

# Living with *Dilated Cardiomyopathy*

A DISCUSSION GUIDE FOR PATIENTS AND CAREGIVERS

## WHAT IS DCM?

Dilated cardiomyopathy (DCM) is a condition in which the heart becomes enlarged and cannot pump blood as effectively as it should. This happens because one or both lower chambers of the heart (called the ventricles) become stretched and weakened, reducing the heart's ability to function properly. If left untreated, DCM can lead to **heart failure**.



DCM IS ALSO ONE OF THE  
*leading causes  
of heart failure*



DILATED CARDIOMYOPATHY  
*is more prevalent  
in men*



DCM CAN RUN IN FAMILIES OR HAVE AN  
INHERITED/GENETIC CAUSE. IF A PARENT  
HAS DCM, THERE IS A  
*50% chance of  
passing it on to each  
of their children*



DCM IS THE  
*most common form  
of cardiomyopathy  
in children*



DCM can occur at any age and, in some cases, may be **inherited**.

## CAUSES OF DCM

Dilated cardiomyopathy can develop for different reasons. Possible causes include:

- ♥ **GENETIC CAUSES**  
inherited and/or runs in families
- ♥ **MYOCARDITIS**  
inflammation of the heart muscle, often caused by infections such as viruses
- ♥ **AUTOIMMUNE CONDITIONS**
- ♥ **CARDIAC CAUSES**  
such as coronary artery disease, long-term high blood pressure (hypertension), heart rhythm problems (arrhythmias), especially long-term fast heart rate, or problems with heart valves
- ♥ **ILLICIT DRUGS**  
(such as cocaine) or misuse of alcohol
- ♥ **CONGENITAL**  
heart conditions present from birth
- ♥ **CERTAIN CANCER**  
chemotherapy medications
- ♥ **HORMONAL CONDITIONS**  
such as thyroid disease
- ♥ **IRON OVERLOAD**  
too much iron in the heart and other organs
- ♥ **NUTRITIONAL DEFICIENCIES**  
low levels of certain vitamins or minerals
- ♥ **PREGNANCY**  
can sometimes cause a type of DCM referred to as post-partum cardiomyopathy, which is quite rare



In some people, no clear cause is found. This is called **idiopathic DCM**.



CHRONIC ALCOHOL CONSUMPTION CAN LEAD TO A SUBTYPE OF DCM CALLED  
*alcoholic cardiomyopathy*

## SYMPTOMS OF DCM

Many people with DCM do not experience symptoms at first. Because the condition can develop gradually, it may take time before you start to feel any changes on your day-to-day activities.

As the disease progresses, you may notice symptoms related to heart failure, such as:



**SHORTNESS OF BREATH**  
during physical activity  
or while lying down



**FATIGUE**  
feeling unusually tired



**SWELLING**  
in your legs, ankles,  
feet or abdomen



**CHEST PAIN**  
or discomfort



**HEART PALPITATIONS OR IRREGULAR HEARTBEATS**  
feeling like your heart is pounding, racing or fluttering

## DIAGNOSING DCM

DCM can sometimes go undiagnosed, especially in its early stages. If you have a family history of DCM or experience symptoms, it is crucial to consult a healthcare professional. Your doctor may perform a **physical exam** to assess your overall health, **review your medical records** and ask about your **family's health history**.

Additional tests may include:



### GENETIC TESTING

helps confirm inherited or genetic forms of DCM and determine whether family members should be tested (cascade testing).



### EXERCISE STRESS TEST

involves walking on a treadmill (usually) to assess how physical exertion affects your heart.



### BLOOD TESTS

to check for infections and other conditions that may be linked to dilated cardiomyopathy.



### CARDIAC MRI SCAN

uses a magnetic field and radio waves to produce detailed images of your heart's structure and function.



### ELECTROCARDIOGRAM (EKG OR ECG)

records your heart's rate and rhythm.



### CARDIAC CATHETERIZATION

a thin tube (catheter) is guided through a blood vessel in your arm or leg to your heart to measure blood flow and pressure in the heart's chambers.



### HOLTER AND EVENT MONITORS

portable devices that you wear, typically for 24-48 hours, to record your heart's EKG during daily activities.



### ANGIOGRAM

an X-ray using contrast dye injected through the catheter to show narrowed or blocked coronary arteries, which bring oxygen to heart muscle.



### ECHOCARDIOGRAM (ECHO)

uses sound waves to create images of your heart, showing its structure, function, size and shape. A "stress echo" involves performing the echo during a stress test.

## TREATING DCM

While DCM usually cannot be cured, treatment can help manage symptoms, improve quality of life, and slow disease progression. Your care plan will depend on your individual needs and may include a combination of the following options:



### HEALTHY LIFESTYLE

Adopting healthy habits like eating **nutritious foods**, maintaining a **healthy weight**, engaging in **regular physical activity** (as advised by your doctor), **managing blood pressure and blood sugar levels**, **not smoking**, **reducing or eliminating alcohol**, and **reducing stress**, can support your heart health and overall well-being.



### MEDICATIONS

Certain medications may help your heart pump more effectively, control your heart rate and rhythm, lower your blood pressure, prevent blood clots and reduce risk of complications.



### DEVICES

These include **pacemakers** for controlling heart rate and rhythm, **implantable cardiac defibrillators (ICDs)** that deliver a shock to your heart if a life-threatening arrhythmia occurs, and **left ventricular assist devices (LVADs)** to help pump blood from the heart to the rest of the body.



### TRANSPLANT SURGERY

In severe cases, when other treatments are no longer effective, a **heart transplant** may be the only option.

## QUESTIONS TO ASK YOUR DOCTOR

- ✓ What caused my DCM?
- ✓ Is my condition genetic?  
Should my family members be tested?
- ✓ How severe is my condition?  
What complications could arise from it?
- ✓ How will we monitor the progression of my condition?
- ✓ What treatment is best for me, and what are the possible risks and benefits?
- ✓ Do I need surgery or other medical procedures?  
What is involved?
- ✓ What lifestyle changes should I make?
- ✓ Can I exercise safely?  
What type of exercise is recommended?
- ✓ Can I continue working?
- ✓ What symptoms should I be vigilant for that would indicate the need to contact you or seek emergency assistance?
- ✓ Where can I find trustworthy resources and information on DCM?
- ✓ How can I cope with anxiety or stress related to my condition?
- ✓ How can I connect with other individuals living with DCM for support and shared experience?



SUPPORTED BY



[WWW.MENDEDEHEARTSEUROPE.ORG](http://WWW.MENDEDEHEARTSEUROPE.ORG)

✉ [MHEUROPE@MENDEDEHEARTS.ORG](mailto:MHEUROPE@MENDEDEHEARTS.ORG)    