SCAN ME

Questions to Ask Your Doctor

- Could ATTR-CM be the cause of my heart failure?
- What type of ATTR-CM do I have?
- How severe is my ATTR-CM? Are other organs affected?
- Should I have genetic testing? Should my family members?
- What treatments are available for me with the risks and benefits of each option?
- What medications should I avoid?
- What happens if I don't get treatment?
- What diet and lifestyle changes should I make, if any?
- How should I monitor my ATTR-CM?
- When should I call you (the doctor) or 911?

Contact Us

If you would like to receive support or need more information, please contact us at:

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Living with ATTR-CM

Mended Hearts®

Discussion Guide for Patients & Caregivers

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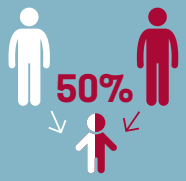
What is ATTR-CM?

Transthyretin amyloid cardiomyopathy (ATTR-CM) is a serious and often overlooked cause of heart failure. In this condition, TTR (transthyretin), a protein in your blood, folds incorrectly causing amyloid deposits to build up. This process is called amyloidosis. The most common place the deposits build up is in your heart muscle, causing a form of restrictive cardiomyopathy (CM). ATTR-CM causes the heart muscle to thicken and stiffen and become unable to pump blood effectively and may cause heart failure.

There are two types of ATTR-CM:

- **Hereditary (hTTR-CM)** is when there is a change (or "mutation") in the TTR gene. This type often runs in families. The most common gene mutation in the U.S. that could cause ATTR-CM is the V1221 mutation. Around 3-4% of African American communities have the V1221 mutation. Not all individuals with the mutation will develop symptoms of hereditary ATTR-CM.



If one parent has hTTR-CM, their child has a 50% chance of inheriting the genetic variant that may cause it.

- **Wild Type** usually affects your heart; no one knows what causes it. It is thought to be associated with aging and most commonly affects Caucasian men over age 60. This type is becoming more common as people are living longer.

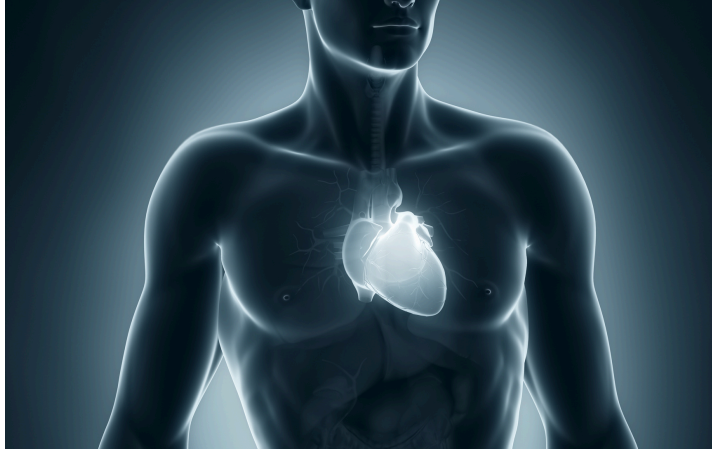
Symptoms

Symptoms of ATTR-CM are often similar to symptoms of heart failure from other causes or to other heart diseases. Since there is very little awareness of the condition, patients may go undiagnosed for years. Most people with wild type ATTR-CM don't get symptoms until after age 60. Some people with ATTR-CM don't have symptoms at all or have very mild symptoms until the disease has progressed to more advanced stages.

Symptoms of ATTR-CM can be very different for each person. Some common symptoms are:

- Shortness of breath (most common)
- Swelling in the lower legs
- Gastrointestinal issues (e.g., diarrhea)
- Fatigue, excessive tiredness
- Numbness, strange tingling sensation, or pain in the toes or feet
- Carpal tunnel syndrome

If your symptoms continue to get worse even if you are taking medication for heart failure, or if you have adverse effects from heart failure medication, you may have undiagnosed ATTR-CM.



Treating ATTR-CM

Although there is currently no cure for ATTR-CM, it is important to discuss treatment options with your doctor. ATTR-CM is a progressive condition, which means it will get worse over time.

Some treatments for ATTR-CM treat the underlying problem while others help with the symptoms.

ATTR-CM is often underdiagnosed due to lack of awareness about the disease.