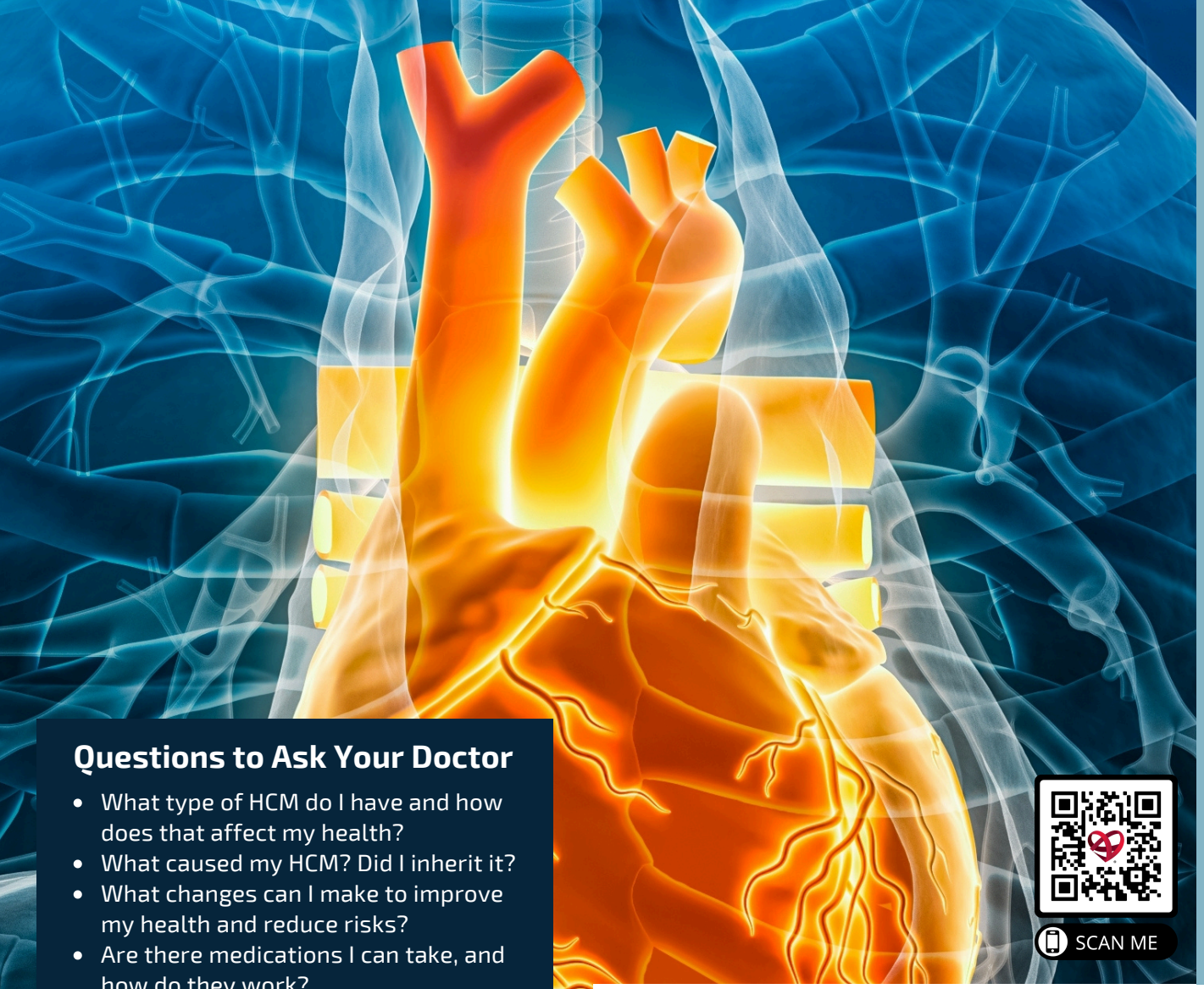

Questions to Ask Your Doctor

- What type of HCM do I have and how does that affect my health?
- What caused my HCM? Did I inherit it?
- What changes can I make to improve my health and reduce risks?
- Are there medications I can take, and how do they work?
- Do I need surgery or other medical procedures? What is involved?
- What are the risks and benefits of each treatment option?
- Should others in my family be tested for a genetic mutation? What are the chances of me passing on HCM to my children?
- Where can I find more information to help me make the best decisions?
- What symptoms require a call to the doctor? To 911?

Contact Us

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

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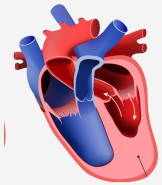
Living with Hypertrophic Cardiomyopathy (HCM)

Mended Hearts®

Discussion Guide for Patients & Caregivers

What is Hypertrophic Cardiomyopathy (HCM)?

Hypertrophic Cardiomyopathy (HCM) is one of four main types of cardiomyopathy When people have HCM, their heart muscle thickens and becomes stiffer. This makes it difficult for the heart to pump blood with oxygen to the body and can cause problems like an irregular heart rhythm called atrial fibrillation, valve disease, fainting, heart failure and sudden cardiac death.



HCM can happen at any age. It is often inherited. In fact, it is the most common type of genetic heart disease. Aging and high blood pressure also can lead to HCM.

Symptoms of HCM

Many people who have HCM have no symptoms. Some may have symptoms that are incorrectly diagnosed as asthma, anxiety or other heart conditions. Some common symptoms are:

- Fluttering heart beat
- Fainting
- Swelling in legs, feet, abdomen
- Shortness of breath
- Chest pain
- A heart murmur
- Feeling very tired

1 in 200 to 1 in 500 people in the U.S. have HCM. About **85%** are undiagnosed.

Two Types of HCM

- **Obstructive HCM**—This is the most common type where the thickened heart muscle blocks or partially blocks blood flow from the heart to the aorta so it can't get to the body.
- **Nonobstructive HCM**—In this type, the thickened heart muscle does not block blood flow.

Diagnosing HCM

Many people who have HCM are undiagnosed, but if you have a family history or have symptoms, you will want to see a doctor who treats patients with HCM. Your doctor will do a physical exam and get your family history. You may also have other tests such as:

- Echocardiogram
- Electrocardiogram (EKG or ECG)
- Cardiac MRI
- Stress test
- Genetic testing

An echocardiogram and cardiac MRI are painless tests that get images of your heart. An EKG or ECG records your heart's rhythm. A stress test to see how well your heart is beating and pumping can be done through exercise, or in some cases medication. You also may have genetic testing to help you find out if you have inherited a genetic mutation for HCM and if othes in your family should be tested.

50% chance of having the genetic mutation for HCM if one parent has it

Treating HCM

Currently, there is no way to prevent HCM, and treating it will depend on the type of HCM you have. Here are some treatment options for HCM:

Medication. There is a new medication available to treat obstructive HCM. There are also medications like Beta Blockers, diuretics, Calcium Channel Blockers, and medications for arrhythmias that can help with symptoms.

Medical Procedures. Sometimes with obstructive HCM, surgery is needed to reduce the blockage. In some cases, this can be done with a non-surgical procedure called an alcohol septal ablation. In severe cases, a heart transplant is needed.

Devices. Sometimes, a cardiac implantable electronic device (CIED) like a pacemaker or ICD is needed to keep your heart in normal rhythm. A left ventricular assist device (LVAD) may be needed before transplant.

Healthy lifestyle. Eating healthy foods, exercising, controlling blood pressure and sugar, and reducing stress help keep you healthy longer.