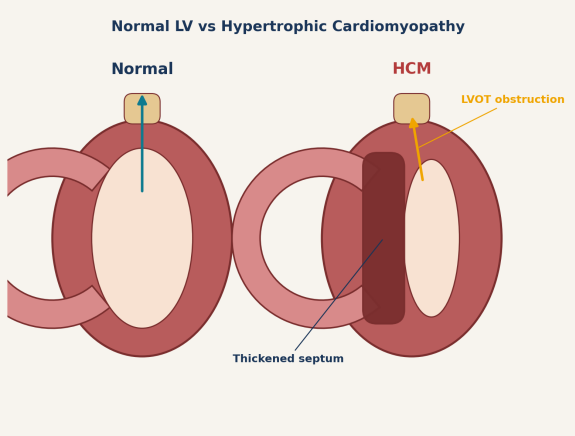
Understanding Hypertrophic Cardiomyopathy

An inherited thickening of the heart muscle (HCM)

Most people with HCM live full lives — with the right care.



Online: https://go.riasalimd.com/hcm-guide

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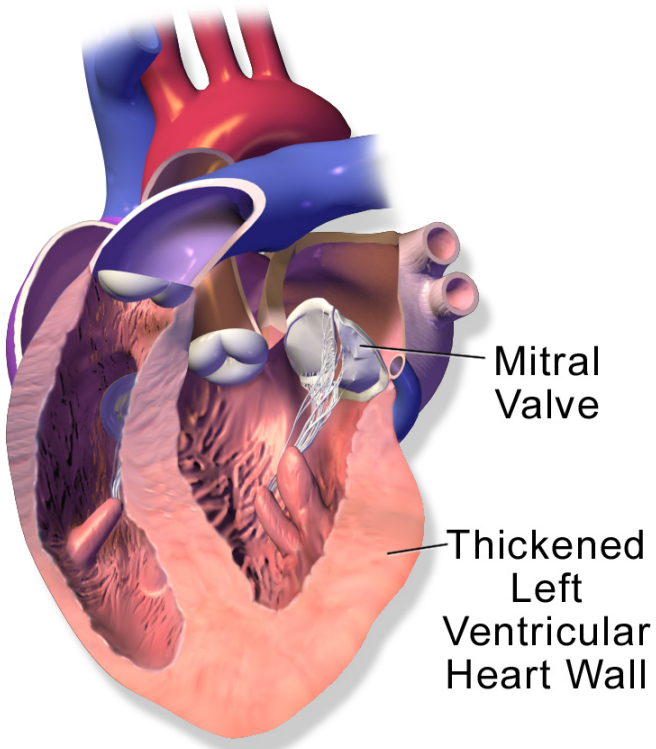
Names & Terms You Will Hear

Term	Meaning
Hypertrophic cardiomyopathy	A gene-based heart muscle disease. The muscle grows too thick. This is not caused by high blood pressure or exercise.
HCM	Short form of hypertrophic cardiomyopathy.
Obstructive HCM (oHCM)	The thick muscle blocks blood leaving the heart. Symptoms get worse with activity.
Non-obstructive HCM (nHCM)	Thick muscle without a flow block.
HOCM	An older name for obstructive HCM. Rarely used today.
Asymmetric septal hypertrophy	The wall between the two pumping chambers is the thickest part. This is the most common pattern.
IHSS	Old name. Stands for idiopathic hypertrophic subaortic stenosis. No longer used much.
Sarcomeric cardiomyopathy	HCM is caused by gene changes in the proteins that make up heart muscle. These proteins are called sarcomere genes.

What Is Hypertrophic Cardiomyopathy?

- HCM is a **genetic disease**. The heart muscle grows too thick — usually in the septum (the wall between the two pumping chambers).
- About **1 in 500** people have HCM. It is the most common inherited heart condition.
- In **obstructive HCM (oHCM)**, the thick muscle blocks blood leaving the heart. This is worse with activity. It causes shortness of breath, chest pain, and fainting.
- In **non-obstructive HCM (nHCM)**, there is no block. But the stiff thick muscle can still cause shortness of breath, irregular heart rhythm, or heart failure.
- Most people with HCM live **normal-length lives** with good care. Sudden cardiac death from arrhythmia is the key risk. It can be prevented with a defibrillator (ICD) in high-risk patients.
- HCM is **autosomal dominant**. This means each parent, sibling, or child of an affected person has a 50% chance of carrying the gene.



Hypertrophic Cardiomyopathy

Asymmetric septal hypertrophy — the wall between the two pumping chambers grows abnormally thick, the most common HCM pattern. Image: Blausen Medical Communications, Wikimedia Commons (CC BY 3.0).

Why It Matters

- HCM is the top cause of sudden cardiac death in young athletes. But most HCM patients are not athletes. Most live normal lives.
- Diagnosis is based on an echocardiogram (echo), EKG, and family history. A cardiac MRI helps in hard-to-read cases.
- **Mavacamten** (Camzyos, FDA-approved 2022) works on the root cause of HCM. The VALOR-HCM trial showed it can help many patients avoid surgery.
- Family screening saves lives. All first-degree relatives should be checked — even those with no symptoms.
- Sudden cardiac death risk can be measured. Your doctor uses your family history, wall thickness, fainting history, and other factors to gauge it.

Risk Factors

Some patients are more likely to develop this condition. Knowing your risk helps your care team take extra precautions.

Risk Factor	Why It Increases Risk
Family history of HCM	HCM is passed down in families. Each close relative has a 50% chance of carrying the gene.
Family history of sudden cardiac death	A close relative who died suddenly raises your own risk level.
Septal wall thickness of 30 mm or more	A very thick wall is a key marker for sudden cardiac death risk.
Unexplained fainting (syncope)	Fainting during or after exercise is a warning sign.
Abnormal heart rhythm on monitor	Short bursts of fast heart rhythm (VT) show a higher risk.
Abnormal BP response to exercise	Used in younger patients to help gauge risk.
Apical aneurysm on MRI	A bulge at the tip of the heart raises the risk of arrhythmia.
Extensive fibrosis on MRI (LGE)	Scar tissue over 15% of the heart muscle is a risk marker.
Young age at diagnosis	Younger patients face a higher lifetime risk of arrhythmia.

Treatment Options

- **Beta-blocker** (metoprolol, propranolol) — first-line for most HCM patients with symptoms. It slows the heart and eases the obstruction during activity.
- **Calcium channel blocker** (verapamil, diltiazem) — used when beta-blockers are not an option. Avoid if the obstruction is severe or blood pressure is low.
- **Disopyramide** — helps with stubborn obstructive symptoms. Side effects include dry mouth and constipation.
- **Mavacamten** (Camzyos) — targets the root cause of HCM. It reduces the obstruction. Regular echocardiograms are required during the first months of use.
- **Septal myectomy** — open-heart surgery that removes a small piece of thick septum. This is the gold standard for severe obstruction. Results are excellent at experienced centers.
- **Alcohol septal ablation** — a catheter procedure. No open surgery is needed. Pacemaker rates are higher than with surgery. Good for selected patients.
- **Implantable cardioverter-defibrillator (ICD)** — placed in high-risk patients to prevent sudden cardiac death.
- **Atrial fibrillation treatment** — AFib is common in HCM. Blood thinners are needed because stroke risk is high.
- **Heart failure management** — many HCM patients develop a stiff-heart type of heart failure (HFpEF) over time.
- **Avoid**: dehydration, heavy alcohol use, and intense weight lifting. Some blood pressure drugs (like nitrates) can make the obstruction worse.

Risks, Benefits, and Alternatives

Every choice has trade-offs. Use this table to start the shared decision conversation.

Option	Risks	Benefits	Alternatives
Beta-blocker or calcium channel blocker	Fatigue, low blood pressure, slow heart rate, sexual side effects.	First-line treatment. Low cost. Easy to stop. Years of safety data.	Mavacamten; septal surgery.
Mavacamten	Frequent echo visits required; high cost; rare heart weakening if dose is too high.	Works on the root cause of HCM. May help you avoid surgery (VALOR-HCM).	Beta-blocker; disopyramide; septal surgery.
Septal myectomy	Open-heart surgery required. Risk of needing a pacemaker. Death risk under 1% at top centers.	Gold standard for severe obstructive HCM. Very good long-term results.	Alcohol septal ablation; mavacamten; medicines only.
Alcohol septal ablation	Higher pacemaker risk (10-20%). Results may vary more than surgery.	No open surgery needed. A good fit for some patients.	Septal surgery; mavacamten.
Implantable defibrillator (ICD)	Risk of infection, lead problems, or unnecessary shocks. Can cause anxiety.	Prevents sudden cardiac death in high-risk patients. Can be life-saving.	Medicines only; under-the-skin (subcutaneous) ICD.

Common Misconceptions

Myth	Reality
"HCM only affects athletes."	Most people with HCM are not athletes. HCM affects 1 in 500 people at all activity levels.
"If my echo is normal, I don't have HCM."	Some HCM is subtle. A cardiac MRI can find cases that echo misses. Genetic testing is key for family members.
"I have HCM so I can't exercise."	Most HCM patients can do moderate aerobic exercise safely. The 2024 guideline allows much more activity than older rules did. Ask your cardiologist what is right for you.
"My HCM is mild, so my kids don't need testing."	Each close relative has a 50% chance of carrying the gene. This is true even if the parent has a mild form of the disease.
"There is no real treatment for HCM."	Mavacamten, septal myectomy, alcohol ablation, ICDs, and other drugs all work. Today is the best time in history to treat HCM.
"HCM and athlete's heart are the same."	Athlete's heart is a normal response to training. It goes away when you stop training. HCM is genetic and does not go away. Imaging and genetic tests tell them apart.

Possible Complications

Knowing what can go wrong helps you spot problems early. Most complications are uncommon, especially with treatment.

Where / What	What Can Happen
Sudden cardiac death	Caused by a dangerous heart rhythm. An ICD can prevent it. Risk is real but manageable.
Atrial fibrillation (AFib) and stroke	AFib is common in HCM. Blood thinners are needed to lower stroke risk.
Heart failure	The thick muscle becomes stiff over time. This leads to shortness of breath and fluid buildup.
Poor exercise tolerance	Breathlessness and chest discomfort can limit daily activity.
Pregnancy complications	HCM raises the risk during pregnancy. A cardiology-OB team should manage your care.
Apical aneurysm	A bulge at the heart tip. It raises the chance of arrhythmia.
Endocarditis	Infection of the heart valves. Risk is higher with obstructive HCM and mitral valve leak.

Points to Know

If you remember nothing else, remember these key points.

- HCM is genetic. All close relatives need to be checked.
- Most people with HCM live normal lives with the right care.
- Whether you have obstruction or not changes which treatment is best for you.
- Sudden cardiac death risk is real. It can be measured. An ICD can prevent it.
- Mavacamten, septal myectomy, and alcohol ablation are all proven options for obstruction.
- Exercise limits are less strict than they used to be. Ask your cardiologist what is safe for you.
- Avoid dehydration, heavy alcohol use, and intense weight lifting.
- Blood thinners are needed for atrial fibrillation regardless of other risk factors.

When to Call Us - and When to Call 911

If you are not sure, call. We would rather hear from you twice than miss a real problem.

- **Call 911** for chest pain, severe shortness of breath, fainting, or cardiac arrest.
- **Call 911** if your ICD fires.
- **Call our office** within 24 hours after fainting or nearly fainting.
- **Call our office** if your shortness of breath is getting worse.
- **Call our office** if you feel a new fast or irregular heartbeat.
- **Call our office** if you are on mavacamten and miss an echo visit.
- **Call our office** before getting pregnant, or as soon as you know you are pregnant.
- **Call our office** if a family member is newly diagnosed with HCM. You and your children may need screening.

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Trusted Resources

The links below are the trusted resources Dr. Ali used to write this guide and that he recommends you visit for more information. Each is a clickable link in the digital version and a Short.io tracked URL on the printed version.

- Hypertrophic Cardiomyopathy Association - Patient community + family screening guidance.
- AHA — HCM Patient Page - Trusted patient-facing overview.
- Mayo Clinic — HCM - Symptoms, genetics, treatment overview.
- NHLBI — Cardiomyopathy - Federal patient resource.
- HCM Foundation Inc. - Education and advocacy.

Sources Used to Build This Guide

Every recommendation in this guide is grounded in one or more of the studies, guidelines, or trusted resources below. Short links are tracked so Dr. Ali can see which references patients are reading; nothing personally identifying is captured.

- 2024 AHA/ACC HCM Guideline *[Guideline]*
  Current US guideline. Diagnosis, mavacamten era, SCD risk stratification, septal reduction therapy.
- EXPLORER-HCM trial (mavacamten) *[Randomized Trial]*
  Pivotal trial demonstrating mavacamten benefit in obstructive HCM.
- VALOR-HCM trial (mavacamten reducing need for septal reduction) *[Randomized Trial]*
  Shows mavacamten can defer septal myectomy / alcohol septal ablation in many patients.
- Hypertrophic Cardiomyopathy Association (HCMA) *[Patient Advocacy]*
  Patient community, family screening guidance, advocacy resources.
- Mayo Clinic — Hypertrophic Cardiomyopathy *[Patient Education]*
  Plain-language overview of symptoms, genetics, and treatment.
- NHLBI — Hypertrophic Cardiomyopathy *[Patient Education]*
  Federally-sourced patient overview.
- AHA — HCM Patient Page *[Patient Education]*
  Trusted patient-facing overview.

About This Guide

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Reviewer note: Reviewed against AHA, Mayo Clinic, NHLBI, and HCMA patient pages. Ours adds: current 2024 guideline + mavacamten era, explicit obstructive vs non-obstructive distinction, sudden cardiac death risk stratification in plain language, and clear family-screening guidance.

Disclaimer

This guide is for educational purposes only and does not replace medical advice from your physician. Recommendations may not apply to every patient. Always follow the specific instructions of Dr. Ali and your care team. In an emergency call 911 or go to the nearest emergency department.

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