

Living with *Hypertrophic Cardiomyopathy*

A DISCUSSION GUIDE FOR PATIENTS AND CAREGIVERS

WHAT IS HCM?

Hypertrophic cardiomyopathy (HCM) is one of the two main types of cardiomyopathy. In HCM, **the heart muscle thickens and becomes stiffer**, making it difficult for the heart to pump blood with oxygen to the body.

This can lead to complications such as:

- ♥ **irregular heart rhythm** (called atrial fibrillation)
- ♥ **heart valve disease**
- ♥ **fainting**
- ♥ **heart failure**
- ♥ **sudden cardiac death**

HCM often appears in children and young adults, though it can occur at any age. It is often passed down through families, making it one of **the most common inherited or genetic heart disease**. Despite its prevalence, many individuals remain unaware of its hereditary nature and the importance of screening when a family member is affected. Even if HCM has not caused any symptoms, it can lead to sudden cardiac death, mostly in adolescents and young adults (especially athletes).

TYPES OF HCM

♥ OBSTRUCTIVE HCM

This is the most common type, where the thickened heart muscle on the left side of the heart blocks, or partially blocks, blood flow from the heart to the rest of the body. The ventricular septum (the wall between the two bottom chambers of the heart) is particularly affected.

♥ NONOBSTRUCTIVE HCM

In this type, the thickened heart muscle does not block blood flow.



1 in 500

PEOPLE MAY
HAVE HCM
IN EUROPE.
MANY REMAIN
UNDIAGNOSED



**50%
chance**

OF INHERITING THE
GENETIC MUTATION
FOR HCM IF ONE
PARENT CARRIES IT

SYMPTOMS OF HCM

Many people with HCM experience no symptoms, while others may have some that are incorrectly diagnosed as **lung problems, anxiety, or other heart conditions**.

Some common symptoms include:



SHORTNESS OF BREATH
especially with
physical activity



SWELLING
in your legs, ankles, feet,
abdomen, or neck veins



COUGHING
especially when
lying down



FATIGUE



CHEST PAIN
especially after physical
activity or after eating
a large meal



**HEART PALPITATIONS
OR ARRHYTHMIAS**
– your heart may feel like it's
pounding, racing or fluttering



**DIZZINESS & FEELING
LIGHTEADED**
or **fainting** (syncope)
during physical activity

DIAGNOSING HCM

Individuals with HCM are often undiagnosed. If you have a family history of this condition or experience symptoms, it is crucial to consult a specialist in treating HCM. The doctor will conduct a **physical exam** to assess your overall health, **review your medical records** and ask about your **family's health**. Additional tests may include:

- ♥ **BLOOD TESTS** – to check the levels of certain substances in your blood that are raised when you have cardiomyopathy or heart failure.
- ♥ **CHEST X-RAY** – shows whether your heart is enlarged and/or whether fluid is building up in your lungs.
- ♥ **ELECTROCARDIOGRAM (EKG or ECG)** – shows your heart's rate and rhythm.
- ♥ **HOLTER AND EVENT MONITORS** – portable devices that you wear, typically for 24-48 hours, to record your heart's EKG as you go about your day.
- ♥ **EXERCISE STRESS TEST** – involves walking on a treadmill (usually) to assess how physical exertion affects your heart.
- ♥ **ECHOCARDIOGRAM (ECHO)** – uses sound waves to generate a dynamic picture of your heart, revealing its structure, function, size and shape. A "stress echo" involves performing the echo during a stress test.
- ♥ **CARDIAC MRI SCAN** – uses a magnetic field and radio waves to create detailed images of your heart's structure and function.
- ♥ **POSITRON EMISSION TOMOGRAPHY (PET) SCAN** – uses a radioactive substance (injected into your veins before the scan) to distinguish healthy from unhealthy heart tissue.
- ♥ **GENETIC TESTING** – confirms inherited HCM and helps determine if other family members should be tested.

TREATING HCM

Currently, there is no way to prevent HCM, and treating this condition will depend on its specific type.

Here are some treatment options:



HEALTHY LIFESTYLE: Adopting healthy habits like **eating nutritious foods**, maintaining a **proper weight**, engaging in **regular physical activity**, **controlling blood pressure and blood sugar levels**, **not smoking**, and **reducing stress**, can improve your overall well-being and longevity.

Conditions such as **high blood pressure**, **obesity**, and **smoking** are risk factors for heart disease and can contribute to the severity of HCM.



MEDICATIONS: Certain medications can help prevent abnormal heart rhythms, slow heart rate, regulate the heart's force of contraction, lower blood pressure, or prevent blood clots.



DEVICES: These include **pacemakers** for controlling heart rate and rhythm, **implantable cardiac defibrillators (ICDs)** that deliver a shock to the heart to correct life-threatening arrhythmia, and **left ventricular assist devices (LVADs)** to help pump blood from the heart's left lower chamber (ventricle) to the rest of the body.



SEPTAL REDUCTION THERAPY: Procedures such as **septal myectomy** (surgical) and **alcohol septal ablation** (non-surgical) can reduce the bulging of the ventricular septum into the left ventricle, improving heart function.



TRANSPLANT SURGERY: In severe cases of HCM, when all other treatment avenues have failed to adequately improve the heart's condition, a **heart transplant** may be the only option.

QUESTIONS TO ASK YOUR DOCTOR

- ✔ What type of HCM am I diagnosed with and how does that affect my health?
- ✔ What caused my HCM? Did I inherit it? Should others in my family be tested for a genetic mutation? What are the chances of me passing on HCM to my children?
- ✔ How severe is my HCM? What complications could arise from my HCM?
- ✔ Are there medications available to manage my symptoms, and what are their associated risks and benefits?
- ✔ Do I need surgery or other medical procedures? What is involved?
- ✔ How can I prevent my HCM from worsening?
- ✔ What changes can I make to improve my health and reduce risks?
- ✔ Where can I access trustworthy resources and information on HCM?
- ✔ What symptoms should I be vigilant for that would indicate the need to contact my doctor or seek emergency assistance?
- ✔ How can I connect with other individuals facing HCM for support and shared experiences?



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