YOUR INFORMATION

Cardiomyopathy

CARDIOMYOPATHY

Your diagnosis

You have been given a diagnosis of heart failure, which usually means your heart is working inefficiently. This inefficiency is usually due to two main causes: firstly, the incapacity of the heart to pump correctly and secondly, its inability to relax sufficiently to fill up with blood. There is generally an underlying problem which has caused this inefficiency. Occasionally, we don't know the exact cause of why your heart is working inefficiently (clinicians call this idiopathic). The question most patients want answering is "WHY is my heart not working efficiently; what has gone wrong?"

We believe that the cause of your heart failure is due to **cardiomyopathy.**

What is Cardiomyopathy?

Cardiomyopathy means cardio (the heart) myopathy (muscle), therefore when we talk about cardiomyopathy we generally mean in relation to a disease of the heart muscle. As a result, your heart will be unable to do its job efficiently. There are different types of cardiomyopathy. There will be different reasons why you may have this particular form of cardiomyopathy. Your doctor will have told you which form of cardiomyopathy you have and you can read about a particular form from the list below. It is important to remember that our understanding of these conditions has changed and our management improved over the years. This means that some of the unregulated internet sites you access may scare you without properly informing you. Please see the pumping marvellous website or some of our recommended cardiomyopathy websites for more information.

Dilated Cardiomyopathy (DCM)

Dilated cardiomyopathy is when the heart muscle around the bottom left-hand side of the heart (the left ventricle) becomes enlarged and fails to pump as well as it should, and the reason for it is not high blood pressure, heart valve problems or ischaemic heart disease.

The term DCM covers conditions that can be acquired in adult life, as a result of a genetic problem (something that you are born with) or a combination of both. However sometimes no actual cause can be found despite extensive investigations. Apart from treating you and discussing the implications of DCM on your life, your cardiologist may also talk about screening family members for this problem too.

Examples of cardiomyopathies that can be acquired in adult life

Peripartum Cardiomyopathy

(or pregnancy associated cardiomyopathy)

This is a rare condition that happens to women either just before or up to 6 months after labour. PPCM can occur to anyone having a baby at any age. It is a rare condition and few valid statistics exist as to how many women develop PPCM in the UK. If you have this condition then we have a Marvellous Guide dedicated to it.

Remember the causes for this form of DCM are still being worked out.

What we do know is that it was NOT your fault.

Environmental toxins

Toxins such as excess alcohol have been associated with DCM – either felt to be due to the alcohol itself or a genetic predisposition (something that you are born with that makes it more likely that you will develop a problem if you are exposed to something that can cause DCM).

Substantially reducing or stopping your alcohol intake can help your treatment.

Medications

Some medications used to treat other medical conditions that you have may contribute to causing DCM e.g. certain powerful cancer drugs or anti-psychotic medications. Your cardiologist will check that none of the medications that you take

Other Diseases

DCM can be part of other medical conditions that you have. These conditions can be as different as hormone problems (such as thyroid disease) to special arthritic conditions to bowel problems to movement disorders and muscle wasting conditions (and many more besides).

Poor Nutrition

Poor diet, malnutrition or gut problems that stop you absorbing the right nutrients can also cause DCM or make its effect worse. So a healthy balanced diet and maintaining an appropriate and healthy weight are important.

'Viruses' and infections

Infections can cause DCM following inflammation of the heart muscle. However as the start of DCM can itself feel like a fluey illness this diagnosis is often used without proof. This diagnosis is often called a diagnosis of exclusion – that is other causes of DCM are ruled out and your cardiologist feels that the term 'viral cardiomyopathy' seems a more appropriate diagnosis than just saying 'I don't know the cause of your DCM' – the term for unknown is 'idiopathic'.

Make sure you ask your cardiologist which type of DCM you may have and whether you need to have family members screened for the same condition.

Hypertrophic Cardiomyopathy (HCM)

This is a condition where part of the heart is thickened (more than is expected for conditions due to heart valve problems, athletic training or high blood pressure) when pictures of your heart are taken with echo or MRI.

Many conditions can mimic HCM and your cardiologist will ensure that these are excluded before giving you a diagnosis of HCM.

HCM is a genetic condition, which means it is passed through families. It is caused by a change or mutation in a gene. It results in the heart muscle becoming thick due to the malformation of cells that make up the muscle of the heart. Apart from treating you and discussing the implications of HCM on your life, your cardiologist may also talk about screening family members for this problem too.

Restrictive Cardiomyopathy

This is a rare form of cardiomyopathy in which the walls of the ventricular chamber of the heart become stiff and thus are not able to relax adequately and fill up with blood. Its cause can be unknown or as a result of rare disorders which result in excessive fibrous tissue in the heart muscle. If you have this condition then ask your cardiologist whether there is a more specific diagnosis inn your case.

This is also a condition that can run in families so your cardiologist may discuss screening family members for the same problem.

Arrhythmogenic Venrticular Cardiomyopathy (AVC)

This form of cardiomyopathy can cause life threatening rhythm problems and, on certain occasions, weakness to the right and left side of the heart. In this condition, the 'glue' that holds the muscle cells of the heart is affected. This is also a condition that can run in families so your cardiologist may discuss screening family members for the same problem.

Implications for family/genetic Cardiomyopathies

If you have a cardiomyopathy it may be something that your family need to be screened for.

When a cardiomyopathy is thought to have a genetic component then family screening is usually considered for first degree relatives. First degree relatives are your parents, your brothers and sisters and your children – three generations (four if your grandparents are still alive).

The screening tests can be arranged by the individual GPs of family members. The initial screening tests are an ECG, an echocardiogram and a review by a specialist to tell family members if they have the condition now, whether they need ongoing screening to see if they will develop the cardiomyopathy or whether they can be discharged as they neither have the condition now or are unlikely to develop the condition in the future. Cardiologists who see family members to discuss this usually have an interest in 'Inherited Cardiac Conditions'.

If a family condition is identified then your cardiologist may discuss the prospect of referring you to a genetic specialist to see whether a DNA blood test can find the responsible gene problem. If they can then it is possible that this blood test can be used to tell who may or may not get this problem in the future.

Your cardiologist is relying on you to pass on to family members you are in contact with about the reasons for family screening.

They will also tell you that family members need to understand that positive findings during screening can affect their ability to obtain mortgages, life insurance premiums or in some special cases can affect their employment. This means that family members volunteering for screening tests can fully decide whether they want to go through the process or not.

Treatments

The treatments for these cardiomyoapthies are as varied as the cardiomyopathies themselves. Your cardiologist will discuss these with you during your clinic visits as many of these cardiomyopathies may result in repeated follow up visits to your cardiologist over the years. This is because different treatments are considered at different stages of each cardiomyopathy.

Pumping Marvellous

The heart failure charity

Contact Pumping Marvellous

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www.pumpingmarvellous.org

heartfailureaware (open)

hearts@pumpingmarvellous.org

helpforhearts (closed support group)

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