

A discussion guide to help people talk with their doctor about their symptoms and hypertrophic cardiomyopathy (HCM)

Full name: _____ Today's date: _____

Do you have unpredictable symptoms that can't be explained?

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

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

These are common symptoms of HCM—a lifelong heart condition where the heart muscle wall thickens and stiffens, which can make it harder for the heart to pump oxygenated blood throughout the body. Complications of HCM can include heart failure, atrial fibrillation (also known as AFib), and stroke.

Symptoms of HCM are similar to those of other conditions and can develop at any age. Ask your doctor about any symptoms you may be experiencing and if HCM could be the cause. Only a healthcare provider can determine whether they are related to HCM or another condition.

Fill out this discussion guide prior to your visit to help ensure a productive conversation.

Please complete the following questions and discuss your answers with your doctor:

1. Which of the symptoms below have you experienced over the last two months?

Please check all that apply:

- | | | | |
|---|---------------------------------------|---|-------------------------------|
| <input type="radio"/> Shortness of breath | <input type="radio"/> Rapid heartbeat | <input type="radio"/> Feeling dizzy or light-headed | <input type="radio"/> Fatigue |
| <input type="radio"/> Tiredness | <input type="radio"/> Chest pain | <input type="radio"/> Fainting | |

2. Do your symptoms only show up or get worse with physical exertion?

- Yes No

3. Which of the below activities have been difficult for you to perform because of your symptoms?

Please check all that apply:

- | | | |
|---------------------------------------|---------------------------------------|--|
| <input type="radio"/> Walking | <input type="radio"/> Standing | <input type="radio"/> Household chores (such as cooking or cleaning) |
| <input type="radio"/> Climbing stairs | <input type="radio"/> Getting dressed | <input type="radio"/> Participating in social activities |
| <input type="radio"/> Exercising | <input type="radio"/> Shopping | <input type="radio"/> Performing your job |

Please include any other activities impacted by your symptoms, or any details you wish to provide:

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

4. Have you noticed yourself making changes to your activities or lifestyle due to your symptoms?

Yes No Not sure If "Yes"/"Not sure," give details/explain. _____

5. The following conditions can share symptoms with HCM.

Have you been previously diagnosed with any of the following conditions?

Please check all that apply and tell your doctor:

- Anxiety
- Heart failure
- Chronic obstructive pulmonary disease, or COPD
- Asthma
- Coronary heart disease
- Other types of cardiomyopathy
- Heart murmur
- High blood pressure
- None of the above
- Mitral valve prolapse, or MVP
- Abnormal heart rhythm (such as AFib)

6. HCM can be inherited. Are you aware of any family members (such as parents or grandparents, aunts or uncles, siblings, or cousins) who have had a cardiac event or who have been diagnosed with HCM?

Yes No Not sure If "Yes"/"Not sure," give details/explain. _____



HCM is the most common inherited genetic heart disease,* meaning it can be passed down in families.

7. Are you currently taking medications or supplements to help manage your symptoms?

Please check all that apply and provide details to discuss with your doctor:

- Prescription medications, including any taken as needed: _____
- Over-the-counter medications: _____
- Supplements: _____

8. Have you ever had an electrocardiogram, stress test, or echocardiogram?

Please tell your doctor if the results were abnormal, as well as the month and year of your test, if you can recall it.

Yes No Not sure If "Yes"/"Not sure," give details/explain. _____

*HCM is not genetic in all patients.



Here are some questions you may want to ask your doctor.

If you're having unexplained symptoms:

What do you think might be causing my symptoms?

If your doctor says it might be HCM, ask if further evaluation is needed.

I'm being/I've been treated for another condition that's not HCM, called _____, but I still experience these symptoms: _____. Could there be an explanation for why that is?

It's possible to have more than one condition at the same time. If that's the case for you, treating only one of your conditions may not be enough. Your doctor may want to make sure you don't have another condition that needs to be managed, such as HCM.

If your doctor suspects you have HCM:

How is HCM evaluated and diagnosed?

Your doctor may mention a few tests you haven't heard of before: An electrocardiogram, or ECG, records the electrical signals of your heart; an echocardiogram, or "echo," is a heart ultrasound. The echo may be performed under stress while you're using a bike or treadmill—or while you're doing a breathing test called a Valsalva maneuver, which checks how well blood flows from your heart under pressure.

Should I be seeking advice about HCM from a specialist?

Depending on your doctor's experience with HCM, you may be advised to follow up with another doctor or a cardiologist (a heart specialist).

If a family member has or may have HCM:

What does it mean if I have a relative with HCM? Do I need to be tested?

If you have a relative with HCM, it's important to be tested. Ask about being tested for HCM if your doctor doesn't suggest it.

Notes from your discussion:

For people with possible symptoms of hypertrophic cardiomyopathy (HCM):

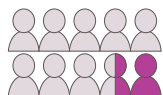
Shortness of breath | Tiredness | Rapid heartbeat | Chest pain | Feeling dizzy or light-headed | Fainting | Fatigue

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

Consider these important facts about HCM.



HCM is a heart condition where the heart doesn't function properly, causing the inner wall of the heart muscle to thicken and stiffen.



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 symptoms may get worse over time—they include shortness of breath, chest pain, and fatigue.



People with HCM may have long-term, life-limiting symptoms and serious complications.



HCM is often misdiagnosed because its symptoms are similar to those of other conditions, such as asthma, anxiety, and high blood pressure.



HCM can run in families and is the most common genetic heart disease.



Your doctor needs to know about any possible HCM symptoms you may be experiencing, as well as any family history of cardiac events or HCM.

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

Sharing details about your symptoms with your doctor is important.

While this guide can help you describe the impact of your symptoms and ask if you should be evaluated for HCM, providing additional symptom-related details can help your doctor determine appropriate next steps with your unique experience in mind.

Download a helpful symptom guide at www.CouldItBeHCM.com and give it to your doctor when you have your discussion.

*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, US-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 US prevalence of HCM (1. ~100,000 patients with diagnosed HCM [based on 2013 US 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 US population (332,330,571 in May 2021), and estimated diagnosed population (~100,000).