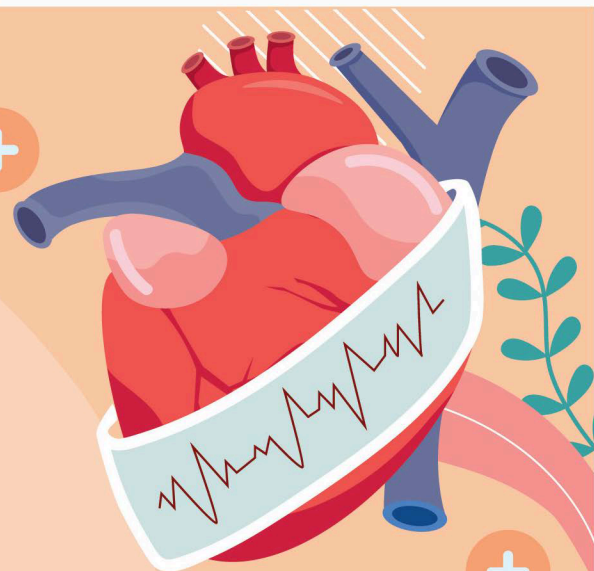


WHEN HEART FAILURE ISN'T THE WHOLE STORY: ATTR-CM EXPLAINED

ATTR-CM occurs when an amyloid protein called transthyretin, made in the liver, is misfolded and accumulates within heart tissue. The accumulation of this protein can cause the heart muscles to become stiff, leading to cardiomyopathy or disease of the heart muscles. When the heart muscles are significantly affected, the heart may not be able to pump blood properly and result in heart failure. This protein may also accumulate in other organs, also causing issues with the nervous system, and other organs.



WHY DOES ATTR-CM HAPPEN?

There are two types of ATTR-CM:

1 Wild Type (wATTR-CM):

This type is not passed down in families and usually affects older adults. It can lead to heart problems and other symptoms, like carpal tunnel and nerve pain in the hands and feet.

2 Hereditary Type (hATTR-CM):

This type is inherited, meaning it runs in families. It's caused by a gene change, or mutation, that makes the protein more likely to misfold. In the U.S., about 3-4% of Black people carry this gene, although not everyone who has the gene will develop ATTR-CM.



SYMPTOMS OF ATTR-CM

One reason ATTR-CM can be hard to diagnose is that symptoms often don't appear until the condition has advanced to heart muscle disease (cardiomyopathy) or heart failure. This lack of early symptoms, combined with low awareness, can lead to misdiagnosis.

When symptoms do appear, they may include:

- + Shortness of breath, even when resting
- + Swelling in the lower legs or feet
- + Chest congestion
- + Bloating in the abdomen
- + Confusion or trouble thinking
- + Fast or irregular heartbeats
- + Palpitations
- + Abnormal heart rhythms

Other symptoms vary by type and could include numbness or tingling in the hands and feet (hereditary type), as well as conditions that are more common that may be related to amyloid such as spinal stenosis and carpal tunnel syndrome.

HOW IS IT DIAGNOSED?

Doctors usually start by looking at symptoms and results from routine heart tests like an electrocardiogram (ECG) and echocardiogram. If they think it could be ATTR-CM, they might order more specific tests, such as a cardiac MRI, amyloid nuclear scan, a biopsy of heart tissue, or genetic testing (for the hereditary type). Because the symptoms of ATTR-CM can be subtle, vary widely, and overlap with other conditions, it may take time to reach a diagnosis. This is why it's essential for doctors to consider the full picture, including any seemingly unrelated symptoms.

HOW IS IT TREATED?

Treatment for ATTR-CM focuses on slowing the disease, reducing symptoms, and improving quality of life. Current medicines can help limit or stop the buildup of amyloid protein in the heart, which can ease symptoms and slow disease. Other treatments can manage heart failure symptoms, irregular heart rhythms, and pain in the hands and feet. In cases of advanced heart failure, a heart transplant may be considered. While current treatments don't remove existing amyloid deposits, there are effective options to manage the condition, and ongoing research is working toward new therapies.

TALKING TO YOUR HEALTHCARE TEAM ABOUT ATTR-CM

If you have heart failure with unresolved or unusual symptoms, ask your doctor if these could be related to ATTR-CM and whether additional tests might help confirm a diagnosis.

If diagnosed with ATTR-CM, consider asking:

- What type of ATTR-CM do I have?
- What treatment options are available?
- How can I manage any side effects?
- What symptoms or complications should I monitor?

Tip: Keep a record of all your symptoms, even those that seem unrelated, to discuss with your doctor.



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WHEN HEART FAILURE ISN'T THE WHOLE STORY: ATTR-CM EXPLAINED

Transthyretin amyloid cardiomyopathy (ATTR-CM) is a condition that often goes unrecognized and is sometimes misdiagnosed. It can cause a variety of symptoms that don't seem connected and may affect the heart, nervous system, and sometimes the kidneys. Since ATTR-CM isn't well known and has been considered rare, many people don't realize their symptoms—or heart condition—could be caused by ATTR-CM. This lack of awareness can lead to misdiagnosis of the cause of heart failure. With new treatments available, early diagnosis and treatment are especially important for better outcomes.



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WOMENHEART: The National Coalition for Women with Heart Disease is the nation's first and still only patient centered organization exclusively focused on serving millions of American women living with or at risk for heart disease — the leading cause of death in women. WomenHeart is solely devoted to advancing women's heart health through advocacy, community education, and the nation's only patient support network for women living with heart disease. WomenHeart is both a coalition and a community of thousands of members nationwide, including women heart patients and their families, physicians, and health advocates, all committed to helping women live longer, healthier lives. To learn more or to donate visit [womenheart.org](https://www.womenheart.org).

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