

Muscular Dystrophy and the Heart

Heart problems are common with muscular dystrophy (MD). The most common heart problem is called cardiomyopathy. This means there are problems in the heart muscle. One or both ventricles (lower pumping chambers) of the heart do not pump, or function, as they should. Sometimes they become enlarged. You may also have heart rhythms that are not normal.

Symptoms

- Feeling tired
- Weight loss
- Trouble sleeping
- Shortness of breath
- Cough
- Nausea and vomiting
- Swelling in your legs or feet
- Heart beats that are not normal

You may not be able to tell if you are having heart problems. It is important to see a heart provider to find heart problems early.

Testing

Echocardiogram (heart ultrasound): This is a test that looks at the function/squeeze and size of the heart. MD patients will have It measures heart function in two ways:

- **Fractional shortening (FS)** measures the percentage of change from the squeeze (systolic) to the relax (diastolic) function of the heart.
- **Ejection fraction (EF)** which is the percentage of blood pumped out of the ventricle during a heartbeat.

Electrocardiogram (EKG or ECG): This test looks at your heart rhythm. Patients have this at least every few years.

Holter monitor: This is a device worn home from clinic. It records the heart rhythm over 24 hours. It tells us heart rates throughout the day and if there are any heart rhythms that are not normal. Patients have this test every 1-3 years.

MRI (magnetic resonance imaging): This test can confirm the results of the heart ultrasound. It can also look for scarring (fibrosis) in your heart muscle. Scarring is a sign that your heart is affected by MD. Patients may have a cardiac MRI every 1-3 years to look more closely at how the heart muscle is working.

Lab tests: Patients will have a lab test to measure brain natriuretic peptide (BNP). BNP is a hormone that may increase as heart function gets worse. Patients may also have other lab tests if they are taking certain medicine(s).

Treatment

In our clinic, patients start medicines when problems with heart function are first seen or as they get older. In most cases, the changes cannot be reversed. Starting medicine early may decrease the damage to your heart.

Medicines

Medicines help your heart muscle to work better.

ACE inhibitors open up your arteries and veins. This decreases the work of your heart. Side effects can include cough, feeling dizzy, swelling, skin rash and high potassium levels. A rare but serious side effect is swelling in your face, mouth, hands or feet, or trouble swallowing or breathing. Get help right away if this happens.

Beta blockers block the effects of the chemicals in your body that can make your heart work too hard. Side effects can include shortness of breath, mood changes, slow heartbeat, feeling tired or dizzy, and swelling. They also help control heart beats that are not normal.

Diuretics are water pills that help your body get rid of extra fluid and salt to make it easier for your heart to pump. Side effects can include leg cramps, feeling weak or dizzy, skin rash, dehydration, and low potassium levels.

Aldosterone antagonists are water pills that blocks a hormone called aldosterone. It can prevent more damage to your heart and blood vessels. It also helps your body hold onto potassium. Side effects can include high potassium levels, breast soreness and swelling in men, rash, and abdominal symptoms. It is **very important to have the lab tests done** that your provider orders if you are taking this medicine.

Respiratory Care

Good respiratory care helps to maintain good heart function. The lungs and the heart work together. The heart has to work harder if the lungs aren't working well. Breathing treatments or BiPAP may help make it easier for the heart to pump.

Nutrition

Healthy eating helps the body to have energy to work well. If you have trouble swallowing, chewing, eating, or if you have other symptoms that prevent you from eating well, let your provider know.

Transition to Adult Cardiology

When you are between 18-20 years of age, we will talk with you about transitioning to the adult cardiology clinic. If you have MD, you will be seen in the Adult Heart Failure Clinic.

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright 8/2021. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#6856