arranged end to end along threadlike structures called chromosomes and are made up of a chemical substance called DNA. Each cell usually carries 46 chromosomes arranged in 23 pairs. One of these pairs determines your gender and is known as the sex chromosomes. There are two types of sex chromosomes, the X and the Y chromosomes. Men have an X and a Y chromosome (XY) and women have two X chromosomes (XX).

Your body is made of trillions of cells



Each cell has a nucleus

Each nucleus has 46 chromosomes, in 23 pairs

Each chromosome is made up of a long spiral of DNA

The DNA spiral is divided into genes. You have between 20,000 and 25,000 genes.

You inherit one set of chromosomes from each of your parents. As chromosomes are made up of genes, this means that you inherit one set of genes from each of your parents. This is why you get certain characteristics from your mother and others from your father.

It may help to think of your DNA as a book:

- The chromosomes are the chapters. There are 23 pairs of chromosomes, so 23 chapters.
- Each gene is like a paragraph in the chapter. Genes provide the code for proteins, which decide characteristics like hair and eye colour.
- The code in each of your genes is determined by a string of DNA. The DNA is like the letters in the words. The way these 'letters' are arranged can influence your risk of developing conditions such as high blood pressure or heart disease. For example, the words BARE and BEAR have the same letters, but they're arranged differently so they mean different things. In the same way, if the codes in the DNA are arranged differently, they may work in different ways.

If one of your genes has a 'mistake' or 'fault' in it, a bit like a spelling mistake in a word, it could lead to an abnormal protein being produced in that particular type of cell. The same mistake will be passed on to the next and following generations. This 'mistake' is known as a genetic variant or a gene mutation. Some changes have little or no effect, but others can result in heart conditions such as dilated cardiomyopathy.

If someone is found to have dilated cardiomyopathy and a gene mutation is identified, this means that their close family members can be tested to see if they have the same mutation and are at risk of developing the condition.

How is dilated cardiomyopathy inherited?

Drawing a medical family tree will allow your doctor to see if there is anyone else in your family who may have the same condition. The family tree, known as a pedigree, will show an inheritance pattern.

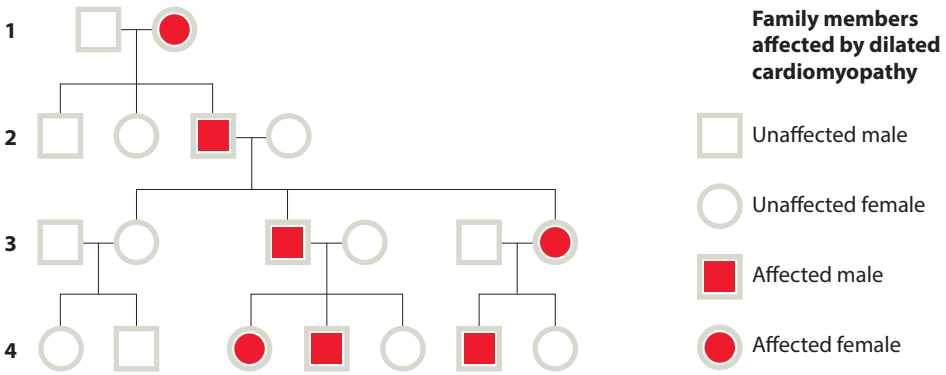
The most common inheritance pattern for dilated cardiomyopathy is known as autosomal dominant. This means that each child of a person who has dilated cardiomyopathy has a 50:50 or one in two chance of inheriting the condition (see the diagram below).

Less commonly, the gene mutation for dilated cardiomyopathy is transmitted on one of the sex chromosomes (the X chromosome).

Men with this so called X-linked form of dilated cardiomyopathy will always pass on the gene mutation to their daughters, but can't transmit it to their sons. This is because their son will only inherit the Y chromosome from their father and their daughter will always inherit an affected X chromosome from their father (see diagram on the next page). Women with X-linked dilated cardiomyopathy tend to be less severely affected (as they have another unaffected X chromosome), but they have a 50:50 or one in two chance of passing on the gene to both their sons and daughters. This is because both the son and daughter can inherit either the unaffected or the affected X chromosome from their mother.

If you inherit the condition, there is no way of knowing how severe it might be.

Autosomal dominant inheritance pattern



Two people in the same family may have different symptoms, and the symptoms may be mild in one person but severe in the other. However, if you don't inherit the gene mutation, you can't pass it on to your children, even if other close members of your family have it.

If you don't know your medical family history, or if this is the first time that dilated cardiomyopathy seems to have been diagnosed in your family, any children of the affected person probably have a 50:50 or one in two chance of having the condition.

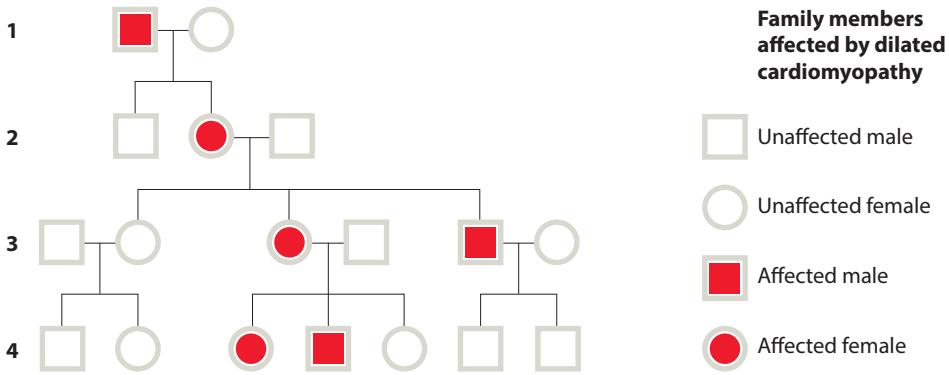
What if something is found in you?

If your doctor thinks that you may have dilated cardiomyopathy, it's important that you have an assessment to find out if you have the condition. We describe all the tests that you may have as part of this assessment on page 28. Confirming a diagnosis will help the doctors decide what treatment is best for you and how often you'll need to be followed up. They will also be able to advise you on what you can do to help you live a normal life.

It may also be possible to have a genetic test to identify the specific gene mutation that has caused your condition. Genetic testing needs to be done at a specialist clinic for inherited heart conditions. Genetic counsellors will explain how likely it is for the gene mutation to be passed on to your children. Your brothers and sisters can also be affected and should be tested.

If you haven't already been referred for an assessment, call the **BHF Genetic Information Service** on **0300 456 8383** to find out where your nearest specialist clinic for inherited heart conditions is, and for information and support about genetic testing.

X-linked inheritance pattern



You should only have genetic testing after you've had advice from a specialist team who can make sure that the right tests are done and that the results are interpreted correctly. Buying genetic tests without the appropriate support and guidance could give you misleading and inaccurate information.

What about screening for your family?
All first-degree relatives (a parent, brother, sister or child) of someone with dilated cardiomyopathy should be provided with enough information to allow them to decide whether they wish to be screened for the condition. Screening usually involves having some tests at a hospital as an outpatient. If a family member has a known gene mutation causing dilated cardiomyopathy, it may be possible to test other family members to see if they have the same gene mutation. We describe the tests for dilated cardiomyopathy below.

ASSESSMENT AT A CLINIC FOR INHERITED HEART CONDITIONS

In this section we describe what happens during an assessment at a clinic for an inherited heart condition such as dilated cardiomyopathy. These clinics are usually in a hospital.

Medical history
Your doctor will ask you lots of questions about you and your family, such as:

- if any medical conditions affect you or your family, including your parents and possibly your grandparents
- if you've ever had symptoms such as blackouts or palpitations
- if there have been any sudden cardiac deaths in your family, including any cot deaths.

If there is a history of sudden death, any coroner's or pathologist's reports that you may have could be helpful.

Medical examination and tests
Most people with dilated cardiomyopathy don't have any visible physical signs of the condition. As part of a medical examination, your doctor will:

- listen to your heart and lungs with a stethoscope
- take your blood pressure
- do an ECG test to check your heart's rhythm and rate.

You'll also need to go to a hospital for a chest X-ray and an echocardiogram to help confirm whether you have dilated cardiomyopathy. You may need further tests to find out how thin your heart muscle is and how much of it is affected. You may also need to have other tests to measure how well you can exercise. We explain more about all of these tests on the next pages.

NON-INVASIVE Tests marked with this symbol are 'non-invasive', which means that the test does not involve penetrating the skin or body.

ECG NON-INVASIVE
Also called an **electrocardiogram**
This is the most basic test. Small sticky patches called electrodes are put onto your chest, arms and legs and are connected by wires to an ECG recording machine. This picks up the electrical activity that makes your heart beat.

Exercise ECG NON-INVASIVE
Also called a **stress test**
This test is the same as the ECG described above, but is recorded before, during and after a period of time spent exercising on a treadmill or an exercise bike. This allows the doctor to examine any changes in the electrical patterns that occur with exercise, and analyse any abnormalities.

Holter monitoring NON-INVASIVE
Also called **ambulatory ECG monitoring**
This test involves using a small digital device that you wear on a belt round your waist. Four or six ECG leads from the device are taped to your chest. The device records the electrical activity of your heart for 24 to 48 hours, or for up to seven days. The doctor can then analyse the electrical activity and rhythm of your heart to find out if you have any arrhythmias such as atrial fibrillation or ventricular tachycardia.

Echocardiogram NON-INVASIVE
Also called an **echo**
This test uses ultrasound waves to look at the structures of your heart. It produces a picture of your heart and allows doctors to measure the size of the chambers of your heart, how thick your heart muscle is and how well it's working. It also looks at the heart valves and can show if there's any regurgitation (when blood leaks back through a valve in the wrong direction – see page 12). Additional equipment, called Doppler ultrasound, can produce a colour image of blood flow within your heart and provide information on how well your heart is working.

Trans-oesophageal echocardiogram
Also called **TOE**
With this procedure, detailed pictures of your heart are taken from your gullet (oesophagus) which lies behind your heart. You will need to have a mild sedative first. You then 'swallow' a small probe which is mounted at the end of a flexible tube. This test allows doctors to accurately assess the structure of your heart.

Cardiopulmonary exercise test NON-INVASIVE
Also called **CPET**
This test analyses the efficiency of your heart muscle by measuring the amount of oxygen your body uses during exercise. You will be asked to breathe into special equipment while you're exercising. If the efficiency of your heart is low, this may suggest that you have cardiomyopathy.

Coronary angiogram and electrophysiological study
If you have chest pain or an abnormal heart rhythm, your doctor may suggest that you have other tests such as a coronary angiogram or an electrophysiological study (EPS). Both these tests are performed in a catheterisation laboratory – or cath lab.

A coronary angiogram involves having a local anaesthetic in your arm or groin, where a catheter (a thin flexible tube) will be passed into your artery. Using an X-ray machine, the catheter will be directed through your blood vessels and into your heart. A special dye will then be passed through the catheter and a series of X-rays taken. This can show up any narrowed areas or blockages in your artery which could be caused by coronary heart disease.

An EPS (electrophysiological study) uses the same technique to place electrical leads inside your heart to analyse its electrical activity and to bring on arrhythmias. This test can be useful for diagnosing and treating abnormal heart rhythms.

Magnetic Resonance Imaging (MRI) NON-INVASIVE
An MRI scan uses a magnetic field to create images of your heart. For this test, you lie in a short 'tunnel', around which there is a large magnet. Short bursts of magnetic fields and radio waves from the MRI scanner allow images to be created, processed and analysed. You must lie still while the scan is done. The whole test takes about an hour. An MRI is not painful or uncomfortable. However, some people with claustrophobia (fear of enclosed spaces) may find they can't cope with having this type of scan.

An MRI is very good at:

- showing the structure of your heart and blood vessels
- measuring the flow of blood through your heart and some of the major arteries
- showing where your heart is working abnormally in conditions such as cardiomyopathy
- identifying defects in the structure of your heart.

An MRI scan can interfere with the way a pacemaker or ICD (see page 36) works. If you have one of these devices, you can't have an MRI scan unless you have an MRI-safe device.

Computerised tomography (CT) scan NON-INVASIVE
A CT scan, sometimes called a CAT scan, uses X-rays to create images of your heart. During this test, you lie on your back while a CT scanner rotates around your body. This produces an image called a tomogram which can be used to look at:

- the pumping action of your heart
- blood flow through your coronary arteries
- the structure of your heart - the heart muscle, valves and coronary arteries.

Myocardial perfusion scan (MPS)
In a myocardial perfusion scan, a small amount of radioactive substance is injected into your blood. The radioactivity in your blood is then measured using a special camera. This test is done both when you're resting and also when you're exercising. It can be used to look at:

- the pumping of your heart
- the flow of blood to your heart
- how your heart works under the stress of exercise.

Endomyocardial or cardiac biopsy
If your cardiologist needs to examine your heart tissue more closely, you may need to have an endomyocardial or cardiac biopsy. You'll be given a mild anaesthetic first. A tube is then put into a vein in your neck or your groin and passed through to your heart. A few tiny pieces of heart tissue are taken and sent to a laboratory for examination.

For more detailed information about these and other tests see our booklet *Tests for heart conditions*. To order our booklets see More information on page 57.

TREATMENT FOR DILATED CARDIOMYOPATHY

Dilated cardiomyopathy is not curable, but most symptoms caused by the condition can be controlled using medicines. Some people may need to have other treatments as well. You'll find information about these treatments on page 36.

Medicines
Below we describe the medicines most commonly used for people with dilated cardiomyopathy. Different people need to take different medicines, depending on their condition and symptoms.

ACE inhibitors (angiotensin-converting enzyme inhibitors)

ACE inhibitors are very effective in reducing and controlling blood pressure. In people with dilated cardiomyopathy, they can help to control the symptoms of heart failure and prevent symptoms getting worse.

Unwanted effects
ACE inhibitors can cause a rapid fall in blood pressure, leading to episodes of fainting and feeling dizzy. Some people develop a dry persistent cough. If this happens your doctor may be able to prescribe different medication, called angiotensin II receptor antagonists.

Angiotensin II receptor antagonists

Angiotensin II receptor antagonists act in a similar way to ACE inhibitors but do not cause a cough.

Unwanted effects
Light headedness.

Beta-blockers

Beta-blockers act by slowing your heart rate. This reduces the amount of work your heart has to do, so that it needs less oxygen, blood and nutrients. Some beta-blockers can help control arrhythmias.

Many preparations of beta-blockers are available, but they differ only slightly from each other.

Unwanted effects
Serious side effects are rare if beta-blockers are used carefully. Minor side effects are common but they tend to lessen as time goes by. The minor side effects include tiredness, fatigue, and cold hands and feet. Other less frequent effects include feeling sick, diarrhoea, skin rashes, impotence, nightmares and dizziness.

You should not stop taking beta-blockers suddenly without medical advice, as coming off them too quickly can make your symptoms worsen suddenly.

Calcium channel blockers (calcium antagonists)

Your heart needs a regular flow of calcium for the muscle cells in the heart to work properly. Calcium channel blockers reduce the amount of calcium entering the muscle cells of the arteries (including the coronary arteries) and cause them to relax and widen. As a result of this, the 'resting phase' of your heart's pumping cycle lasts longer. (The resting phase is when your heart rests in between heartbeats and the coronary arteries fill up and supply your heart muscle with blood.) This means that your heart receives a better supply of blood and has to do less work to pump enough blood around your body.

Some calcium channel blockers may increase or reduce your heart rate while you are resting, while others may have no effect on your heart rate. So different calcium channel blockers are used for different heart conditions.

Unwanted effects
Serious side effects are not common. Minor effects include flushing, headache, dizziness, feeling faint or fainting, swollen ankles, indigestion, feeling sick and vomiting.

Anti-arrhythmic medicines

Anti-arrhythmic medicines are used to control the rhythm of your heart. Beta-blockers, and the calcium channel blocker verapamil, are also often used to treat arrhythmias, but there are several other medicines that are used almost exclusively for this purpose. One of these is amiodarone.

Amiodarone

Amiodarone is very effective in controlling arrhythmias, especially atrial fibrillation (see page 18).

Unwanted effects
At low doses, most people tolerate amiodarone well, but it may produce headache, flushing, dizziness and stomach upsets. More seriously, and more rarely, it may cause disorders of the thyroid gland, lungs and liver. To avoid these complications, you will need to have regular blood tests. You may also have chest X-rays and tests to see how your lungs are working.

Amiodarone tends to make the skin very sensitive to sunlight so, if you're taking this medicine, you should use a powerful sunscreen cream when you're in strong daylight or bright sunshine, and wear a hat.

Ivabradine

Ivabradine slows your heart rate so that your heart doesn't have to work as hard. This can help treat the symptoms of angina and heart failure. Your cardiologist may prescribe ivabradine for you if you're taking other medicines to treat either your angina or heart failure but you still get symptoms.

Unwanted effects
Ivabradine causes a slow heart rate that can sometimes make you feel tired and unwell. It can also cause problems with your eyesight.

Anticoagulants

Some people with dilated cardiomyopathy develop atrial fibrillation (see page 18). Atrial fibrillation carries a risk of blood clots forming. Blood clots are made up of platelets (tiny blood cells) clumped together, and a protein called fibrin. Anticoagulants prevent fibrin from forming and so prevent clots from forming too. However, in doing so, they may cause internal bleeding or make bleeding from a minor injury worse. There are two main types of anticoagulants – heparin and warfarin.

Heparin is injected into a vein and has an immediate effect in preventing further blood clots from forming. This is known as intravenous heparin and is only given in this way if you are in hospital. Another form of heparin called 'low molecular weight heparin' may be given by injection just under your skin, over a longer period of time. This can be given to you either in hospital, or by a nurse at home.

Warfarin (or another oral anticoagulant) is given when long-term prevention of clotting is needed. This medicine is most often used for people with disease of the heart valves, especially those who have been given an artificial heart valve, or for some people who have an abnormal heart rhythm such as persistent atrial fibrillation.

Because the desired effect of anticoagulants is to make the blood thinner so that it doesn't clot so easily, you'll need regular blood tests to make sure that the clotting activity of your blood is within safe but effective levels. At the start, these tests may be carried out almost every day, but later on they will be done only every four to eight weeks. If you've been taking warfarin for a long time and your condition is stable, you may be able to get a home-testing kit and do the tests yourself.

If you're taking oral anticoagulants, you should check with your doctor or pharmacist before taking any other medicines. This is because oral anticoagulants interact with many medicines including antibiotics, aspirin and cimetidine, and with some medicines used to treat arthritis, gout, epilepsy, high blood cholesterol and heart rhythm disorders. Alcohol increases the effect of warfarin, so it's important to avoid excessive drinking or binge drinking.

If you're taking oral anticoagulants, you should avoid drinking cranberry juice as this can affect the amount of time it takes for your blood to clot. Your anticoagulation clinic should be able to give you advice on what changes you may need to make to your diet.

If you're taking anticoagulants, you should always carry an **Anticoagulant card** and remember to tell any doctors, dentists and nurses who are treating you that you are taking anticoagulants.

Any of the following symptoms could mean that your dose of anticoagulants may be too high:

- prolonged bleeding from cuts
- bleeding that does not stop by itself
- nose bleeds that last for more than a few minutes
- bleeding gums
- severe bruising
- red or dark brown urine
- red or black faeces
- for women, heavier bleeding during periods, or other vaginal bleeding.

If you're worried, contact your GP or anticoagulation clinic or the casualty department at your local hospital. Make sure that you have your dosage record card and any other medications with you.

Diuretics

Diuretics, or water tablets, increase the output of water and salt in your urine. They reduce the workload of your heart by making sure that your body doesn't hold too much water or salt.

Diuretics can also help to control your blood pressure. If you have too much fluid in your body, your heart has to work harder to pump it around the body. This extra workload increases your blood pressure.

There are three main types of diuretic:

- thiazide diuretics
- loop diuretics
- potassium sparing diuretics.

Thiazide diuretics (such as bendroflumethiazide) and loop diuretics (such as furosemide and bumetanide) can cause you to lose potassium, so your doctor will arrange a blood test a few weeks after you start taking your tablets to check the potassium level in your blood. If this is getting low, you may be given potassium supplements or a potassium sparing diuretic instead, to correct the problem with the potassium level.

If you're taking a diuretic, you shouldn't have too much salt in your food, as this will counteract the effects of the diuretics. Don't add any salt to food during cooking or at the table, and avoid salty foods. Many processed foods and ready meals contain high levels of salt. It's also important to avoid using salt substitutes as these contain potassium which may have an effect on your blood test results.

Unwanted effects
People with diabetes may find that diuretics raise their blood sugar. People with gout may find that diuretics make their condition worse.

For more information about medicines see our booklet *Medicines for your heart*. To order our booklets see More information on page 57.

Other treatments for dilated cardiomyopathy

Implantable devices

People with dilated cardiomyopathy are at risk of having a heart rate that's too slow and may develop heart block. This may mean you need to have a pacemaker fitted. If you're at high risk of sudden death (for example, if you've already had a cardiac arrest), or if the pumping function of your heart is severely reduced, your doctor may advise you to have an ICD fitted. ICD stands for 'implantable cardioverter defibrillator'.

Both a pacemaker and an ICD consist of:

- a small box called a pulse generator, containing a battery
- one, two or three electrode leads that deliver electrical impulses to the heart.

Pacemaker

A pacemaker can prevent your heart from beating too slowly by 'pacing' your heart to make your heart rate faster. A pacemaker works by:

- monitoring and storing information about your heart rhythm and heart rate
- sending electrical impulses to your heart that stimulate it to contract. This helps to control your heart rate and stop any excessive slowing of your heart that could trigger an arrhythmia.

Most pacemakers are set to work on demand – they monitor your heart and only deliver an electrical impulse if your heart has missed a beat, or if it's beating too slowly. Other pacemakers send out impulses all of the time and are known as fixed rate pacemakers.

A pacemaker is usually implanted just under your left collarbone. This procedure usually takes about an hour and is normally done with a local anaesthetic and mild sedation. The pacemaker battery usually lasts between six and ten years (and sometimes even longer), but you should receive regular check-ups.

For more information on pacemakers, see our booklet *Pacemakers*. To order our booklets see More information on page 57.

ICD

An ICD monitors your heart rhythm through electrodes placed into your heart. If it detects a dangerous arrhythmia it can deliver a small electrical shock to restore your heart's normal rhythm. This is called shock therapy. An ICD can deliver the following treatments:

- pacing your heart to correct your heart rhythm
- cardioversion – one or more small electric shocks to restore your heart's normal rhythm
- defibrillation – one or more larger electric shocks to get your heart back into a normal rhythm.

An ICD is slightly larger than a pacemaker and is usually positioned under your chest wall muscle below your left shoulder. The procedure may take between one to three hours. Most people have a local anaesthetic and mild sedation, but some may have a full (general) anaesthetic. The ICD battery lasts between four and eight years, but you should have regular check-ups at an ICD clinic.

A new type of ICD called a subcutaneous ICD – or S-ICD for short – is suitable for some people. An S-ICD works in the same way as an ICD, but is inserted just under the skin of your chest (outside of the ribcage) and the leads are placed next to your breastbone.

For more on ICDs, see our booklet *Implantable cardioverter defibrillators (ICDs)*. To order our booklets see More information on page 57.

Biventricular pacemaker

If your symptoms are severe, you may need to have a biventricular pacemaker. This is a special type of pacemaker that helps to organise the electrical impulses and coordinate the contracting of your heart muscle. This is sometimes known as cardiac resynchronisation therapy (or CRT for short).

For certain people who have heart failure and who might also be at risk of a life-threatening heart rhythm, a single device which combines a biventricular pacemaker and an ICD can be used. This is known as cardiac resynchronisation therapy with a defibrillator (or CRT-D).

Left ventricular assist device

If your heart failure is very severe and pacing and medicines have failed, an artificial mechanical device can be fitted to help your heart muscle pump blood out of your heart. The device will allow you to live as normal a life as possible out of hospital. These devices are used if you're waiting for a heart transplant. For more information, see our booklet *Heart transplantation*.

Heart transplantation

For a very small number of people, heart transplantation may be considered. However, in 2012/13, there were only 193 heart transplants in the UK. For more information, see our booklet *Heart transplantation*.

For more information and to order our booklets on these treatments, see More information on page 57.

TREATMENT FOR OTHER CONDITIONS WHICH CAN OCCUR AS A RESULT OF DILATED CARDIOMYOPATHY

On page 18 we explained that certain other conditions can occur as a result of dilated cardiomyopathy. These are the treatments you may need if you've developed one of those conditions.

- The two arrhythmias, ventricular tachycardia or atrial fibrillation, usually require treatment with medicines (see page 33).
- heart block can be treated by implanting a pacemaker (see page 36).
- If your doctor thinks you're at increased risk of sudden death, you may be offered treatment to help prevent this.

EVERYDAY LIFE

JANEY'S STORY

After my son Toby was born, I started to become breathless. I struggled to carry Toby, or even push his buggy. I went for a chest X-ray. That's when I found out I had a hugely enlarged heart.

I was admitted to the cardiology ward. I remember feeling out of place because everyone else in the ward was much older than me. I was told I had an abnormal heart rhythm and needed treatment. My husband had just gone out to get a hot drink. When he came back, I'd had a cardiac arrest and doctors were working to resuscitate me.

I started getting better, but they wanted me to have an ICD. I was really worried about it, so I spoke to a young woman who already had one. As a result I agreed to getting the ICD and I've had no problems living with it. I've learnt to listen to my body. I'm in control now and that's important to me.

I love my family

I'm happy to be back at work

I'm determined to keep going

I live with an inherited heart condition

LIVING WITH DILATED CARDIOMYOPATHY

Who should be involved in routine medical care?
Your GP should be involved with your general everyday care. They can discuss your condition with your cardiologist and make any changes to your treatment. You will probably see your cardiologist once a year, but this will depend on your overall condition and your symptoms.

Do I have to make any changes to my everyday life?
For many people, dilated cardiomyopathy does not interfere with their lifestyle. However, there are some things that could make your symptoms and condition worse. On the next few pages we talk about the everyday things that concern people with dilated cardiomyopathy.

Physical activity
Your heart is a muscle and needs exercise to stay healthy. However, some people with dilated cardiomyopathy become short of breath or get chest pain when they are physically active. Moderate intensity exercise is best for you. This is exercise that makes you feel warm and slightly out of breath, but still able to hold a conversation. However, everyone is different and you should always discuss with your doctor the type and level of physical activity that you should do.

Diet, alcohol and weight
Being overweight places extra strain on the heart. Eating a healthy, balanced diet will help you to maintain a healthy weight. See our booklet *Keep your heart healthy* for more information. (To order our booklets see More information on page 57.)

Drinking more than the recommended amount of alcohol can damage your heart health and can lead to high blood pressure. Alcohol is also a depressant, so it can make feelings of anxiety or depression worse. Talk to your doctor to find out what is a sensible limit for you.

Weight gain
If you're eating a healthy diet but you notice that you've put on weight over a few days (about a half to one kilo, or one to two pounds), you'll need to see your doctor. The weight gain could be due to fluid retention which can be treated by adjusting your medicines.

Smoking
Although tobacco smoking is not directly associated with dilated cardiomyopathy, smoking increases your risk of developing coronary heart disease and reduces the flow of blood to your heart muscle. It also reduces the amount of oxygen being carried in your blood and makes your heart work harder. For information on giving up smoking see our booklet *Stop smoking*. To order our booklets see More information on page 57.

Recreational drugs
Recreational drugs will generally increase the workload of your heart and increase your heart rate. If you have dilated cardiomyopathy, you should avoid taking these drugs.

Sex
Sexuality, sexual intercourse, pregnancy, erectile dysfunction (when a man is unable to get or maintain an erection), and loss of sex drive are some of the concerns that people with dilated cardiomyopathy have.

Knowing your limitations and what brings on your symptoms can help you enjoy a full and sexually active life. Like any other physical activity, having sex can increase your heart rate and blood pressure. This increases the work of your heart and, for some people with a heart condition, sex may bring on symptoms such as breathlessness or chest discomfort. However, sex is just as safe as other equally energetic forms of physical activity or exercise.

To reduce the chance of these symptoms during sex, avoid having sex after a heavy meal, and try not to be too energetic at the start of your sexual activity.

Loss of sex drive is not uncommon in people with a heart condition. Some men may experience impotence. This may be the result of:

- taking certain medicines, such as beta-blockers, which can affect your sex drive
- the emotional stress you may be feeling
- poor blood circulation or diabetes.

Impotence is a common problem so, if you're having difficulties, talk to your doctor about it. Talking to your partner can also help to lessen your concerns and fears and help your partner to understand your situation.

Other common causes of loss of sex drive are:

- depression
- concerns and fear about how safe it is for you to have sex
- anxiety about the possibility of your ICD delivering an electrical shock during sexual activity
- lack of communication between you and your partner.

If you have a heart condition, you should be cautious about taking PDE-5 inhibitors such as Viagra. You should not take these medications if you're taking GTN or any other medication containing nitrates. PDE-5 inhibitors can also interfere with other medicines for your heart, so always check with your doctor beforehand.

General health

Do I need to have a flu vaccination?

Having a flu vaccination will not prevent you from getting a flu virus, but it will reduce the severity of the flu if you do get it. Every year there is a different strain of the flu virus and a new vaccine is developed. If your doctor recommends that you have the flu vaccine, you will need to have a vaccination each year.

What if I need an anaesthetic?

In most people with dilated cardiomyopathy, having a general or local anaesthetic is not associated with any additional risk. Your anaesthetist will monitor your blood pressure and heart rate carefully during your surgery or procedure. Some spinal blocks or epidurals can cause a drop in blood pressure, so they should be used with caution.

Anxiety and depression

Finding out that you have a diagnosis of cardiomyopathy can be distressing. In the early days it's normal to feel shock, anger and disbelief. We all have different ways of adjusting, and there is no right or wrong way. Stress, fear and anxiety can sometimes help us to re-examine and to change our lifestyles. However, when emotions like this persist for long periods of time, or begin to overwhelm you, they can lead to anxiety and depression that may need medical treatment.

Talking to someone can be very helpful. Friends and relatives may be able to understand how the condition is affecting you, but sometimes it's easier to talk to someone who's not so closely involved. Talking to other people with cardiomyopathy may help you come to terms with your condition and help you to see that you're not alone. There are also many organisations and charities that can help you to cope. See page 58 for details.

Recognising and understanding the cause of your anxiety can help you to deal with it. Using relaxation techniques can help. If simple techniques don't help, or if you feel overwhelmed with your anxiety, you should speak to your doctor who will be able to decide if you need medical treatment.

Depression

It's normal to feel fed up or miserable from time to time, and feelings like this usually don't last for long or interfere significantly with our lives. However, if these feelings persist and severely interfere with your life, you may have clinical depression. Clinical depression can last for months and can affect you in a variety of ways, both physically and psychologically. You may be unable to sleep properly, lose your appetite, or frequently think that life is not worth living. Depression usually comes on gradually. Some people may not recognise that they are becoming depressed because they are paying more attention to their physical symptoms than their psychological state.

Having a routine and remaining active can help to deal with mild depression. It can help you to feel in control and get back to a natural sleeping pattern. Your doctor may suggest that taking sleeping tablets for a short time will help you. Although dilated cardiomyopathy often restricts vigorous exercise, it shouldn't stop you being active. (See page 42 for more on physical activity.)

If you have severe or chronic depression, you may benefit from taking anti-depressants. They help by altering the transmission of chemical substances in the brain, thereby improving your mood. It can take several weeks for you to feel the benefits of anti-depressants. Your doctor may also suggest that you would benefit from speaking to a clinical psychologist. See our booklet *Heart to heart* for more information. To order our booklets see More information on page 57.

Driving
You may continue to drive if your symptoms are well controlled and your doctor says that you're fit to do so. You may need to notify the DVLA (Driver and Vehicle Licensing Agency) about your heart condition or about a treatment you've had for it. For more information, contact the DVLA:

- visit www.gov.uk/health-conditions-and-driving
- call the DVLA on 0300 790 6806
- write to them at DVLA, Swansea SA99 1TU.

Work
Most people who are diagnosed with dilated cardiomyopathy will be able to continue in their normal job. However, if you have a heavy manual job which involves strenuous activity you should discuss this with your doctor.

Whatever your job, your doctor may be able to provide additional information for your employer which could mean that you're able to continue working. If your employer (or potential employer) asks you to fill out a medical questionnaire, you must tell them about your condition.

Holidays and travel insurance
If you have dilated cardiomyopathy, there are no restrictions on flying provided that your symptoms are well controlled, but make sure you plan ahead:

- if you think you might need oxygen during the flight, speak to your doctor about this and then to your travel company or airline
- if you have heavy bags, make sure there is someone who can lift them for you
- remember to leave enough time to get to the departure gates without rushing
- if you get breathless easily, you may also want to organise help at the airport. Airlines can often provide transport to a departure gate or a wheelchair for you to use.

If you want to travel within the European Union, you should get a European Health Insurance Card (EHIC) and take it with you when you're travelling. This card ensures EU nationals obtain the same level of health care as a local resident in a member country when travelling. You can apply for this card online through the NHS website or by phoning the automated service on 0300 3301350.

If you're diagnosed with dilated cardiomyopathy, an insurance company may charge more for your travel insurance. For a list of insurance companies who are sympathetic to people with heart conditions, contact the British Heart Foundation or Cardiomyopathy UK. Their contact details are on pages 57-58.

Life insurance and mortgages
If you have dilated cardiomyopathy, you may have difficulty obtaining life insurance or a mortgage.

The Association of British Insurers (ABI) says that insurers will take into account a family history of all medical conditions. They will not ask people to take genetic tests when applying for life insurance. However, if you wish to take out a new life insurance policy, you will be required to report the results of any genetic tests you have already had, unless otherwise indicated by the life insurance company.

Financial support
Some people with dilated cardiomyopathy may be able to apply for Personal Independence Payment (PIP). This is a social security benefit that helps towards some of the extra costs arising from a long-term illness or disability. Between April 2013 and October 2017, PIP will start to replace Disability Living Allowance (DLA) for people aged 16 to 64. If you already receive DLA, you'll need to check how this change affects you. There are also other benefits and allowances available for those people whose symptoms result in severe restrictions. For more information, search online for GOV.UK.

PREGNANCY AND CHILDBIRTH

Dilated cardiomyopathy can sometimes occur for the first time in pregnancy. See page 15 for more on this.

If you know you have dilated cardiomyopathy, you may be concerned about taking medications during pregnancy and the effect they may have on your baby. If you're planning a family, you should discuss these concerns with your doctor before becoming pregnant.

If you're thinking of having an epidural during your labour, you should discuss this with your doctor early on in your pregnancy, as an epidural can cause a significant fall in blood pressure.

Should I have children?
Some cases of dilated cardiomyopathy are genetic, but not all are. If your dilated cardiomyopathy is not caused by a gene mutation, you will not pass the condition on to your children. However, it's possible to have a faulty gene that can lead to a heart condition, yet never develop any signs of symptoms of the condition itself. You can still pass the gene on and there's no way of knowing how it may affect your child, even if they do inherit the same faulty gene. Some people with an inherited heart condition do not develop symptoms, yet their child could inherit the same faulty gene and develop symptoms.

If you have peripartum cardiomyopathy – dilated cardiomyopathy which developed during your pregnancy – and it has not gone away after the delivery, your doctor may advise you not to have any more children. (See page 15 for further information.)

You will find information about the risk of passing on the condition to your children on page 26. The decision about whether to have children is one that you should make only after discussing it with your partner and at a clinic for inherited heart conditions. To find out where your nearest clinic is, call the **BHF Genetic Information Service** on **0300 456 8383**.

Family planning
If your family is affected by cardiomyopathy, you should think carefully about family planning. You will need to consider the possibility of passing the condition to your child, as well as the potential risk of pregnancy to a mother with cardiomyopathy. Safe and effective methods of contraception are available to people with cardiomyopathy, which can be discussed with your care team.

If you or your partner have cardiomyopathy and know that it's caused by a mutation in one of your genes, you may be suitable for treatment called pre-implantation genetic diagnosis (PGD). This treatment involves IVF treatment (*in-vitro* fertilisation). Embryos created through IVF are tested to see if they contain the same gene mutation as that of you or your partner. Only embryos that do not contain the mutation are then implanted into the womb.

The Human Fertilisation and Embryology Authority have granted licences for PGD in some types of cardiomyopathy. For more details contact the **Cardiomyopathy UK** helpline on **0800 018 1024**.

LOOKING FORWARD

I like travelling to see my family

I love the outdoors

I'm still fighting

I live with an inherited heart condition

JUNE'S STORY

About 15 years ago, I started to have heart palpitations. I had a busy job as a community midwife, so I put it down to being busy. But soon after, my heart rate started to race and didn't stop for hours. I was told I had atrial fibrillation.

During a two week stay in hospital I had every test you could imagine. My symptoms got worse and eventually I was diagnosed with dilated cardiomyopathy. I had an ICD fitted the same year. It was an anxious time, but I kept positive as I knew it would help me.

A few years later, I started to feel breathless. Tests showed that my heart function had decreased and I had heart failure. My saving grace was home visits from BHF nurses who would assess my symptoms and advise me how much I could push myself.

My condition has vastly improved now and I know there's support if I need it. I've always been a really active person and even with my condition, I can still enjoy pushing myself.

THE FUTURE

Diagnosis and treatment of dilated cardiomyopathy has improved recently, and many people who get an early diagnosis and treatment recover their normal heart function and lead normal lives. Further research into better and more effective treatment and screening options means that the quality of life, treatment and monitoring of people with dilated cardiomyopathy is likely to improve further in the future. New areas of research and development include:

- Faster and cheaper technologies that allow more of the gene mutations causing cardiomyopathy to be identified. A new project is looking at the genes of 100,000 people with inherited heart conditions and is expected to inform care and lead to new treatments for these conditions.
- Very small pacemakers that don't use electrode leads and are inserted directly into the heart through a vein in the groin.
- Smaller ECG recorders that can send information straight from a patient to their doctor through email.
- A new pacemaker-like device designed to improve heart failure symptoms and slow heart failure progression by stimulating the vagus nerve in the neck.
- A sticking plaster like patch to stick on the chest and record heart rhythms.
- 3D electronic membranes that fit over the outside of the heart and use sensors and electrodes to monitor the heart's electrical activity. In the future, these membranes may replace pacemakers and ICDs.
- Research on the use of stem cells to reduce scarring in the heart, increase the number of healthy, working heart cells and improve the heart's ability to pump properly.
- Gene therapies - drugs to treat the actions of particular gene mutations causing cardiomyopathy.

TECHNICAL TERMS

A

Angina
Heaviness or tightness in the centre of your chest, which may spread to your arms, neck, jaw, back or stomach. Or it may affect just your neck, jaw, arms or stomach.

Angiogram
An X-ray picture of your blood vessels which shows whether the arteries are narrowed and, if so, how narrow they have become. An angiogram can be used to examine the coronary arteries (a coronary angiogram) or other arteries in your body.

Anticoagulation
Treatment with medicine, to thin your blood and reduce the risk of clots.

Aorta
The large artery (blood vessel) leading out of the left side of your heart and supplying your whole body with blood.

Arrhythmia
An abnormal heart rhythm.

Ascites
Collection of fluid in the abdomen.

Atrial fibrillation
A fast, abnormal heart rhythm.

Atrium
One of the two top chambers of your heart. (The plural of 'atrium' is 'atria'.)

Autosomal inheritance
Where a condition is passed on in a family from one generation to the next without skipping any generations.

Autosomal dominant inheritance
In this type of inheritance, if one of your parents has a faulty gene, there's a 50:50 chance you could inherit it.

C

Cardiac arrest
When a person's heart stops pumping blood around the body and they stop breathing normally. This is fatal if the heart's normal rhythm is not restored within a few minutes.

Cardiologist
A doctor specialising in diseases of the heart.

Cardiomyopathy
A disease of the heart muscle.

Cardioversion
A procedure to restore a regular heart rhythm.

Chromosome
A threadlike fibre which is in all cells and which carries genetic information.

D

Diuretics
Also known as 'water tablets'. Diuretics increase the output of water and salt in your urine.

DNA
The genetic code from which proteins 'the building blocks of life' are made. We all receive a copy of half of each of our parents' DNA when the egg and sperm meet to conceive a new human being.

Doppler ultrasound
A test usually combined with an echocardiogram to produce a colour-coded image of blood flow within your heart.

E

Electrophysiological study (EPS)
A technique for detecting and analysing abnormal heart rhythms.

Endomyocardial biopsy
A procedure where a small amount of heart muscle tissue is taken for examination under a microscope.

G

Gene
A segment of DNA responsible for the production of a specific substance such as a protein, which in turn is essential for a particular characteristic or function in your body.

H

Heart block
When the electrical impulses sent by the atria to the ventricles are delayed or are blocked.

Heart failure
When the pumping action of your heart is inadequate to meet your body's demands.

Holter monitor
A 24-hour recording of an ECG (electrocardiogram).

I

Implantable cardioverter defibrillator (ICD)
A metal electronic device similar to a pacemaker. It is implanted under the chest wall muscle below your left shoulder. It can regulate the rhythm of your heartbeat and, if a dangerous arrhythmia occurs, it can deliver an electrical shock to your heart to restore the normal heart rhythm.

L

Left ventricular enlargement
When the left ventricle becomes enlarged, but the structure of your heart muscle is not affected.

M

Mitral regurgitation
When your blood flows in a backward direction through the mitral valve.

Mutation
A mutation or 'mistake' in the DNA code that causes its eventual product (usually a protein) to function abnormally, which in turn is responsible for a disease.

Myocardium
Your heart muscle.

P

Pacemaker
An electronic device which takes over the role of your heart's natural pacemaker and regulates the rhythm of your heartbeat. It is usually implanted just under your left collarbone.

Palpitation
When you become aware of your heartbeat – for example, when it feels as if it is beating abnormally fast or slowly, or irregularly or heavily.

Pulmonary artery
Artery carrying blood from the right side of your heart to your lungs.

S

Septum
The thick, muscular wall between the left and right sides of your heart.

Side effects
Unwanted effects of a medicine.

T

Tachycardia
A fast heart rate.

Transoespohageal echocardiogram
A procedure where detailed pictures of your heart are taken from your gullet (oesophagus) which lies behind your heart.

V

Ventricles
The two bottom chambers of your heart.

Ventricular
From, or belonging to, the ventricle.

X

X-linked inheritance
When a mutation of a gene is carried specifically on the X sex chromosome.

FOR MORE INFORMATION

For information on your nearest clinic for inherited heart conditions

BHF Genetic Information Service (GIS)
Greater London House
180 Hampstead Road
London NW1 7AW

Phone: 0300 456 8383
Website: bhf.org.uk

The BHF GIS can provide you with information and support if someone in your family has been diagnosed with, or has died from, a suspected inherited heart condition. This includes supporting you and your family by helping you get an expert assessment in a specialist clinic that deals with inherited heart conditions.

BHF publications

You can find out more about the topics covered in this booklet in some of our other resources:

Atrial fibrillation (HIS24)

Heart rhythms (HIS14)

Heart transplantation (HIS13)

Implantable cardioverter defibrillators (ICDs) (HIS19)

Living with heart failure (HIS8)

Losing someone to heart disease (G419)

Medicines for your heart (HIS17)

Pacemakers (HIS15)

Stop Smoking (G118)

Sudden arrhythmic death syndrome (M111A)

Tests for heart conditions (HIS9)

We also have a range of booklets that cover other inherited heart conditions, how to have a healthy lifestyle and how to keep your heart healthy. Visit our website **bhf.org.uk** for more information.

To order any of these booklets:

- call the BHF Orderline on 0870 600 6566, or
- email orderline@bhf.org.uk or
- visit bhf.org.uk/publications

Our resources and services are free of charge, but we rely on donations to continue our vital work. If you'd like to make a donation, please call our donation hotline on **0300 330 3322** or visit our website at **bhf.org.uk/donate**

FOR MORE ON CARDIOMYOPATHY

Cardiomyopathy UK
Unit 10 Chiltern Court
Asheridge Road
Chesham
Bucks HP5 2PX

Freephone Helpline: 0800 018 1024
(Monday to Friday, 8.30am to 4.30pm)
Website: www.cardiomyopathy.org
Email: info@cardiomyopathy.org

Cardiomyopathy UK is a registered charity that helps people who are affected by cardiomyopathy.

Cardiomyopathy UK provides information and support to families affected by cardiomyopathy. It has cardiomyopathy support nurses, patient information days, support groups and a network of affected volunteers who provide support to others by telephone and email. To become a member of the charity, call the helpline or see the website.

Other Cardiomyopathy UK publications

- Living with cardiomyopathy
- Cardiomyopathy in children and young people
- Hearty – children's guide to cardiomyopathy

FOR SUPPORT ON COPING AS A FAMILY WHERE THERE HAS BEEN A SUDDEN CARDIAC DEATH

Cardiac Risk in the Young – CRY
Unit 7 Epsom Downs Metro Centre
Waterfield
Tadworth
Surrey KT20 5LR

Phone: 01737 363222
Email: cry@c-r-y.org.uk
Websites: www.c-r-y.org.uk
www.sads.org.uk
www.cry-csc.org.uk

CRY offers help, support and counselling to families where there has been a sudden cardiac death of an apparently fit and healthy young person.

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About the British Heart Foundation

The British Heart Foundation is the nation's heart charity, saving lives through pioneering research, patient care and vital information.

What you can do for us
We rely on donations to continue our vital work. If you would like to make a donation to the British Heart Foundation, please call our donation hotline on **0300 330 3322**, visit **bhf.org.uk/donate**, or post it to us at the address below. Thank you for supporting our fight.

There are lots of other ways that you can help us. Go online at **bhf.org.uk** to find out how.

Have your say
We would welcome your comments to help us produce the best information for you. Why not let us know what you think? Contact us through our website at **bhf.org.uk/contact** or write to us at the address below.

British Heart Foundation
Greater London House
180 Hampstead Road
London NW1 7AW
bhf.org.uk

Heart Helpline
0300 330 3311
(a similar cost to 01 and 02 numbers)
For information and support on anything heart-related.

Genetic Information Service
0300 456 8383
(a similar cost to 01 and 02 numbers)
For information and support on inherited heart conditions.

About Cardiomyopathy UK

Cardiomyopathy UK is a registered charity that provides information and support to families affected by the heart muscle disease cardiomyopathy. We provide information on the different types of cardiomyopathy and help people to understand cardiomyopathy, reducing their fears and promoting independence. We provide a free helpline, information booklets, cardiomyopathy support nurses, information days, support groups and a network of volunteers, called key contacts, who provide one-to-one support over the telephone or by email.

Cardiomyopathy UK Website
Cardiomyopathy UK is the only UK charity dedicated to providing support and information to families affected by cardiomyopathy. It is supported by supporter donations, gifts in wills and fundraising. For more information about the charity and what it does, please call **0800 018 1024** or visit our website **www.cardiomyopathy.org**

Freephone Helpline
We have a freephone helpline (0800 018 1024) that is manned from 8.30am to 4.30pm on weekdays. Callers can usually speak to one of our cardiomyopathy support nurses.

British Heart Foundation

Cardiomyopathy UK
the heart muscle charity

At the British Heart Foundation, we've pioneered research that's transformed the lives of people living with heart and circulatory conditions. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease.

Cardiomyopathy UK campaigns for more heart checks and gene tests for affected families to find those at risk and save lives. We educate doctors about best practice in diagnosing and treating affected families so they get better care.

But so many people still need our help.

Join the British Heart Foundation and Cardiomyopathy UK in our fight for every heartbeat in the UK. Every pound raised helps to make a difference to people's lives.

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