Hypertrophic Cardiomyopathy Center

at Advocate Heart Institute Downers Grove

Hypertrophic cardiomyopathy (HCM) is the most common genetic cardiac disease. It is one of cardiology's "great masqueraders" with mistakes and delays in diagnosis being very common.

It can present with a wide variety of signs and symptoms that make accurate diagnosis challenging. Although with treatment a long and uneventful life is possible there are a wide variety of complications that may develop requiring special expertise to manage. Optimal care of hypertrophic cardiomyopathy requires a team of cardiac specialists devoted to understanding and treating this condition. It is no longer a condition that can be optimally managed by a single medical specialist.

At our Hypertrophic Cardiomyopathy Center, we have assembled all the medical talent and technology devoted to managing your condition with the best possible outcomes. It takes a team and we have the team you need all in one place.

Our Team

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Genetic Counseling for Hypertrophic Cardiomyopathy

- Genetic testing is important to determine whether you and your family members are at risk of developing hypertrophic cardiomyopathy (HCM).
- Genetic counseling can help individuals and their families understand their testing options and discuss their test results.
- Early detection and diagnosis of HCM may help prevent, delay, or lessen complications and adverse symptoms.

What is a genetic counselor? Genetic counselors have advanced training in medical genetics and counseling to guide and support individuals seeking more information about how inherited diseases and conditions might affect them or their families.

What will a genetic counselor do at our appointment?

- Collect a detailed family history focused on heart problems.
- Discuss information about the genetics of HCM, recurrence risks for family members, insurance concerns, and genetic testing and surveillance options.
- Review possible test results and the implications of the results for you and your family.
- Provide support and information on additional resources available to individuals and their families living with HCM.

Clinical Screening Strategies for Detection of HCM in Families*

Initial screening should be done in first degree relatives with Echocardiography and 12-Lead ECG. It should be repeated periodically based on age and clinical circumstances as outlined below.

<12 yrs old

Optional unless:

- Malignant family history of premature HCM death or other adverse complications
- Competitive athlete in an intense training program
- Onset of symptoms

12 to 25 yrs old†

- Every 12–18 months.
- If competing in athletics, every 12 mos.

>25 yrs old†

- Every 3- 5 yrs.
- More frequent intervals with a family history of late-onset HCM and/or malignant clinical course

*In the absence of laboratory-based genetic testing.
†Age range takes into consideration the acknowledged individual variability in achieving physical maturity.

Adopted from :

1.Maron et al.
JACC Vol. 44, No. 11,
December 7, 2004:2125–32

2. Ommen et al.
2020 AHA/ACC Guideline for the Diagnosis and Treatment of Patients with Hypertrophic Cardiomyopathy: A Report of the ACC/AHA Joint Committee on Clinical Practice Guidelines.
Circulation. 2020 Dec 22;142(25): e 558-e631.
doi: 10.1161/CIR.0000000000000937.

HYPERTROPHIC CARDIOMYOPATHY (HCM)

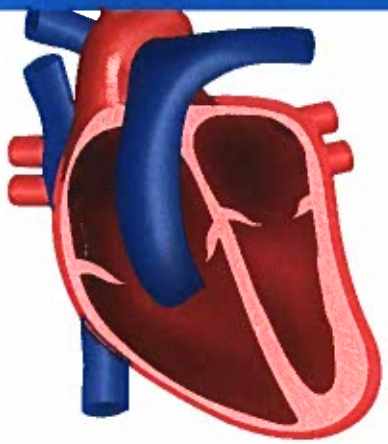
CardioSmart
American College *of* Cardiology

THE PROBLEM WITH A THICKENED HEART MUSCLE

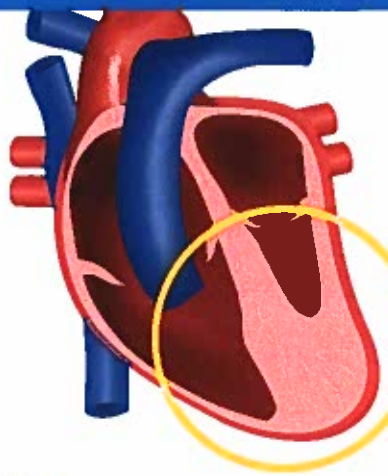
If you have hypertrophic *(hy-per-tro-fik)* cardiomyopathy, or HCM, your heart muscle gets too thick. This makes it harder for your heart to do its job.

It's usually passed down in families.

NORMAL HEART



HYPERTROPHIC HEART



THICKENED HEART MUSCLE

KNOW THE SIGNS

- Shortness of breath
- Dizziness or fainting
- Chest pain
- Heart palpitations or fluttering
- In rare cases, sudden cardiac death

But many people don't have symptoms

WHAT YOU CAN DO

If you have HCM, talk with your care team about:

- Shared decision-making to decide your treatment
- Genetic testing for you, your children, siblings, or parents
- Exercise—How much? Is it OK to play sports? Which ones?
- Lifestyle changes
- Ways to find support

If a parent has HCM, in most cases there's a 50/50 chance that a child will have it.

HOW TO TREAT HCM

- Medications to ease symptoms
- Devices to prevent sudden cardiac death
- Surgery to remove thickened areas

Visit *CardioSmart.org/HCM* to learn more.

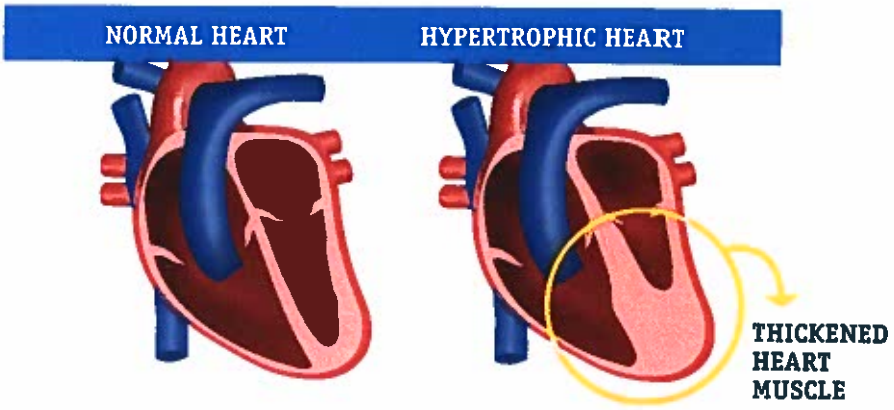
@CardioSmart

HYPERTROPHIC CARDIOMYOPATHY (HCM)

CardioSmart
American College of Cardiology

Your heart is a muscle. There are four spaces inside of it. If you have **hypertrophic cardiomyopathy**, or HCM, your heart muscle gets thicker, making these spaces smaller. This makes it harder for your heart to pump blood out to your body.

If untreated or poorly managed, HCM can cause heart failure, dangerous heart rhythms, and even sudden death. Finding it early is key.



Signs and Symptoms

How someone with HCM might feel varies. Many people have no symptoms. Others may notice something is wrong only with exercise or when doing certain things. They might feel:

- **Short of breath, especially when exercising or being active**
- **Dizzy or faint**
- **Chest pain**
- **Fluttering of the heart or heart palpitations**
- **Overly tired or little energy to do usual activities**

What Increases Your and Your Family's Risk

HCM is usually passed down in families. If you have it, each of your children has a 50/50 chance of having it, too. Ask your care team about genetic counseling and screening. Screening can involve genetic testing, imaging tests, or both.

Treatment

Treatment may include a combination of medications, procedures, and lifestyle changes. The goal of treatment will be to ease your symptoms and prevent future problems.

It's also important to treat other conditions that can affect your heart: high blood pressure, high cholesterol, diabetes, smoking, carrying too much weight. These can make HCM worse.

Shared Decision-Making:
HCM screening and treatment decisions are not always clear cut. What might be the right choice for one person may not be the same for another.

Shared decision-making can help you work with your care team to find the right option for you.

Living With Hypertrophic Cardiomyopathy

Exercise

For most people with HCM, light or moderate exercise is good for overall health.

Light Exercise	Moderate Exercise
• Walking slowly (2 mph pace or less) • Cooking • Light household chores such as washing dishes or tidying up	• Brisk walk (2.5 mph to 4 mph)

Talk with your care team about safe ways for you to stay active.

Sports

You might be able to consider taking part in more vigorous exercise or competitive sports. But before doing so, you should have an in-depth talk with your care team about your situation and the risks involved.

Lifestyle Changes

Healthy habits can help keep your heart strong. They also can help you feel better and have more energy. What you can do:

- **Eat healthy:** Choose whole, unprocessed foods and include lots of fresh fruits, vegetables, whole grains, and lean meats.
- **Manage stress:** Find ways to lower stress (deep breathing, listening to music, journaling).
- **Watch your alcohol intake:** Ask how much alcohol is safe. Too much can trigger irregular heart rhythms and make blood flow in the heart worse.
- **Keep up with health visits and heart tests:** These will help you and your care team know if more needs to be done to manage your condition. Ongoing care can help prevent problems, too.
- **Ask for a flu shot each year.**

For more information, visit

CardioSmart.org/HCM