British Heart Foundation

Inherited heart conditions
Dilated cardiomyopathy

In association with

CMA
CARDIOMYOPATHY ASSOCIATION

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

Contents

Introduction

You may be reading this booklet because you have been diagnosed with a heart condition called dilated cardiomyopathy. Or maybe your doctor has suggested that you should have some tests to find out if you have inherited this condition because someone else in your family has been diagnosed with 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 for short)
- 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 64 for details.

In most cases, having dilated cardiomyopathy does not affect a person's quality of life or lifespan. However, a small number of people with the condition do experience significant symptoms and could be at risk of sudden death. It is important that families affected receive an 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 is important that the close blood relatives of someone with the condition should have an assessment to find out if they have inherited the same condition
- describes the tests your doctor or cardiologist 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 are found to have dilated cardiomyopathy.

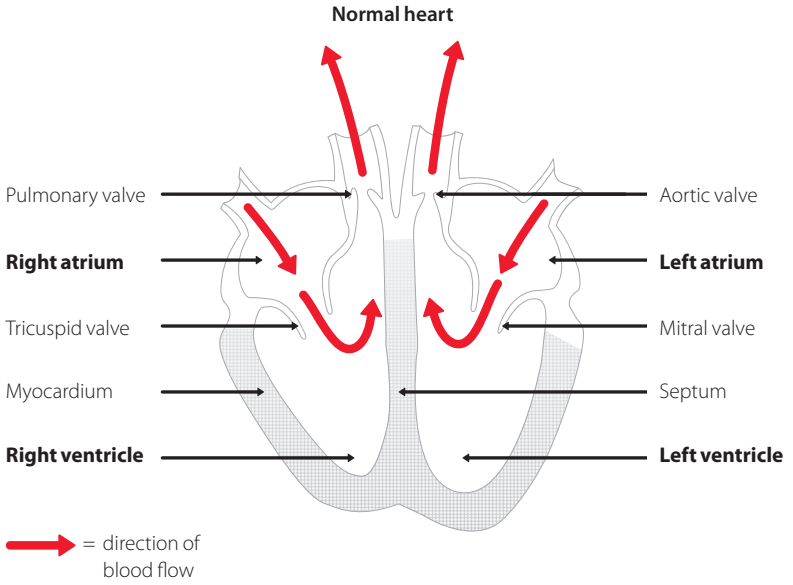
We explain the medical and technical terms as we go along but, if you find a word you don't understand, look it up in the list of Technical terms on page 59.

This booklet has been produced with the help of cardiologists and other health professionals, and also people who have dilated cardiomyopathy. We hope that the booklet will help you to understand your condition and to come to terms with what it means for your close family. If you need further support or information, see page 64.

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.

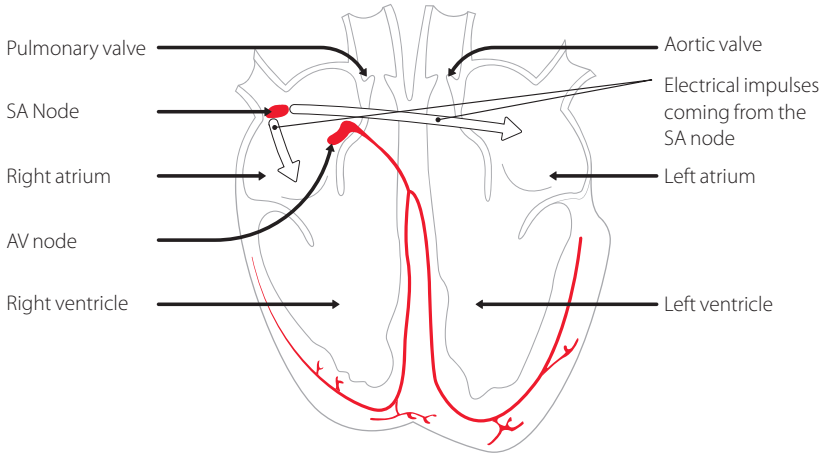


How the heart functions electrically

The pumping action of the heart is caused by a flow of electricity through the heart that repeats itself in a cycle. The normal trigger for the heart to contract comes from the heart's natural pacemaker, the SA node (sino-atrial node), which is in the right atrium (see the diagram on page 10). 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 electrical impulse spreads into the ventricles, causing the heart muscle to contract and to pump

blood out of the ventricles. The blood from the right ventricle goes through the pulmonary artery and then 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 consists 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 is the myocardium that is affected by cardiomyopathy.

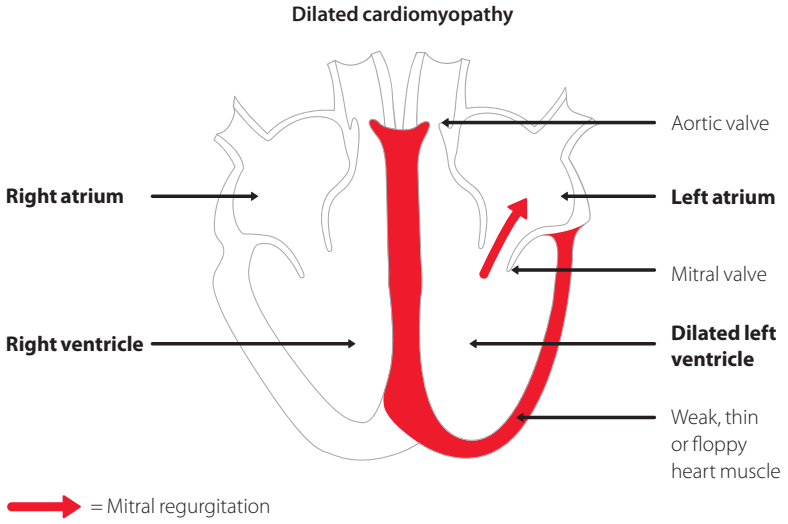
The pericardium is a thin, double layer that forms a protective sac around the outside of the heart. It contains a small amount of fluid – called pericardial fluid – which acts as a lubricant when the heart is contracting.

Dilated cardiomyopathy

What is dilated cardiomyopathy?

Dilated cardiomyopathy is a disease of the heart muscle. It is often a genetic condition. This means that it is caused by a mutation in one or more genes that can be passed on through families. We explain more about how cardiomyopathy is inherited on page 27.

How does dilated cardiomyopathy affect the heart muscle?
Having dilated cardiomyopathy means that the left ventricle becomes dilated (stretched). When this happens, the heart muscle becomes weak, thin, or floppy and is unable to pump blood efficiently around the body (see the diagram below). This can lead to fluid building up in the lungs, ankles, abdomen and other organs of the body and a feeling of being breathless. This collection of symptoms is known as heart failure. In most cases dilated cardiomyopathy develops slowly, so most people have quite severe symptoms before they are diagnosed. There may also be 'mitral regurgitation'. This is when some of the blood flows in the wrong direction through the mitral valve, from the left ventricle to the left atrium.



Other conditions – such as coronary heart disease, high blood pressure (hypertension), or heart valve disease – can also cause the heart to become dilated and these conditions can also lead to the symptoms of heart failure. So, if you have symptoms of heart failure, your doctor will need to do tests to find out exactly what is causing the symptoms. Dilated cardiomyopathy occurs because of a problem with the heart muscle and not because of another condition.

What causes dilated cardiomyopathy?

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 different. Our genes make us who we are – for example, how tall we will be or what colour hair we will have. This genetic information is held in our DNA in the cells of our body. The genetic information is produced through a coding system of proteins, that tells all of the cells in our bodies what their function should be.

If there is a mistake in one of these codes, the cells will do something different or not develop as they should do. These mistakes are known as genetic mutations. We explain more about genetic inheritance and coding on pages 25–30.

In most cases, the exact reason for dilated cardiomyopathy is not known and the condition is called 'idiopathic dilated cardiomyopathy'. ('Idiopathic' means that there is no known cause).

Scientists have identified some abnormal genes that are known to affect the development of heart muscle, and that may cause dilated cardiomyopathy. But they have also found many other genetic mutations that could possibly cause the condition, so this makes it more difficult to do reliable genetic testing on individuals to find out if they have the condition (see page 29).

Also, some non-genetic conditions are known to be linked to an increased risk of developing dilated cardiomyopathy. These are:

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

In people who develop dilated cardiomyopathy and who have one of the four conditions above, we do not know for sure if they already had a genetic mutation which caused the dilated cardiomyopathy, or if it was their condition (for example, the viral infection or auto-immune disease) that caused the dilated cardiomyopathy.

Viral infections

We are all exposed to many viruses every day. Normally, the 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.[1] This is known as viral myocarditis.

Viral myocarditis is commonly caused by enteroviruses (most commonly Coxsackie B virus), and adenoviruses. It is thought that dilated cardiomyopathy may occur when the heart muscle is badly damaged by the initial infection. Or it may be that the virus triggers the body's own defence system (the immune system) which then attacks and damages the heart muscle.

Auto-immune disease

The body's immune system is responsible for defending the body against infection – for example, against viruses and bacteria. Sometimes the immune system breaks down and starts to attack the body's own tissues. This is called auto-immune disease. Some people who are diagnosed with dilated cardiomyopathy appear to have this condition.[1]

Exposure to toxins (or poisons) or certain medicines

In very rare cases, exposure to certain toxins can cause dilated cardiomyopathy. In these cases, we do not 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 the heart muscle, which can lead to dilated cardiomyopathy. The risk of this happening is usually related to the total dose of anthracyclines received.

It can take years for dilated cardiomyopathy to develop and so the effects on the heart may not be seen immediately. If you have 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.

Pregnancy

In about 1 in every 1500 to 1 in every 15,000 pregnancies, the woman can develop dilated cardiomyopathy.[2] It can occur from mid to late pregnancy or soon after delivery and is known as peripartum cardiomyopathy. It is possible that, in these circumstances, the woman may already have 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 she gets the appropriate treatment. However, it is possible that the condition could develop again in subsequent pregnancies.

If you have had peripartum cardiomyopathy but do not fully recover from it, your cardiologist may advise you not to have any more children.

Women who know they have dilated cardiomyopathy and who wish to become, or who unexpectedly find that they are, pregnant should see their cardiologist and obstetrician for specialist advice.

What are the symptoms of dilated cardiomyopathy?

Most people who are affected by dilated cardiomyopathy remain well. Some people have a few symptoms, but others may develop problems which need more complex treatment. Once the condition has been diagnosed, in most cases it can be controlled with medication or other treatments (see page 35).

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 the heart muscle becomes less efficient at pumping blood around the body. Not everyone who has dilated cardiomyopathy goes on to develop all the symptoms of heart failure. These symptoms include shortness of breath, ankle and abdominal swelling, and tiredness. The symptoms usually come on slowly, but sometimes they can come on suddenly – for example, in the circumstances described on page 14. See our booklet *Heart failure* for more information. (To order our booklets see 'More information' on page 64).

Shortness of breath

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

Ankle and abdominal swelling

Fluid can accumulate around the ankles or small of the back causing swelling (oedema), or sometimes there can be swelling in the abdomen (ascites).

Tiredness

The reduced blood supply to the body can lead to a feeling of heavy limbs and excessive tiredness, and can affect a person's ability to exercise.

Palpitations

Some people with dilated cardiomyopathy get palpitations. This is a sensation of an extra or skipped heartbeat. 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 the 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 64).

Other symptoms

Sometimes, other conditions can develop as a result of dilated cardiomyopathy and may produce other symptoms. We describe these on page 20.

How is dilated cardiomyopathy diagnosed?

Your doctor may suspect that you have dilated cardiomyopathy because of your symptoms, or because you have a heart murmur, or because of the results of your ECG (electrocardiogram). Or, you may 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, he or she will send you to the hospital, usually as an outpatient, 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 32.

Is there a cure for dilated cardiomyopathy?

At present there is no cure for dilated cardiomyopathy, but treatment with medicines helps to control symptoms and reduce the risk of the condition getting worse or of getting new symptoms. Some people may need to have a pacemaker or an ICD (internal cardiac defibrillator) fitted. In some very rare cases, a heart transplant may be considered. We explain more about all these on page 35.

What other conditions can occur as a result of dilated cardiomyopathy?

In some people with dilated cardiomyopathy, a number of other conditions can develop. These may include the following:

Arrhythmias

When the heart muscle becomes dilated, it stretches the myocardial cells (the cells in the heart muscle) which can interfere with the way that the electrical impulses pass through the heart muscle. This can lead to slow, fast or erratic heart rhythms known as arrhythmias.

Arrhythmias can cause a fall in blood pressure and lead to episodes of dizziness or fainting. They can sometimes disturb the flow of blood through the 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 37.

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.

In atrial fibrillation, the atria (the two upper chambers of the heart) beat irregularly and often very fast. This can lead to feelings of palpitations or fluttering in the chest. The condition can usually be controlled with medication (see page 36). For more information on atrial fibrillation, see our booklet *Atrial fibrillation*. (To order our booklets see 'More information' on page 64).

Ventricular tachycardias are arrhythmias that affect the ventricles – the lower pumping chambers of the heart. The ventricles take over the heartbeat independently of the SA node, leading to a rapid heartbeat. Ventricular tachycardias can be controlled with medication (see page 36), but they can sometimes lead to more life-threatening arrhythmias, and an increased risk of sudden death. For more information on sudden death, see page 22.

Ventricular ectopics usually occur as single extra beats. They need to be investigated but do not normally 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 the heart contracts. For information on treatment for heart block, see page 42.

For more information on abnormal heart rhythms see our booklet *Heart rhythms*. (To order our booklets see 'More information' on page 64).

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 37.

Chest pain

Chest pain or angina is normally caused by a narrowing of the coronary arteries – the blood vessels that supply blood to the heart muscle. If a coronary artery becomes completely blocked, it can cause a heart attack. However, in people with dilated cardiomyopathy the chest pain is usually caused by the high pressure on the dilated wall of the left ventricle. This pressure reduces the supply of blood to the heart muscle, causing the pain. Treatment for this is usually medication to widen the arteries and reduce the pressure. See page 35 for information about medication.

If you experience chest 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 unusual sounds from the 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, he or she may send you for an echocardiogram (see page 32) to check the structure of your heart.

Endocarditis
This is an infection of the endocardium, the lining of the heart. It is a rare but serious condition, but it can be treated (see page 42).

Is there a risk of sudden cardiac death with dilated cardiomyopathy?
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 getting a life-threatening arrhythmia, a small proportion of people with dilated cardiomyopathy are at an increased risk of sudden cardiac death.

Sudden cardiac death is the result of an arrhythmia (when the heart beats too fast and chaotically), which may eventually cause the heart to stop beating. This is called a cardiac arrest. (This is different to a 'heart attack', which happens when one of the coronary arteries that supply the 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 cardiac death, see page 42.

Testing, treatment and your family

Implications of a diagnosis of dilated cardiomyopathy

How do people get dilated cardiomyopathy?

Our bodies are made up of millions of cells. Each cell has a nucleus, which contains information that makes each one of us unique. These are our genes. Your 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 a threadlike structure called a chromosome. The chromosomes and genes are made up of a chemical substance called DNA. Each cell usually carries 46 chromosomes arranged in 23 pairs. See the diagram below.

We inherit one set of chromosomes from each of our parents. As the chromosomes are made up of genes, this means that we inherit one set of genes from each parent. This explains why we inherit certain characteristics from our parents.

It may help to think of yourself as a book:

- The chromosomes are the chapters. There are 22 pairs of chromosomes and one pair of sex chromosomes (men have an X and a Y chromosome XY, and women have two X chromosomes XX), so 23 chapters.
- The genes are coding for proteins that dictate characteristics like hair and eye colour or your height. The coding is like the words in the chapters.
- The code in your 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' 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 could be passed on to the next and following generations. This is known as a genetic mutation. Some changes have little or no effect, but others can result in heart problems such as dilated cardiomyopathy, or other genetic conditions such as cystic fibrosis (a disease affecting the lungs and pancreas).

Research has shown that screening of the relatives of people who have dilated cardiomyopathy can identify others in their family who may be at risk of developing the condition. In one research study in which the close relatives of people with dilated cardiomyopathy were screened, 1 in 3 of the people with dilated cardiomyopathy were found to have at least one relative with the condition, even though the relatives did not have any symptoms.[3]

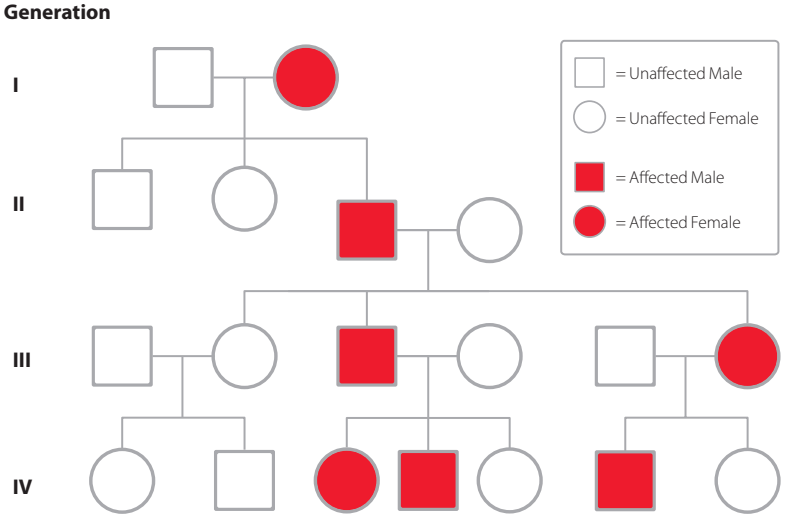
If someone is found to have dilated cardiomyopathy and a mutation is identified, this means that their close family members can be tested to see if they have the same mutation.

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 1 in 2 chance of inheriting the condition (see the diagram below). The condition may be passed on from an affected male or female.

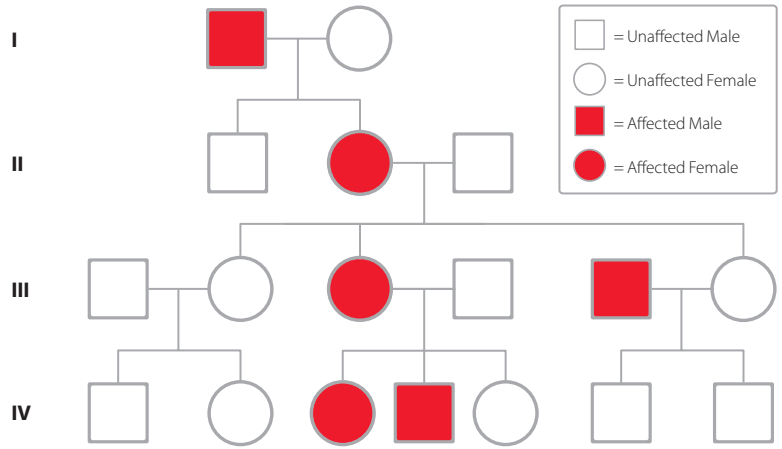
A family tree

This family tree shows four generations affected by dilated cardiomyopathy. Each child of an affected person has a 50:50 chance of inheriting the condition.



Autosomal dominant inheritance pattern

Less commonly, the abnormal gene 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 abnormal gene to their daughters, but cannot 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 below). 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 1 in 2 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.



X-linked inheritance pattern

If you inherit the condition, there is no way of knowing how severe it might be. 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 mutation, you cannot 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 has a 50:50 or 1 in 2 chance of having the condition.

What if something is found in you?

If your doctor thinks that you may have dilated cardiomyopathy, it is important that you have an assessment to find out whether you do have the condition. We describe all the tests that you may need to have as part of this assessment on page 32. Confirming a diagnosis will help the doctors to decide what treatment is best for you and how often you will need to be followed up. They will also be able to advise you on what you can do to help you to live a normal life.

It may also be possible to have a genetic test to try to identify the specific genetic mutation that has caused your condition. Genetic testing needs to be done at a specialist clinic for inherited heart conditions. Genetic counsellors will explain, to people who have a genetically determined disease, how likely it is that they will pass the abnormal gene on to their children. Brothers and sisters of the affected person can also be affected and may be tested.

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

You should only have genetic testing and screening after you have had advice from a specialist team who can make sure that the right test is 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 who has 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. We describe these tests on page 32.

If a family member is found to have enlargement of the left ventricle but does not have any symptoms of dilated cardiomyopathy, their condition is normally described as left ventricular enlargement. There is no specific treatment for left ventricular enlargement, but anyone with this condition should be seen by their cardiologist once a year for follow-up.

If another family member with dilated cardiomyopathy has had a genetic test which has found a particular mutation to be the cause of the condition, it may be possible to screen other family members to see if they have the same genetic mutation.

Assessment at a clinic for inherited heart conditions

Below we describe what happens when someone has an assessment at a clinic for inherited heart conditions to find out if they have inherited a particular heart condition. These clinics are usually in a hospital.

Medical history
Your cardiologist will ask you lots of questions about your medical history. They will also ask you about your family, including your parents and possibly your grandparents. They may ask you if you have ever had symptoms such as blackouts or palpitations, or if there have been any sudden 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. Your cardiologist will:

- take your pulse to check your heart rhythm and the pumping action of your heart
- listen to your heart and lungs with a stethoscope
- take your blood pressure.

Your cardiologist will do an ECG to look at the electrical rhythm of your heart. You will also need to go to a hospital for a chest x-ray and an echocardiogram to confirm whether you have dilated cardiomyopathy. You may also need further tests to find out how thin the heart muscle is and how much of it is affected. And you may 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 below 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. It involves taping electrical leads onto your legs, arms and chest and taking readings of the electrical activity of your heart. These are printed out onto paper for the doctor to examine.

Exercise test NON-INVASIVE

Also called an **exercise ECG**

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.

24-hour ECG monitoring NON-INVASIVE

Also called **Holter monitoring**

This test involves using a small digital device in the shape of a pager. You wear the device 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 structure of the heart. It produces a picture of the heart and allows doctors to measure the size of the chambers of the heart and how thick the heart muscle is and how well it is working. It also looks at the heart valves and can show if there is any regurgitation (when some of the blood leaks back through a valve in the wrong direction – see page 13). Additional equipment, called Doppler ultrasound, can produce a colour image of blood flow within the heart and provide information on how well the heart is working.

Transoesophageal echocardiogram

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

Cardiopulmonary exercise test

Also called **CPET**

Some hospitals may also ask you to do a cardiopulmonary exercise test – or CPET for short. This test analyses the efficiency of the heart muscle by measuring the amount of oxygen your body uses during exercise. You will be asked to breathe into special equipment while you are 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 cardiologist may suggest that you have other tests such as a coronary angiogram or an electrophysiological study (or EPS for short). Both these tests are performed in an x-ray laboratory. The tests allow doctors to see parts of the body, and any medical items such as cardiac catheter tubes or pacing wires, using an x-ray camera. You will be asked to lie down on a special table and will be given a local anaesthetic in your groin. The cardiologist will then place fine tubes, called cardiac catheters or electrodes, into blood vessels in your groin. These are gently passed through to the heart.

During a coronary angiogram, the coronary arteries (the arteries that supply blood to the heart muscle) are injected with a dye to reveal any narrowing that could be caused by coronary heart disease.

An EPS (electrophysiological study) involves placing electrical leads inside the heart to analyse its electrical properties and to bring on arrhythmias. This test can be useful for diagnosing and treating abnormal heart rhythms.

Magnetic Resonance Imaging (MRI)

An MRI scan uses a magnetic field to create images of the 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 cannot cope with having this type of scan.

An MRI is very good at showing the structure of your heart and blood vessels. It can also measure the flow of blood through the heart and some of the major arteries. An MRI scan can also show where the heart is working abnormally in conditions such as cardiomyopathy. And it can identify defects in the structure of the heart.

You cannot have an MRI scan if you have a pacemaker or an ICD (see page 40), because it can interfere with the way these devices work.

Radionuclide tests and CT scans

Radionuclide tests and CT scans give more detailed information than the exercise ECG test (see page 32). They are less common than ECGs or echocardiograms, because the specialised equipment and staff are only available at some hospitals in the UK.

Endomyocardial biopsy

If your cardiologist needs to examine your heart tissue more closely, you may need to have an endomyocardial biopsy. You will be given a light 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 tests, and for information about levels of radiation with these investigations, see our booklet *Tests for heart conditions*. (To order our booklets see 'More information' on page 64).

Treatment for dilated cardiomyopathy

Dilated cardiomyopathy is not curable, but most symptoms caused by the condition can be controlled by using medicines. Some people may need to have other treatments as well. You will find information about these treatments on page 40.

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, but if this happens your doctor may be able to prescribe a different medication, called angiotensin II receptor antagonists, for you.

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 the heart rate. This reduces the amount of work the heart has to do, so that it needs less oxygen, blood and nutrients. Some beta-blockers can help control abnormal heart rhythms.

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 angina worse.

Calcium channel blockers (calcium antagonists)

The 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 the heart's pumping cycle lasts longer. (The resting phase is when the heart rests in between heartbeats and the coronary arteries fill up and supply the heart muscle with blood). This means that the heart receives a better supply of blood and has to do less work to pump enough blood around the body.

Some calcium channel blockers may increase or reduce the heart rate while you are resting, while others may have no effect on the 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 the heart. Beta-blockers, and the calcium channel blocker verapamil, are also often used to treat disturbances of the heart rhythm (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 disturbances of the heart rhythm, especially atrial fibrillation (see page 20).

Unwanted effects – At low doses, amiodarone is well tolerated, but it has important side effects. 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 are taking this medicine, you should use a powerful sunscreen cream when you are in strong daylight or bright sunshine, and wear a hat.

Anticoagulants

Some people with dilated cardiomyopathy develop atrial fibrillation (see page 20). Atrial fibrillation carries a risk of blood clots forming inside the heart. 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 the 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 irregular 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 will need regular blood tests to make sure that the clotting activity of the 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 have 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 are taking oral anticoagulants, you should check with your doctor or pharmacist before taking any other medicines – both over-the-counter and prescription medicines. This is because oral anticoagulants interact with many medicines including antibiotics, aspirin and cimetidine, and with some medicines that are used to treat arthritis, gout, epilepsy, high blood cholesterol and heart rhythm disorders.

Alcohol increases the effect of warfarin, so it is important to avoid excessive drinking or binge drinking.

If you are taking oral anticoagulants, you should also 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 what you eat and drink.

If you are 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 stools

- for women, heavier bleeding during periods, or other vaginal bleeding.

If you are worried, contact your GP or anticoagulant 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 the urine. They are particularly valuable in reducing the workload of the heart by making sure that the body does not hold too much salt or water.

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 and the extra workload increases your blood pressure.

There are three main types of diuretic – thiazide diuretics, loop diuretics and 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 are taking a diuretic, you should not 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 is 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 the heart*. (To order our booklets see 'More information' on page 64).

Other treatments for dilated cardiomyopathy

Pacemakers and ICDs

People with dilated cardiomyopathy are at risk of having a heart rate that is too slow or developing heart block. So if you have dilated cardiomyopathy, you may need to have a pacemaker fitted, to regulate your heart rate.

Or, if you are at high risk of sudden death (for example, if you have already had a cardiac arrest), or if medicines have failed to control your symptoms, your cardiologist may advise you to have either a pacemaker or an ICD fitted. ICD stands for 'implantable cardioverter defibrillator'.

A pacemaker and an ICD both consist of a very small box containing a battery, and special electrode leads. The box is inserted under the skin and attached to the heart by the electrode leads.

A pacemaker controls the heart rate and stops any excessive slowing of the heart that could trigger an arrhythmia. The pacemaker is usually implanted just under your left collarbone. The procedure usually takes about an hour and is normally done with a local anaesthetic and sedation. You will need to have follow-up checks every three to twelve months. The pacemaker battery usually lasts between six and ten years (and sometimes even longer). When a new battery is needed, the box containing it can be replaced easily. For more information on pacemakers, see our booklet *Pacemakers*. (To order our booklets see 'More information' on page 64).

An ICD acts in the same way as a pacemaker, but it can also identify any dangerous arrhythmias and deliver an electrical shock to 'reset' the heart. Some people have described the shock as feeling like having a 'kick in the chest'. An ICD is slightly larger than a pacemaker and is usually positioned under the chest wall muscle below the left shoulder. The procedure may take between one to three hours. Most people have a local anaesthetic as well as sedation, but some may have a full (general) anaesthetic. You will need to have check-ups at the ICD clinic once every three to six months. The battery lasts between four and eight years. When a new battery is needed, the box containing it can be replaced easily. For more on ICDs, see our booklet *Implantable cardioverter defibrillators (ICDs)*. (To order our booklets see 'More information' on page 64).

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 the heart muscle. This is sometimes known as cardiac resynchronisation therapy (or CRT for short).

Left ventricular assist device

If your heart failure is very severe, an artificial mechanical device can be fitted to help the heart muscle pump blood out of the heart. The device allows people to live as normal a life as possible out of hospital. These devices are commonly used if someone is waiting for a heart transplant. For more information, see our booklet *Heart transplantation*. (To order our booklets see 'More information' on page 64).

Heart transplantation

For a very small number of people, heart transplantation may be considered. For more information, see our booklet *Heart transplantation*. (To order our booklets see 'More information' on page 64).

Treatment for other conditions which can occur as a result of dilated cardiomyopathy

On page 20 we explained that certain other conditions can occur as a result of dilated cardiomyopathy. These are the treatments you may need if you have developed one of those conditions.

The two arrhythmias, ventricular tachycardia or atrial fibrillation, usually require treatment with medicines (see page 36).

Heart block can be treated by implanting a pacemaker (see page 40).

If you get endocarditis (an infection of the lining of the heart), you will need to go into hospital for several weeks and have antibiotics through an injection in a vein. In the past, people who had ever had endocarditis were advised to take antibiotics before having dental treatment, but this advice has now changed and you don't need to take antibiotics unless you are specifically told to do so.

If your cardiologist thinks you are at increased risk of sudden cardiac death, you may be offered treatment which could include taking medication, or having an ICD fitted (see page 40), or both.

Living with dilated cardiomyopathy

Who should be involved in routine medical care?
Your GP should be involved with your general everyday care. He or she 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.

Exercise
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 (angina) when they are physically active. Moderate intensity exercise is best for you. By moderate intensity we mean 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 an extra strain on the heart. Eating a healthy, balanced diet will help you to maintain a healthy weight.

Drinking more than the recommended amount of alcohol can damage your heart health and can lead to high blood pressure. See our booklet *Keep your heart healthy* for information on sensible limits, or ask your doctor what is a sensible limit for you. (To order our booklet see 'More information' on page 64). Alcohol is also a depressant, so it can make feelings of anxiety or depression worse.

Weight gain
If you are eating a healthy diet but you notice that you seem to have been putting on weight over a few days (about a half to 1 kilo, or 1 or 2 pounds),

you will 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 will increase the risk of developing coronary heart disease and of reducing the flow of blood to your heart muscle. It also reduces the amount of oxygen being carried in the blood and makes your heart work harder. For information on giving up smoking see our booklet *Smoking and how to give up.* (To order our booklets see 'More information' on page 64).

Recreational drugs

Recreational drugs will generally increase the workload of the 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), loss of sex drive, and safe sex are some of the concerns that people with dilated cardiomyopathy have. Feeling embarrassed and not talking about your concerns can lead to feelings of inadequacy and delays in finding appropriate solutions.

Knowing your limitations and what brings on your symptoms can help you to enjoy a full and sexually active life. Like any other physical activity, having sex can increase the heart rate and blood pressure. This increases the work of the 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 having angina 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. Or it may be the result of the emotional stress you are feeling, or the result of poor blood circulation or diabetes.

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.

Impotence is a common problem so, if you are 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.

If you have a heart condition, you should be cautious about taking medicines known as PDE-5 inhibitors such as Viagra. You should not take these medications if you are 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 the flu viruses, 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 is 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 is 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 are not alone. There are also many organisations and charities that can help you to cope. See page 65 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 45 for more on exercise).

Alcohol is associated with a feeling of being happy but it is actually a depressant. You should not exceed the recommended levels of alcohol. See our booklet *Keep your heart healthy*, for information on this, or ask your doctor. (To order our booklets see 'More information' on page 64).

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.

Driving

If your symptoms are well controlled and your cardiologist says that you are fit to drive, you may continue to drive. For more details, contact the Driver and Vehicle Licensing Agency (DVLA) on 0300 790 6801.

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 may be able to continue in your job. 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. If you think you might need oxygen during the flight, speak to your doctor about this and then to your travel company. 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. Many of them are a long way from the security gates. If you get breathless easily, you may also want to organise in advance to have help at the airport. The 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 at most post offices.

If you are 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 the Cardiomyopathy Association. Their contact details are on pages 64–65.

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 Disability Living Allowance. This is a social security benefit for people who have an illness or disability and who need help getting around or help with personal care. There are other benefits and allowances available for those people whose symptoms result in severe restrictions.

To find out more about the benefits you are entitled to, call the Benefit Enquiry Line on 0800 882 200 (a freephone number), or visit your social security office, citizens advice bureau or local social services department.

For information about Tax Credits, contact the Inland Revenue helpline on 0845 300 3900.

Pregnancy and childbirth

Dilated cardiomyopathy can sometimes occur for the first time in pregnancy. See page 16 for more information on this.

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

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

Should I have children?
Some types of dilated cardiomyopathy are genetic, but not all incidences of dilated cardiomyopathy are. If your dilated cardiomyopathy is not caused by a genetic mutation, you will not pass the condition onto your children. However, some people who inherit the gene that can cause dilated cardiomyopathy do not develop symptoms, but they can pass on the gene to their children who could develop the condition.

You will find information about the risk of passing on the condition to your children on page 27. 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**.

If you have peripartum cardiomyopathy – dilated cardiomyopathy which developed during your pregnancy – and it has not gone away after the delivery, your cardiologist may advise you not to have any more children. (See page 16 for further information).

Looking forward

The future

Research is being carried out into many different aspects of dilated cardiomyopathy, in many countries.

Diagnosis and treatment has improved recently and many people with dilated cardiomyopathy with early diagnosis and treatment can be stabilised or even recover their normal heart function and lead normal lives.

Developments in genetic testing have enabled screening and testing of close family relatives to find out if they carry the same gene mutation. The results of this research can help improve the quality of life, treatment and monitoring of people with dilated cardiomyopathy, including those who do not yet have symptoms.

Technical terms

A

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

Angiogram
An x-ray picture of the 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 the blood and reduce the risk of clots.

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

Arrhythmia
A disturbance of the heart's rhythm.

Ascites
Collection of fluid in the abdomen

Atrial fibrillation
A fast, irregular heart rhythm.

Atrium
One of the two top chambers of the 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.

C

Cardiac arrest
The state of the heart when it is pumping so erratically or ineffectively that there is no significant blood pressure to supply blood to the heart and brain. If basic life support is not started within two minutes, there could be permanent brain damage, and if left untreated the person will quickly die.

Cardiologist
A doctor specialising in diseases of the heart.

Cardiomyopathy
Any disease of the heart muscle that is not caused by narrowings in the coronary arteries, valve disease or high blood pressure.

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 the 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 the heart.

E

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

Endocarditis
An infection of the inner lining of the heart, usually affecting the valves.

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

G

Gene
The segment of DNA responsible for the production of a specific substance such as a protein, which in turn forms the basis for the body to exist and function.

H

Heart block
A failure of the electrical system in the heart to conduct electrical impulses properly from the top chambers (atria) to the bottom chambers (ventricles) via the atrio-ventricular (AV) node. The severity of the condition and the risk associated with it can vary.

Heart failure
When the pumping action of the heart is inadequate.

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

I

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

Implantable cardioverter defibrillator
See 'ICD'.

L

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

M

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

Mutation
An abnormality or 'mis-spelling' of the DNA code that causes its eventual product (usually a protein) to function abnormally, which in turn is responsible for a disease.

Myocardium
The heart muscle.

P

Pacemaker
A metal electronic device which can regulate the rhythm of the heartbeat. It is usually implanted just under the 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 the heart to the lungs.

S

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

T

Tachycardia
A fast heart rate.

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

X

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

V

Ventricles
The two bottom chambers of the heart.

Ventricular
From, or belonging to, the ventricle.

For more information

For information on your nearest clinic for inherited heart conditions

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

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

The BHF Genetic Information Service provides information, for families affected by an inherited heart condition, on where to go for an assessment. The service is staffed by specialist cardiac nurses and a bereavement counsellor.

BHF publications

Pubications in the *Inherited heart conditions* series:

Hypertrophic cardiomyopathy

Arrhythmogenic right ventricular cardiomyopathy
(Due November 2009)

Sudden arrhythmic death syndrome

Inherited heart rhythm disturbances

Other BHF publications

Atrial fibrillation

Heart failure

Heart rhythms

Heart transplantation

Implantable cardioverter defibrillators (ICDs)

Keep your heart healthy

Pacemakers

Smoking and how to give up

Tests for heart conditions

Losing someone to heart disease
Offers help and support in coping with the loss of someone due to heart disease.

We also have a range of booklets on how to have a healthy lifestyle and 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**

For more on cardiomyopathy

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

Freephone Helpline 0800 0181024
(Monday – Friday, 8.30am – 4.30pm)
Website: www.cardiomyopathy.org
Email: info@cardiomyopathy.org

The Cardiomyopathy Association (CMA) is a registered charity that helps people who are affected by cardiomyopathy. It provides support and information on the different types of cardiomyopathy on its website, in booklets, and in DVDs and videos.

It also offers support through a nationwide network of support groups and people affected by the condition, and through regional information days where cardiologists provide information on the latest research in cardiomyopathy.
To become a member of the association, call the helpline above.

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

www.c-r-y.org.uk
www.sads.org.uk
www.cry-csc.org.uk

Phone: 01737 363222
Fax: 01737 36344
Email: cry@c-r-y.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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[3]Baig MK, Goldman JH, Caforio AL, Coonar AS, Keeling PJ, McKenna WJ. 1998 Familial dilated cardiomyopathy: cardiac abnormalities are common in asymptomatic relatives and may represent early disease. J Am Coll Cardiol. Jan;31(1):195–201.

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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 BHF, please ring our Supporter Services team on 0844 847 2787 or contact us through our website at bhf.org.uk/donate or send it to us at the address on the back cover. 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 bhf.org.uk/contact or write to us at the address on the back cover.

About the Cardiomyopathy Association

The Cardiomyopathy Association (CMA) is a national UK charity which provides information and support to families affected by cardiomyopathy and promotes excellence in clinical practice through education and direct funding. To learn more about the CMA please call 0800 0181024 or visit our website www.cardiomyopathy.org

GENETIC INFORMATION SERVICE

0300 456 8383
A local rate number

bhf.org.uk
Phone lines open 9am
to 6pm Monday to Friday

Information and support on inherited heart conditions

Cardiomyopathy Association
Unit 10, Chiltern Court, Asheridge Road
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