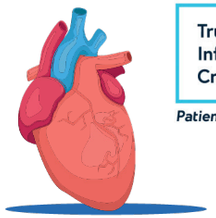
Cardiac Amyloidosis

Patient information booklet



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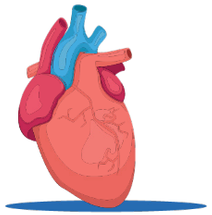
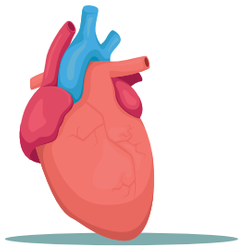


What is Cardiac Amyloidosis?



Amyloidosis (pronounced am-uh-loy-doh-sis)

is a disease that causes abnormal protein (called amyloid) to build up in certain places in your body where it shouldn't be, like your liver, nerves, or heart. The two most common types are called light chain cardiac amyloidosis (AL) and transthyretin cardiac amyloidosis (ATTR-CM).

When these abnormal proteins build up, organs may not work properly.

Amyloidosis can affect your whole body or just a certain part. It is a disease that cannot be cured and usually gets worse over time.

There are two forms of ATTR-CM:

Wild-type (ATTRwt) amyloidosis that can develop as you age.

Hereditary mutant (hATTR) amyloidosis that is passed down from your parents.

Why Does ATTR-CM Happen?

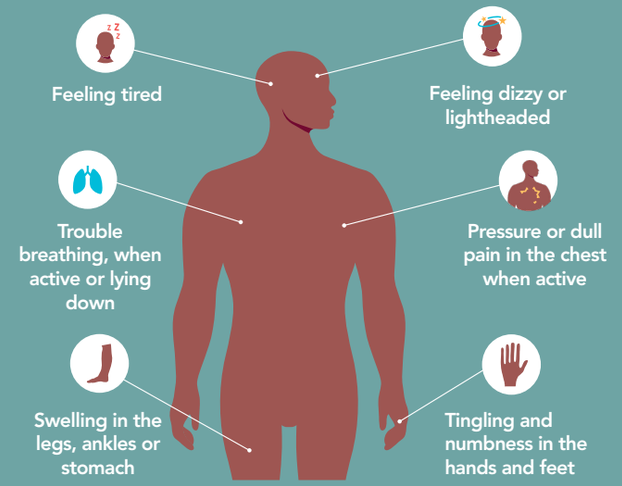
Transthyretin (TTR) is a type of protein that is made naturally in the liver.

In ATTR-CM, the TTR protein becomes unstable, causing it to break apart.

These pieces of protein then misfold and clump together, eventually leading to the formation of insoluble amyloid fibrils.

It is the build-up of these fibrils in the walls of the heart that lead to the symptoms of the condition.

What Are Common Symptoms Of Amyloidosis?



How Does Amyloidosis Affect My Heart?

When amyloidosis affects your heart, it is called cardiac amyloidosis. Cardiac amyloidosis causes:

your heart walls to thicken over time. This makes it hard for your heart to squeeze and relax normally. This affects how your heart pumps blood to your body.

your heart rhythms to be abnormal (called arrhythmias).

blocks in your heart's electrical system, which tells your heart to beat. This is called heartblock.

Are There Treatments For Cardiac Amyloidosis?

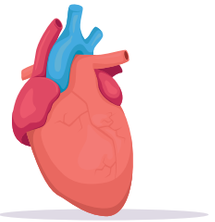
Yes, but first you need to find out which type of cardiac amyloidosis you have. This will help determine which treatment may work best for you. It will also let you know whether your family members may be at risk from the disease.

Some treatments for cardiac amyloidosis treat the underlying problem, others help with the symptoms.

Diagnosing and treating amyloidosis early is important. It can help you live a longer, healthier life. It could help you family members too.

Steps to find out if you have

Cardiac Amyloidosis



Patient-Doctor Conversation
You will discuss any symptoms you may have and how you feel. You will also talk about your family medical history.

Your doctor will request tests

Tests to find out IF you have Cardiac Amyloidosis

Electrocardiogram (ECG)
Your doctor will see if you have irregular heart rhythms, spikes on the ECG that are smaller than normal, or blocks in your heart's electrical system.

Echocardiogram
Your doctor will see if there are any patterns to how your heart squeezes blood. They will also look at how thick your heart walls are.

Cardiac MRI
Your doctor will measure how thick the walls of your heart are and see if any excess thickness is caused by amyloids (abnormal proteins). Your doctor may also see how a contrast dye travels through your heart tissue. Certain patterns suggest cardiac amyloidosis.

Six Minute Walk Test

This test measures your exercise capacity. You will be asked to walk as quickly as you can manage on a hard, flat surface. The distance you complete at repeat clinic visits will give an ongoing assessment.

Tests to find out what TYPE of Cardiac Amyloidosis you have

Blood and Urine Tests
These investigations are used to see if you might have light chain cardiac amyloidosis (AL) and other conditions that can occur with cardiac amyloidosis. These tests on their own are not enough to make a definitive diagnosis of AL. If these tests results are abnormal, your doctor may request additional investigations.

Scintigraphy
Helps determine if you have transthyretin cardiac amyloidosis (ATTR-CM).

Possible results

The tests look normal. This likely means you do not have a heart condition. You may need to see a different type of doctor to better understand what is causing your symptoms.

Your doctor finds that you have signs of cardiac amyloidosis. You may be asked to do more testing.

Your doctor finds you have a medical condition that is not cardiac amyloidosis.
If this happens, your doctor will talk to you about this other condition and treatment options. You may or may not need more tests.

What is Electrocardiogram?

An electrocardiogram (ECG) is a test that measures the electrical signals that make your heart beat.

It helps doctors see if there are any abnormalities with your heart's electrical function.

What Should I Know About This Test?

People usually have this test at a clinic or hospital.

It will take about 10 minutes to complete this test.

Is This Test Safe? Will It Hurt?

This test is common and is usually safe and well tolerated. It is not painful.

The test uses sticky pads that are placed on your skin. Rarely, the sticky substance on the pads can irritate your skin and cause a slight rash. This rash does not last long and is not dangerous.

What Should I Expect When Getting Tested?

You may be asked to put on a hospital gown or to remove or lift your shirt.

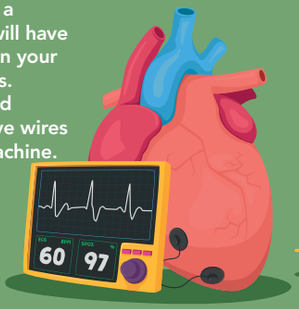
You will lie down on a padded table. You will have sticky pads placed on your chest, arms, and legs. These pads are called electrodes. They have wires that connect to a machine.

While you are lying down, the machine will record the electrical activity in your heart.

In order to get a good test, you cannot talk or move for 10 seconds.

What Results Might Suggest I Have Cardiac Amyloidosis?

Some results that may be signs of cardiac amyloidosis include:



atrial fibrillation (known as AF) or other irregular heart rhythms.

spikes on the ECG that are smaller than normal. This is called "low voltage."

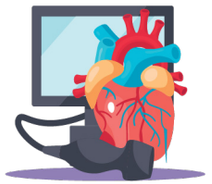
heartblock, or blocks in the heart's electrical system that tells your heart to beat.

What Comes Next?

Your doctor will review your test results and talk to you about them. Results will be different for each person.

Cardiac amyloidosis cannot be diagnosed based on an electrocardiogram alone. Depending on your results, your doctor might ask you to do more testing.

What is Echocardiogram?



Echocardiogram is a test that uses sound waves (ultrasound waves) to take pictures of your heart and the surrounding structures.

It helps doctors see how your heart muscle and heart valves are functioning. It can alert doctors to some heart abnormalities.

What Should I Know About This Test?

People usually have this test at a clinic or hospital.

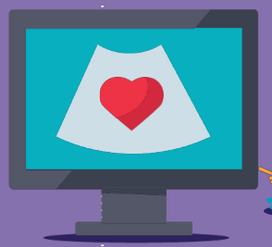
Is This Test Safe? Will It Hurt?

This test is common and is usually safe and well tolerated. It is not painful.

What Should I Expect When Getting Tested?

A technician will put a cold, water-based gel on your chest. This will help the soundwaves pass through your body and will improve the quality of the pictures.

A small, handheld machine (called a transducer) will be run over your chest. A technician will move it around to see all the different parts of your heart. You will hear the sound waves as the technician performs the test. These soundwaves are made into pictures that your doctor can view. Sometimes you will have to change your position to help improve the quality of the pictures.



What Results Might Suggest I Have Cardiac Amyloidosis?

Usually, cardiac amyloidosis causes the heart walls to be thicker than normal and to not relax well between heartbeats.

When the heart muscle doesn't relax normally, it makes it harder for the heart to fill with enough blood for the next beat. This can make the heart not work as well as it should.

Your doctor will look at pictures from the echocardiogram to see how well different parts of your heart squeeze. There are specific patterns of thickness and squeezing that can suggest cardiac amyloidosis.

What Comes Next?

Your doctor will review your test results and talk to you about them. Results will be different for each person. Here are some common examples of what your results might show:

The test results indicate you may have cardiac amyloidosis. If this happens, your doctor will want to run additional tests to find out what type of cardiac amyloidosis you have.

The test results indicate you may not have cardiac amyloidosis. If this happens, your doctor will talk to you about what other medical condition could be causing your symptoms and what needs to be done to treat it. You may or may not need more tests.

It is unclear if you have a condition or not. This could mean your heart is healthy or it could mean that the test was unable to identify the problem. If this happens, you may need further testing.

What is Cardiac MRI?

Cardiac magnetic resonance imaging (MRI) is a test that uses strong magnets to take detailed pictures of your heart. The magnets work together with radio waves to help the machine to create a 3D image of your heart.

It provides doctors with a lot of information about your heart including how thick your heart muscle is and how well your heart is working. It can also show if there are any other abnormalities in your heart.

What Should I Know About This Test?

People usually have this test at a hospital.

Most MRIs last about 1 to 2 hours.

People who have an implanted medical device, such as a pacemaker, implantable-cardioverter defibrillator (ICD), cardiac resynchronisation therapy device (CRT-D), implantable loop recorder, artificial joints etc, should make their doctor aware so that they can decide whether an MRI is appropriate.

Is This Test Safe? Will It Hurt?

This test is common and is usually safe and well tolerated. It is not painful.

Women who are or might be pregnant, or who are breastfeeding, should make their doctor aware so they can decide the appropriate course of action.

Tell your doctor before your appointment if you have a fear of small, enclosed spaces as you may find the MRI uncomfortable. They may be able to offer an alternative test, or a medicine to help you relax.

The MRI machine may be loud. The technician will give you ear protection to keep you comfortable.

What Should I Expect When Getting Tested?

You will be asked to put on a hospital gown. You will also need to remove any jewellery and metal items, including bras.

A small drip (cannula) will be placed in one of your veins. You may receive an intravenous (IV) injection of a contrast dye through the cannula. This is a substance that is used to make the pictures clearer.

While you are laying down, a machine will scan your body to take images of your heart. The technician will be able to see, hear, and speak with you at all times and will guide you through the test.

During the test you may be asked to take deep breaths or to hold your breath for up to 10 or 20 seconds. This can help technicians get the right pictures. Otherwise, you will be asked to stay as still as possible during the scan.

What Results Might Suggest I Have Cardiac Amyloidosis?

Cardiac MRI can help your doctor measure how thick the heart walls are.

Sometimes, the cardiac MRI will reveal specific patterns based on how the dye passes through the heart tissue. These patterns are often very important in making a diagnosis of cardiac amyloidosis.

What Comes Next?

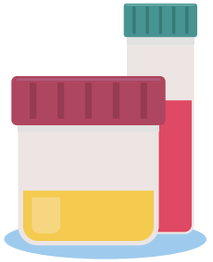
Your doctor will review your test results and talk to you about them. Results will be different for each person. Here are some common examples of what your results might show:

The test results indicate you may have cardiac amyloidosis. If this happens, your doctor will want to run additional tests to find out what type of cardiac amyloidosis you have.

The test results indicate you may not have cardiac amyloidosis. If this happens, your doctor will talk to you about what other medical condition could be causing your symptoms and what needs to be done to treat it. You may or may not need more tests.

It is unclear if you have a condition or not. This could mean your heart is healthy or it could mean that the test was unable to identify the problem. If this happens, you may need further testing.

What are Blood & Urine Tests?



A **Free Light Chain Assay** is a blood test. It measures specific proteins in your blood. Too many of these proteins can be a sign of health problems.

Serum Protein Electrophoresis with Immunofixation is a blood test. It is used to estimate how many and what type of proteins are in the blood.

Urine Protein Electrophoresis with Immunofixation is a urine test. It is used to estimate how many and what type of proteins are in the urine.

What Should I Know About These Tests?

People usually have these tests at a clinic or hospital.

The results can take several days to come back.

You may be asked to bring a 24-hour urine sample with you. This is done by collecting your urine in a special container over a full 24-hour period.

Are These Tests Safe? Will They Hurt?

These tests are common and are usually safe and well tolerated.

For the blood tests, you may have light pain or bruising in the place where the needle is inserted.

For the urine test, there are no risks.

What Should I Expect When Getting Tested?

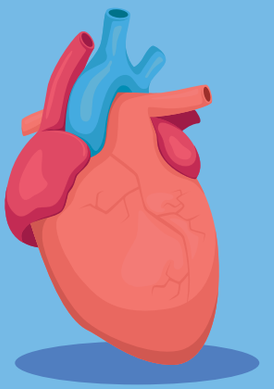
For the blood tests, a health provider will use a small, clean needle to draw blood from your arm or hand. The blood will be collected in a test tube and then tested in a lab.

For the urine test, you will be asked to use special containers to provide a sample of urine.

Some medicines can interfere with these tests. Your doctor will let you know if you should stop taking any medicines before these tests.

What Results Might Suggest I Have Cardiac Amyloidosis?

In some cases, the abnormal proteins associated with cardiac amyloidosis can be detected by these blood and urine tests. The results may tell your doctor whether you have the light chain (AL) type of cardiac amyloidosis.



What Comes Next?

Your doctor will review your test results and talk to you about them.

These tests, on their own, are not enough to make the diagnosis of light chain cardiac amyloidosis (AL). If the tests results indicate a potential abnormality, your doctor might request other tests to explore further.

What is Scintigraphy?

Scintigraphy is a test that uses a substance called a tracer and a scanning machine to create detailed images of your heart.

If the tracer finds amyloid proteins in the heart, it will bind to them and light up on the pictures of your heart like a heat map with a hot spot.

Scintigraphy can help doctors see if you have cardiac amyloidosis. It can also help identify which type of cardiac amyloidosis you have. This will help determine which treatment is best for you.

What Should I Know About This Test?

People usually have this test at a hospital.

Wear comfortable clothes. Leave your jewellery at home.

People who have an implanted medical device, such as a pacemaker, implantable-cardioverter defibrillator (ICD), cardiac resynchronisation therapy device (CRT-D), implantable loop recorder, artificial joints etc, should make their doctor aware so that they can decide whether an MRI is appropriate.

Is This Test Safe? Will It Hurt

This test involves an injection with a tracer, which has a very small amount of radioactivity. This is similar to or less than the amount of radioactivity you would get with a CT scan. It is very unlikely to cause any problems.

Women who are or might be pregnant, or who are breastfeeding, should make their doctor aware so they can decide the appropriate course of action.

People who have a fear of small, enclosed spaces may find the scanning machine uncomfortable. They may need medicine to help them relax.

What Should I Expect When Getting Tested?

A small drip (cannula) will be placed in one of your veins. You will then receive an intravenous (IV) injection of a substance called a tracer through the cannula.

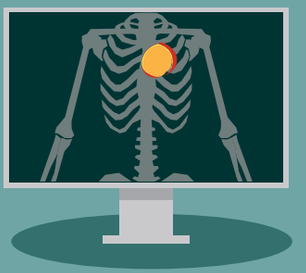
You will be asked to wait for up to 4 hours for the tracer to pass through your body. You will not be able to feel the tracer.

Next, you will be asked to lie down on a padded table. A machine will scan you to take images of your body and your heart.

During the scan, you will be asked at some points to raise your arms or to lay still. The technician will be able to see, hear, and speak with you at all times. The entire scan will take less than 1 hour.

What Results Might Suggest I Have Cardiac Amyloidosis?

Not all types of cardiac amyloidosis will show up on a scintigraphy test. If the image of your heart looks like a heat map with a hot spot, you might have a type of cardiac amyloidosis called transthyretin cardiac amyloidosis (ATTR-CM).



What Comes Next?

Your doctor will review your test results and talk to you about them. Results will be different for each person. Here are some common examples of what your results might show:

The test results indicate you may have cardiac amyloidosis. If this happens, your doctor will want to run additional tests to find out what type of cardiac amyloidosis you have. The type of cardiac amyloidosis will determine the best treatment for you, and impact prognosis.

The test results indicate you may not have cardiac amyloidosis. If this happens, your doctor will talk to you about what other medical condition could be causing your symptoms and what needs to be done to treat it. You may or may not need more tests.

It is unclear if you have a condition or not. This could mean your heart is healthy or it could mean that the test was unable to identify the problem. If this happens, you may need further testing.

Where to go for Patient Support

For more information you can contact:

Irish Heart Foundation

Tel : +353 1 6685001

Visit https://irishheart.ie/

Croí, The West of Ireland Cardiac and Stroke Foundation

Tel : 091 544310

Visit https://croi.ie