

HEART FAILURE PATIENTS,

# YOUR HEART

## mATTRs

GET THE MESSAGE

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

ATTR-CM (transthyretin amyloid cardiomyopathy) is a serious, underrecognized, and underdiagnosed type of amyloidosis that affects the heart and is associated with heart failure.<sup>1-5</sup>

ATTR-CM SYMPTOMS MAY INCLUDE:<sup>1,3,6-13</sup>

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

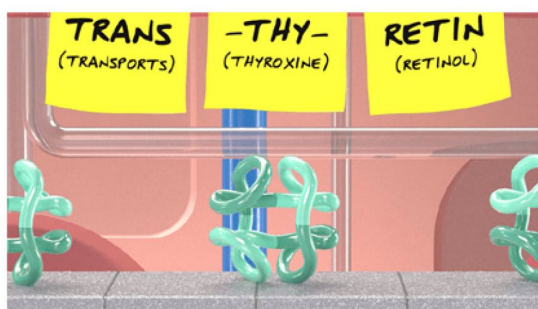
Learn more about ATTR-CM throughout this brochure or visit [heartsmattr.com.hk](https://heartsmattr.com.hk)

# WHAT IS ATTR-CM?

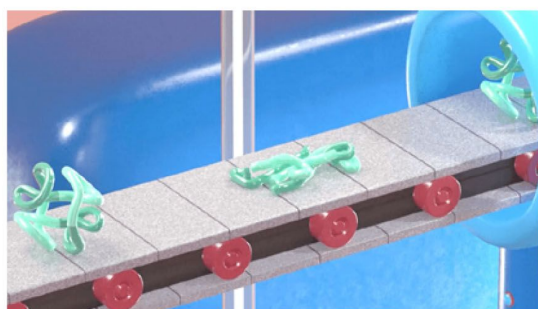
Amyloidosis is a group of diseases in which certain proteins change shape, or “misfold,” and can build up in different parts of the body. When these misfolded transthyretin proteins build up in your heart, it may lead to ATTR-CM, a serious and often underdiagnosed condition that is associated with heart failure.<sup>1-6,14</sup>

## HERE'S WHAT HAPPENS IN THE BODY WHEN YOU HAVE 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.<sup>3,6,14</sup>



When someone has ATTR-CM, either due to aging (wild-type) or an inherited genetic variant (hereditary), the protein **becomes unstable and misfolds**.<sup>3,6,14</sup>



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).<sup>3,6,14</sup>

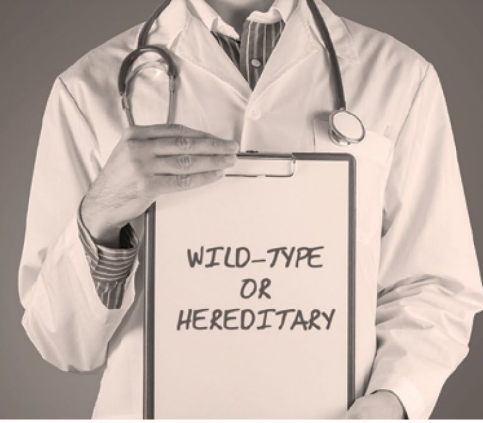


### WANT TO LEARN MORE?

[Click here](#) or 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 recognize 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.<sup>3,6</sup>



## WILD-TYPE ATTR-CM (wATTR)<sup>14,15</sup>



- **Associated with aging**
- May be the most common form of ATTR-CM

## HEREDITARY ATTR-CM (hATTR)<sup>6,14-16</sup>

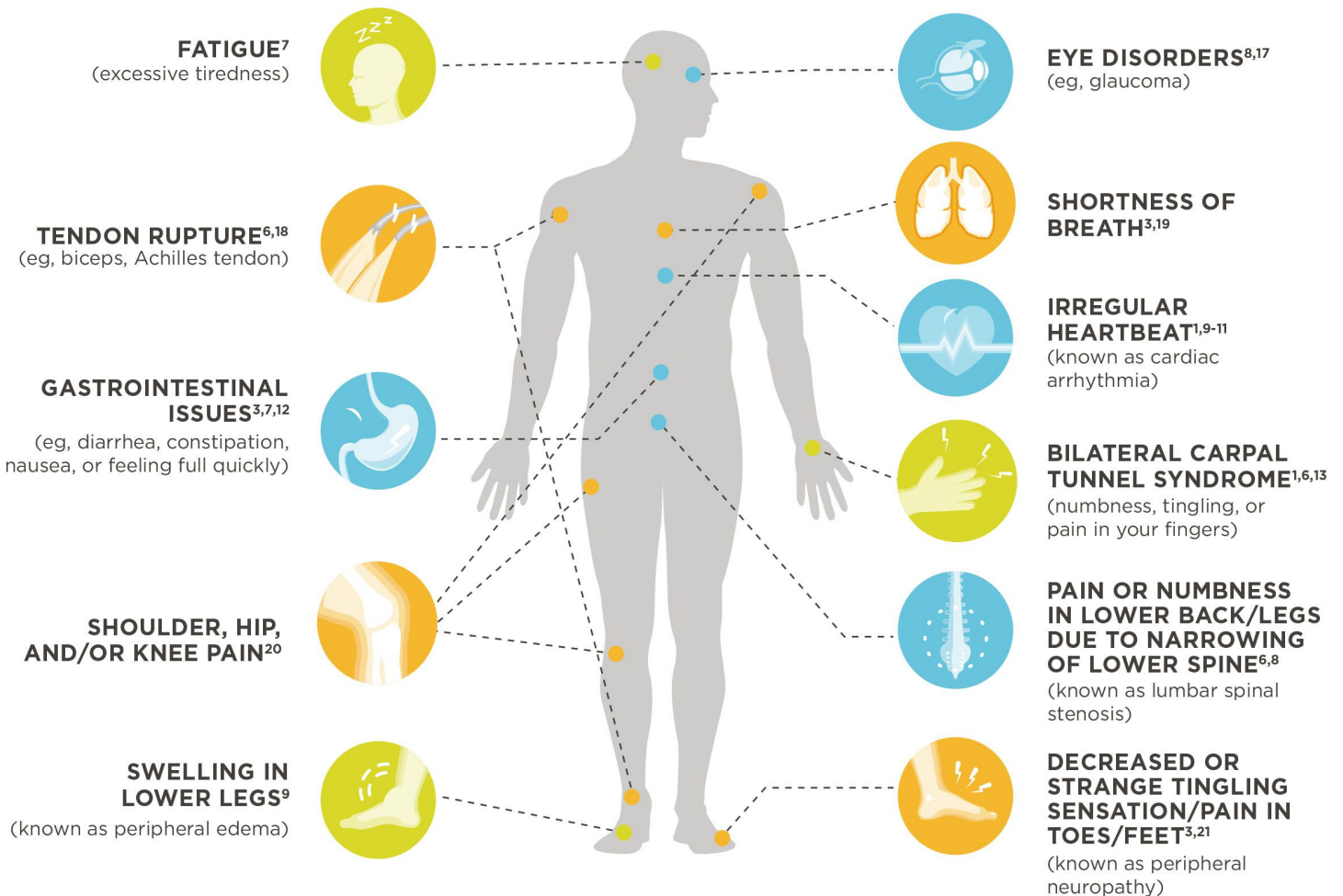


- **Caused by a change (or “mutation”) in one of your genes**
- Passed down from a relative
- Affects both men and women, with symptoms beginning as early as 50 to 60 years old
- There are more than 120 known mutations that cause hATTR

# 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,<sup>1</sup> 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<sup>22</sup>



Ready to talk to your doctor about ATTR-CM but aren't sure how to start the conversation? [Click here](#) or scan the QR code (using your phone's camera) to create a custom doctor discussion guide—a useful tool to help get the conversation started.



“I WAS DIAGNOSED WITH ATTR-CM 11 YEARS AFTER THE PRESENTATION OF MY FIRST SYMPTOM OF CARPAL TUNNEL AND 10 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)<sup>6,23</sup>**

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



### **Echocardiogram (ECHO)<sup>6</sup>**

- 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



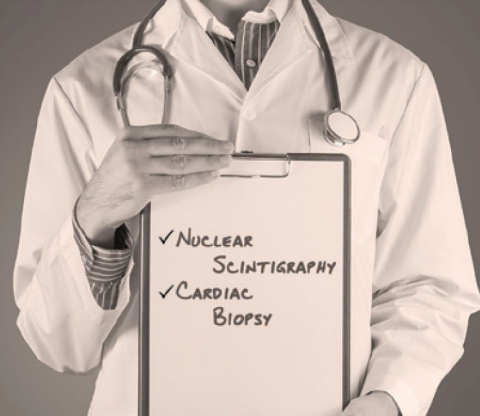
### **Cardiac magnetic resonance imaging (cardiac MRI)<sup>6</sup>**

- 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<sup>6</sup>

- 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 PYP (pyrophosphate) scan



### Cardiac biopsy—samples taken from your heart muscle tissue<sup>6</sup>

- Your cardiologist conducts the biopsy while you are awake
- If amyloid fibrils are found in the removed tissue sample, it is sent out to a lab
- 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 counseling is recommended to determine whether you have the wild-type or hereditary form<sup>1</sup>**



### 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<sup>24</sup>

# YOU ARE NOT ALONE

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



香港罕見疾病聯盟  
RARE DISEASE HONG KONG

## Rare Disease Hong Kong

- Enhances the understanding of rare diseases among patients, carers, and their families
- Educates the public on rare diseases to raise awareness, understanding and support for the rare disease community
- Advocates the government and related parties to formulate policies in rare diseases
- Supports and assists in rare disease research

[hkard.org](http://hkard.org)



關心您的心  
Care For Your Heart

## Care For Your Heart

- Provides knowledge about heart diseases for patients and their families
- Acts as the bridge between patients and healthcare institutions
- Unites patients to safeguard and fight for reasonable rights and benefits
- Raises public awareness on heart health and the prevention of heart diseases

[careheart.org.hk](http://careheart.org.hk)



聖雅各福群會持續照顧服務  
St. James' Settlement Continuing Care

## St. James' Settlement Continuing Care: The Philanthropic Community Pharmacy

- Provides self-financed medication, prescribed by hospitals and clinics under the Hospital Authority, at a much affordable price for patients
- Provides pharmacist consultations
- Assist patients with chronic diseases in receiving timely drug treatment

[cc.sjs.org.hk](http://cc.sjs.org.hk)



## Pharmaceutical Care Foundation

- Promotes the general public and elderly's overall awareness and knowledge about the correct and safe use of medications
- Provides professional pharmaceutical care services for old-age homes

[pcfhk.org](http://pcfhk.org)



HKF  
Hong Kong Healthcare Foundation Ltd  
香港健康基金會有限公司

## Hong Kong Healthcare Foundation

- Committed to providing reliable medical information for Hong Kong residents
- Promotes health management and disease prevention
- Subsidizes people in need for disease screening

[hkhcf.org](http://hkhcf.org)

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## FIND SUPPORT FROM THESE TRUSTED ORGANIZATIONS

**References:** 1. Maurer MS, et al. *Circulation* 2017;135:1357-1377. 2. Gonzalez-Lopez E, et al. *Eur Heart J* 2015;36:2585-2594. 3. Maurer MS, et al. *J Am Coll Cardiol* 2016;68:161-172. 4. Sipe JD, et al. *Amyloid* 2016;23:209-213. 5. Donnelly JP, Hanna M. *Cleve Clin J Med* 2017;84:12-26. 6. Siddiqi OK, Ruberg FL. *Trends Cardiovasc Med* 2018;28:10-21. 7. Nativi-Nicolau J, Maurer MS. *Curr Opin Cardiol* 2018;33:571-579. 8. Wittles RM, et al. *JACC Heart Fail* 2019;7:709-716. 9. Connors LH, et al. *Circulation* 2016;133:282-290. 10. Grogan M, et al. *J Am Coll Cardiol* 2016;68:1014-1020. 11. Mints YY, et al. *ESC Heart Fail* 2018;5:772-779. 12. Coelho T, et al. *Curr Med Res Opin* 2013;29:63-76. 13. Pinney JH, et al. *J Am Heart Assoc* 2013;2:e000098. 14. Gonzalez-Lopez E, et al. *Rev Esp Cardiol (Engl Ed)* 2017;70:991-1004. 15. Castano A, et al. *Heart Fail Rev* 2015;20:163-178. 16. Shah KB, et al. *Circ Heart Fail* 2016;9:e002558. 17. Taban M, et al. *Ophthalmic Plast Reconstr Surg* 2004;20:162-165. 18. Geller HI, et al. *JAMA* 2017;318:962-963. 19. Bishop E, et al. *Amyloid* 2018;25:174-179. 20. Rubin J, et al. *Amyloid* 2017;24:226-230. 21. Zivkovic S, et al. *Amyloid* 2020;27:142-143. 22. Lousada I, et al. *Orphanet J Rare Dis* 2017;12(Suppl 1):P7. 23. Rapezzi C, et al. *Nat Rev Cardiol* 2010;7:398-408. 24. Invitae. Invitae hereditary transthyretin-mediated amyloidosis (hATTR amyloidosis) test. Available at: [www.invitae.com/en/physician/tests/O2265/#info-panel-assay\\_information](http://www.invitae.com/en/physician/tests/O2265/#info-panel-assay_information). Accessed September 2021.

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