British Heart Foundation

Amyloidosis

What is amyloidosis?

Amyloidosis describes a group of disorders in which one or more organ systems in the body (such as the kidneys, the liver, or the heart) accumulate deposits of abnormal proteins.

The causes of amyloidosis are not clear. A hereditary form of the condition does exist, but it is rare.

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Different forms of amyloidosis

- **Primary amyloidosis**, the most common form, originates in the bone marrow. Amyloid proteins then build up in one or more of the body's major organs, causing them to malfunction. The parts of the body most frequently affected are the heart, kidneys, nervous system and gastrointestinal tract.
- **Secondary amyloidosis** is caused by a long-lasting infection, or an inflammatory disease such as rheumatoid arthritis or osteomyelitis.

How does it affect the heart?

If amyloidosis affects the heart it is called cardiac amyloidosis – or 'stiff heart syndrome'.

Cardiac amyloidosis tends to make the ventricles (the two lower pumping chambers of the heart) stiff, leading to the symptoms of heart failure.

What are the symptoms?

The main symptoms are fatigue and weight loss. Other symptoms may include feeling faint, breathlessness, abnormal heart rhythms and swollen ankles.

Heart Helpline

Our cardiac nurses and information support officers are here to answer your questions and give you all the heart health information and support you need.

Call us on 0300 330 3311

Similar cost to 01 or 02 numbers.
Lines are open 9am - 5pm Monday to Friday.

This information does not replace the advice that your doctor or nurse may give you. If you are worried about your heart health in any way, contact your GP or local healthcare provider.

What tests will I need?

Cardiac amyloidosis can mimic many other diseases and so a number of tests may be required. These may include an ECG (electrocardiogram), an echocardiogram, a CT scan, MRI scan, or a radionuclide heart scan.

An endomyocardial biopsy is often used to confirm the diagnosis of cardiac amyloidosis. This is a procedure in which a small piece of tissue from the heart muscle is taken and examined. Certain blood and urine tests are also needed.

Will I need treatment?

Cardiac amyloidosis is treated in the same way as heart failure, using several common medicines. Immunosuppressant drugs such as steroids may also help in some cases, but there is not enough evidence to confirm whether other forms of treatment are as beneficial.

Other treatments such as chemotherapy, stem cell transplant and a heart transplant may be considered for some people with cardiac amyloidosis. The outlook is poor for people affected by the condition – and there is no known cure for amyloidosis, however it can remain stable for a number of years.

Modern genetic testing may be able to identify whether any family member is carrying the gene for the rare hereditary form of amyloidosis.