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# Talking With Patients About Hypertrophic Cardiomyopathy

This resource is designed to highlight new research and recommendations about hypertrophic cardiomyopathy (HCM) to support clinician-patient discussions, enhance patients' understanding of the disease and improve outcomes. Greater awareness of HCM detection, guideline-directed care, and the issues that weigh foremost on the minds of many of our patients remains essential to improving overall care.

The need for a practice-based discussion guide emerged from several efforts. These include the American College of Cardiology's "Advances in Hypertrophic Cardiomyopathy" clinical roundtable (2021), which convened leading cardiologists, HCM specialists, interventionalists, geneticists, and patients.

The ACC also hosted a unique patient forum, "Shining a Light on HCM: The Patient Perspective" (2021). During this meeting, individuals living with HCM emphasized the need for heightened awareness of HCM management, including sudden cardiac death (SCD) risk assessment and stratification, treatment options, genetic evaluation, as well as the psychosocial burdens that shape the patient experience.

This guide reflects the latest recommendations for optimally managing HCM. It underscores the role of shared decision-making, appropriate referral to multidisciplinary HCM centers – especially for complex septal reduction therapies – genetic testing, SCD risk assessment and prevention, new medications, and emerging evidence supporting the benefits of exercise.

This resource can be used at the point of care to help encourage timely HCM diagnosis and treatment, and to educate patients about the disease, the associated cardiovascular risks, and its strong familial link.

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# Optimizing HCM Detection and Patient Education – 8 Points to Guide Discussions

*The following highlights key challenges and opportunities to improve awareness, diagnosis and treatment of HCM. These points can serve as practical reminders in clinical practice. Note: This list isn't intended to be inclusive of all of the emerging guidance for, or gaps in, HCM care.*



## 1. HCM is more common than you might think; diagnosing it can be challenging.

HCM, which is typically characterized by left ventricular hypertrophy that can't be explained by another cause (e.g., hypertension, valvular disease), affects an estimated 1 in every 500 people. Yet, a large percentage of patients remain undiagnosed. HCM affects females and males equally, although women are diagnosed less commonly than men.

### The underdiagnosis of HCM is due, in part, to the fact that:

- Many patients are asymptomatic or only mildly symptomatic.
- Symptoms can be subtle, and some patients may compensate for reduced functional capacity and under-report symptoms.
- The age of onset and timing of disease expression is highly variable, ranging from infancy to 70+ years.
- The symptoms of HCM overlap with many other conditions so HCM may be misdiagnosed as coronary artery disease, heart failure, atrial fibrillation, mitral prolapse, asthma, chronic obstructive pulmonary disease (COPD), or even anxiety.
- Many patients are unaware of a family history of HCM.

### Know the symptoms

The most commonly reported symptoms include:

- Dyspnea, especially exertional
- Fatigue
- Syncope or presyncope
- Chest discomfort or pressure
- Palpitations

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## When to evaluate for HCM

- With presentation of unexplained dyspnea, syncope or presyncope, fatigue, angina, palpitations
- Incidental detection of a heart murmur
- Abnormal ECG or echocardiogram
- Family history of HCM with or without positive genetic test in a family member

**ACTION STEP: If HCM is suspected, further evaluation is needed, including:**

**Comprehensive physical exam**, review of any symptoms and limitations



**Thorough health history** of any cardiac issues, unexplained syncope (especially during or after exertion), sudden cardiac arrest, progressive exertional intolerance or lightheadedness



**Three-generation family history** of sudden cardiac arrest, "thickened heart," stroke or unexplained mortality, especially at younger ages; some patients may equate a heart attack with sudden cardiac arrest in their reports



**Imaging**
Echocardiography is the primary imaging modality; cardiac magnetic resonance (CMR) imaging can play a role, too, to better define anatomy and scarring; imaging can confirm diagnosis (increased left ventricular wall thickness of 15 mm or more) and characterize the pathophysiology, and identify risk markers



**If HCM is confirmed, the following should be considered:**

**Additional testing**

- Cardiac magnetic resonance imaging, if not done previously
- Exercise stress testing
- Ambulatory monitoring for arrhythmias



**SCD risk assessment**
SCD risk is different for pediatric patients; new risk calculators specific to children and adolescents are available



**Family evaluation** for genetic screening and/or testing



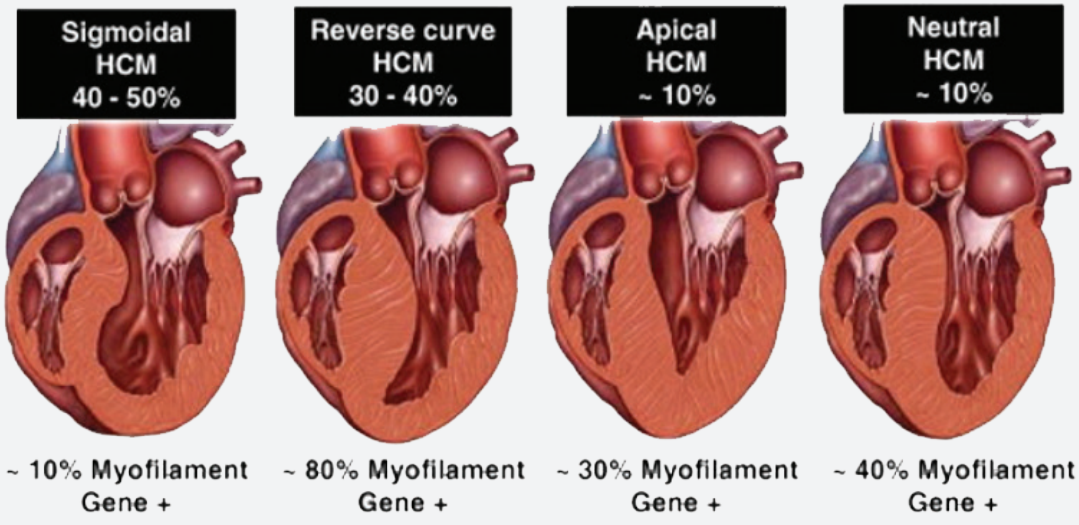
**Get to know what matters to the patient, help reassure**



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## Did You Know?

- HCM is the most common inherited cardiac disorder.
- HCM is most commonly inherited in an autosomal dominant pattern, though a family history may not always be apparent.
- Many people remain undiagnosed or don't know they carry a genetic predisposition for HCM.
- HCM can manifest very differently and with varying degrees of disease severity, even among members of the same family carrying the same genetic variant.
- Some cases of HCM are non-Mendelian and may arise from a combination of the presence of polygenic risk alleles, and non-genetic factors such as older age, hypertension, metabolic syndrome, and obesity.
- Some patients may have little to no left ventricular outflow tract obstruction at rest but develop obstruction with exercise or physiologic provocation; as a result, exercise stress testing can play an important role in evaluation and risk assessment.
- There are multiple phenotypes and structural subtypes that can influence prognosis, genetic risk and therapeutic decision-making.
- There are important differences in risk stratification for SCD between children and adult patients.




*Citation: J Am Coll Cardiol. 2009; 54:201-211.*



## 2. HCM weighs heavily on patients' hearts and minds. These feelings should ideally be addressed as part of their overall care.

Many patients worry about their future and the unpredictability of the disease.

In the beginning, it often feels as though their world has stopped and they worry they will not be able to live their lives the way that they want to. They may grieve these losses, struggle to find a new way of life, and cope with the burden it has on their families, including concerns that their children or grandchildren will inherit it. There is also considerable survivor's guilt among people with HCM who lose family members to the disease.

**ACTION STEP:**
Try to reassure patients. Include assessing patients' psychosocial health, coping and support systems as part of comprehensive HCM care planning.

HCM also plays a defining role in how people plan their day-to-day living. Decisions are often influenced by what they think they can and can't do, for example, with travel, life events, and activities. Take time to ask about how HCM affects various aspects of a person's life and family interactions.



## 3. Education and risk discussions are recommended for all aspects of HCM care, including genetic testing, activity, lifestyle, and therapy choices.

This involves a full discussion of all testing and treatment options; disclosure of the risks, benefits, and potential outcomes of all options; as well as the opportunity for individual patients to express their goals and concerns for managing HCM.

Many patients share that they would have benefited from more clarity about the risks of sudden cardiac arrest, sudden cardiac death and other complications, as well as knowing all of the options for treatment based on their disease (e.g., medications, lifestyle, myectomy, alcohol septal ablation) and what to reasonably expect at different stages of their journey. Treatment choices depend on symptoms, the presence of obstructive vs. non-obstructive disease, personal SCD risk, and complications, including atrial fibrillation, ventricular arrhythmias and heart failure. Lifestyle is a leading concern for many patients and families with HCM.

**ACTION STEP:**
Carve out time to ask patients what matters most to them when it comes to managing their HCM. One of the best ways to engage patients in their care is to understand their specific goals for care and tailor treatment plans to address them.

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## Treatments

Recommended medications or procedures vary based on morphology and other factors.

### Non-Obstructive HCM

**Medications** for **symptomatic** non-obstructive HCM

- Beta blockers (for symptom relief, especially exertional intolerance)
- Non-dihydropyridine calcium channel blockers (verapamil/diltiazem)
- Diuretics

**Guideline directed medical therapy** for heart failure (low-dose diuretic, if congested), atrial fibrillation and any other co-morbid conditions

### Obstructive HCM

**Medications**

**First-line**

- Beta blockers (titrate to symptom relief)
- Non-dihydropyridine calcium channel blockers (used when beta blockers are not tolerated)

**Add-ons if symptoms persist**

- Disopyramide
- Cardiac myosin inhibitor (aficamten, mavacamten)

**Procedures**

When symptoms persist despite maximally tolerated medications

- Surgical septal myectomy
- Alcohol septal ablation

**Cardiac rehabilitation** post-procedure

For patients with AFib, atrial flutter, ventricular tachycardia, premature ventricular contractions (PVCs), consider adding:

- **Antiarrhythmic medications** (typically limited to amiodarone, sotalol, or disopyramide)
- **Anticoagulants** for everyone with AFib and HCM, regardless of CHADS-VASc score

**ICD placement** for some people

1 out of 5 patients with HCM also have atrial fibrillation and should be started on an anticoagulant to reduce their risk of stroke regardless of CHADS-VASc score.

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## Shared decision-making for patients eligible for medical therapy or septal reduction therapy

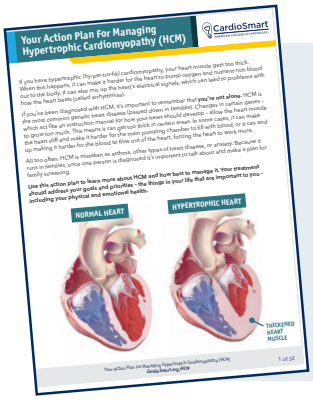
Be sure to discuss:

- **Individual patient goals and preferences**
- **Symptom burden**
- **Durability of treatment**
- **Recovery time**
- **Adverse effects, risks**
- **Center expertise**



## Clinical Trials

Taking part in a clinical trial may be a good option for some patients. Studies are testing new drugs to see whether they improve symptoms, exercise capacity, and/or heart structure and function.




Use ACC's patient tool, **Your Action Plan for Managing HCM**, which includes worksheets for patients to write down their personal goals and concerns, as well as the risks and benefits of a particular treatment choice – for example, whether to get an ICD placed dependent on risk or the best option for septal reduction if that's being considered. Also included is a symptom and activity tracker, exercise planning sheet, and questions to help guide initiation of genetic screening and testing for families.

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## 4. Timely referral to an HCM center with expertise in treating HCM is important in some cases.

Referral to, or collaboration with, a multidisciplinary HCM center should be considered for patients with HCM when specialized expertise may help guide diagnosis, risk stratification or complex disease-related management decisions, including septal reduction therapies.

While patients with HCM can be effectively evaluated, treated and followed by their primary cardiology care team, consultation with an experienced HCM center can help optimize patient care. This includes situations when treatment decisions are not always clear-cut – for example, with challenging phenotypes, uncertainty about sudden cardiac death risk, suitability for septal reduction therapy (myectomy or alcohol septal ablation), as well as concomitant heart failure, atrial fibrillation and ventricular arrhythmias, or interpretation of genetic testing results.

Patients may also benefit from specialized consultation when treatment decisions are nuanced or when multiple reasonable management strategies exist, including decisions regarding primary prevention ICD placement and HCM-specific invasive therapies.

A multidisciplinary, team-based approach can further support shared decision-making and patient counseling related to exercise, lifestyle, pregnancy and family planning.



**ACTION STEP:**
When appropriate, refer patients to a multidisciplinary HCM center with appropriate expertise especially when the potential treatment path isn't well defined or when septal reduction procedures are a consideration. Ask about and be sensitive to potential barriers to referral, including transportation, out-of-pocket costs, insurance coverage.

### At-A-Glance Referral Checklist

Consider referral to an HCM expert or center if the patient has any of the following needs or considerations:

- LVOT obstruction despite first-line therapy
- Genetic counseling
- Interest in considering myosin inhibitor therapy or septal reduction therapy
- Complex ICD decision
- Pregnancy planning

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## KEY BENEFITS OF AN HCM CENTER

- A team of experts specially trained in HCM disease management, imaging and genetics who are knowledgeable about best practices and the latest evidence
- Access to advanced care and coordinated services at one location
- Close coordination and consultation across multiple disciplines, which may include:
  - **Electrophysiologists**
  - **Interventional cardiologists**
  - **Imaging specialists**
  - **Cardiac surgeons**
  - **Genetic counselors**
  - **Cardiac psychologists**
  - **Nutritionists**
  - **Heart failure specialists**
- Education about HCM – what it is, how it is passed on in families, SCD risk assessment and prevention, and heart-healthy living
- Genetic counseling for patients and families
- Level of experience and patient volumes
- Clinical trials

### The Ideal Care Team



Local cardiologist + Comprehensive HCM center for specialty care = Best outcomes for patients

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## 5. Many patients live in fear of SCD, even though the risk is low and can often be managed with good monitoring and care.

While HCM increases the risk of SCD, especially in younger people, it's still a very rare occurrence. The absolute risk varies considerably but can be well approximated using validated risk prediction algorithms.

Comprehensive SCD risk assessment should be completed upon initial evaluation and every 1-2 years subsequently because risk can change over time, and new markers and risk factors continue to emerge.

### ACTION STEP:

Explore a patient's level of concern about sudden cardiac death. Provide reassurance when their risk profile is low, as the negative predictive value of these algorithms is very high. When their risk is intermediate or higher, then weighing the risks and benefits of having an ICD implanted is an important part of the shared decision-making discussion.

## RISK FACTORS TO AID IN HCM RISK STRATIFICATION

- Prior event (SCD, ventricular fibrillation/VF, sustained VF)
- Family history of sudden death in a first-degree relative under the age of 45, or definitively due to HCM at any age.
- One or more episodes of unexplained syncope
- Significant hypertrophic burden
- Multiple, repetitive ventricular tachycardia episodes on ambulatory ECG monitoring
- Left ventricular apical aneurysm
- Extensive late gadolinium enhancement of the myocardium on cardiac magnetic resonance
- Systolic dysfunction with EF <50% by echocardiography or CMR imaging

For patients with one or more risk factors, consideration of an implantable cardioverter defibrillator (ICD) should be considered.

*Source: 2024 ACC/AHA/Multisociety HCM Guideline*

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## 6. Exercise should be part of routine HCM care in nearly all cases.

In a shift from earlier guidance recommending caution with exercise in patients with HCM largely due to concerns about possibly triggering ventricular arrhythmias, physical activity is now recommended and should be encouraged for nearly all patients with HCM.

The new recommendations reflect growing evidence that the beneficial effects of exercise on general health can be extended to patients with HCM and can improve cardiorespiratory fitness, physical functioning and quality of life. Studies also show exercise can reduce symptom burden, increase exercise tolerance and may lead to favorable cardiovascular remodeling. Routine activity can help guard against obesity, which heightens the risk of myocardial infarction, stroke, type 2 diabetes, sleep apnea, and depression. Reports of rising rates of obesity among patients with HCM may be an unintended consequence of activity and exertional restrictions that promote sedentary lifestyles. One large cohort study found that 70% of individuals with HCM were found to have pre-obesity or obesity.

### Overcoming hesitations

Because many patients may have been asked to stop playing a sport or advised not to exercise or exert themselves at all, some may worry about being active or pushing their heart too hard. It's important to have open discussions about exercise and to offer appropriate guidance.

Discuss rigorous exercise and competitive sports through shared decision-making and seek input from expert HCM professionals to develop individualized exercise plans, and to establish a regular schedule for reevaluation.



### ACTION STEP:

As our understanding of HCM has evolved, discouraging exercise is no longer an acceptable strategy and can lead to more harms than good. Take time to assess individual patients' current level of physical activity and explore any self-imposed limits or reluctance. Because patients may have been told not to exercise or exert themselves at all, efforts to help reassure them based on new guidance and data may be needed. Ask about their personal goals for becoming or staying active, as well as any barriers to activity.

## Other relevant research findings:

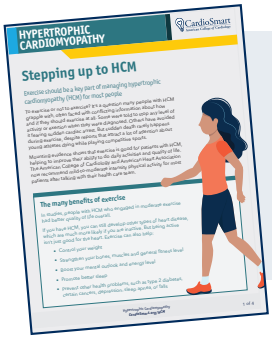
- Individualized exercise programs have been associated with improvements in functional capacity, including increases in peak VO2.
- Moderate or vigorous intensity physical activity is not associated with a higher rate of ventricular arrhythmias or serious cardiac events in appropriately evaluated patients with HCM.
  - In LIVE-HCM a study of more than 1,500 individuals with HCM or genotype-positive/phenotype-negative disease, participants engaging in vigorous exercise were not more likely to experience death, cardiac arrest, arrhythmic syncope, or ventricular arrhythmias treated with an ICD during approximately three years of follow-up compared with participants reporting moderate activity levels or inactivity. Most participants were cared for at experienced HCM centers using shared decision-making approaches regarding exercise participation.
- In observational cohorts of patients with HCM and ICDs, ICD shocks were not found to occur more frequently during exercise compared with usual daily activity.

## TAILORED ADVICE

Exercise recommendations should ideally be personalized and based on:

- A thorough history and physical exam
- Recent SCD risk assessment
- Other baseline parameters, including general fitness level and exercise stress testing
- Individual goals and types of activities they enjoy
- Other considerations, including good hydration and avoiding exercise in extreme heat and humidity

Participation in vigorous intensity recreational exercise is reasonable, and participation in competitive sports can be considered after a shared and comprehensive discussion that balances potential risks and benefits, with an expert provider.




ACC created handouts for patients to help guide conversations and advice about exercise, including a **worksheet** to help tailor physical activity recommendations to meet their needs and activity goals. Scan the QR code to find this handout and more tools for your patients.

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## 7. Patients need more education about the genetic transmission of HCM to avoid missed opportunities to initiate cascade testing, encourage family screening.

Patients with HCM should be offered genetic testing to find out whether they have a known genetic variant linked to the disease and, in turn, assess the risk to family members.

It's important that patients meet with a genetic counselor who is knowledgeable in HCM before and after undergoing genetic testing so that they 1) know better what to expect and make an informed decision, and 2) they are fully educated about the clinical significance of the results and what they mean. A patient's test results will also help guide next steps for testing and clinical screening in first-degree relatives.

For patients with genetic variants of uncertain significance, serial re-evaluation of test results is recommended to assess for variant reclassification, as this may trigger testing for family members. Preconception and prenatal reproductive and genetic counseling should also be offered.

**ACTION STEP:**
Counseling patients with HCM about the mechanism of genetic transmission of HCM is one of the cornerstones of care. Screening first-degree family members of patients with HCM, using either genetic testing or an imaging/electrocardiographic surveillance protocol, can begin at any age and should account for specifics of the patient/family history and family preference.

## 8. Atrial fibrillation is common among patients with HCM.

Because of the heightened risk of thromboembolism and primary stroke, all patients with HCM should be started on an anticoagulant for prophylaxis regardless of commonly used risk scoring (for example, the CHADS-VASc score). AFib also is often not well tolerated and worsens effort tolerance. Rhythm control should be strongly considered for patients with HCM and atrial fibrillation. Since antiarrhythmic medication options are limited in HCM, often moving straight toward radio-frequency ablation is the best option.

**ACTION STEP:**
Make sure to follow up on any suspicions of AFib to initiate anticoagulants to reduce related stroke risk and improve quality of life.

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# Talking With Patients About HCM



When talking to patients about HCM, it's important to tailor the information you give to best meet an individual patient's needs. The following concepts can go a long way to engage patients, build trust and deepen your discussions.

**Patients share that trust in their care team is the most important factor in making decisions about their treatment.**

- ✓ **Show empathy** through active listening; patients share that living with HCM can be frightening, exhausting and unpredictable and the familial effects have wide-reaching effects.
- ✓ **Ask about personal goals and preferences** – what matters most to them as it relates to managing their HCM.
- ✓ **Keep explanations simple** and check in to be sure they understand HCM and key considerations; ask them to explain, in their own words, what they heard. A person's health literacy can affect how patients seek information, make decisions and what they recall.
- ✓ **Actively involve patients in their care** and treatment decisions, which can lead to better adherence and outcomes.
- ✓ **Anticipate – and make time – for questions** by asking "Tell me how you are feeling?" or "What questions do you have?" There is often limited time during a routine visit, and patients may feel reluctant to take up time, but have questions or concerns that have been worrying them.
- ✓ **Empower each patient to know they have control** and HCM can be managed.
- ✓ **Offer hope** with more knowledge, disease-modifying and targeted treatment options under investigation today than ever before.

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# Talking Points – Common Patient Questions Answered

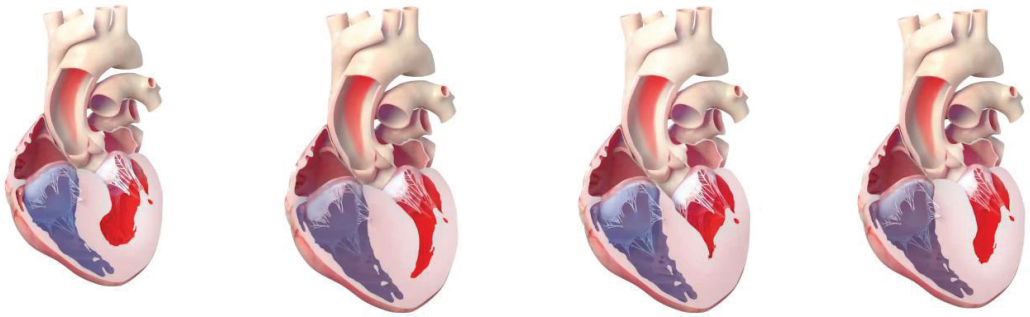
Patients tell us that it is often hard to know where to start when it comes to asking the right questions. HCM is complicated, and there are also many misconceptions about it.

The following questions and accompanying suggested language can be used to help you provide easy-to-digest information to help educate and engage patients. Feel free to make adjustments to meet the needs of individual patients.

## What is HCM?

If you have hypertrophic cardiomyopathy, or HCM for short, your heart muscle gets too thick in places. When this happens, it can make it harder for your heart to pump oxygen and nutrient-rich blood out to the body.

There are several types of HCM, and the thickening (shown here) can vary and happen in different areas of the heart. Which type you have can affect how your HCM is treated.



**Sigmoidal** **Reverse Curve** **Apical** **Neutral**

Depending on where the thickening is – and how much as well as other structural changes that can be seen on imaging tests – it can:

- **Cause the muscle to become stiff**, making it harder for the main pumping chamber to fill with blood to be pumped out to the body (this is called non-obstructive HCM)
- **Limit or block blood flow** from the heart to the body, forcing the heart to work harder (this is obstructive disease); sometimes someone can have non-obstructive disease, but upon exercise or exertion blood flow out of the heart is blocked or slowed
- **Mix up the heart's electrical signals**, which can lead to problems with how the heart beats (called arrhythmias)

## What does HCM look and feel like?

How someone with HCM might feel varies. In fact, HCM can look and feel very different even among people in the same family. Some people have no symptoms. For others, symptoms may happen only with exercise or when exerting themselves; they may notice that an activity they used to do – jogging, hiking, or even climbing stairs – seems more difficult and leaves them short of breath and very tired. Others may have symptoms most of the time.

Some common symptoms, which often occur during or right after activity, include:

- Shortness of breath
- Dizziness
- Fainting
- Chest pressure
- Fluttering of the heart or heart palpitations
- Feeling overly tired or having little energy to do usual activities

## What makes HCM a genetic condition?

Changes (called variants) in certain genes – which act like an instruction manual for how your heart should develop – allow the heart muscle to grow too much. These gene variants can be inherited. If someone has a variant that causes HCM, there is a 50/50 chance of passing it on to children.

If you have HCM, it is important to:

- Know your family history of HCM or possible HCM and talk about it.
- Meet with a genetic counselor to learn more about genetic testing to find out if you have a gene variant that caused HCM. They can also explain what the results mean. This also helps to determine if certain family members – usually parents, brothers, sisters and children – need to be screened, too.

## Finding HCM early or following people who are likely to develop it is essential

HCM can lead to other conditions, such as:

- Heart failure
- Dangerous heart rhythms and
- Sudden death

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## Is HCM always passed down in families?

It often is; however, it can sometimes occur due to a combination of multiple small changes in the DNA, and lifestyle factors such as hypertension and obesity.

## What are the treatment options for HCM?

Treatment depends on a number of factors, including your type of HCM and what your heart and blood vessels look like, if you have abnormal heart rhythms, and your preferences. Most often, HCM can be managed with healthy choices and medications.

**Lifestyle changes, including:**

- Eating nutritious, healthy foods
- Getting exercise
- Taking care of your emotional health
- Not smoking





**Medications to:**

- Treat shortness of breath, slow your heart rate and lower blood pressure
- Treat or prevent abnormal heart rhythms
- Reduce the risk of stroke (for people with atrial fibrillation)
- Ease chest tightness




**Procedures** to remove or reduce part of the thickened area of the heart muscle. These are reserved for if the excess tissue is blocking blood flow from the heart and if medications haven't helped to improve symptoms.

Some people with HCM may consider having an implantable cardioverter defibrillator placed to monitor and respond to dangerous heartbeats.



**Regular monitoring and follow-up** – even if you feel well and don't have symptoms. For example, with ECGs, remote monitoring, echocardiograms and other imaging tests, reassessing your risk of sudden cardiac arrest, and sometimes repeating genetic testing.



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## How do we decide what treatment is best for me?

### First, it's important to:

- Talk about your family history of HCM or possible HCM (for example, a family member who died at a young age suddenly or because of a "heart attack")
- Use imaging tests to see where the thickening is, how much there is and if it is affecting blood flow out of the heart
- Look for any abnormal heart rhythms by doing an ECG in the office and with a monitor that you wear at home for a period of time; a monitor lets us record your heartbeats over a longer period of time and as you go about your usual activities
- Assess your risk of sudden cardiac death

Exercise testing will tell how the heart responds during activity.

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### Your treatment will then depend on:

- Your age
- Burden of symptoms, including any signs of heart failure or irregular heart rhythms
- How much thickening you have and if it is blocking or slowing blood flow from the heart to the body
- How well your heart is working overall
- Your risk of sudden cardiac death
- How your HCM is affecting your life
- Your goals and preferences for your care

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### The main goals of treatment are to:

- Ease your symptoms (for example, chest pain, palpitations, shortness of breath)
- Prevent or lessen complications, such as blood clots, heart failure, dangerous heart rhythms that can lead to sudden cardiac death
- Improve your quality of life and your physical and emotional health

It's important to see a doctor and medical team trained in treating HCM.

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## Is it normal to feel scared and uncertain?

Yes, many patients feel this way, especially when they first learn about having HCM. But you're not alone. HCM is the most common genetic heart disease (passed down in families). There is also a lot of information to digest, especially in the beginning. You may feel as though your life has been turned upside down. It may feel difficult at times, but you should always feel comfortable asking questions and sharing any concerns.

The good news is that there is a lot we can do to help manage HCM and the risks that come with it.

## I've heard people with HCM can collapse or die at any moment?

This is definitely the most feared complication of HCM. The truth is it is quite rare.

Your risk of sudden cardiac death will depend on:

- Unexplained fainting spells
- Previous cardiac arrest – when the heart suddenly stops beating
- Family history of someone who died suddenly at a young age because of HCM or an unknown reason
- Greater thickening of the heart's main pumping chamber (left ventricle)
- Unusually fast heartbeat, 130+ beats per minute (non-sustained ventricular tachycardia)
- Excessive scarring in your heart
- An apical aneurysm, or outpouching of the tip of the heart

Having one or more of these signals a greater risk. There are medications to help and a device, about the size of a bar of soap, that can be placed in or near the heart to reset a normal rhythm.

## What changes can I make in my day-to-day life that might help?

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

- **Eat healthy** – choose whole, unprocessed foods and include lots of fresh fruits, vegetables, whole grains, fish, and lean meats.
- **Exercise** – come up with a plan you and your care team are comfortable with. Remember to stay hydrated.
- **Manage stress** – find ways to lower stress (deep breathing, yoga, listening to music, journaling, taking a walk, talking with other people who have HCM)
- **Watch your alcohol intake** – alcohol can trigger irregular heart rhythms and make blood flow in the heart worse.
- **Keep up with health visits and heart tests** – repeat imaging and other heart checks will help you and your care team know if more needs to be done to manage your HCM. It can help prevent other health problems, too.
- **Avoid using tobacco**
- **Get a flu shot each year** and ask about other vaccines, too.
- **Stay on top of other health conditions** that can affect your heart, perhaps making HCM worse; for example, high blood pressure, high cholesterol, diabetes, carrying too much weight.

## How do medications help?

Beta blockers and calcium channel blockers are used to help ease symptoms. They slow your heart rate and lower blood pressure, reducing the heart's workload. Some common examples include metoprolol, verapamil, and diltiazem.

Other medications may also be used, including:

- **Heart rhythm (antiarrhythmic) medications** that control how the heart beats. These can help block irregular rhythms caused by the thickening of the heart's walls for people with atrial fibrillation (or AFib), atrial flutter, ventricular tachycardia or premature ventricular contractions (PVCs).
- **Anticoagulants**, also called blood thinners, to prevent blood clots that could lead to a disabling stroke in people with AFib. Warfarin or a direct oral anticoagulant (DOAC) – such as apixaban, dabigatran, rivaroxaban – are examples.
- **Cardiac myosin inhibitors** (aficamten or mavacamten) for patients with symptomatic obstructive HCM who don't get sufficient symptom relief from other medications; these drugs inhibit actin-myosin interaction, thus decreasing cardiac contractility and reducing left ventricular outflow tract obstruction.
- **Be sure to tell your doctor if you are considering getting pregnant.** Most, but not all, HCM medications may be taken during pregnancy, and patients with HCM often need extra monitoring.
- **Other medicines to protect the heart**.

Therapies that specifically target HCM are being studied, but so far there isn't any medicine that directly treats HCM; just its symptoms.

## What's the difference between a myectomy and alcohol septal ablation? Is one right for me?

These are procedures to remove or destroy part of the thickened area of the heart, helping the blood leave the heart more easily and relieve symptoms. These may be a good option if 1) you have obstructive disease (when the thickened heart muscle blocks or limits blood flow out of the heart) and 2) your symptoms haven't improved with medications.

- **Myectomy** is open-heart surgery to remove part of the excess muscle from the septum to improve blood flow.
- **Alcohol septal ablation** is a catheter-based procedure that thins out part of the heart muscle that is obstructing blood flow. But you also need a certain type of anatomy for an ablation. Alcohol is injected through a thin tube (catheter) into an artery near the thickened part of the heart wall.

## If I have a procedure to remove part of the thickened heart muscle, will it come back?

Typically only one septal reduction procedure is required. Talking about the risks and benefits of each procedure, as well as your goals, is essential to making the best decision for you. It is important that you find a physician who has experience and knowledge about whether you should consider septal reduction therapy, and which procedure would best suit you.

## Can I exercise?

Yes, regular exercise has many health benefits. Mild- to moderate-intensity exercise is recommended as a routine part of HCM care for most people.

For a long while, people with HCM have been told not to exercise or exert themselves. This was mostly because of fears that doing so could trigger dangerous heart rhythms and possibly sudden cardiac death. But moderate-intensity physical activity has not been associated with these arrhythmias, according to studies. In fact, not exercising has been linked to obesity, poor mental health, diabetes, as well as other heart problems and health issues. Exercise can help people feel better, increase their exercise tolerance or ability, and it benefits their heart and overall health.

Work with your care team to come up with an exercise plan that works for you. It should take into account your HCM, fitness level and interests. Everyone is different and the exercise routine needs to be tailored to you.

## What about taking part or competing in certain sports?

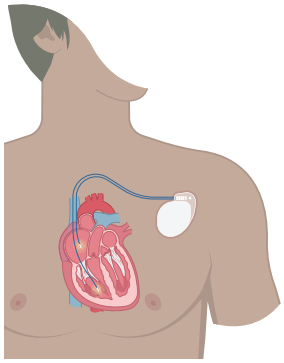
Many people with HCM are able to participate in vigorous exercise or competitive sports. Before doing so, talk with your care team about your situation and the risks and benefits of more intense exercise.

Many people with HCM may be able to participate in more vigorous exercise. Talk with your care team about the potential risks and benefits and what may be appropriate for your individual situation.

## I've heard a lot of people with HCM have an ICD. Does everyone need one?

An implantable cardioverter defibrillator, or ICD, is usually recommended for people who are at certain level of risk of having sudden cardiac arrest. An ICD is a small device that is placed in the chest. It monitors for dangerous heart rhythms and, if needed, delivers an electric shock to the heart to stop a life-threatening heart rhythm.

Scan the QR code to use our decision aid for patients considering an ICD who don't have heart failure or visit CardioSmart.org/ICD.



## What is an HCM specialist or HCM center?

HCM centers offer the very latest testing and treatment options. They will pull together a team of professionals to address as many of your needs as possible (called multidisciplinary care). They will also coordinate with your general cardiologist and make sure you are getting the best care, follow-up and advice on advanced therapies. You may have the opportunity to enroll in ongoing clinical trials if you are eligible and interested in participating.

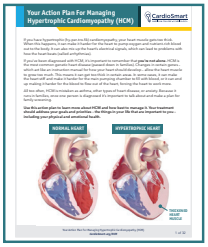
## What about pregnancy concerns?

Be sure to tell your doctor if you are thinking about getting pregnant. Most, but not all HCM medications may be taken during pregnancy. Patients with HCM often need extra monitoring.

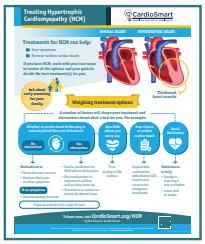
# Helpful Resources for Your Patients

It is important to encourage open and ongoing dialogue about HCM. Efforts to educate patients should also be guided by their individual preferences and priorities.

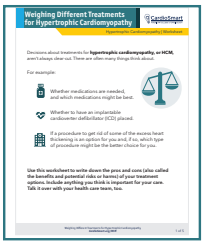
Below are several resources developed by the American College of Cardiology that can be used to help prioritize goals, treatments and decisions; dispel myths around exercise and create an individualized plan; and explain and encourage family HCM screening. Download all the tools at *CardioSmart.org/toolkitHCM*.



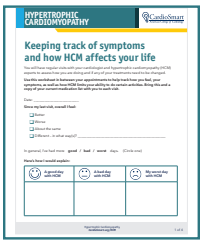

**Your Action Plan for Managing HCM**
Workbook helps patients learn more about HCM and how best to manage it with detailed information about treatment options, common worries, and questions to ask. Patients can also write down their goals for managing. HCM.




**Treating Hypertrophic Cardiomyopathy**
Use this infographic to review treatment options and spark discussions about patient goals



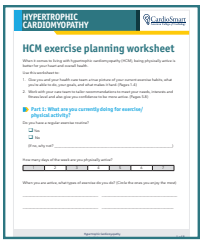

**Weighing Different Treatments for HCM**
Patients can use this worksheet to write down the pros and cons of different treatment options – medications, devices, or procedures – to support discussions with their health care team




**Keeping Track of Symptoms and How HCM Affects Your Life**
Patients use this worksheet in between health visits to help track how they feel, their symptoms, and if HCM is limiting their ability to do certain activities.




**Stepping Up to HCM**
Fact sheet helps patients understand how exercise is a key part of managing hypertrophic cardiomyopathy (HCM) for most people.



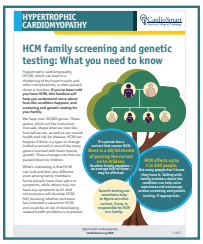

### HCM Exercise Planning Worksheet

Worksheet helps patients assess current habits and level of activity so they can talk with their care team to tailor recommendations to meet their needs and activity goals.



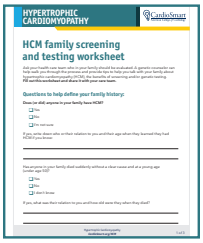

### Patients Considering an ICD Who Don't Have Heart Failure

Use this decision aid with your patients to talk about the benefits and risks of getting an ICD placed.



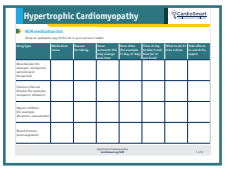

### HCM Family Screening and Genetic Testing: What You Need to Know

Handout explains how HCM can be passed down in families and the importance of family screening and genetic testing.



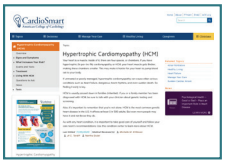

### HCM Family Screening and Testing Worksheet

Patients with HCM can use this worksheet to write down their family history and talk about which family members should have screening and/or genetic testing.




### HCM Medication List

Use this worksheet to track the medications you're taking to manage your HCM.




### *CardioSmart.org*

For more information, direct patients to *CardioSmart.org/HCM*.

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