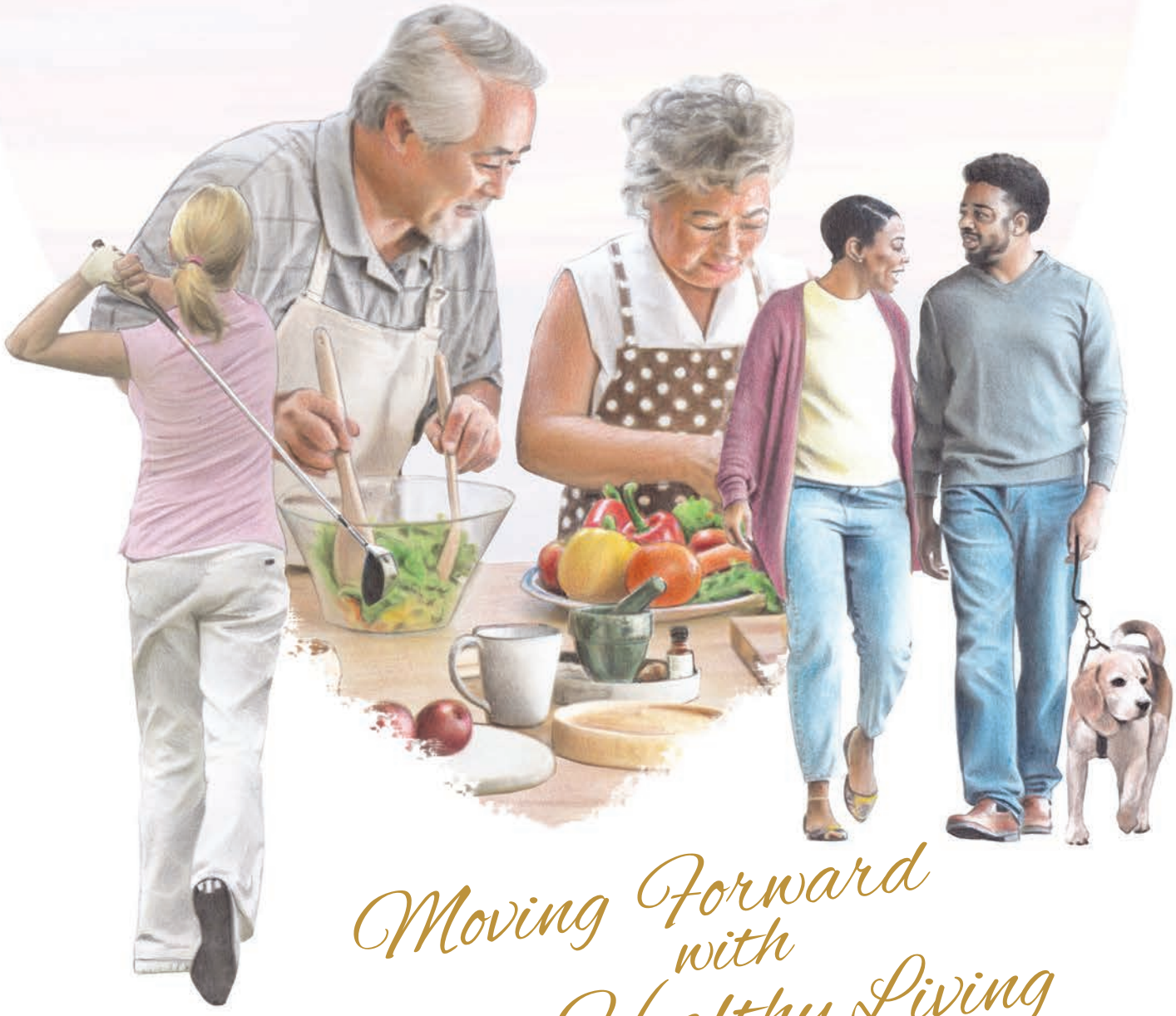
PATIENT RESOURCE

3rd Edition

A GUIDE TO LIVING WITH

HYPERTROPHIC CARDIOMYOPATHY



Moving Forward with Healthy Living

PRP PATIENT RESOURCE PUBLISHING®

IF YOU'VE HIT A WALL WITH SYMPTOMATIC OBSTRUCTIVE HCM,

TODAY YOU MAY HAVE AN OPENING WITH A DIFFERENT TREATMENT OPTION

CAMZYOS™
(mavacamten) 2.5, 5, 10, 15mg capsules

CAMZYOS™—the first and only FDA-approved treatment of its kind*—targets the source of symptomatic obstructive hypertrophic cardiomyopathy, or HCM.

CAMZYOS is a prescription medicine used to treat adults with symptomatic obstructive HCM and **may improve your symptoms and your ability to be active.**

***CAMZYOS is a cardiac myosin inhibitor. Scan to see how it works.**

INDICATION & IMPORTANT SAFETY INFORMATION FOR CAMZYOS (mavacamten)

What is the most important information I should know about CAMZYOS?

CAMZYOS may cause serious side effects, including:

- **Heart failure,** a condition where the heart cannot pump with enough force. Heart failure is a serious condition that can lead to death. You must have echocardiograms before you take your first dose and during your treatment with CAMZYOS to help your healthcare provider understand how your heart is responding to CAMZYOS. People who develop a serious infection or irregular heartbeat have a greater risk of heart failure during treatment with CAMZYOS. Tell your healthcare provider or get medical help right away if you develop new or worsening:
  - shortness of breath
  - swelling in your legs
  - chest pain
  - fatigue
  - a racing sensation in your heart (palpitations)
  - rapid weight gain
- **The risk of heart failure is also increased when CAMZYOS is taken with certain other medicines.** Tell your healthcare provider about the medicines you take, both prescribed and obtained over-the-counter, before and during treatment with CAMZYOS.
- **Because of the serious risk of heart failure, CAMZYOS is only available through a restricted program called the CAMZYOS Risk Evaluation and Mitigation Strategy (REMS) Program.**
  - Your healthcare provider must be enrolled in the CAMZYOS REMS Program in order for you to be prescribed CAMZYOS.
  - Before you take CAMZYOS, you must enroll in the CAMZYOS REMS Program. Talk to your healthcare provider about how to enroll in the CAMZYOS REMS Program. You will be given information about the program when you enroll.
  - Before you take CAMZYOS, your healthcare provider and pharmacist will make sure you understand how to take CAMZYOS safely, which will include returning for echocardiograms when advised by your healthcare provider. CAMZYOS can only be dispensed by a certified pharmacy that participates in the CAMZYOS REMS Program. Your healthcare provider can give you information on how to find a certified pharmacy. You will not be able to get CAMZYOS at a local pharmacy.
  - If you have questions about the CAMZYOS REMS Program, ask your healthcare provider, go to www.CAMZYOSREMS.com, or call 1-833-628-7367.

See **"What are the possible side effects of CAMZYOS?"** for information about side effects.

What is CAMZYOS?

CAMZYOS is a prescription medicine used to treat adults with symptomatic obstructive hypertrophic cardiomyopathy (HCM). CAMZYOS may improve your symptoms and your ability to be active.

Before taking CAMZYOS, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. CAMZYOS may harm your unborn baby. Tell your healthcare provider right away if you become pregnant or think you may be pregnant during treatment with CAMZYOS. You may also report your pregnancy by calling Bristol-Myers Squibb at 1-800-721-5072 or www.bms.com.

  If you are a female and able to become pregnant:
  - Your healthcare provider will do a pregnancy test before you start treatment with CAMZYOS.
  - You should use effective birth control (contraception) during treatment with CAMZYOS and for 4 months after your last dose of CAMZYOS.
  - CAMZYOS may reduce how well hormonal birth control works. Talk to your healthcare provider about the use of effective forms of birth control during treatment with CAMZYOS.
- are breastfeeding or plan to breastfeed. It is not known if CAMZYOS passes into

Learn more at camzyos.com,
and ask your doctor if CAMZYOS may be right for you.

your breast milk. Talk to your healthcare provider about the best way to feed your baby during treatment with CAMZYOS.

Before and during CAMZYOS treatment, tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking CAMZYOS with certain medicines or grapefruit juice may cause heart failure. **Do not stop or change the dose of a medicine or start a new medicine without telling your healthcare provider.**

Especially tell your healthcare provider if you:

- Take over-the-counter medicines such as omeprazole (for example, Prilosec), esomeprazole (for example, Nexium), or cimetidine (for example, Tagamet).
- Take other medicines to treat your obstructive HCM disease.
- Develop an infection.

How should I take CAMZYOS?

- Take CAMZYOS exactly as your healthcare provider tells you to take it.
- Do not change your dose of CAMZYOS without talking to your healthcare provider first.
- Take CAMZYOS once a day.
- Swallow the capsule whole. Do not break, open, or chew the capsule.
- If you miss a dose of CAMZYOS, take it as soon as possible and take your next dose at your regularly scheduled time the next day. Do not take 2 doses on the same day to make up for a missed dose.
- Your healthcare provider may change your dose, temporarily stop, or permanently stop your treatment with CAMZYOS if you have certain side effects.
- If you take too much CAMZYOS, call your healthcare provider or go to the nearest hospital emergency room right away.

What are the possible side effects of CAMZYOS?

CAMZYOS may cause serious side effects, including:

- **Heart failure.** See **"What is the most important information I should know about CAMZYOS?"**

The most common side effects of CAMZYOS include: dizziness and fainting (syncope).

These are not all of the possible side effects of CAMZYOS.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

You may also report side effects to Bristol-Myers Squibb at 1-800-721-5072.

How should I store CAMZYOS?

Store CAMZYOS at room temperature between 68°F to 77°F (20°C to 25°C).

Keep CAMZYOS and all medicines out of the reach of children.

General information about the safe and effective use of CAMZYOS.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use CAMZYOS for a condition for which it was not prescribed. Do not give CAMZYOS to other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for information about CAMZYOS that is written for health professionals. For more information, go to www.CAMZYOS.com or call 1-855-226-9967.

This is a brief summary of the most important information about CAMZYOS. For more information, talk with your healthcare provider, call 1-855-226-9967, or go to www.CAMZYOS.com.

Bristol Myers Squibb™

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A GUIDE TO LIVING WITH HYPERTROPHIC CARDIOMYOPATHY

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Knowledge is your biggest asset

When you receive a hypertrophic cardiomyopathy (HCM) diagnosis, education becomes vitally important. From understanding your diagnosis and finding a skilled medical team to guiding you to where to look for the most trusted resources, everything you learn will help you better manage this chronic condition and live your life to the fullest.

HCM is a type of obstructive heart disease that primarily involves a thickening of the wall (septum) between the two bottom chambers of the heart (see Figure 1). The walls of the left ventricle can also become stiff. This may block or reduce the blood flow from the left ventricle to the aorta, a large artery that carries oxygen-rich blood from the left ventricle of the heart to other parts of the body. This obstruction prevents the heart from carrying out its intended function.

When this occurs, it forces the ventricles to pump harder to overcome the narrowing or blockage. Additionally, the septum may bulge into the left ventricle and partially block the blood flow out of the heart to the rest of the body.

Both conditions cause the heart to work harder and may increase pressures in the heart, resulting in fatigue, shortness of breath and potentially heart failure.

NEXT STEPS

Having a plan helps. Begin your journey by doing the following.

1 Consult with a team of HCM experts. Depending on the experience your current cardiologist and medical team have with diagnosing and treating HCM, they may recommend you get a first or second opinion from an HCM specialist or HCM treatment center. Look for an HCM Center of Excellence (COE). A treatment center must meet specific criteria to receive this designation. A COE typically employs a multidisciplinary team to provide whole-person HCM care (see *Meet Your Health Care Team*, page 9). If you are not located near an HCM COE, ask whether it is possible to arrange a consultation with your local medical team.

2 Learn about your heart. Familiarizing yourself with the components of the heart makes it easier to understand the parts that are not working as they should (see Figure 2).

The heart is a muscle that is about the size of a fist. It sits slightly to the left of the center of the chest. Along with blood and blood vessels, it makes up the cardiovascular system.

Blood is pumped throughout the body through blood vessels as the heart beats. It beats about 60 to 100 times per minute, sending oxygen and nutrients throughout the body and carrying away unwanted carbon dioxide and waste products. Electrical signals tell the heart muscle when to contract and relax and ensure it continues to pump regularly.

The two top chambers of the heart – the right atrium and left atrium – receive incoming blood. The two bottom chambers, the right ventricle and the left ventricle, pump blood out of the heart. The chambers are separated by a wall of muscular tissue called the septum.

The heart also has four valves — one for each chamber of the heart. They open and close to let blood flow through the heart and keep it moving in only one direction. The mitral valve and tricuspid valve are located between the atria (upper heart chambers) and the ventricles (lower heart chambers). The aortic valve and pulmonic valve are located between the ventricles and the major blood vessels leaving the heart.

The walls of the heart are made of three layers. The endocardium is the thin membrane that lines the interior of the heart. The middle layer of the heart is the myocardium, which is the heart muscle and the thickest layer of the heart. The epicardium is a thin layer on the surface of the heart on which the coronary arteries lie.

The right atrium receives blood depleted of oxygen from the body and pumps it to the right ventricle to be sent to the lungs to pick up oxygen. The oxygenated blood from the lungs flows into the left atrium and is then transferred to the left ventricle, which pumps it around the body.

3 Adjust your mindset and find support. Although you will manage HCM for the rest of your life, it does not have to define you. And, it is not something to face alone. Surround yourself with a support system (see *Moving Forward*, page 10). Build your supportive community by exploring HCM advocacy and support groups. Sharing with and learning from people who live with HCM can offer valuable practical advice and be a source of hope. ■

FIGURE 1
HYPERTROPHIC CARDIOMYOPATHY

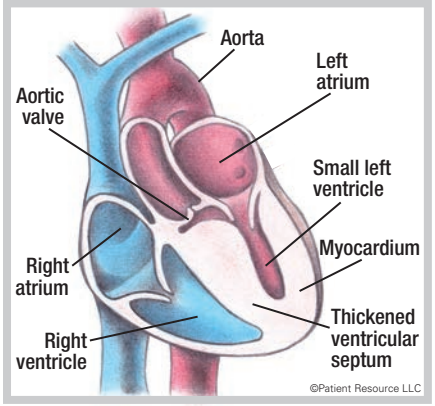
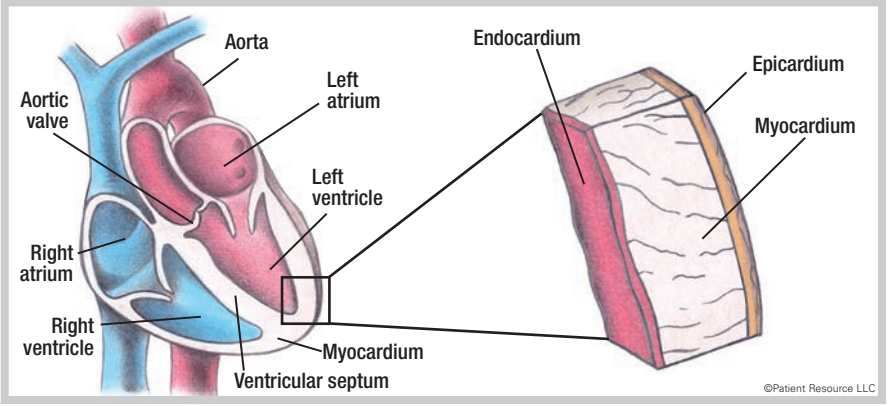


FIGURE 2
HEALTHY HEART



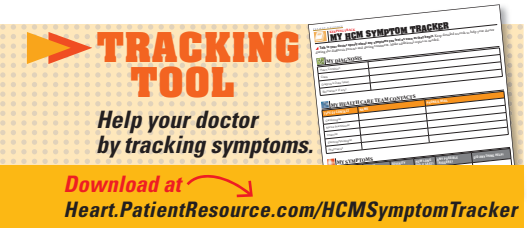
Recognizing the signs that may point to HCM

The symptoms of HCM can be difficult to distinguish from other conditions and may be confused with asthma, chronic obstructive pulmonary disease (COPD), panic attacks, poor fitness or sleep apnea. In some cases, people with HCM can go a long time without realizing they have symptoms. It can also be hard to differentiate HCM from other heart-related problems in older patients. As a result, diagnosing HCM may take some time.

Unlike some other heart conditions, HCM is not preventable because it is inherited from one or both of your parents. The main risk factor for HCM is having a parent with the mutated gene, and only a single copy of the mutated gene is needed to cause the disease. HCM can run in families without the family's awareness. Signs that it may run in your family include the following:

1. A family history of certain conditions, including:
   - Cardiomyopathy or an enlarged or weak heart
   - Heart failure or sudden cardiac arrest (SCA)
   - Recurrent syncope (fainting)
   - Sudden death
   - Unexplained death from drowning or a single-vehicle crash
   - A pacemaker or atrial fibrillation on its own before age 65
   - Any type of skeletal muscle disease, such as Duchenne muscular dystrophy
2. Long-term high blood pressure or alcoholism
3. Coronary heart disease or heart attack
4. A viral infection that inflames heart muscle
5. Diabetes or severe obesity
6. Diseases that damage the heart

If you have any relatives with the above conditions, it may be time to discuss whether genetic testing would be helpful. Genetic testing helps determine whether you have inherited a mutation that increases your risk for developing certain types of disease — even if you have not been diagnosed.



COMMON SYMPTOMS

One person with HCM may have different symptoms than another person with the same disease. The symptoms can also show up at any age, develop slowly and range from mild to severe. There is no list of symptoms used to definitively diagnose HCM, but some of the most common include the following:

1. Having trouble exercising over time
2. Fatigue
3. Chest pain, especially after a heavy meal or when being active
4. Shortness of breath or trouble breathing, especially when being active
5. A fluttering or pounding feeling in the chest (palpitations), which may be due to an abnormal heart rhythm (arrhythmia)
6. Feeling dizzy or lightheaded
7. Fainting when being more active
8. Heart murmurs (unusual sounds linked with heartbeats)
9. Muscle pains
10. Brain fog

In some cases, there are no recognizable symptoms. Whether a person has symptoms or not, HCM can be challenging to diagnose. It is important to tell your doctor about any symptoms you experience and provide regular updates to your medical team. Keep track of your symptoms, note when they occur, how long they last and whether anything makes them better or worse. This information is valuable to your doctor.

COMPLICATIONS OF HCM

HCM can lead to other health problems:

- Mitral valve problems, including blocked blood flow that prevents the mitral valve from closing correctly or mitral valve regurgitation (backward blood leakage), which can increase symptoms.
- A weakened and ineffective heart muscle.
- Atrial fibrillation (AFIB). A thicker heart muscle and abnormal heart cells can cause changes in your heart's electrical system that result in AFIB (fast or irregular heartbeats). AFIB can also lead to blood clots, stroke or other heart complications.
- Arrhythmias. Irregular heartbeats are common in HCM. Examples include ventricular tachycardia (arising from the ventricles) or atrial fibrillation.
- Sudden cardiac arrest (SCA) and, in rare cases, sudden cardiac death (SCD). Younger patients with HCM are at higher risk of experiencing SCD than older patients. However, SCD is rare (see *Finding cardiac conditions early*, page 7).
- Heart failure. This occurs when the heart is not pumping hard enough or may not fill well enough. As a result, there is insufficient blood to meet the body's needs.
- Blocked blood flow.
- Heart block. This occurs when the normal electrical signal travels too slowly to the ventricles or is partially or completely blocked. ■

The symptoms of heart failure

Heart failure is a potential complication of having HCM. In this case, "failure" does not mean your heart suddenly stops. Rather, heart failure starts slowly and gets worse over time. It occurs when your heart muscle is injured and cannot pump enough blood throughout your body.

Heart attack and high blood pressure are two common risk factors for heart failure. Your heart may become weak and unable to pump blood (systolic heart failure), or stiff and unable to fill with blood (diastolic heart failure). Both can lead to a buildup of extra fluid and other symptoms.

Symptoms of heart failure may be subtle and show up at a later stage after the heart becomes really weak. Heart failure shares some of the same symptoms of HCM and may cause you to experience the following:

- **Frequent coughing, coughing up pink, blood-tinged sputum or a dry, hacking cough when lying down**
- **Swollen feet, ankles, legs or abdomen from a buildup of fluid**
- **A greater need to urinate at night**
- **Nausea and lack of appetite**
- **Cold legs and arms**
- **Trouble concentrating**

Marlin Colón's quality of life changed once she began having heart issues due to hypertrophic cardiomyopathy (HCM). Then it changed again – for the better – once she found the resources that helped her learn how to manage this lifelong condition.

Moving forward with strength & support

Heart issues began for me when I was 13 years old. For two years, doctors attributed them to the fact that I was growing. At 15, they finally determined I had supraventricular tachycardia (SVT), which is basically a group of arrhythmias or irregular heartbeats. I had an ablation, and that solved the issue for many years.

At 23, I gave birth to our first child, and I could feel something was wrong in my chest. An echocardiogram showed that my heart was enlarged because of a condition called hypertrophic cardiomyopathy (HCM). I saw a specialist and was put on a beta blocker. I followed up annually and felt so good that, against medical advice, I got pregnant again. My heart condition made it a high-risk pregnancy, but our daughter was born healthy.

When we moved to Florida, I saw a new cardiologist. Unfortunately, it was never a good relationship. With every visit, I felt more lost. I could tell my condition was deteriorating and I tried to advocate for myself by asking whether a change of diet or something else might help, but I didn't get any answers. Although it wasn't the smartest decision, I stopped my follow-up visits for a year or two.

Finally, I felt so bad that I went back to him. Extreme fatigue made me stop working in the middle of the day just to take a nap. I'd wake up during the night sweating, with a racing heart. He ordered an echo. On my way out, he told me that if he saw anything that required attention, the office would let me know so I could be seen faster.

I went home and burst into tears as I told my husband about the visit. I told him that I thought I was dying. He suggested we go back to the specialist in Boston. Because we had the kids to think about, I hesitated. I prayed and meditated, then it dawned on me to look on Facebook for any groups focused on my condition. That is where I found the Hypertrophic Cardiomyopathy Association (HCMA). I'm convinced it saved my life.

So many doors suddenly opened for me that day. With their support, I was able to:

1 **Get educated.** I learned so much during my first call with Lisa, the CEO. She asked questions and provided trusted resources. I realized how much I didn't know about my own condition.

2 **Find a local specialist.** The same day, I was connected with an HCM specialist in my city. I didn't realize there was one so close that I could have been seeing all along.

3 **Begin a personalized treatment plan.** The specialist saw me the very next day. He determined I needed an internal cardioverter defibrillator (ICD) placed immediately, followed by open heart surgery to perform a septal myectomy to alleviate my symptoms. The surgery was successful. I found out later that he removed twice as much heart muscle as he typically does! I still take a beta blocker and may for the rest of my life.

4 **Surround myself with support.** My husband, mom and sister were immensely helpful, but heart surgery is a scary concept. HCMA introduced me to people who'd had the same procedure. It was comforting to learn how they felt before and after the surgery. I also had the support of my mom's husband, my dad, extended family and close friends. My Facebook community was praying for me and supporting me through a GoFundMe page.

5 **Get my family members tested.** Imaging tests showed that the lower part of my mom's heart is affected, so she is being monitored. The kids show no signs of HCM, but they will continue to see a pediatric cardiologist because things can change as they get older. My genetic test was inconclusive, so the kids will have genetic testing as often as insurance allows.

6 **Share my story to help others.** The day I gave this interview was my one-year "heartaversary" – the day I had open heart surgery – and it reaffirmed for me that sharing my story as a patient advocate is all part of God's plan for me.

7 **Live longer and better!** I don't think the cardiologist I saw was experienced enough with HCM because he didn't see the urgency the specialist did. Had I not been connected with the new specialist, I may not be here today. I get very emotional when I think about the time I lost with my children by not having the right treatment and medical care. Kids take energy, and I didn't have it. At one point, my daughter asked me if I knew how to run because she'd never seen me do it. That was heartbreaking. But every day, things are looking up.

Even though recovery from open heart surgery takes a long time, I am so much better than I was before. Do I still get tachycardia? Yes. Am I still fatigued? Yes. But I don't wake up sweating with a racing heart anymore, and I can play basketball with my kids. And, yes, I can even run. ■

Tests and genetics help diagnose HCM

The HCM conversation with your doctor can be started for many reasons. You may be having symptoms; your doctor may have heard a heart murmur during a physical exam or seen something abnormal during an electrocardiogram (EKG); or you may have just learned you have a family history of HCM. Regardless of what brings you to see your doctor, be aware that the amount of time needed to determine an HCM diagnosis may vary.

Symptoms linked to HCM may be caused by other conditions, such as high blood pressure or a narrowed aortic valve (aortic stenosis). Because of this, you will likely undergo a variety of tests as your doctor rules out other possible problems before making a diagnosis.

Most often a cardiologist will be the specialist to diagnose your condition. Ideally, that cardiologist will be an HCM specialist. If not, consider getting a second opinion from an HCM specialist or at a center known for treating HCM (see *Introduction*, page 3).

After reviewing your medical history, family medical history and your lifestyle habits, your doctor will begin the exams and testing needed to diagnose or rule out HCM.

PHYSICAL EXAMINATION

Your doctor will listen to your heart and lungs with a stethoscope. The loudness, timing and location of a heart murmur may point to HCM. A crackling sound in the lungs may be a sign of heart failure — when the heart cannot pump well enough to meet your body's demands (see *The Symptoms of Heart Failure,* page 4).

DIAGNOSTIC TESTS AND PROCEDURES

One or more of the following may be used to diagnose or monitor your condition.

Cardiac catheterization. This checks the pressure and blood flow in the chambers of your heart. Your doctor inserts a catheter (a thin, flexible tube) through a blood vessel into your heart. This allows the doctor to collect blood samples and check for heart blockages.

Cardiac computed tomography. This may be an option if an echocardiogram cannot confirm HCM and an MRI cannot be done, but your doctor continues to suspect HCM.

Cardiac magnetic resonance imaging (MRI). This special imaging technique may be used in the following instances:

- An echocardiogram cannot confirm the diagnosis.
- Extra information is needed about the amount and location of thickening or about the anatomy of the mitral valve.
- Placement of an implantable cardioverter defibrillator (ICD) is being considered.

Chest X-ray. This X-ray can show whether your heart is enlarged or fluid has built up in your lungs.

Coronary angiography. Dye is injected into your coronary arteries, which allows your doctor to view blood flow on an X-ray. This procedure is often done during cardiac catheterization.

Echocardiogram (echo). An echo is often key for diagnosis. It uses sound waves to create a picture of your heart in action. It can show how well your heart is working, including how blood flows from your heart. It also shows your heart's size and shape, as well as its muscle thickness.

Another type of echocardiogram called a transesophageal echo (TEE) is sometimes used. It provides a view of the back of your heart. It can also be used to assess your mitral valve and to monitor the results of surgery to lessen heart thickening (myectomy), if it has been performed.

Electrocardiogram (EKG). This test records your heart's electrical activity. It can show the rhythm of your heart and how fast it is beating. In addition, an EKG can detect a heart attack, heart failure and arrhythmias. To track problems that may come and go, your doctor may have you wear a portable EKG at home.

Event monitor. This portable device is a self-activated monitor that records your heart's electrical activity. You will wear the monitor until the number of recordings your doctor requests take place.

Genetic tests. These tests cannot predict whether you will develop symptoms or your long-term outlook, but they can show whether HCM runs in your family.

Holter monitor. This wearable device continuously records your heart's electrical signals for 24 to 48 hours to capture arrhythmias.

Myocardial biopsy. The doctor removes a bit of heart muscle to view under a microscope for signs of changes that suggest HCM. The biopsy may also be taken during cardiac catheterization.

Stress test. This test checks how your heart responds to stress while other tests are being done. You walk on a treadmill or take special medication to make your heart beat faster. Despite its name, a stress test is safe and can help your doctor know how much your condition is keeping you from being active.

This test may also include an echocardiogram, positron emission tomography (PET) or nuclear heart scan. A PET myocardial perfusion imaging scan, commonly known as a PET stress test or a Rubidium PET, shows how well blood flows to your heart's muscles while you are at rest and during stress. A nuclear heart scan involves injecting a radioactive substance into a vein then taking pictures of the blood flowing in and around the heart.

THE ROLE OF GENETICS IN HCM

You may wonder what you have or haven't done to get HCM. The answer is nothing. If you have HCM, it is likely that one of your parents has or had the condition. The most common cause is abnormal genes (mutations) that are inherited, or passed down, through families. This is known as familial hypertrophic cardiomyopathy.

Familial HCM is passed down in an autosomal dominant pattern. This means the mutated gene is on a non-sex chromosome. Only a single copy of this gene is needed in each cell to cause the disease. Rarely, you may have a mutation in both copies of the mutated gene. If that is the case, the signs and symptoms of HCM are more severe.

Certain genes give the body instructions to make proteins that play important roles in the contraction of the heart muscle, which is needed to pump blood to the rest of the body. Mutations of these genes are thought to lead to the abnormal structure or function of certain cell components within muscles called sarcomeres (SAR-kuh-meers) that allow the heart to contract (see *Glossary*, page 12). These abnormal or mutated genes in the heart muscle cause the walls of the heart chamber (left ventricle) to contract harder and become thicker than normal (hypertrophy). Changes in heart muscle fibers may happen even before the muscle thickens or symptoms show up.

Several mutations are known to be associated with HCM. The most commonly involved genes are *MYBPC3*, *MYH7*, *TNNI3* and *TNNT2*. A mutation in any of these genes can lead to HCM.

Genetic testing is performed using a sample of saliva or blood. Multi-gene panels are used to identify the presence of these and other known mutations. During testing, DNA is extracted from the blood to analyze 30 to 50 genes for the known mutations linked to HCM. Experts believe more research is needed to identify more mutations, so it is possible that your testing may not indicate HCM. However, it is important to keep your doctor aware of your condition for ongoing monitoring and testing.

A referral to a genetic counselor, either on staff or elsewhere, is highly encouraged. The genetic counselor can help you understand the often-complicated test results and what they mean for you and for your family members and their future health.

If results show that you have an HCM mutation, testing for that same mutation is recommended for your first-degree relatives (parents, children and siblings). By sharing this valuable information, you are giving them the opportunity to follow up with their doctors and take appropriate precautions. Many people do not realize they have HCM until something life-threatening or life-ending occurs, and knowing they may be at risk could potentially be lifesaving. ■

Finding cardiac conditions early

➥ ***In an effort to identify undiagnosed abnormal heart conditions in*** young people, comprehensive heart screening programs are becoming more widespread across the U.S. These screenings are not just for student athletes; rather, they are designed for any young person between the ages of 8 and 25 who has not already been identified as at-risk for HCM or other heart-related issues.

To reach the desired demographic, many programs are partnering with school districts and other organizations to offer mobile cardiac screenings to middle school, high school and college students. It is important to note, however, that one screening does not last a lifetime. As people age, certain conditions can develop, so follow-up screenings every couple of years until age 25 are recommended.

One such program, In A Heartbeat (inaheartbeat.org), was created by Mike Papale. At 17, he experienced sudden cardiac arrest (SCA). A nearby volunteer EMT's quick action prevented Mike from experiencing sudden cardiac death (SCD). Today, he lives a healthy life in spite of a hypertrophic cardiomyopathy (HCM) diagnosis, and he works hard to prevent others from having similar life-threatening situations by raising awareness about SCA and HCM, and promoting the importance of CPR and automated external defibrillators (AEDs).

"We hold cardiac screening programs for kids ages 8 to 22," Mike explained. "We have volunteers, including my pediatric cardiologist, and other medical personnel on site to read the EKGs. If a problem is detected, they sit down and talk about it with the parents. We also provide AEDs and emergency training to organizations. You can't prevent HCM, but with a little knowledge, you can manage it."

About HCM-related SCD

Sudden cardiac death (SCD) is caused by a cardiovascular condition. During periods of strenuous exertion and/or dehydration, the degree of obstruction to blood flow progresses and can prevent the heart from pumping blood to the rest of the body, including to the heart. It can cause the heart to stop, resulting in death.

In athletes under 35 years old, HCM is the leading cause of SCD. However, not all cases of SCD are caused by HCM, and most people with HCM are considered low risk for it. Learning about the risks for HCM-related SCD and the preventive measures can be lifesaving.

Telling your doctor whether any of the following apply to you may help prevent a serious episode or early death:

- A family history of SCD, such as a first-degree relative (a parent, sibling or child) with HCM
- Several episodes of fainting
- An abnormal blood pressure response with exercise
- A history of arrhythmia with a fast heart rate
- Severe HCM symptoms and poor heart function

Shared decision-making guides your HCM treatment plan

Partnering with your health care team is the key to developing a treatment plan that will enable you to live an active and enjoyable life while managing hypertrophic cardiomyopathy (HCM). Your treatment plan will address your HCM diagnosis as well as any conditions that contribute to it. The goal is to reduce symptoms, complications and the risk of sudden cardiac arrest (SCA).

Your doctor will begin by asking you about your lifestyle. It is important for you to be honest during this discussion because doctors generally classify patients' heart failure according to the severity of their self-reported symptoms. You are the only source of answers for these important questions:

- Employment: What type of work do you do? Is it physical? If so, do you hope to continue in that same capacity?
- Exercise: What physical activities do you enjoy? How often do you exercise? Do you have any breathing difficulties or chest pain while you exercise?
- Lifestyle: Do you use alcohol and/or tobacco products? How often?
- Medications: Do you take medication to control your cholesterol?
- Nutrition: Do you generally follow a healthy diet?

To classify your heart condition based on symptoms and limitations experienced during physical activity, including breathing difficulties and chest pain, your doctor will then consult the New York Heart Association (NYHA) Functional Classification System. This system uses four categories (see Table 1). In addition to influencing treatment decisions, the results are often an indicator of prognosis.

TREATMENT OPTIONS

Your treatment may include one or more strategies. Keep in mind that the strategy may change as your condition changes. Follow-up appointments and keeping the lines of communication open with your health care team will help you stay alert to any indications that a change in treatment is necessary.

Medication is generally the first line of treatment to help relieve and control HCM symptoms (see Table 2, page 9). Ensure your doctor and your pharmacist are aware of any medications (over-the-counter and prescription) you currently take for other conditions. It is possible those medications may interact with new ones and could pose an additional risk to you.

Before beginning a new HCM medication, ask about potential side effects and what to do if a side effect occurs. You will feel more confident when you have a plan in place.

Many HCM medications are oral (pills). Because you are responsible for taking them as opposed to going to your doctor's office for a treatment, it is important that you are educated about medication adherence. For them to be fully effective, you must take them exactly as your doctor instructs. Most therapies are designed to maintain a specific level of drugs in your system for a certain time based on your condition, your overall health, previous therapies and other factors. If your medications are not taken exactly as prescribed, the consequences can be serious — even life-threatening.

Depending on the number of medications you take daily, staying on schedule can be confusing. You are encouraged to use tools that can help. Make a daily medication schedule that allows you to note the time, the dosage and any side effects that you experience. Sharing these details allows your doctor to manage and monitor these side effects. Download a free symptom tracker at Heart.PatientResource.com/HCMSymptomTracker. These suggestions may also help.

- **Talk with your pharmacist.** Pharmacists are an underused resource, but they are skilled in counseling patients on the safe and appropriate use and storage of their medications. Your pharmacist is an excellent source for helping you understand new medications and potential interactions, especially if you already have multiple prescriptions for other conditions.
- **Report missed doses.** Alert your doctor about any changes in the schedule. If you miss a dose, tell your health care team so they can advise you whether to take a dose immediately or wait until your next scheduled dose. Do not make changes to your treatment regimen without being told to do so by your doctor.
- **Use reminders.** Life gets busy, and it is easy to forget to take your medications. You have many options: alarms, phone reminders, a weekly pillbox, calendars, sticky notes or smartphone apps.

Surgery is often recommended when medication does not offer enough relief. Depending on your unique situation, your doctor may recommend one or more of the following procedures.

Maze is a type of open-heart surgery designed to treat atrial fibrillation (AFIB). It creates scar tissue that traps the electrical signals that cause AFIB. It is most commonly performed when another open-heart procedure is taking place.

TABLE 1

NEW YORK HEART ASSOCIATION (NYHA) FUNCTIONAL CLASSIFICATION SYSTEM

Class Type	Description
Class I	No limitation of physical activity. Ordinary physical activity does not cause symptoms of heart failure.
Class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in symptoms of heart failure.
Class III	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes symptoms of heart failure.
Class IV	Symptoms occur even at rest; discomfort with any physical activity. Unable to carry on any physical activity without symptoms of heart failure.

Mitral valve repair or *replacement* can be performed to repair a faulty mitral valve or replace it with a mechanical or biological tissue valve.

Septal myectomy is a type of open-heart surgery designed to reduce muscle thickening. It is generally reserved for younger patients. During this procedure, the surgeon removes part of the thickened septum to improve blood flow within the heart and out to the body.

An implantable device may be part of your treatment plan and may include one of the following:

- A cardiac resynchronization therapy (CRT) device coordinates contractions between the left and right ventricles of the heart.
- An implantable cardioverter defibrillator (ICD) is a small electronic device that helps maintain a normal heartbeat by sending an electric shock to the heart if an irregular heartbeat is detected. This reduces the risk of sudden cardiac death (SCD). This device is inserted under the skin like a pacemaker and is designed to deliver a small shock to the heart in the event that you suffer a life-threatening heart rhythm problem.
- A pacemaker is a small, implanted device that uses electrical pulses to prompt the heart to beat at a normal rate.

Heart transplant replaces a person's diseased heart with a healthy donor heart. It may be considered at end-stage disease.

Non-surgical procedures include types of ablation. Ablation is the removal or destruction of a body part or tissue or its function. It typically offers an easier recovery than a surgical procedure and may reduce or help control symptoms. Your doctor may choose one of the following:

Alcohol septal ablation is a percutaneous (through the skin) procedure that involves injecting alcohol into a blood vessel in the ventricular septum. This causes some of the heart muscle cells to die, making the septum thinner.

Catheter ablation to treat arrhythmias involves accessing the heart using a catheter (a thin, flexible tube) to destroy tissue around the heart to block arrhythmia-causing electrical signals. This procedure may be performed by radiofrequency ablation using low voltage, high frequency electricity or by cryoablation, which uses extreme cold.

Pulmonary vein isolation (PVI) is designed to treat atrial fibrillation (AFIB) by creating scar tissue that limits or blocks the abnormal signals that cause AFIB.

Clinical trials may be an option to discuss with your doctor about your treatment plan or for a family member to consider. Clinical trials are research studies that test a new medical approach, including new drugs, drug combinations, medical procedures or devices that help diagnose and treat HCM. They also explore methods to improve patient screening, new diagnostic tools, ways to prevent and manage side effects, and lifestyle changes that may improve the health of a person who has HCM.

By participating, you are contributing to how HCM is diagnosed, treated and hopefully, one day, cured. Recent studies have shown that the quality of research increases when the volunteers come from diverse groups because different life experiences add valuable perspectives to these projects.

The ultimate goal is to help anyone facing HCM enjoy longer, more fulfilling lives. Ask your doctor whether a clinical trial may fit into your treatment plan. ■

TABLE 2

TYPES OF COMMONLY USED HCM MEDICATIONS

Type of Medication	Goal
Antiarrhythmics	Help the heart beat normally by blocking irregular electrical activity and rhythms caused by the thickening of the heart's walls.
Beta blockers	Reduce the heart rate and reduce blood pressure by dilating blood vessels. They can also prevent further heart attacks and death after a heart attack.
Blood thinners (anticoagulants)	Prevent the formation of blood clots.
Calcium channel blockers (CCBs)	Lower blood pressure and slow the heart rate. CCBs dilate the arteries, reducing pressure within the heart and making it easier for it to pump blood. As a result, the heart needs less oxygen.
Cardiac myosin inhibitor*	Improves functional capacity and symptoms of NYHA Class II-III symptomatic obstructive HCM by helping the heart beat less forcefully.
Cholesterol-lowering medications	Designed to regulate cholesterol and can complement the dietary changes that are recommended.
Corticosteroids	Reduce inflammation.
Diuretics	Remove excess fluid and sodium from the body.
Sodium channel blockers	Inhibit the movement of sodium into cells; may be used with beta blockers to reduce symptoms.

**mavacamten (Camzyos) is FDA-approved and indicated for symptomatic obstructive HCM*

» Meet Your Health Care Team

Ideally, you will work with a highly skilled multidisciplinary team that includes these and other professionals:

Cardiac surgeon: a heart surgeon who specializes in the surgical care of conditions and diseases of the heart and blood vessels

Cardiologist: a doctor who has special training to diagnose and treat diseases of the heart and blood vessels

Electrophysiologist: a cardiologist who specializes in irregular heart rhythms, also known as arrhythmias

Genetic counselor: a licensed professional who can explain the genetic conditions that may have contributed to your HCM diagnosis and how these test results may affect your family members

HCM specialist: a cardiologist with experience treating HCM

Internist: a doctor who has special training in internal medicine and works with adult patients to prevent, diagnose and treat diseases without using surgery

Nurse practitioner: a registered nurse who has additional education and training in how to diagnose and treat disease

Nutritionist: a specialist who helps people form healthy eating habits to improve health and prevent disease through nutritional counseling, meal planning and nutrition education programs

Physiatrist: a doctor who has special training in physical medicine and can help develop an exercise plan for you

Psychologist or therapist: a specialist who can talk with patients and their families about the emotions that accompany an HCM diagnosis

Prepare for a fulfilling life after an HCM diagnosis

Learning you have a life-long genetic condition like HCM can feel overwhelming, but you can take steps to reduce your risk of future heart-related issues by empowering yourself to make good lifestyle choices. It may help to think of managing HCM like other chronic conditions, such as diabetes or asthma. With the help of your medical team, treating and managing HCM is possible.

GETTING A SECOND OPINION

Knowledge is power, and learning as much as you can about HCM may help you feel more confident moving forward. This may include getting a second or third opinion to confirm the diagnosis and potential treatment options. Another doctor's opinion may change the diagnosis or reveal a treatment your first doctor was not aware of. And, this is the perfect time to seek out a doctor who specializes in HCM and who may have access to leading-edge therapies.

Other opinions are valuable because doctors bring different training and experience to treatment planning. Some may favor one treatment approach, while others might suggest a different combination of treatments.

A second opinion is also a way to make sure your pathology diagnosis is accurate. You need to hear all the facts about your treatment options. There is often collective wisdom gained from the experience and opinions of different specialists who are experts in HCM.

Finding these experts is not always easy, and you may worry that you will offend or hurt your doctor's feelings if you seek the advice of another expert. Do not permit yourself to feel uncomfortable or disloyal by seeking another opinion. Most doctors welcome a second opinion and will recommend another physician or hospital. Above all, the goal is for you to have the best care available.

Before meeting with another medical professional for a second opinion, make sure medical records related to your condition are available. This may include laboratory, biopsy or imaging test results as well as any other tests or procedures. It may be helpful to call the doctor's office to find out whether any information needs to be sent ahead of the appointment.

SURROUND YOURSELF WITH SUPPORT

Finding out you have a genetic heart condition can lead to a range of emotions. Facing HCM is easier when you have support. You can start with your built-in support system, which includes your family, friends, neighbors and coworkers.

Connect with a local or national HCM advocacy group or join an HCM support group. Many offer peer-to-peer support through programs that match you with a person who has had a similar diagnosis. Talking with someone who knows what you are going through is extremely helpful. Use the resources in the back of this guide to get started, and ask your medical team for more resources.

Keep in mind that you are also part of your support team. Feeling good about the decisions you make can be uplifting. Supporting yourself can include adopting a healthy lifestyle. And though you may feel as if many parts of your life are out of your control, you can – for the most part – choose the foods you eat, the exercise you take part in and the activities that give you joy.

Follow a nutritious diet. Maintaining a healthy weight is important. Make sure to eat the essential nutrients, including carbohydrates, fats and protein. If following a healthy diet is a challenge, consider meeting with a registered dietitian who can recommend foods to eat to reduce symptoms and help you feel better. Discuss your concerns and create a nutrition plan together. If a dietitian is not on your health care team, ask for a referral.

In general, try to consume a wide variety of healthy foods and drink plenty of liquids. The following recommendations may also be helpful:

- Avoid saturated and trans fats. Choose lean meats, such as chicken and fish.
- Reduce salt (sodium) intake.
- Stay hydrated.
- Limit added sugars in foods and drinks.
- Include foods high in fiber, such as beans.
- Lower or eliminate alcohol consumption.
- Cook your own meals rather than eating prepared or processed foods.
- Do not fry foods or cook items in butter. Instead, boil, steam, roast, broil, bake or sauté your food.

Take part in physical activity. Discuss the topic of exercise with your doctor. It may

If your HCM is stable, pregnancy is generally safe. Talk with your doctor before becoming pregnant, if possible, to evaluate your ability to tolerate pregnancy and what risks to consider so you can move forward safely and confidently. This is known as preconception counseling. Your doctor can recommend precautions to take, such as the following:

- Seek out reproductive and genetic counseling — before and during pregnancy
- Coordinate care with your cardiologist and obstetrician
- Consult with an expert in maternal-fetal medicine if you are at high risk
- Take medications to lower the risk of stroke or symptoms related to an arrhythmia
- Deliver vaginally, if possible
- Discuss general or epidural anesthesia during delivery
- Understand the risks that a child might inherit the genetic mutation for HCM

feel concerning to begin an exercise regimen after discovering you have HCM. This diagnosis does not mean you have to stop all activity. Completely stopping exercise may do more harm than good.

Your doctor can tell you how to limit or modify your activity level. Moderate exercise can improve cardiorespiratory fitness and physical functioning, and decrease the risks of heart attack, stroke and heart failure. In general, mild to moderate recreational exercise is helpful for overall health and can boost your mood and provide other benefits.

Pay attention to your sexual health. It is an important part of life. Your treatments may have physical or emotional side effects that affect your desire, confidence or physical ability. Talk with your doctor about ways to maintain your sexual health, or ask for a referral to a therapist who has experience working with people who have HCM.

TAKE CARE OF YOUR EMOTIONAL WELL-BEING

An HCM diagnosis affects more than just your body. It also affects you emotionally. It is important to know that you may face the following feelings after you learn about your HCM diagnosis.

Anxiety can begin as soon as you receive your diagnosis. Moderate to severe anxiety is often treated with medication, therapy or a combination of both. Explore relaxation techniques, such as meditation, muscle relaxation, yoga or guided imagery.

Depression is a psychological reaction to your situation as a whole. Don't avoid talking to your doctor about it because you think depression is just part of having HCM. If you feel hopeless, helpless or numb for more than a few days or if you have thoughts of death or of attempting suicide, seek medical attention immediately.

Doubt can lead to confusion and questions about the meaning of life and its purpose. Some people find strength in support from family, friends, the community or spirituality. It may also help to open up to a counselor or support group.

Fear is common. Making plans may become difficult because every ache and pain triggers a concern. Do your best to stay focused on the present and stick to your treatment plan.

Guilt may occur if you feel you've been a burden to loved ones. Talk with a therapist about these feelings.

Scanxiety describes the anxiety that can happen when you are awaiting results from imaging scans or laboratory tests. It is normal to feel this way. It may help to set up expectations with your medical team so you can know when to expect results instead of being left waiting and wondering. Keep your mind occupied with things you enjoy. Staying busy gives you less time to worry. Try to calm your nerves with meditation or other relaxation exercises.

Activities you enjoy can help you manage the emotional side effects of your HCM diagnosis. Read a book, watch a movie, take a walk or get a massage. Make time to do whatever puts you in your happy place. Having a positive mindset can benefit both your mind and your body.

THE NEED FOR CARDIAC REHABILITATION

Maintaining or improving your cardiovascular health could be part of your care regardless of whether you have had a cardiac event or are at risk for one. Your doctor may suggest cardiac rehabilitation to help you recover some of your heart health after having a heart-related issue, such as a heart attack, heart failure, heart surgery or heart complications from atrial fibrillation (AFIB). It may also be used to prevent a recurrence.

You will be guided by a cardiac rehabilitation team that may include doctors, nurses, nutritionists and exercise specialists. They will consider your level of HCM, your risk for sudden cardiac death (SCD), the severity of your symptoms and your baseline physical fitness. ■

Long-term considerations

► **Keep follow-up appointments.** They help your doctor determine how your HCM is responding to treatment and lifestyle changes, and identify any signs of progression. These visits also give you an opportunity to address any new symptoms or concerns. Types of information to share include the following:

- New or ongoing physical symptoms that are not adequately relieved, including pain, nausea and vomiting, signs of infection and dizziness.
- Cognitive (thinking-related) symptoms, such as difficulties with memory, concentration, processing information, word-finding or completing tasks.
- Emotional issues, such as depression, anxiety, fear, anger, grief, hopelessness, emotional numbness, feeling overwhelmed or other concerns.
- Visits to the emergency room, urgent care or other doctors, even if not HCM-related.

► **Take medications as prescribed.** It is vital that you take your medications on time, every time (see *Treatment Planning*, page 8). Never stop taking a medication without talking to your doctor. If side effects are problematic, check with your health care team to see what can be done to make you feel better. Another medication may be available. Know that your doctor may need to fine-tune the doses of your medications over time.

► **Be aware of other health conditions.** People with HCM often have other conditions, such as high blood pressure, obesity, cardiovascular disease or sleep apnea. These may also increase symptoms. It is important to manage these and any other underlying conditions. Your doctor will monitor you and recommend how to prevent and treat them.

► **Understand possible job limitations or restrictions.** If you have a job that requires manual labor, heavy lifting or lots of physical stamina, you may need to consider making modifications. Thoroughly evaluate the situation and talk with your doctor.

► **Prevent infections.** Ask your doctor what vaccinations are recommended for you. People with HCM are at an increased risk of infection and complications, and they are encouraged to get all of their appropriate vaccinations.

Support and financial resources available for you

CAREGIVERS AND SUPPORT

ACHA Wellness Wednesdays..... www.achaheart.org/your-heart/webinars, 888-321-2242
American Heart Association Support Network..... www.supportnetwork.heart.org
American Transplant Foundation 1+1=Life Mentorship Program..... www.americantransplantfoundation.org/programs/mentorship-program-2
Caregiver Action Network..... www.caregiveraction.org, 855-227-3640
CaringBridge..... www.caringbridge.org, 651-789-2300
Chai Lifeline..... www.chailifeline.org, 877-242-4543
Family Caregiver Alliance..... www.caregiver.org, 800-444-8106
The Heart2Heart Foundation..... www.theheart2heartfoundation.org, 800-805-1421
Heart to Heart Peer Mentors..... www.achaheart.org/your-heart/programs/heart-to-heart, 888-921-2242
HeartSistersOnline..... www.womenheart.org/find-support/heartsisters, 202-728-7199
Hypertrophic Cardiomyopathy Association Support Groups..... www.4hcm.org/patient-discussion-groups, 973-983-7429
In A Heartbeat Foundation..... www.inaheartbeat.org, 203-980-3599
Mended Hearts Support Groups..... www.mendedhearts.org/connect, 229-518-2680
MyHeartVisit..... myheartvisit.org, 844-432-7887
National Council on Aging..... www.ncoa.org
National Transitions of Care Coalition..... ntocc.org/consumers
Share Your Heart..... www.shareyourheart.live, 888-432-7899
SisterMatch by WomenHeart..... www.womenheart.org/find-support/sistermatch, 202-728-7199
Smart Patients Heart Transplant Community..... www.smartpatients.com
Sudden Cardiac Arrest Foundation..... www.sca-aware.org
UNOS Transplant Support Groups..... www.unos.org
Well Spouse Association..... www.wellspouse.org, 732-577-8899

CLINICAL TRIALS

Center for Information & Study on Clinical Research Participation..... www.searchclinicaltrials.org
ClinicalTrials.gov..... www.clinicaltrials.gov
National Heart, Lung, and Blood Institute..... www.nhlbi.nih.gov/health-topics/clinical-trials, 877-645-2448

HEART HEALTH RESOURCES

Adult Congenital Heart Association..... www.achaheart.org, 888-921-2242
American Heart Association..... www.heart.org/cardiomyopathy, 800-848-8721
CardioSmart American College of Cardiology..... www.cardiosmart.org/topics/hypertrophic-cardiomyopathy, 800-253-4636, ext. 5603
DCM Foundation..... www.dcmfoundation.org, 833-326-4673
Heart Failure Society of America..... www.hfsa.org, 301-312-8635
HFSA Patient Webinar Series..... www.hfsa.org/patient-hub/patient-webinar-series, 301-312-8635
Hypertrophic Cardiomyopathy Association..... www.4hcm.org, 973-983-7429
National Heart, Lung, and Blood Institute..... www.nhlbi.nih.gov, 877-645-2448
UpBeat, Heart Rhythm Society..... www.upbeat.org

MEDICAL CARE AND LIVING EXPENSES

Help Hope Live..... www.helphopelive.org, 800-642-8399
National Council on Aging Benefits CheckUp..... www.benefitscheckup.org
National Foundation for Transplants..... www.transplants.org, 800-489-3863
NeedyMeds..... www.needymeds.org, 800-503-6897
NeedyMeds Drug Discount Card..... www.needymeds.org/drug-discount-card, 800-503-6897
Patient Advocate Foundation..... www.copays.org/funds/heart-failure, 866-512-3861
Patient Assistance for Lab Services (PALS)..... www.pals-labs.org, 844-770-7257
United Disabilities Services Foundation..... www.udservices.org, 888-837-4235
WISEWOMAN Screening and Evaluation..... www.cdc.gov/wisewoman, 800-232-4636

MENTAL HEALTH RESOURCES

American Heart Association..... www.heart.org/en/healthy-living/healthy-lifestyle/mental-health-and-wellbeing/mental-health-and-heart-health, 800-242-8721
American Psychological Association..... www.apa.org/topics/chronic-illness/heart-disease, 800-374-2721
Mental Health America..... www.mhanational.org/depression-and-heart-disease, 800-969-6642
National Institute of Mental Health..... www.nimh.nih.gov/health/find-help, 866-415-8051

NUTRITION, SMOKING CESSATION AND HEALTHY LIVING

American Heart Association..... www.heart.org/en/healthy-living/healthy-eating, 800-242-8721
CardioSmart American College of Cardiology..... www.cardiosmart.org/topics/healthy-living, 800-253-4636, ext. 5604
CDC How to Quit Smoking..... www.cdc.gov/quit, 800-784-8669
CDC Quitline..... 800-784-8669
DCM Foundation..... www.dcmfoundation.org/diet-and-nutrition, 833-326-4673
Food and Nutrition Service Nutrition Programs..... www.fns.usda.gov/programs, 707-305-2062
The Heart2Heart Foundation..... www.theheart2heartfoundation.org, 800-805-1421
Nutrition.gov..... www.nutrition.gov
Smokefree.gov..... smokefree.gov
SmokefreeTXT..... smokefree.gov/smokefree

PATIENT ASSISTANCE AND REIMBURSEMENT

American Transplant Foundation..... www.americantransplantfoundation.org/programs/pap
Bristol Myers Squibb Patient Assistance Foundation..... bmspaf.org, 800-736-0003
Could it be HCM?..... www.CouldItBeHCM.com
Hypertrophic Cardiomyopathy Association..... www.4hcm.org, 973-983-7429
Medtronic Implantable Cardioverter Defibrillator Reimbursement..... www.medtronic.com/us-en/patients/patient-services.html, 866-877-4102
MyCAMZYOS Patient Support..... www.camzyos.com/patient-support, 855-226-9967

➥ *For links to resources, go to* Heart.PatientResource.com

GLOSSARY Words to Know

These definitions may help as you discuss your diagnosis and disease management plan with your health care team.

- **Antiarrhythmics:** medications that help control irregular heart rhythms
- **Atrial fibrillation (AFIB):** an arrhythmia (a type of irregular heartbeat)
- **Automated external defibrillator (AED):** a medical device that can analyze the heart's rhythm and, if necessary, deliver an electrical shock, or defibrillation, to help the heart re-establish an effective rhythm
- **Beta blockers:** drugs that make your heart beat slower and with less force
- **Bradycardia:** a heart rate slower than 60 beats per minute
- **Cardiopulmonary resuscitation (CPR):** an emergency lifesaving procedure performed when the heart stops beating
- **Coronary artery disease:** narrowing of the coronary arteries that supply oxygen and nutrients to the heart
- **Endocardium:** the innermost layer of the heart
- **Epicardium:** the thin layer on the surface of the heart
- **Hypertrophy:** a condition in which muscle cells become larger, and so the muscle itself increases in size
- **Internal cardioverter defibrillator (ICD):** an implanted device that can track the heart rate and shock the heart into a normal rhythm if it is too slow or abnormal
- **Myocardium:** the heart muscle and thickest layer of the heart
- **Sarcomere:** long, fibrous proteins in muscle tissue that slide past each other when a muscle contracts or relaxes
- **Scanxiety:** a term used to describe the anxious feelings that arise in the time leading up to an imaging scan, during the scan, and while waiting for results
- **Sudden cardiac arrest (SCA):** when the heart stops beating suddenly due to an electrical malfunction
- **Syncope:** fainting, which is the temporary and sudden loss of consciousness
- **Tachycardia:** a heart rate of more than 100 beats per minute

Join the Community

Education • Advocacy • Support

The Hypertrophic Cardiomyopathy Association is the preeminent organization improving the lives of those with Hypertrophic Cardiomyopathy, (HCM), preventing untimely deaths and advancing global understanding. Founded in 1996, we are committed to providing support, education, advocacy, advancing research, understanding, and care to those with HCM.

Centers of Excellence (COE)

HCMA Recognized Centers of Excellence programs provide multidisciplinary care for HCM.

Navigation Calls & Peer-to-Peer Support

The HCMA provides education and support to assist you in understanding your diagnosis.

Patient Education

The HCMA brings together thought leaders in patient care and advocacy with free monthly webinars and weekly podcasts. Patients can find more information about these resources on our social media pages and our website.

Online Discussion Groups

The HCMA holds online patient discussion groups to give members of our community easy access to peer support resources, right from the comfort of their own home.

HCM Academy

HCM Academy is a free digital CME initiative developed with renowned HCM specialists for physicians, aiming to improve HCM patient outcomes.

The Lori Fund

The HCMA Lori Fund provides micro travel grants to HCM patients traveling to an HCMA Recognized Center of Excellence for care.

@4hcm.org

@Hypertrophic Cardiomyopathy Association

@4hcmwarriors

To learn more visit : 4hcm.org

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