

HEART FAILURE PATIENTS,

YOUR HEART'S

MESSAGE

YOUR HEART mATTRs

**YOUR SYMPTOMS COULD
ADD UP TO SOMETHING
MORE SERIOUS THAN YOU REALISE.**

ATTR-CM (transthyretin amyloid cardiomyopathy) is a serious, underrecognised, and underdiagnosed type of amyloidosis that affects the heart and is associated with heart failure.

ATTR-CM SYMPTOMS MAY INCLUDE:

HEART
FAILURE
WITH
PRESERVED
EJECTION
FRACTION

IRREGULAR
HEARTBEAT

GI
PROBLEMS

PAIN OR
NUMBNESS IN
LOWER BACK
OR LEGS

SHORTNESS
OF BREATH

DIAGNOSED
CARPAL
TUNNEL
SYNDROME

Learn more about ATTR-CM throughout this brochure or visit yourheartsmessage.ie

WHAT IS ATTR-CM?

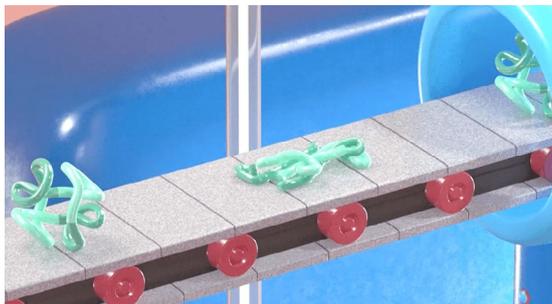
Amyloidosis is a group of diseases in which certain proteins change shape, or “misfold,” and can build up in different parts of the body. When these misfolded transthyretin proteins build up in your heart, it may lead to ATTR-CM, a serious and often underdiagnosed condition that is associated with heart failure.

HERE'S WHAT HAPPENS IN THE BODY WITH ATTR-CM

Imagine your body as a factory, composed of many systems working together to maintain your health. The liver is just one part of that system, but it carries out many important jobs that can affect your entire body, including the heart.



The liver produces **transthyretin**, a transport protein that carries the hormone thyroxine and vitamin A (retinol) throughout the bloodstream.



When someone has ATTR-CM, either due to ageing (wild-type) or an inherited genetic variant (hereditary), the protein **becomes unstable and misfolds**.



Over time, the misfolded proteins **join together and build up in the body**, including in the heart (causing the heart muscle to thicken and stiffen, eventually leading to heart failure).

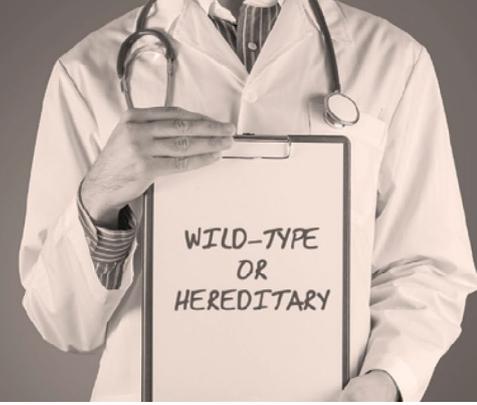


WANT TO LEARN MORE?

Scan the QR code to watch a video about how ATTR-CM affects the body. Using the camera on your smartphone, hold your device so that the QR code is visible on your screen. Your device will recognise the code and provide a notification that links to the video.

TYPES OF ATTR-CM

There are 2 types of ATTR-CM – wild-type and hereditary.



WILD-TYPE ATTR-CM (wtATTR)



- **Associated with ageing**
- Most often affects white men over the age of 60
- May be the most common form of ATTR-CM

HEREDITARY ATTR-CM (hATTR)

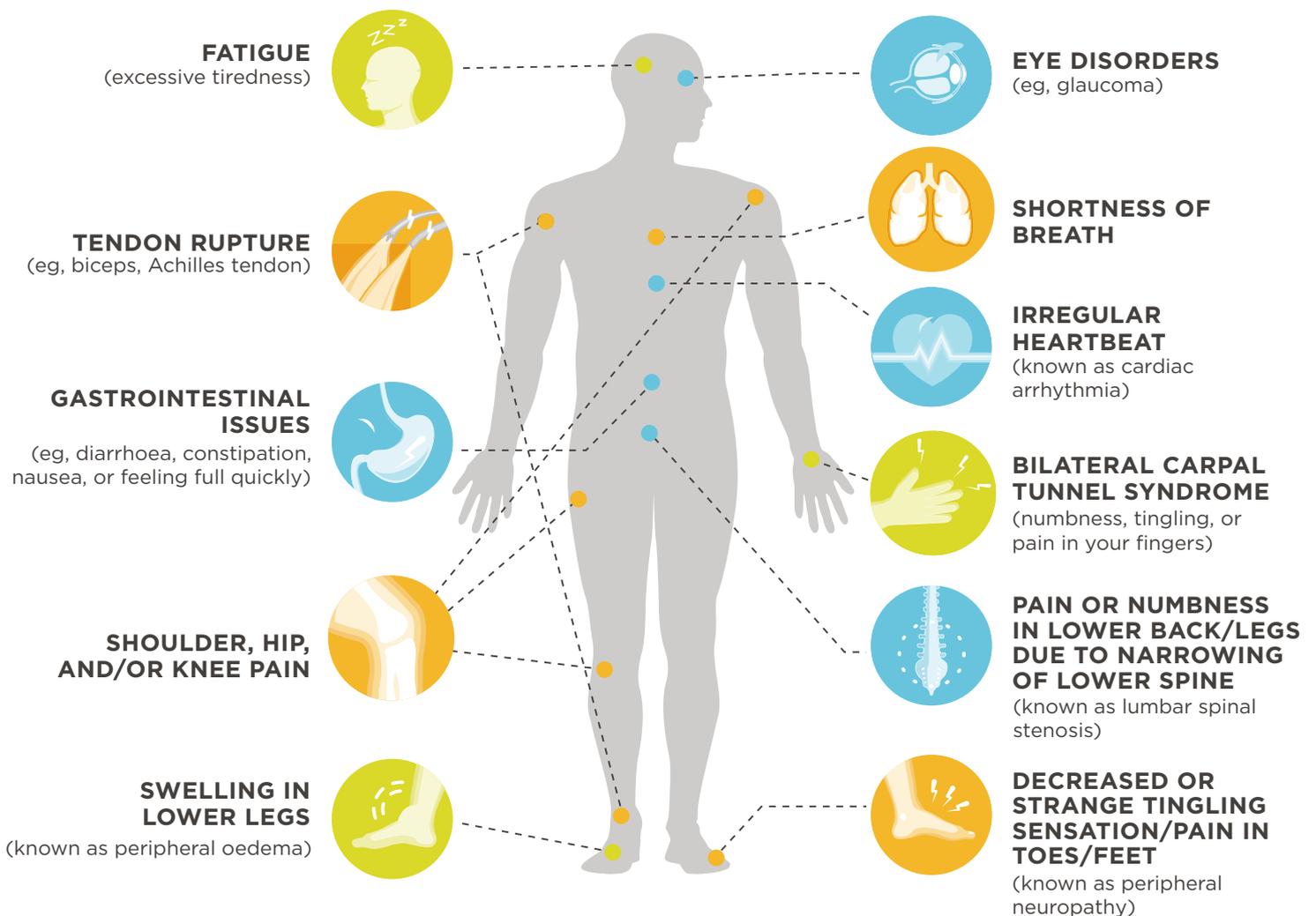


- **Caused by a change (or “mutation”) in one of your genes**
- Passed down from a relative
- Affects both men and women, with symptoms beginning as early as 50 to 60 years old
- In the Irish population, the T60A mutation is the most common mutation that can affect both the heart and nerves leading to cardiac failure and polyneuropathy

UNDERSTAND THE SIGNS AND SYMPTOMS OF ATTR-CM

Did you know that some seemingly unrelated signs and symptoms could be caused by ATTR-CM? Your body may be sending you a message.

SYMPTOMS OF ATTR-CM MAY INCLUDE:



These examples are for illustrative purposes only. Signs and symptoms may vary from patient to patient.

While these signs and symptoms don't necessarily indicate that you have ATTR-CM or another condition, any one or combination should be mentioned to your doctor.

TALKING TO YOUR DOCTOR

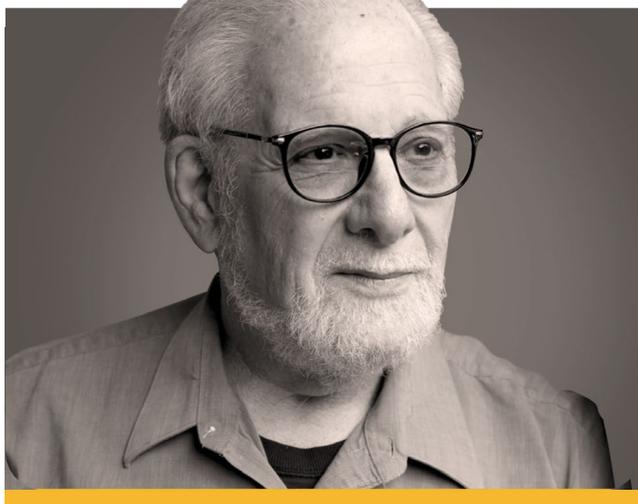
Advocating for yourself or a loved one with the disease can help you get many of the answers you need.



THE ROAD TO AN ATTR-CM DIAGNOSIS CAN BE COMPLEX AND FRUSTRATING

Awareness among patients, and even physicians, remains low, which results in ATTR-CM being underdiagnosed.

- Underdiagnosis and delayed diagnosis occur because the symptoms of ATTR-CM mimic those of other more common causes of heart failure
- Some ATTR-CM patients report visiting up to 5 different doctors before receiving the correct diagnosis



“I WAS DIAGNOSED WITH ATTR-CM ELEVEN YEARS AFTER THE PRESENTATION OF MY FIRST SYMPTOM OF CARPAL TUNNEL AND TEN YEARS AFTER MY SECOND SYMPTOM OF HEART FAILURE”

– WALT, ATTR-CM patient, age 71

If you have unresolved heart failure symptoms, ask your doctor about ATTR-CM as soon as possible.

HOW ATTR-CM IS SUSPECTED

If your doctor suspects ATTR-CM based on clinical clues, they may conduct certain diagnostic tests for further evaluation.

INITIAL TESTS

Your doctor may first order tests to assess how your heart is working and look for signs of ATTR-CM. While none of these tests are typically used to confirm an ATTR-CM diagnosis, they can help your doctor learn more about your heart and determine the need for additional diagnostic testing.



Electrocardiogram (ECG)

- Reads electrical signals from your heart
- Can reveal conditions like irregular heartbeat (i.e. atrial fibrillation), among other findings, that may be related to ATTR-CM



Echocardiogram (ECHO)

- Uses sound waves to create images of your heart
- Findings help determine the speed and direction of blood flow in the heart
- Findings associated with ATTR-CM include, but are not limited to, heart failure with preserved ejection fraction (HFpEF), which relates to the amount of blood that passes through the heart with each beat



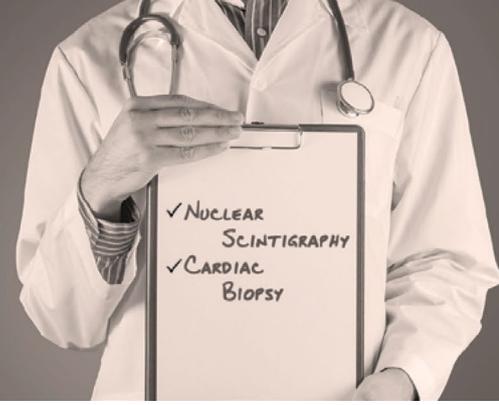
Cardiac magnetic resonance imaging (cardiac MRI)

- Uses radio waves, magnets, and a computer to create images of your heart to look for abnormalities

Your doctor must also rule out another form of cardiac amyloidosis, known as light-chain amyloidosis (AL), using blood and urine tests. This is an important step, as AL amyloidosis and ATTR-CM are managed in different ways.

DIAGNOSING ATTR-CM

Once AL amyloidosis is ruled out, your doctor may order additional tests to help diagnose ATTR-CM.



DIAGNOSTIC TESTS

There are several tests that can help confirm a diagnosis of ATTR-CM or identify whether you or a loved one are at risk.



Nuclear scintigraphy—a noninvasive imaging test

- A small amount of dye is injected into your body
- After 1-3 hours, a special camera takes images of your body
- These images can help your doctor understand if transthyretin (TTR) amyloid fibrils are present in your heart
- Also referred to as a DPD scan



Cardiac biopsy—samples taken from your heart muscle tissue

- Your cardiologist conducts the biopsy while you are awake
- The heart muscle tissue sample is sent to the lab for analysis
- The lab can help determine if they are TTR amyloid strands or not
- Your doctor may also do biopsies from other parts of your body—but a cardiac biopsy is more accurate to detect ATTR-CM

If you are diagnosed with ATTR-CM, genetic testing and counselling are recommended to determine whether you have the wild-type or hereditary form



Genetic Testing

- Will help confirm or rule out the hereditary form of ATTR-CM (hATTR)
- Determines whether family members are at risk, as the mutation that causes hATTR can be inherited
- Usually performed using blood or saliva samples

YOU ARE NOT ALONE

Resources are available to help if you or a loved one have been diagnosed with ATTR-CM.



Amyloidosis
Research
Consortium

Amyloidosis Research Consortium

- Provides comprehensive support and information for patients
- Accelerates development of and access to new and innovative treatments
- Drives research that will have the greatest impact on patients

arci.org



amyloidosis
foundation

Amyloidosis Foundation

- Supports research for an earlier diagnosis
- Educates medical professionals
- Provides patients with a comprehensive range of services

amyloidosis.org

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