A guide to understanding hypertrophic cardiomyopathy (HCM)

UNEXPLAINED SYMPTOMS HOLDING YOU BACK?

COULD IT BE **HCM**

Ask your doctor about your symptoms and if you should see a cardiologist.

Learn more inside.

Common symptoms can include:

Shortness of breath | Tiredness | Rapid heartbeat | Chest pain | Feeling dizzy or light-headed | Fainting | Fatigue

Symptoms can be representative of many conditions. Only a healthcare provider can determine whether these symptoms indicate HCM or another condition.

Not a real patient. For illustrative purposes only.

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Could It Be **HCM**?

HCM is a lifelong heart condition where the heart muscle wall thickens, stiffens, and makes it harder for the heart to pump oxygenated blood throughout the body. (For a detailed description, see pages 6–8.)

The reported prevalence of HCM ranges from 1 in 200* to 1 in 500† people in the general population. However, only ~100,000‡ patients in the US have been diagnosed with HCM, which suggests that:

Approximately 85%§ may remain undiagnosed

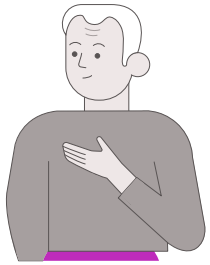
HCM can affect people of any age, gender, or ethnicity. It can also be inherited.

*The 2015 Semsarian publication identified that the prevalence of HCM gene carriers could be as high as 1 in 200.
†The 1995 CARDIA study—a multicenter, U.S.-population–based echocardiography study of 4111 subjects (aged 23–35)—identified the prevalence of HCM as 1 in 500 people in the general population.
‡Based on 2013 ICD-9 claims data analysis (N=169,089,614): An estimated ~700,000 overall U.S. prevalence of HCM (1. ~100,000 patients with diagnosed HCM [based on 2013 U.S. Census population], 2. ~600,000 patients with undiagnosed HCM [based on analysis' assumption that 1-in-500 prevalence represents clinically unrecognized cases]).
§Estimated undiagnosed range calculated using prevalence of 1 in 500, estimated U.S. population (332,330,571 in May 2021), and estimated diagnosed population (~100,000).

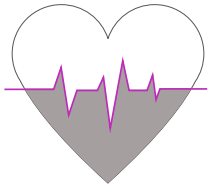
Are you experiencing any of the symptoms below?

If so, it's important to seek medical attention and talk with your doctor about what may be the cause.

Shortness of breath



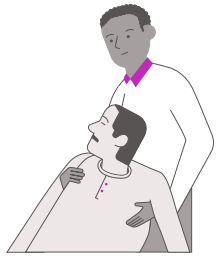
Chest pain



Rapid heartbeat

Unexplained tiredness

Feeling dizzy or light-headed



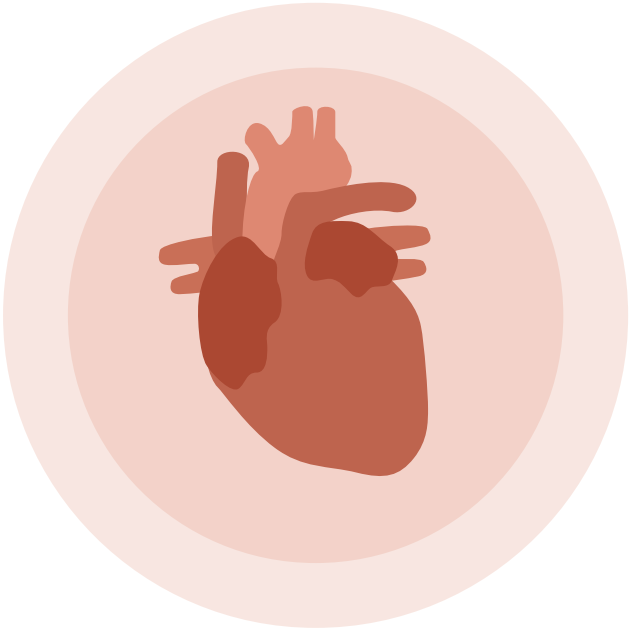
Fainting

HCM affects people in different ways. For some people, symptoms come and go, and for others, symptoms can persist. Symptoms can develop at any age and may get worse over time.

People with HCM may experience additional symptoms that are not represented here.

HCM can be misdiagnosed and difficult for doctors to recognize.

Symptoms of HCM are similar to those of other conditions. These can include:



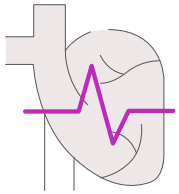
- Anxiety
- Asthma
- Heart failure
- Coronary heart disease
- High blood pressure
- Atrial fibrillation, or AFib, a type of irregular heartbeat
- Chronic obstructive pulmonary disease, or COPD
- Other types of cardiomyopathy

This is not a complete list of conditions that share symptoms with HCM.

While your doctor may suspect HCM after a physical assessment and a review of your family history, confirming HCM requires a diagnostic test such as an echocardiogram, or "echo" (an ultrasound of the heart).

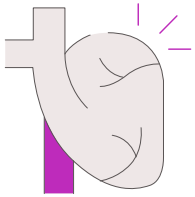
A first evaluation for HCM may include:

Physical exertion tests
such as walking, leg raises, or standing

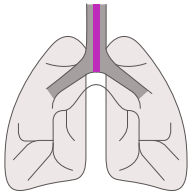


An electrocardiogram, or ECG
to record the electrical signals of your heart

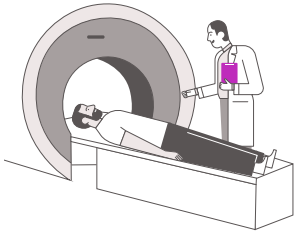
Next, to diagnose HCM, your doctor may perform:



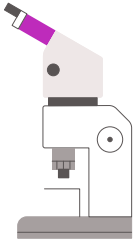
An echocardiogram
to measure the thickness of your heart's inner wall



A breathing method
to check how well blood flows through your heart under pressure

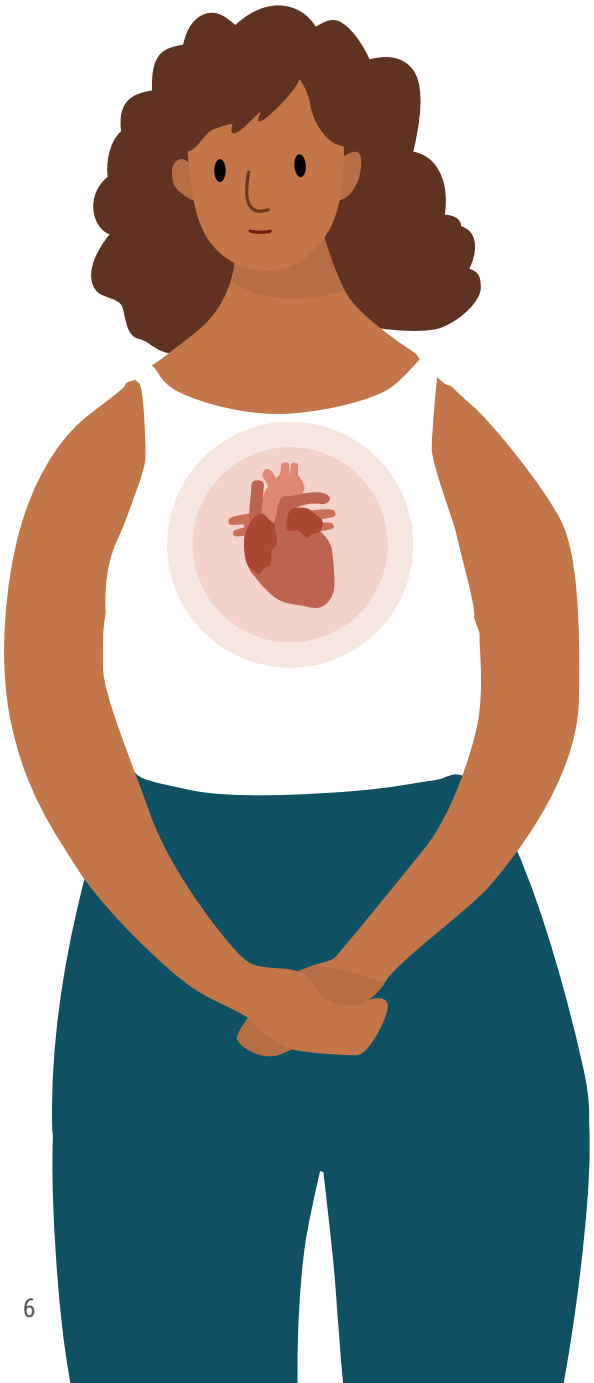


An MRI
if echocardiogram results are inconclusive or complementary information is needed



A genetic test
to evaluate if your HCM is inherited

Your doctor may refer you to a cardiologist (a heart specialist).

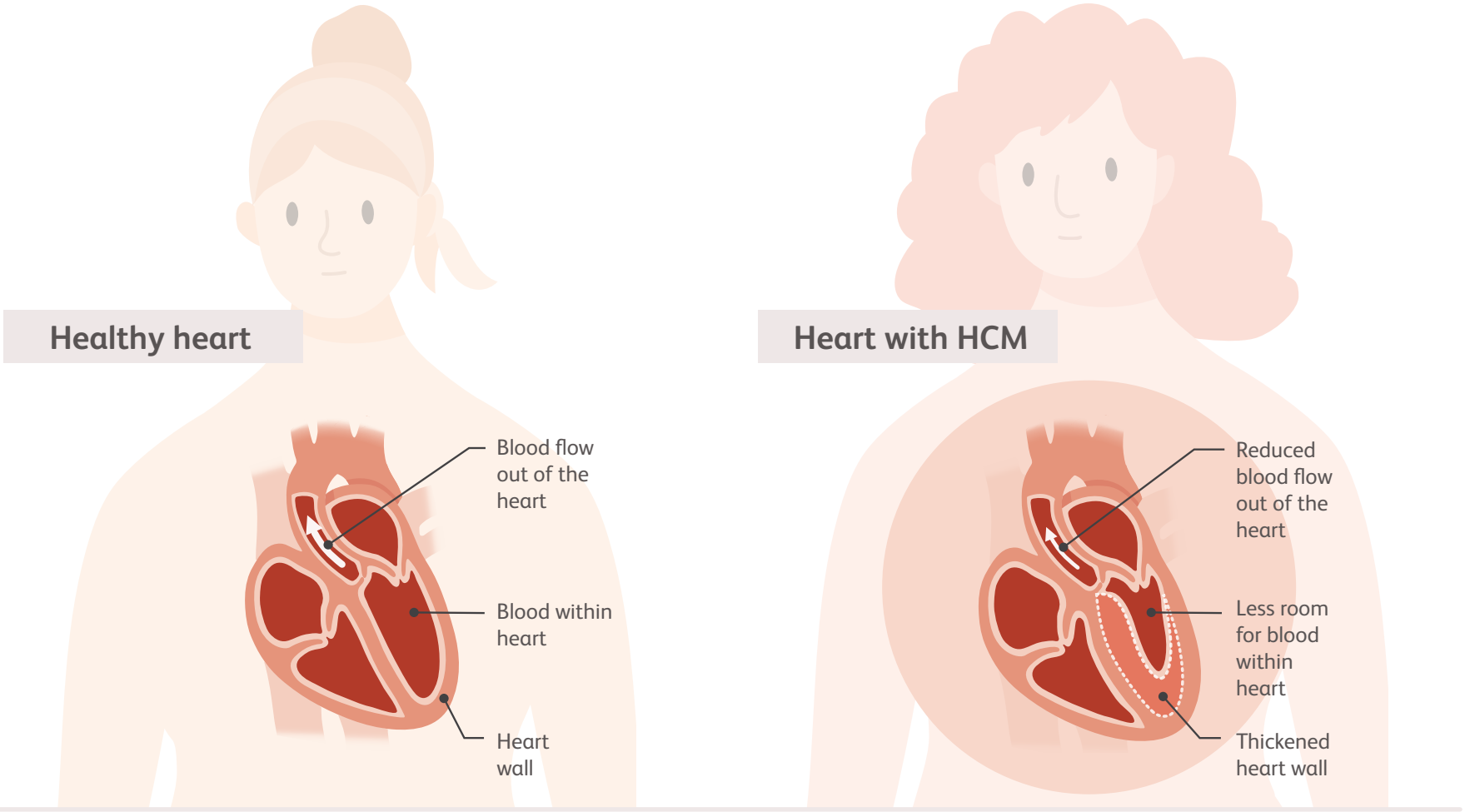


When a thickened heart muscle reduces or blocks blood flow to the rest of the body, that could be a form of HCM.

For people diagnosed with HCM, doctors can recommend management approaches that are appropriate for each patient.

People with HCM have what could be described as a “hidden disease.”

They may not appear to be sick, but in fact, their hearts are not functioning like a healthy heart.

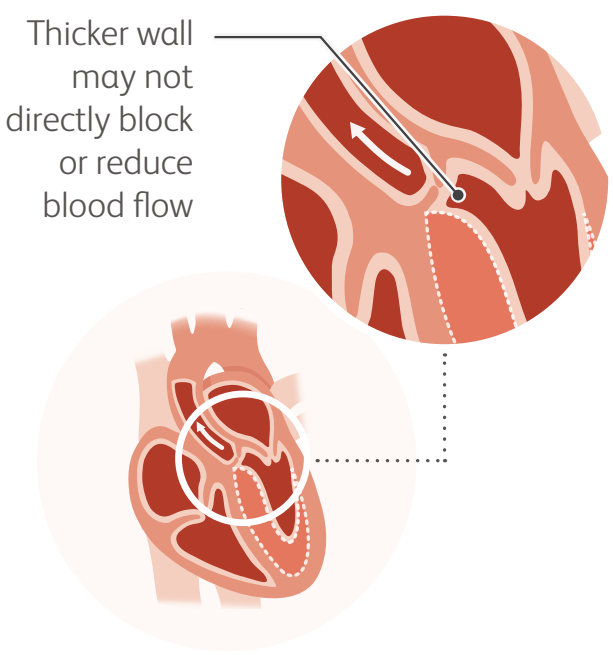


This means a heart affected by HCM has to work harder and may have difficulty pumping oxygen-rich blood out to the rest of the body. As a result, those with HCM can experience a lack of energy, a fast heartbeat, chest pain, or other symptoms. For a list of symptoms, see page 3 of this brochure.

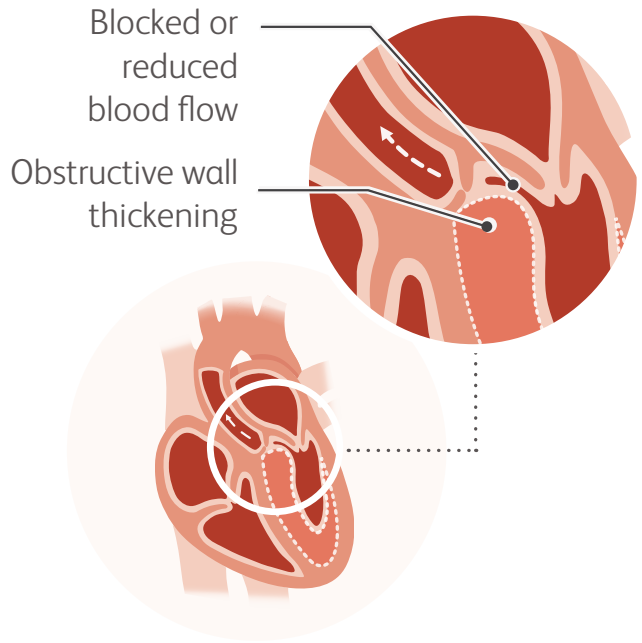
What is nonobstructive HCM vs obstructive HCM?

There are two types of HCM: nonobstructive HCM and obstructive HCM.

Both types of HCM result in thicker heart walls, but in obstructive HCM, the thicker wall may block or reduce blood flow out of the heart.



Nonobstructive HCM

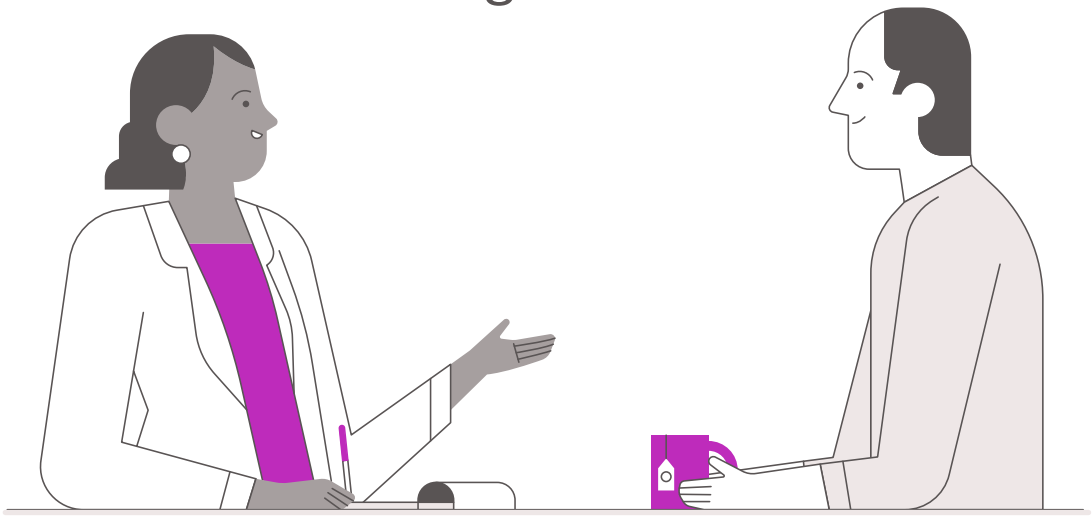


Obstructive HCM

Talk with your doctor to learn more about HCM.

HCM can result in potentially serious complications.

A delayed or missed HCM diagnosis may put a patient's health at a greater risk.



Consider these statistics:

Risk of death

- Compared with the general U.S. population, the risk of death is substantially higher for both younger people (**>4x risk** for ages 20–29 years) and older people (**≥3x risk** for ages 50–69 years) who have HCM*

Complications

- Complications of HCM include heart failure (where the heart cannot pump enough blood to meet the body's needs), stroke (where a change in blood flow through the brain leaves certain brain cells without oxygen), and AFib (where the heart beats irregularly). In a study of 480 patients with HCM,† those patients were:

  - **6x** more likely to develop AFib
  - **8x** more likely to have a stroke if they had both HCM and AFib

Sudden cardiac death

- While a rare occurrence, **HCM is the most common cause of sudden cardiac death, or SCD, in young people** and athletes under the age of 35 years‡

*Data from the SHaRe (Sarcomeric Human Cardiomyopathy Registry) database were compared with the Centers for Disease Control and Prevention WONDER database to estimate general U.S. population mortality rates from 1999 to 2014.

†Based on a community-based population study of 480 patients, AFib occurred in n=107/480 (22%). Stroke occurred in n=23/107 (21%) of patients with HCM and AFib.

‡Sudden cardiac death occurs in ~1% of patients with HCM annually.

HCM can be passed down within families.

Do you know of any family members (for example, a grandparent, aunt, or cousin) who have HCM or who died from a sudden cardiac event? It's important to share your family history with your doctor.

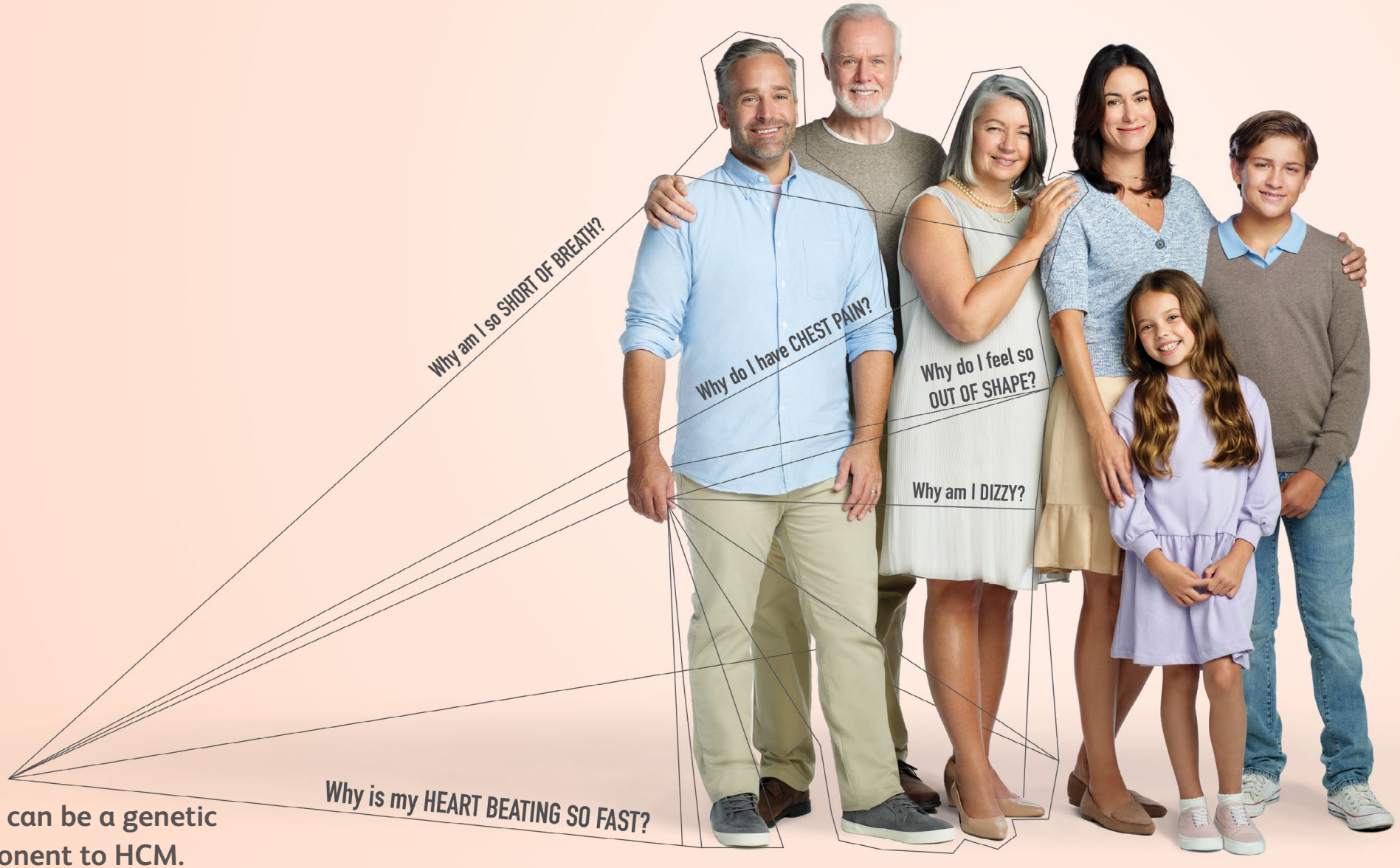
- If someone in your family has HCM, your doctor may check *you* for HCM
- If *you* have HCM, your family members may want to ask their doctors whether they would recommend an evaluation

"My father had HCM, and he had a couple of strokes during his life. So **I knew of my family history** and thought that it was something that I should get looked at."

Cynthia, **real HCM patient**

All patients were compensated for their time in the creation of this content.

HCM is the most common inherited heart condition.



There can be a genetic component to HCM.

Not real patients. For illustrative purposes only.

Symptoms of HCM can sometimes be life-limiting.

HCM can be a debilitating and life-changing disease that reduces physical functioning and overall well-being.

Worsening HCM symptoms may limit people's physical activities, keep them from everyday tasks, and impact their ability to work. HCM can also affect people mentally and emotionally.

For example, someone with HCM might:

- Exercise less (including walking)
- Perform fewer daily household chores
- Have trouble sleeping through the night
- Withdraw from socializing with others

If you've noticed that your symptoms are impacting your daily activities, it's important to tell your doctor.

Be assured, there are many resources available for information regarding HCM.

Find further information, educational materials, and resources for advocacy through the following organizations:

Hypertrophic Cardiomyopathy Association (HCMA)—Focused on providing support, advocacy, and education to patients, families, and the medical community on HCM while supporting research and fostering the development of treatments. Online at **www.4hcm.org**

The Mended Hearts, Inc.—Focused on inspiring hope and improving the quality of life of heart patients and their families through peer-to-peer support, education, and advocacy. Online at **www.mendedhearts.org**

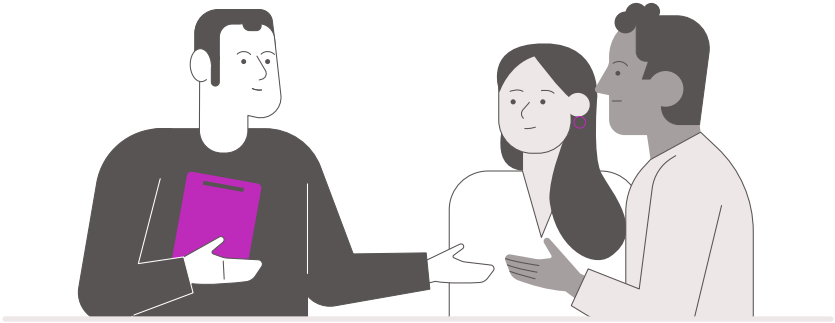
WomenHeart—Focused on improving the health and quality of life of women living with or at risk of heart disease and advocating for their benefit. Online at **www.womenheart.org**

Sign up for more information on HCM.

If you have questions about HCM, we want to help.
If you would like to learn more about HCM, sign up to receive these resources:

Helpful information
Get educational information and support tools, such as doctor discussion tips and a symptom guide.

Support and advocacy groups
Discover organizations and associations that may be able to provide you with even more helpful information.



To sign up for additional information about HCM:

Call **866-4HCM-INFO** (866-442-6463), 8 AM to 8 PM ET, Monday to Friday

Or visit **www.CouldItBeHCM.com**

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