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).

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

ELECTROCARDIOGRAM (EKG OR ECG)
records 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 during daily activities.

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.

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

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

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.

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

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?

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