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GETTY IMAGES

THE LATEST ON

OBSTRUCTIVE HYPERTROPHIC CARDIOMYOPATHY

OBLIVIOUS TO OHCM?

Do you have a diagnosis of obstructive hypertrophic cardiomyopathy (OHCM)? Many people with the condition don't even know they have it, a new study shows. Researchers looked at rates of OHCM diagnoses from 2016 to 2018 and found that the numbers were stagnant. Across genders, races, and age groups, the number of individuals with OHCM didn't go up much over the 3 years. That doesn't mean people don't get the condition anymore. It means they aren't being diagnosed.

SOURCE: Frontiers in Cardiovascular Medicine

\$20,290

The estimated total annual disease-related health care costs for a

SOURCE: American Heart Journal Plus: Cardiology Research and Practice

Amount of people diagnosed with HCM who have OHCM.

SOURCE: American Heart Association

GOODBYE ATYPICAL GENES

What if scientists could rewrite DNA so that it didn't contain the abnormal genes in the heart muscle that most often cause hypertrophic cardiomyopathy? It's not science fiction. It could happen one day. Researchers are exploring the use of CRISPR/Cas9 to edit the DNA of embryos so that it doesn't contain this disease-causing gene. While not without its challenges, the early-stage research is showing promise so far.

SOURCE: European Journal of Heart Failure



GET MOVING

For the longest time, doctors weren't sure just how safe exercise was for people with hypertrophic cardiomyopathy (HCM) and whether they should recommend it. They'd play it safe and advise patients to stick with low-intensity activity, like tai chi or an easy stroll. That's changed now. Based on more than a decade of research, brand-new guidelines recommend 150 minutes of moderate-intensity physical activity, such as hiking or doubles tennis, every week for most people with HCM. Doctors only ask that you go at a pace that feels comfortable to you and don't push yourself if your symptoms are holding you back.

IF YOU'VE HIT A WALL WITH SYMPTOMATIC OBSTRUCTIVE

HCM, TODAY YOU MAY HAVE AN OPENING WITH A DIFFERENT TREATMENT OPTION



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.



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 ochest pain ofatigue oa racing sensation in your heart (palpitations) o 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

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.

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

- 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.



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STATS & FACTS

By Sonya Collins

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

1 in 500

Amount of people who have hypertrophic cardiomyopathy (HCM). Most have the obstructive type. 39

Average age at which a person with HCM gets a diagnosis.



1N4



Amount of people diagnosed with obstructive hypertrophic cardiomyopathy who have a hospital stay within a year of diagnosis.

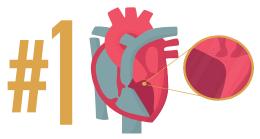
6 N 10

Amount of people diagnosed with HCM who are men.

Average number of doctor visits a person diagnosed with obstructive hypertrophic cardiomyopathy has in the first year of their diagnosis.



Amount of people diagnosed with obstructive hypertrophic cardiomyopathy who visit an emergency room within a year of their diagnosis.



Hypertrophic cardiomyopathy's rank among the most common genetic heart diseases.



Most often the number of parents you have with HCM when you have HCM.

SOURCES: American Heart Association, American Heart Journal Plus: Cardiology Research and Practice, National Library of Medicine, Journal of the American Heart Association, Hypertrophic Cardiomyopathy Association

UNDERSTANDING OBSTRUCTIVE HYPERTROPHIC CARDIOMYOPATHY

KNOW YOUR CONDITION

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Hypertrophic cardiomyopathy (HCM) is a heart condition that means your heart muscle around the main chamber of your heart [left ventricle] is thicker than normal. Heart muscle is called myocardium. The ending "pathy" in medicine tells you there is disease or a disorder. Cardiomyopathy is disease of the heart muscle. Hypertrophy means excessive growth.

HCM is common—about 1 in every 500 people have a diagnosis. Many more may have it and not know, because it doesn't often cause symptoms.

HCM becomes obstructive hypertrophic cardiomy opathy (OHCM) when the heart muscle grows thick enough that it blocks blood from being pumped into your body. Two-thirds of people with HCM have OHCM.

"It's almost like trying to squeeze a tube of toothpaste with all your might when the tube is tight at the very top—when the muscle squeezes, it squeezes everywhere and it actually obstructs its own outflow," says Andrew Freeman, MD, director of clinical cardiology and director of cardiovascular prevention and wellness at National Jewish Health in Denver.

WHO GETS IT

You get HCM because of abnormal genes. You can inherit this abnormal gene from a parent. Many people don't have signs or symptoms of OHCM until later in life, so knowing it runs in your family is a clue to be on the lookout.

"The disease has something called variable penetrance, which means even if you have the genes, it may not show up right away," Freeman says. "We typically recommend screening for first-degree relatives every 5 years or so, because people can develop it pretty late in life, like middle age."

Your doctor will typically use a test called an echocardiogram (echo) as well as other tests to screen you. An echo is an ultrasound of your heart. Your doctor might take this echo while you're exercising.

COMPLICATIONS AND OUTLOOK

If your OHCM causes symptoms such as dizziness or shortness of breath, it's usually from the blockage of blood flow. But you can develop other issues like an arrhythmia, which is an irregular heartbeat.

"The heart muscle gets so thick that the electrical signals inside of it aren't handled properly," Freeman says. This puts you at risk for improper blood flow to the rest of the body. If it happens for long enough, it can even cause sudden cardiac death.

But regular screenings aid in prevention and treatments have made big strides in helping people with OHCM live longer and better.

"There are new drugs out now that can significantly help with managing the disease that never existed before," he says. "It used to be a surgical disease, basically, that would require an enormous amount of intervention. And now it's possible to take care of this disease with medication, at least for the short term."



OBSTRUCTIVE HYPERTROPHIC CARDIOMYOPATHY



By Vi Tang

Reviewed by Brunilda Nazario, MD, Chief Physician Editor, Medical Affairs

When I was 15 and living in Vietnam, I was at the pediatrician for a cold when the doctor heard something odd about my heartbeat. She listened with her stethoscope for a long time. She thought it might be a heart murmur, but thought I needed more tests. I left with an appointment to see a cardiologist and an order for an echocardiogram.

Because of how the Vietnam health care system works, my appointment was the next day. In less than 24 hours, I had an echo and got a diagnosis of hypertrophic cardiomyopathy. While it was amazing to find out the issue that quickly, my doctors didn't provide

much information about the condition itself. They started me on a beta blocker and told me to come back for follow-up visits every few months.

Things were fine for a while. After all, I hadn't been having symptoms before my diagnosis. At age 18, I moved to the U.S. and started college. Two years into my studies, I was sitting in class about to take an exam when my heart rate suddenly skyrocketed. I nearly blacked out for a few seconds. It wasn't enough to make me lose consciousness—I was still aware of my surroundings—I just couldn't see anything. And then just as quickly as it

came on, it went away.

I took the exam and went to the school clinic, and after hearing I had a heart condition, they sent me to a local urgent care. The doctor there recommended I go straight to the emergency room because she suspected I had had an arrhythmia—an irregular heartbeat that could be fatal. The emergency room doctors agreed, but they also told me even if I [had not had an arrhythmia], the thickness of my heart's septum alone qualified me for an implantable cardioverter-defibrillator (ICD). They admitted me, and two days later, the ICD was in.





The recovery was mild-I couldn't lift my arm or shoulder up for about 6 weeks and the pain was minimal. It was during that time that I started being more open about my condition. Everyone was very supportive. That same year I started a summer research internship at the University of Michigan in an HCM lab. I also began receiving care at the school's cardiovascular center. They knew a lot about HCM treatment and what to look for.

Soon I moved permanently to Michigan, and around the same time started having more symptoms. I got out of breath more easily walking up stairs, for example. Sometimes it was hard just to walk to class. I went in for an echo and they found that I had severe obstructions caused by OHCM. My cardiologist had told me 3 years earlier I might need a myectomy for obstructive hypertrophic cardiomyopathy within the next 10 years, but after that echo she said the time was now.

Open heart surgery sounds scary, but my recovery was quick. I was able to get up and move to a chair about an hour after I woke up from anesthesia. Three days after surgery, I was

discharged. I went for a walk outside and could already feel a difference. I still had some shortness of breath, but it felt different. There wasn't the same pounding in my chest anymore. I was able to be back at work after a month. Looking back, I think it was hard to recognize I was in decline. Sometimes you don't realize how bad things are until you get the surgery. After the surgery, I started exercising more regularly and felt much better. Now I would say my health is near excellent. I like to cycle, and I've even hiked up mountains and run a 5K-things I never thought I could do before.

KNOWING THE SIGNS MANAGING OHCM

RECOGNIZING AND MANAGING YOUR DISEASE

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Hypertrophic cardiomyopathy (HCM) means your heart muscles around the main chamber of the heart are thicker than normal. You may not notice any symptoms until the condition gets in the way of blood flow out of your heart. However, obstructive hypertrophic cardiomyopathy (OHCM) can cause a range of symptoms.

It's rare, but OHCM can cause life-threatening heart rhythms and sudden death. You can lower your chances of this by knowing what your risk is and finding and treating the condition early.

WHAT TO WATCH FOR

If a first-degree relative of yours has HCM, doctors recommend you get an echocardiogram once every 5 years to screen for the condition. You can also have genetic testing to learn if you have the variant that would cause HCM. With this early identification, your doctor will know better how to treat you and monitor other family members.

"You've got a 50/50 chance of having the illness if one of your parents have had



it," says William W. O'Neill, MD, director of the Henry Ford Health Center for Structural Heart Disease in Detroit. "But it's important not to screen too early, because the disease itself doesn't manifest itself until later in teenage years."

Most often, people with OHCM start having symptoms in their 50s, 60s, or 70s. Usually it starts with shortness of breath. "People often say, 'You know, a year ago I could climb a flight of stairs, and now I can't,' and that means it's becoming symptomatic and something should be done," O'Neill says.



You may also notice you're lightheaded more often when you stand up quickly or when you exert yourself. You may even faint.

"You could pass out for a number of reasons," says Fawwaz I. Hamati, MD, a cardiologist in Johnson City, TN. "Your heart might be pumping so hard that very little blood is getting out because of the obstruction, or you could have a big significant arrhythmia."

Arrhythmias are abnormal heart patterns that happen when the electrical signals in your heart malfunction. Thick muscle can make these

signals go awry and cause a fluttery feeling in your chest.

LIFESTYLE MANAGEMENT

HCM is chronic, meaning you always have it. It can get worse over time, depending on how you manage it. One simple thing you can do, O'Neill says, is to drink plenty of water every day.

"If you're dehydrated, then the heart sort of shrinks in size and the obstruction gets worse," he says. Getting enough water is important especially if you're outside in warm weather and exercising, since you're losing even

more water to sweat. If you replenish your fluids, you can help keep symptoms at bay.

As for exercise, the key is moderation. Exercise is good for your heart because it helps strengthen the muscle and improves your circulation. But if you overdo it, you can bring on OHCM symptoms. And it may not take much to "overdo." Because a thick heart muscle may already be blocking blood flow to the body, the body's normal response to exercise can make the blockage and blood flow to the body worse.



TIPS FOR LIVING WELL

- + LEARN ABOUT IT
- + LISTEN TO YOUR BODY
- + HAVE HOPE

This goes for isometric exercises such as weight lifting, and also cardio-heavy workouts such as running.

"Both of those cause a marked increase in the stimulus of the heart muscle to thicken," O'Neill says. "It's fine to do a mild aerobic exercise, but don't make it intense."

Other good practices to follow:

- · Avoid extreme hot and cold temperatures.
- Watch for infection, including gum infection.
- · Ask your doctor for guidance on healthy levels of caffeine or alcohol.
- · Avoid diet pills or over-the-counter cold medications.

Most of all, keep tabs on your day-to-day wellness and let your doctor know any time you notice a difference in your ability to do regular activities.

"If you can't climb a flight of stairs without getting short of breath, then you should seek some help," O'Neill says.



TAKE THE FIRST STEP

LIFESTYLE CHANGES YOU CAN MAKE EVEN WHEN SYMPTOMS DO NOT EXIST

By Kendall K. Morgan

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, **Medical Affairs**

When you have obstructive hypertrophic cardiomyopathy (OHCM), the muscular wall that separates your heart's two bottom chambers is thicker than it should be. In about 2 in every 3 cases, this abnormally thick wall partially blocks blood from flowing out of your heart. While you may not notice any symptoms and since genes are the main cause of OHCM, lifestyle changes can help keep any symptoms at bay.

"There are clearly nongenetic lifestyle factors that influence and are causal for the disease," says Sharlene M. Day, MD, a genetic cardiologist at Penn Medicine's Heart and Vascular Center in Philadelphia.

EAT HEALTHY

Studies haven't tested specific diets when you have OHCM, but Day suggests a heart-healthy, Mediterranean-inspired diet. Mediterranean diets focus on plant-based foods, including:

- · Whole grains
- Vegetables
- Beans
- Fruits
- · Nuts and seeds
- · Herbs and spices

Most added fat in a Mediterranean diet should come from olive oil. Eat seafood, dairy, and lean meats in moderation.

WATCH YOUR WEIGHT

In addition to eating for heart health, you'll want to limit calories to maintain a healthy weight or lose weight if needed. Many people with HCM are also overweight or obese, Day says. Obesity often comes with more thickening in the heart. When you're overweight, you're more likely to have worse symptoms and other heart conditions, too.

"Studies looking at genetics versus lifestyle factors have shown that obesity is one of the causal factors [in HCM], even without a strong genetic predisposition," Day says.

GET ACTIVE

Doctors used to tell people with OHCM to keep exercise intensity low, Day says. But she says recent evidence shows more moderate exercise helps people feel better. With regular exercise, their hearts also perform better in stress tests. Aim for 150 minutes a week of moderate-intensity aerobic exercise. Talk to your doctor first about what they

recommend for you, especially if you're just getting started or are thinking about more intensive exercise or competitive sports.

STAY HYDRATED

What you drink matters, too. Day recommends 64 oz of water a day. Keeping your body well hydrated keeps your blood volume up, which helps limit obstructions in your heart. Watch how much caffeine and alcohol you drink, as they can dehydrate vou.

"If you go out, have a glass of water for every glass of wine or beer," Day says. "That's my general rule."

KEEP YOUR OPTIONS OPEN

Don't let OHCM limit your plans for the future, including kids. Most women will do just fine with pregnancy, Day says. "There are few circumstances where we would recommend someone not get pregnant."

There's no reason to worry too much about thrill-seeking activities, whether it's bungee jumping or roller coasters, Day added. But be sure to check with your doctor first about any lifestyle concerns or questions you may have.



HEART HEALTH

THE IMPORTANCE OF PRACTICING **GOOD DIET AND EXERCISE**

By Kendall K. Morgan Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

When you have hypertrophic cardiomyopathy (HCM), it's harder for your thickened heart to pump your blood. These changes often arise early in life, but changes in the heart also can happen later.

"When your heart pumps blood out into the aorta, it ideally should do that with no pressure on the outer side," explains Theodore Abraham, MD, a cardiologist at the University of California San Francisco Health. "It should be efficient like a garden hose that flows nice and easy. In HCM, thickening muscle is like a thumb pressing down."

That pressure can partially obstruct blood flow. About two-thirds of people with HCM will have obstructive hypertrophic cardiomyopathy (OHCM).

DIETARY CONSIDERATIONS

Abraham says that, while your diet may not change the underlying thickening of heart muscle, it will help you to avoid adding other heart problems. For instance, he suggests avoiding a diet that's high in saturated fats and salt.

"On top of OHCM, you don't want to have a heart attack or high blood pressure," he says. "General heart health is important."

If you have high blood pressure or diabetes on top of OHCM, which isn't uncommon, he says it's important to make sure it's fully controlled. Diet can help along with any medications your doctor prescribes.

"Diet is important because one of the main

things you can do for yourself [with OHCM] is to be healthy in general," says Steve R. Ommen, MD, a cardiologist at the Mayo Clinic and director of the Mayo Hypertrophic Cardiomyopathy Clinic in

QUESTIONS FOR YOUR DOCTOR



Rochester, MN. "If you are healthier, you are more likely to do better."

KEEP MOVING

In the past, doctors were hesitant to encourage exercise for people with OHCM. But, Ommen explains, that was based on findings that competitive athletes who'd died suddenly often had OHCM.

"It got extrapolated to: You shouldn't exercise," he says.

Doctors have since come to realize, however, that those studies represent a highly select group. They don't tell you about the risks and benefits of more moderate exercise for people diagnosed and in treatment for OHCM today.

"What we're seeing now is that patients [with OHCM] who engage in exercise as

part of a healthy lifestyle derive the same benefits [that anyone else would] without excess risk of dying suddenly or hurting the heart."

Ommen recommends starting with walks 5 days a week for 20 minutes, and moving up from there. "You want to be able to speak a full sentence while you're active, not a full paragraph," he says. He still recommends avoiding high-intensity exercise and extreme heat or cold until more evidence on safety is in.

"Our goal is for patients to participate in an active lifestyle, like the rest of us," Ommen says. "If there are symptoms, they may need therapy. The goal is to be out there and be active. That's quite achievable with HCM."

OBESITY WOES

A healthy diet and exercise are two of the best things any of us can do to maintain a healthy

weight. When you have OHCM, your heart may already be less efficient and extra pounds will make it that much harder.

"The way I put it to my patients is that, at a healthier weight, it takes less effort to move," Ommen says. When your heart is already not as efficient as it should be, keeping your body in the best shape that you can makes everything easier.

"Obesity contributes to even more thickening of the heart," Abraham adds. "If you have obesity, we would suggest you lose weight to help reduce the thickening. Every little bit helps."

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