

MYOCARDITIS PATIENT INFORMATION LEAFLET

What Is Myocarditis?

Myocarditis is an inflammation of the heart muscle (myocardium). Inflammation can be thought of as the body's immune systems response to an irritant. Myocarditis can affect the heart muscle and your hearts electrical system, reducing the hearts ability to pump effectively and causing rapid or abnormal heart rhythms (arrhythmias).

Understanding Myocarditis

In simple terms, myocarditis is a disease that causes inflammation of the heart muscle. This inflammation enlarges and weakens the heart, creates scar tissue (fibrosis) and forces it to work harder to circulate blood and oxygen throughout the body.

Myocarditis can affect anyone, at any age, and can occur in people with no history of previous illness.

It is important to remember that the majority of patients with myocarditis will recover with no long-term effects on their lifestyle or heart function. However, approximately 20% of patients with myocarditis will however develop a condition called dilated cardiomyopathy, where the heart enlarges and its ability to pump blood to the body and lungs is impaired.

How do patients present?

This can be in several ways. Most commonly, patients experience chest-pain, or breathlessness or have a heart rhythm abnormality that makes them collapse or feel as though they are going to collapse. This is often but not always after a viral infection or an adverse drug reaction. They then seek medical attention where one of the key goals is to differentiate myocarditis – where the heart muscle has taken a direct hit, from a heart attack (or myocardial infarction), where there is a blockage in the blood supply to the heart muscle. Doctors looking after patients often classify patients when they present into different subgroups depending on how they presented:

Typical acute myocarditis – patients presenting with symptoms such as chest-pain, shortness of breath, or having a blackout or feeling as though they will have a blackout, have an increase in troponin levels – troponin is a blood test that shows evidence of heart damage in the acute phase. They will also often have an abnormal ECG or heart tracing. Subsequent tests described below will then help confirm the diagnosis and differentiate from a heart attack (myocardial infarction).

Occasionally, myocarditis can also present in some different ways.

1. *It* can be associated with additional inflammation of the lining around the heart called the pericardium causing pericarditis. Pericarditis is frequently found alongside myocarditis of the outside layers of the heart muscle.
2. **Myocarditis resembling acute or chronic heart failure:** Patients with myocarditis often experience shortness of breath, fatigue and a much lower exercise tolerance

level. These patients generally have enlarged hearts with symptoms that occur about 2 weeks to a few months after acute gastrointestinal or upper respiratory infections. In more chronic cases, the body's immune system continues to attack the heart even when the infection has passed.

WHAT MAKES MYOCARDITIS SO CONFUSING?

Myocarditis is easily confused with other heart conditions as symptoms like shortness of breath, fatigue, inability to tolerate exercise and breathing difficulty when lying down or sleeping are common to many heart diseases as well as myocarditis. Myocarditis can also mimic a heart attack as the cardiac inflammation occurs in the regions of the heart closest to the surface and it causes chest pain.

WHAT CAUSES MYOCARDITIS?

Myocarditis is a rare condition. The inflammation of the heart muscle may be caused by a number of factors, but most commonly include:

- A viral, bacterial or fungal infection
- Autoimmune conditions, which can occur if your immune system attacks your own tissues and organs. Examples include systemic Lupus Erythematosus (SLE), Wegener's granulomatosis and giant cell arteritis.
- Connective tissue diseases
- Medications – most medications are very safe and well tolerated. Rarely, for reasons that are not clear, they may cause an allergic or toxic reaction. These include drugs used to treat cancer, antibiotics such as penicillin and sulphonamide drugs, some anti-seizure medications.
- Recreational drugs and especially cocaine can cause inflammation of the heart.
- Chemicals or radiation, eg radiotherapy used for the treatment of some cancers.

It may not be possible to confirm the exact cause of myocarditis. When a clear cause can't be determined, it may be referred to as "Idiopathic" (or unknown) myocarditis.

SYMPTOMS OF MYOCARDITIS

The symptoms of myocarditis are varied but the most common include fever, chest pain, severe fatigue and an achy feeling as if suffering from a bad cold or flu. Some patients experience irregular heartbeats (arrhythmia), fainting, or have trouble breathing. Swollen ankles and tummy may be an indication of a fluid build-up in the tissues because the heart is not pumping effectively to remove excess fluid. In some cases, severe myocarditis may not be diagnosed until you have the symptoms of heart failure.

DIAGNOSING MYOCARDITIS

Myocarditis is difficult to diagnose because it resembles many other diseases. There are some tests that your Doctor or cardiologist may order if they suspect myocarditis.

- Blood tests: Blood tests will check the Troponin levels in your blood. An elevated Troponin count is an indication of damage to the heart muscle, for example caused by the inflammation seen with myocarditis. The BNP (B-natriuretic peptide) is another routinely performed blood test which is raised when the heart function is impaired.

- Electrocardiography (ECG) – a heart tracing - will show your hearts rhythm and may reveal changes that are non-specific but can be present in myocarditis. A normal ECG does not exclude myocarditis.
- Echocardiography – a scan of the heart using ultrasound - can be used to assess the size and function of your heart.
- Chest X-Ray: this looks at the size and structure of the heart to see if it is enlarged and whether there is fluid on the lungs.
- MRI (Magnetic Resonance Imaging) scan – this produces high quality images and is used to look at the shape and structure of the heart in great detail. It is used to assess the function of the heart and to see if the heart muscle is inflamed or if any scar tissue (fibrosis) has developed as a result of myocarditis.
- PET (positron Emission Tomography) scan – this scan uses radioactive dyes to create images of the body and to see how the heart is working. This is usually combined with a CT or MRI scan.
- Endomyocardial biopsy is a procedure in which very small samples of the heart muscle are removed. This can be used to detect the amount and type of inflammation caused by myocarditis. Sometimes, but not always, a virus or another infectious organism can be detected on a heart sample, which can further clarify the cause of myocarditis. Because biopsies involve inserting tubes into the heart directly, and so carry a small risk, they are usually only done in the sickest of patients in the UK.

TREATMENT

In most cases, myocarditis improves on its own or with treatment leading to a full recovery. In mild cases, patients should avoid competitive sports and strenuous exercise for at least 3 – 6 months. Changes to diet, rest and medication may be all you need.

Certain types of myocarditis respond to corticosteroids or other medications to suppress your body's immune system. Your cardiologist will only prescribe the medications you need if and when you need them. Unlike many other illnesses, there is not really a "one treatment fits all" plan when it comes to myocarditis and your treatment may look very different to another patient also being treated for myocarditis. If your myocarditis is part of another illness (such as rheumatoid arthritis), treating that illness will treat the heart as well. Some treatment may include the following:

- ACE inhibitors – They help improve the heart function in patients with heart failure.
- ARB's: They work in the same way as ACE inhibitors and are used when ACE inhibitors can't be used due to side effects.
- Beta Blockers: slow down heart rate and control arrhythmias.
- Diuretics: help to reduce water retention (which causes the swelling in the ankles and around the lungs) by encouraging the kidneys to produce more urine. They may not be needed once the ACE inhibitors and Beta Blockers begin to work.
- Anticoagulants may be used to prevent blood clots forming. This may be used in patients with atrial fibrillation as the uneven flow of blood through the heart could cause a clot to form.

If myocarditis has not damaged the heart too much, medication and follow – up visits may be all that are needed. In some cases, where more extensive damage has occurred, patients may need limit some of their activities and take medications for the rest of their lives. In very rare cases, patients may need an artificial heart support with a VAD (ventricular assist device) and in severe cases, a heart transplant may be needed.

EFFECTS OF MYOCARDITIS

Due to the difficulty of the diagnosis and the limited information available on this rare condition, many patients feel they have more questions than there are answers and are left feeling vulnerable and unsupported. Many patients experience side effects for weeks and months afterwards that can be alarming and may add to experiencing feelings of anxiety.

Some of these side effects are:

- Continued chest pain
- Shoulder pain
- Pain below the ribs
- Physically exhausted
- Quick to tire – much more than is normal
- Unable to do sustained or long periods of exercise

Whilst these may not be all the symptoms, any persistent symptoms after being diagnosed should be checked by your Dr or cardiologist.

DECIPHERING THE JARGON

During and after diagnosis, patients may hear a number of terms that can lead to unnecessary stress and anxiety. We won't be able to list them all but have included some of the most common terms to help ease the confusion. Remember, if you don't understand anything at all, always ask your consultant to explain.

1. EF %: The Ejection Fraction (EF) is a measurement, expressed as a %, of how much blood the left ventricle pumps out with each contraction of the heart. This indication of how well your heart is pumping out blood can help to diagnose or track heart failure. A normal EF% at rest is anything between 50 -70%
2. Troponin is a protein contained by the heart muscle cells. When the cells are damaged by a number of reasons the protein is released and can be detected in the blood. It is a common test and it is usually raised in the acute phases of myocarditis. Sometimes, it can stay up if there is low level inflammation. Reading may also go up if there has been a flare up or reoccurrence of myocarditis.
3. DCM (Dilated Cardiomyopathy) is a condition where the chambers of the heart become enlarged, which affects its ability to pump. DCM is a common cause of heart failure. Approximately 20% of patients with myocarditis will develop dilated cardiomyopathy. The term "cardiomyopathy" is a general term that refers to the abnormality of the heart muscle itself.

HERE FOR YOU

The Alexander Jansons Myocarditis UK charity was set up to deal directly with the lack of awareness, information and support for both myocarditis sufferers and their loved ones. We offer a support group on Facebook where you can chat to people experiencing and living with the same feelings and issues that you may be experiencing and are always available via our website, www.myocarditisuk.com to offer any additional information or support.

We are grateful to Dr Sanjay Prasad and Dr Alma Iacob for their clinical advice and for approving this fact sheet.

Alexander Jansons Myocarditis UK**Registered charity number 1186345**

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