

## Your action plan for managing hypertrophic cardiomyopathy (HCM)

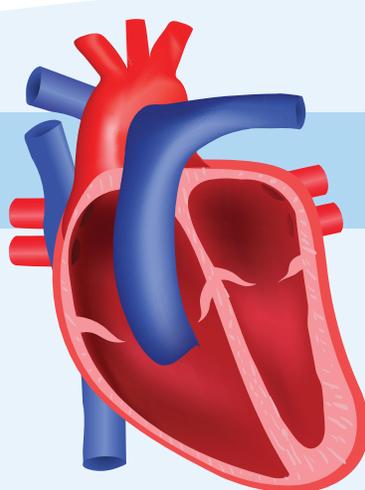
If you have hypertrophic (hy-per-tro-fik) cardiomyopathy, your heart muscle gets too thick. When this happens, it can make it harder for the heart to pump oxygen and nutrient-rich blood out to the body. It can also mix up the heart's electrical signals, which can lead to problems with how the heart beats (called arrhythmias).

If you've been diagnosed with HCM, it's important to remember that **you're not alone**. HCM is the most common genetic heart disease (passed down in families). Changes in certain genes - which act like an instruction manual for how your heart should develop - allow the heart muscle to grow too much. This means it can get too thick in certain areas. In some cases, it can make the heart stiff and make it harder for the main pumping chamber to fill with blood, or it can end up making it harder for the blood to flow out of the heart, forcing the heart to work more.

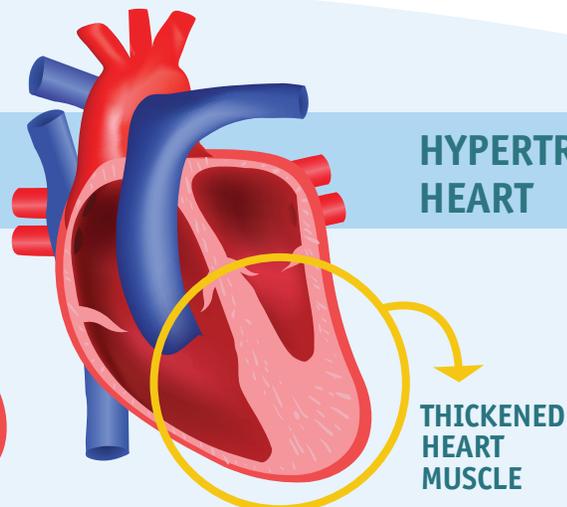
All too often, HCM is mistaken as asthma, other types of heart disease, or anxiety. Because it runs in families, once one person is diagnosed it's important to talk about and make a plan for family screening.

**Use this action plan to learn more about HCM and how best to manage it. Your treatment should address your goals and priorities - the things in your life that are important to you - including your physical and emotional health.**

NORMAL  
HEART



HYPERTROPHIC  
HEART





## Helpful hints from the start

Now, and throughout your journey, make sure to:

- **Take a deep breath, and go one step at a time.** When you find out you have HCM, there is a lot to take in. Learning to live with the condition is a process.
- **Consider asking for a referral to an HCM specialist, especially if you are considering a procedure or surgery.** HCM centers offer the very latest testing and treatment options. They will pull together a team to address your needs (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.
- **Play an active role in your care and ask questions,** especially when it comes to:
  - Understanding your treatments, including the risks and benefits
  - Finding ways to exercise - being physically active in some way is good for your heart and overall health, according to the latest HCM guideline
  - Knowing which family members may need to be screened for HCM and when
  - Building your support team

Knowledge is power: The more you know about your HCM and options to manage it now and down the line, the more in control you will feel.

- **Write down and share your goals for managing HCM.** Decisions about physical activity, therapy choices and genetic testing aren't always clear-cut. Share what matters most to you.
- **Talk openly with your care team about your concerns, how you are feeling overall, as well as how the disease impacts your day-to-day life.** For example, side effects or costs of medications, difficulty getting to or finding an HCM expert in your area, coping with symptoms such as extreme tiredness or shortness of breath, or managing fears (worries about exercise, having children, suddenly collapsing).
- **Keep an updated list of the medications you take** - both prescription and over-the-counter drugs and supplements - and review it at each visit. Make sure you understand what each one does to help and write down any changes.
- **Connect with other people affected by HCM.** Finding out that you have HCM can be scary. It can be unpredictable and may look different even among family members who have it. Sharing stories and hearing advice from other people living with the disease can be empowering. You'll also know that you're not alone.

## What you'll find inside

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Thanks to new research, better therapies and earlier detection, most people with HCM can live a long and fulfilling life.

## Your HCM summary

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Name: \_\_\_\_\_ Age: \_\_\_\_\_

### Your core health team

	Name of clinician or clinic	Phone number
Primary care		
Cardiologist (heart doctor)		
HCM specialist or center		
Genetic counselor (for HCM screening or testing)		
Electrophysiologist (heart rhythm doctor)		
Other specialists you see regularly: _____ _____ _____		

## About your HCM

### Do you have:

- Obstructive disease (when the thickened area in the heart interferes with blood flow)
- Non-obstructive disease (when the thickening does not interrupt blood flow, but the main pumping chamber becomes stiff, limiting how much blood the heart can take in and pump out to the body)
- I don't know

**Note:** *About 2 in 3 people with HCM have obstructive disease. Some people may have non-obstructive disease at rest, but when they exercise, their blood flow may be limited. So sometimes it's not clear until more tests are done.*

### What symptoms have you had: (Check all that apply)

- Shortness of breath
- Chest pain
- Extreme tiredness/fatigue, low energy
- Sensations of rapid, fluttering heartbeats (palpitations)
- Dizziness/feeling lightheaded
- Fainting
- Swelling in legs or feet
- Other symptoms: \_\_\_\_\_
- None, HCM found based on family history

Many people with HCM don't have symptoms. But others can develop heart failure, dangerous heart rhythms (the way the heart beats) and, in rare cases, sudden death.

## Treatments tried

**What steps have you taken to manage HCM?** (Check all that apply)

- I'm newly diagnosed and just learning about treatment options
- Taking medication(s) to help protect the heart (for example, mavacamten)
- Making lifestyle changes, such as healthy eating, limiting alcohol and caffeine, not using tobacco
- Being physically active to the degree I feel comfortable
- Had an implantable cardioverter defibrillator, or ICD, implanted (Date: \_\_ / \_\_ / \_\_ )
- Ablation for atrial fibrillation
- Alcohol septal ablation (Date: \_\_ / \_\_ / \_\_ )
- Surgical myectomy (Date: \_\_ / \_\_ / \_\_ )
- Heart transplant (Date: \_\_ / \_\_ / \_\_ )
- Talked about genetic counseling for family members
- Other: \_\_\_\_\_

## Family history

**Does anyone else in your family (brothers, sisters, parents, children) have HCM?**

- Yes (If yes, who: \_\_\_\_\_)
- No
- I don't know

**Has anyone in your family gone through genetic testing?**

- Yes (If yes, who: \_\_\_\_\_)
- No
- I don't know

## Main sources of support or coping

Living with HCM can be scary at times. It can also take a toll on your emotional and mental health, relationships, and your ability to fulfill work and family responsibilities. Be honest about how you are coping overall and if you need more support.

**Think about your sources of support and coping. Which are most helpful?**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

## Other heart conditions

**Other heart conditions/complications you have:** (Check all that apply)

- Atrial fibrillation (AFib)
- Other heart rhythm problem \_\_\_\_\_
- High blood pressure
- Heart valve problems
- Heart failure
- Family history of sudden cardiac arrest or ICD
- Other: \_\_\_\_\_

## Your goals for managing HCM

Be sure to talk openly with your health care team about your concerns, goals and values. Knowing what is important to you can help guide your health care choices, including the type of treatment you might be comfortable trying.

Think about and write down:

1. **What worries you most about living with HCM?**

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2. Your goals for managing your HCM. What do you most want to achieve with your treatment plan?

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Do you have specific goals for different parts of your life?



**At Work:**

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**At home:**

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**At play:**

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**For your mental well-being:**

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Print the worksheet *Keeping Track of Symptoms and How HCM Affects Your Life* at the end of this action plan and fill it out. This will help you and your care team know how well your treatment is working, how HCM is affecting your quality of life, and what might need to be changed.

3. **Is it important that your treatment:** (Check all that apply and write down any helpful notes)

**Helps ease symptoms**

Which do you find to be most bothersome?

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**Improves your ability to do certain activities**

Which activities are most important to you? Are there new activities or hobbies you could try?

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**Lowers the chance of having other health issues or complications**

(For example, fainting episodes, sudden cardiac death, atrial fibrillation or other heart rhythm issues, heart failure)

Which ones are you especially concerned about?

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**Reduces the likelihood of needing a procedure to remove or shrink the thickened area of the heart**

What worries you about having a procedure or surgery?

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**Addresses the emotional side of living with HCM**

What do you find to be the hardest part?

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**Helps family members who may not show signs of HCM become aware of the condition and get screened**

Use ACC's *HCM Family Screening and Testing Worksheet* to help.

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**Other goals or things that are important to you:**

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**TIP:** Your goals may change over time. Let your health care team know so they can best meet your needs.

**4. Are there questions about HCM that you would like answered? For example:**

- How is HCM affecting your heart health and what are you able to do?
- Which medications help people feel better?
- What are the long-term effects of HCM?
- How to be more physically active?
- Best ways to talk with family members about being screened or tested for HCM?

Write down any other unanswered questions here:

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## Managing your HCM

Your treatment plan will include making healthy lifestyle choices and taking medications to ease your symptoms and improve your quality of life. For some people, procedures to remove part of the excess heart tissue may also be an option. In rare cases, getting a new heart (heart transplant) may be needed.

### Key steps for managing HCM

<p><b>Assessing your risk of complications</b> from HCM and talking about family screening. Knowing your family history, risk of sudden death or if you have an abnormal heart rhythm can help you decide on the best treatment for you.</p> 	<p><b>Live a healthy lifestyle.</b> Regular physical activity, to the degree you are able, and a nutritious diet are important steps to improve your heart and overall health.</p> 	<p><b>Start or adjust medications.</b> The medications you take will depend on your type of HCM, but they can go a long way to help you feel better and protect your heart.</p> 	<p><b>Procedures or surgeries</b> if the thickening in your heart is blocking blood from being pumped out to meet the body's needs and if medications haven't worked.</p> 	<p><b>Ongoing monitoring</b> with an HCM expert and follow-up imaging tests.</p> 
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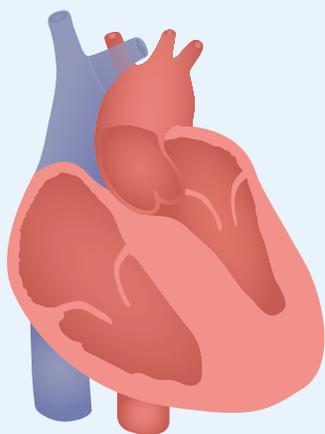
## Factors shaping your treatment plan

Before reviewing HCM treatment options, it's important to talk about what may influence decisions about your treatment plan.

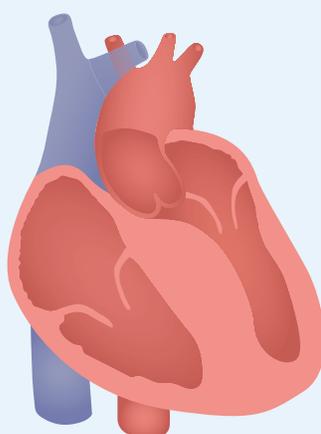
Your treatment will depend on a number of things. For example:

- Your age
- Your symptoms, including any signs of heart failure or irregular heart rhythms
- How much thickening you have and whether it is blocking or slowing blood flow from the heart to the body (obstructive or non-obstructive HCM)
- How well your heart is working overall
- Your risk of sudden cardiac death, which though rare, may need to be addressed depending on your risk and family history
- Your personal goals for treatment and how your HCM is affecting your life

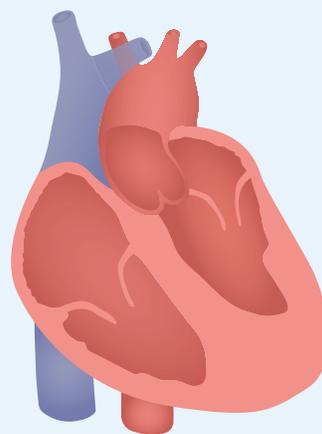
There are several types of HCM, and the thickening (shown below) can vary and happen in different areas of the heart. Which type you have can affect how your HCM is treated.



**Symmetrical hypertrophy**



**Septal hypertrophy**



**Apical hypertrophy**

## Assessing your risk of sudden cardiac death

People with HCM have very small chance of sudden cardiac death. Still, your care team will assess your risk and offer treatment, if needed. This is a routine part of HCM care and guides treatment decisions.

In doing so, your care team may consider the following risk factors:

- 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 increased risk.

**Although the chance of sudden cardiac arrest is well known, it is very rare. More common – and less talked about – are the day-to-day struggles that come with living with HCM and the burden it can have on families. Talk about your feelings. Your care team can help.**

## HCM often runs in families

While some cases of HCM can be due to other factors - older age, random genetic changes, or uncontrolled blood pressure - most are passed down in families. If untreated, HCM can lead to other conditions such as heart failure, dangerous heart rhythms and, in rare cases, sudden death.

**That's why knowing your family history, meeting with a genetic counselor, and talking with and encouraging relatives to get screened - if needed - is important.**

There is a 50/50 chance of passing HCM on to children. So half of family members could be affected in some way. What makes it harder is that some people with HCM feel fine, while others are very limited by the disease. Regardless of how someone feels, it's important that first-degree relatives - parents, brothers, sisters, and children - of anyone who has been diagnosed with HCM also be screened.

**Ask your care team who in your family should be evaluated.** For more information, read the handout *HCM Family Screening and Genetic Testing: What You Need to Know*.



## ▶ Your treatment plan for HCM

There are many treatment options to help manage HCM. Some can benefit anyone with HCM, and others will depend on the type of HCM you have, as well as other factors.

The following are important considerations and treatments for most people with HCM.

### Self-care and healthy life choices



#### Move more.

Getting some type of exercise is an essential part of managing HCM. It can help you feel better and be more active. Physical activity has many health benefits, including:

- Lowering blood sugar, blood pressure and cholesterol
- Strengthening the heart
- Preventing other health problems, such as type 2 diabetes, certain cancers, depression, sleep apnea, or falls
- Boosting your energy level, mood and outlook

Work with your care team to come up with an exercise plan that takes into account your HCM, fitness level and interests.

Aim to get \_\_\_\_\_ minutes of **light / moderate** (circle) exercise most days.

Types of activities that are good for me include:

Walking

Jogging

Hiking

Dancing

Gardening

Others: \_\_\_\_\_

Biking (some people like the type of bike that allows you to recline against a back rest and pedal)

Swimming

Cardio-type classes

- Other recommendations/advice: (For example, taking part in a supervised exercise program, symptoms to watch for during exercise that should signal you to ease up or stop)

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Use the *HCM Exercise Planning Worksheet* at the end of this action plan together with your care team to 1) get a sense for your current activity level and 2) create a tailored exercise routine that you can enjoy and feel confident doing.

Many people with HCM say they worry about exercising or pushing their heart too hard. Some were told not to be active at all given fears about sudden death.

Research now shows light- to moderate-exercise is good for overall health and does not increase the chance of dangerous heart rhythms or sudden cardiac arrest.



### **Eat a heart-healthy, nutritious diet.**

Several eating plans are known to be good for the heart  
It's generally a good idea to:

- Eat a diet rich in vegetables, fruits, fish and healthy sources of protein.
- Limit processed or packaged foods. These tend to have little nutrition and a lot of salt or added sugars.
- Other recommendations/advice: (For example, nutrition counseling)

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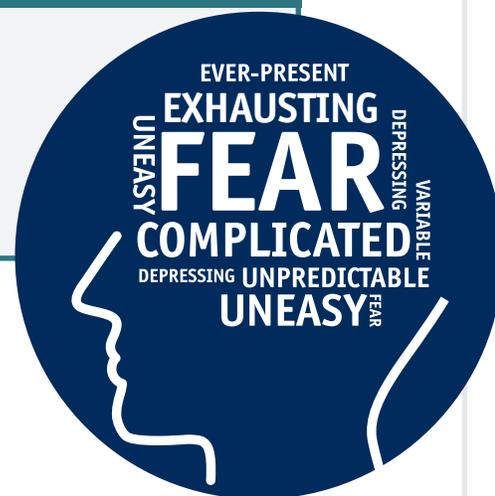


## Reduce stress and find ways to adjust to life with HCM so that you have a good quality of life.

Stress and anxiety can make the heart work harder. It can also make it harder to cope and stay positive.

- Keep an eye on your emotional health** and let your care team know if you are feeling unusually sad, depressed or worried about things.

Many people with HCM live with the fear that they may collapse at any moment because of what they've heard. In reality, cases of sudden death are very rare. Talk with your care team if you feel overwhelmed. There are many things you can do to protect your heart and feel more at ease.



- Find healthy ways to cope with stress.** For example:

- Deep breathing exercises
- Yoga
- Exercise
- Writing in a journal
- Music therapy
- Positive self-talk - you can do this!
- Other ideas: \_\_\_\_\_

- Build a trusted support team.** Join a local or online peer support program. Talking with someone else who has HCM and sharing tips and advice can be very helpful.
- Seek counseling** with a mental health professional or cardiac psychologist, which are now part of many HCM programs. Ask for a referral or recommendation if you think this would be helpful.

Name and contact number: \_\_\_\_\_

- Other recommendations/advice:**

\_\_\_\_\_



### Quit using tobacco.

Let your health care team know if you smoke and need help quitting. It's not easy, but there are resources to help.

- Set a date to quit: \_\_\_/\_\_\_/\_\_\_
- Get help quitting - 1-800-QUIT-NOW (1-800-784-8669)
- Ask your care team about medications and nicotine replacement therapies that can help.
- Avoid other people's smoke as best you can.
- Other recommendations/advice:

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### Get a good night's sleep.

Sleep is at the heart of so much of one's health and well-being. Too often we don't get enough.

- Aim for 7-8 hours of sleep a night.
- Set a regular time to go to bed and get up each day.
- Do something to wind down and relax (a warm bath, soothing music, read a book - make sure to put devices away at least an hour before bedtime).
- Doing some sort of exercise or activity each day - though not right before going to bed - can promote good sleep.
- Pay attention to and report any regular sleep disruptions. Let your care team know if you snore to the point that you wake yourself up, if you never feel rested, or if a sleep mate notices that you have pauses in your breathing.
- Other recommendations/advice:

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### Maintain a healthy weight or lose weight, if needed.

In addition to moving your body more, find easy ways to cut calories (for example, not adding cream and sugar to coffee or tea, cutting back on sweets, limiting alcohol and sugar-sweetened drinks, all of which have empty calories).

- What three things can you realistically do to curb calories:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

- Other recommendations/advice:

\_\_\_\_\_  
\_\_\_\_\_



### Prevent infections.

- Get an annual flu shot and ask about other vaccinations to stay healthy. If you have heart disease, you are more likely to get very sick from the flu, COVID and other diseases. Getting vaccinated is the best way to protect yourself and your loved ones.
- Other recommended vaccines and when you should get them:

\_\_\_\_\_  
\_\_\_\_\_



### Limit alcohol and caffeine.

Too much can result in abnormal heart rhythms.

- Limit to \_\_\_\_\_ caffeinated drinks a day.
- Limit alcoholic beverages to \_\_\_\_\_

## Medications and procedures

Which medications are recommended and if a procedure is needed will depend on many factors, including whether you have non-obstructive or obstructive disease.

If you have non-obstructive disease	If you have obstructive disease
<p><b>Medications</b> are used to help manage the symptoms of HCM. Commonly prescribed medications help to:</p> <p>Slow your heart rate and lower blood pressure, and reduce the heart's workload</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Beta blockers</b> (for example, metoprolol, atenolol and bisoprolol, but there are many)</li> <li><input type="checkbox"/> <b>Calcium channel blockers</b> (for example, verapamil, diltiazem)</li> </ul> <p>Taking the right combination of heart medications can help you feel better and may lessen some of the heart thickening</p>	<p><b>Medications</b></p> <p>If you have obstructive disease, <b>beta blockers</b> and <b>calcium channel blockers</b> are also recommended, although the amount (dose) you start with and how it is increased over time may be handled differently.</p> <p>In addition, you may be prescribed:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Disopyramide</b>, a type of antiarrhythmic, reduces the force with which the heart contracts</li> <li><input type="checkbox"/> <b>Mavacamten</b>, a medication that reduces the connections between muscle fibers in the heart to lower the force with which the heart contracts</li> </ul> <p><b>Procedures</b></p> <p>When medications aren't enough to improve symptoms, you may be offered:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Myectomy</b> - surgery to remove part of the thickened portion of the heart muscle to improve blood flow</li> <li><input type="checkbox"/> <b>Alcohol septal ablation</b> - a less invasive option; alcohol is injected through a catheter into a section of the heart's blood vessels to shrink the muscle, relieve any obstruction and lessen HCM symptoms</li> </ul> <p><b>Ask about cardiac rehabilitation after having one of these procedures.</b></p>

For anyone with HCM, if you also have an irregular heart rhythm (for example, AFib, atrial flutter, ventricular tachycardia, premature ventricular contractions, or PVCs), medications may be prescribed to:

- Control how the heart beats (called heart rhythm or **antiarrhythmic medications**), blocking irregular rhythms caused by the thickening of the heart's walls
- Thin the blood to prevent blood clots that could lead to a disabling stroke. These are called **anticoagulants** and include:
  - Warfarin
  - Direct oral anticoagulants (DOACs, such as apixaban, dabigatran, rivaroxaban)

**Other medications that may be recommended:**

- ACE-inhibitors
- ARBs
- Other:

## Clinical trials

Taking part in a clinical trial may be a good option for some people. Studies are testing new drugs to see whether they improve symptoms, exercise capacity, and/or heart structure and function. Ask your care team whether there are any studies that might be right for you.

# HYPERTROPHIC CARDIOMYOPATHY

## HCM medication list

Keep an updated copy of this list in your purse or wallet.

Drug type	Medication name	Reason for taking	Dose (amount); this may change over time	How often (for example 1/ day, 2/ day)	Time of day to take it and how (w/ or w/o food)	What to do if I miss a dose	Side effects to watch for, report
Beta blocker (for example, metoprolol, atenolol and bisoprolol)							
Calcium channel blocker (for example, verapamil, diltiazem)							
Mavacamten							
Blood thinners (anticoagulants)							
Water pill (diuretic)							

Drug type	Medication name	Reason for taking	Dose (amount); this may change over time	How often (for example 1/ day, 2/ day)	Time of day to take it and how (w/ or w/o food)	What to do if I miss a dose	Side effects to watch for, report
Other heart medicines you take (for example, ACE-inhibitor, ARBs)							
Other prescription medications, over-the-counter drugs or supplements							



## Medication reminders

- Medication should always be coupled with healthy lifestyle choices.
- Make sure you understand why each medicine is recommended and how it benefits your heart and health.
- You may start taking a medication at a low dose (amount). Your clinician will gradually increase the dose based on how you are doing. Always take your medications as directed.
- You will likely be prescribed more than one medication; they will work together to improve your heart health.
- Be sure to review all of the medications you take, including for other conditions. Ask if there are medications, including supplements and those available over-the-counter, that you should avoid.
- Try to use the same pharmacy for all of your medications and don't forget that your pharmacist can answer questions and review your medications.

Let your care team know if you have any issues with your medications - for example, remembering to take them, concerns about side effects/how they make you feel, difficulty paying for them, and/or not understanding why certain medications are needed.

## Devices to prevent sudden death

Heart thickening can disrupt or jumble electrical signals that tell the heart muscle when to beat and contract. It's why patients newly diagnosed with HCM are asked to wear a Holter monitor for a few days to record the heart's electrical activity. It gives your care team detailed information about your heart's rhythms beyond an ECG, which shows what the heart is doing only in that moment in time.

Because of this, some people may need an **implantable cardioverter defibrillator (ICD)** placed to be able to detect and correct any dangerous heart rhythms.

### How it works

An ICD is designed to prevent someone from dying suddenly from a dangerous heart rhythm. It is placed under the skin near the heart. Wires (called "leads") connect the ICD to the heart. If it senses a dangerous heart rhythm, it gives an electric shock to reset the heart to a normal beat.

Patients say that getting shocked feels like "being kicked in the chest." Some patients pass out before they are shocked and don't remember it happening.

### Making the decision

The decision of whether to have an ICD placed is a personal one. While some people with HCM are at high risk of having a life-threatening heart rhythm, others fall in between low and high risk. It is important to talk about and weigh the risks, benefits, as well as your own feelings about having a device placed.

**With an ICD** ... you may stop a dangerous heart rhythm that could cause sudden death by giving an electrical shock to the heart

**Without an ICD** ... you will have a higher risk of dying suddenly if a dangerous heart rhythm happens

My care team and I talked about placing an ICD because of these reasons:

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Based on our discussions, together, we decided:

- I should have an ICD placed
- We should revisit our discussion about a device as an option in \_\_\_\_\_ (months / year)
- As of now, I do not need an ICD
- I don't want an ICD

Use the space below or the *Weighing Different Treatments for HCM* worksheet at the end of this handout to write down other important notes or follow-up questions:

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A pacemaker is different from an ICD, which combines both pacing (regulating heart rate) with a defibrillator to prevent sudden death. A pacemaker may be a better option in some cases. For example, after a myectomy or alcohol septal ablation if the heart needs help with pacing and an ICD is not recommended, or if someone develops heart block. Heart block happens when the electrical signal that controls your heartbeat is partially or completely blocked.

## Follow-up visits and tests

Keeping up with regular heart monitoring and check-ins with your cardiologist and HCM specialist is an important part of managing HCM over the long run. This is true even if you don't have symptoms.

**Plan ahead and schedule health visits and imaging tests** to check your heart and the thickening.

- You should see your heart doctor/HCM specialist every \_\_\_\_\_ months.

Next visit, if known: \_\_\_\_\_ at \_\_\_\_\_ a.m./p.m.

One or more of the following imaging tests should be done every \_\_\_\_\_ months:

- Electrocardiogram (ECG) - records the electrical signals of the heart, which can become jumbled if there is thickening in the heart
- Echocardiogram or "echo" - shows moving pictures of your heart and how well it is pumping and can also measure areas of thickening
- Heart MRI - gives more detailed pictures of the heart, including whether there is any scarring, helps define the anatomy better and assess one's risk for sudden cardiac death
- Exercise stress test to monitor your heart rate and blood pressure response during activity when the heart is beating faster

Date of next imaging test(s), if known: \_\_\_\_\_ at \_\_\_\_\_ a.m./p.m.

### In between health visits:

- Keep track of how you are feeling (better, worse, the same or different in some way) and
- Ask what symptoms or changes to watch for and when and whom to call.

For example, if you notice:

- Chest pain or pressure
- Worsening shortness of breath
- Stronger or more noticeable heart palpitations or flip flopping
- Fainting spells
- Obvious swelling in your legs, feet or ankles

The best way to reach your care team is:

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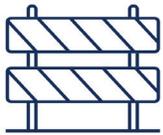
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Use the worksheet *Keeping Track of Symptoms and How HCM Affects Your Life* in between visits.

## ▶ Sticking with your care plan and advocating for yourself

It is helpful for your health care team to know what might get in the way when it comes to your treatment plan. For example:

- You might find it hard to take your medications as directed either because you take too many or the cost is too high
- You may not have easy access to a medical facility or HCM expert
- You may be scared about exercising and need more help finding a routine that works for you
- You may need more help trying to weigh the pros and cons of one therapy over the other



Use this chart to write down any barriers to your treatment plan. Talk with your care team so they can help find solutions and support you.

	What makes it hard	What seems to help
<b>Eating heart healthy</b>	<i>(Example: not having healthy options to choose from, it's easier or cheaper to pick up food to-go)</i>	<i>(Example: when my family joins me in making healthy choices, planning ahead)</i>
<b>Being physically active</b>	<i>(Example: fears that I'm going to collapse or hurt my heart, previous advice not to exercise, lack of time)</i>	<i>(Example: coming up with a plan with my care team, joining a class)</i>

<b>Taking medications</b>	<i>(Example: side effects, taking too many, not knowing why certain medicines are needed, can't read the label)</i>	<i>(Example: using a pillbox, setting an alarm)</i>
<b>Paying for/accessing medications</b>	<i>(Example: I can't afford to pay)</i>	
<b>Making it to medical visits or getting follow-up imaging tests</b>	<i>(Example: need after hours, don't have reliable way to get to appointments, cost of travel to HCM specialist)</i>	
<b>Talking with family about genetic testing</b>	<i>(Example, feeling too guilty or not knowing where to start)</i>	

## Advocate for yourself

**Speak up** if you need more help or advice with:

- Healthy eating
  - Getting regular physical activity
  - Weight loss or maintaining a healthy weight
  - Managing other health conditions
  - Coping, managing stress and finding ways to boost your mental health
  - Understanding how your treatment works
  - Paying for or taking your medicines
  - Talking with family members about genetic evaluation
  - Talking to a cardiac psychologist
  - Family planning
  - Managing AFib or other conditions
  - Other:
- 
- 

**Don't downplay the social and psychological impact of living with HCM.** For many people with HCM the day-to-day struggle can't be seen.

Talk about your feelings and surround yourself with people who are willing to understand how HCM affects you. Many people share stories about:

- Enormous guilt they felt in learning that they gave HCM to a loved one or the heartbreak of losing family members to it
- Concerns over family planning
- Lingering fears of suddenly collapsing or dying
- Burden of needing to explain and re-explain the condition and why they might need to rest to people who may think they "look fine"
- Disappointment that comes with having to give up certain activities or find new ways of doing things without feeling a sense of loss

## From now until your next visit

Write down 3 things you can do to help manage your HCM and take care of your mental and emotional health, too.

Set yourself up for success by choosing specific goals you can measure. For example, I will eat 5-7 servings of fruits and vegetables most days of the week, or I will walk for 10 minutes every day of this week.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

## Common questions

### About HCM

- Why is my heart too thick/big? Is there anything I can do to stop it?
- How does or can this thickening affect how my heart works?
- What is the difference between obstructive and non-obstructive HCM? Is it true that people can go back and forth between the two depending on how their disease evolves or after myectomy for example?
- How will HCM affect my life? Are there activities I should limit or avoid?
- I've heard a lot about HCM and sudden death. How worried should I be? What can I do to lower my risk?
- What routine tests are needed to check my heart health?
- How will I know if my HCM is getting worse?
- I often have a hard time keeping up with other people, but to them I look fine and healthy. What's an easy way to explain HCM and how it affects what I'm able to do and for how long?
- Why is it that HCM can affect people in the same family so differently?

## About treatments

- Can you explain how each medicine you are recommending works to manage symptoms and help protect my heart?
- Are there side effects I need to watch for? If so, which ones?
- I understand that HCM can lead to dangerous heart rhythms in some people. How will we know? At what point should I consider having an ICD or other device to help correct abnormal rhythms? What does it feel like to get a shock?
- Under what circumstances would a myectomy or alcohol ablation be recommended (procedures that reduce the excess thickness in the heart muscle)? Which would be better for me and why?
- How much of my treatment will be covered by insurance?
- Are there clinical trials that I should consider?
- Are there treatments that can prevent HCM in someone carrying the genetic mutation?

## About coping

- How can I best explain HCM to other people and help them understand that I'm not being lazy if I need to take a break or stop an activity?
- It's not easy to talk about HCM as a family. Is there support for families? Do you have advice on how to broach the topic?
- I worry about having children. Would my heart be able to handle the stress of pregnancy? What about the guilt of possibly passing along a gene variant that could cause my child to develop HCM?
- I get out of breath so easily. Are there accommodations that can help?
- Are there support groups or relaxation exercises that can help?

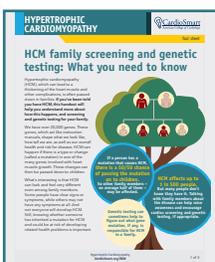


## ▶ More information and resources to help

Managing HCM may seem overwhelming at times. The American College of Cardiology has developed information and tools with input from patients and experts to help you.



### Hypertrophic Cardiomyopathy *CardioSmart.org/HCM*



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



### Stepping Up to HCM: Exercise should be a key part of managing HCM for most people

Organizations providing support for people with HCM:

#### **Hypertrophic Cardiomyopathy Association**

<https://4hcm.org>

#### **Mended Hearts**

<https://mendedhearts.org>