

## Muscular Dystrophy and the Heart

With muscular dystrophy, MD, such as Duchene's (DMD) and Becker's (BMD), it is common to have a heart problem as you get older. The main heart problem in DMD and BMD is called cardiomyopathy. This means an abnormality in the heart muscle. One or both ventricles (lower pumping chambers) of the heart do not pump, or function, as they should. You may also have heart rhythms that are not normal.

### Signs and 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 doctor or nurse practitioner to find heart problems early.

### Testing

An echocardiogram (also called a heart ultrasound) looks at the function/squeeze of your heart. This is done about every year until you are 10 years old, then every 6-12 months. It measures heart function in two ways: fractional shortening (FS) and ejection fraction (EF). FS measures the percentage of change from the squeeze (systolic) to the relax (diastolic) function of the heart. EF is the percentage of blood pumped out of the ventricle during a heartbeat.

An EKG (also called an ECG or electrocardiogram) looks at your heart rhythm. This is done at least every few years.

A Holter monitor is worn home from clinic, this will be done every 1-3 years. It records your heart rhythm over 24 hours. It tells us your average heart rate and if there are any heart rhythms that are not normal.

As you get older, it can be harder to get good pictures on the echocardiogram. A cardiac MRI (Magnetic Resonance Imaging) may also be done every 1-3 years to look more closely at how your heart muscle is working. It can confirm the results of the heart ultrasound and look for scarring (fibrosis) in your heart muscle. Scarring is a sign that your heart is affected by MD.

Watch our videos of these tests at [uwhealth.org/kidshearts](http://uwhealth.org/kidshearts)

A lab test is done to measure brain natriuretic peptide (BNP). BNP is a hormone that may increase as heart function decreases.

You may have other lab tests depending on the medicine(s) you are taking.

### Treatment

In our clinic medicines are started at the first sign of problems in heart function on the echocardiogram. Often the first sign is in the relaxation (diastolic) function of your heart. Changes aren't usually reversible. Starting medicine early may decrease the impact of the muscle disease on your heart.

## **Medicines**

Medicines help your heart muscle to work better.

**ACE Inhibitors** (ACE) (Enalapril) open up your arteries and veins. This decreases the work of your heart. Side effects can include cough, feeling dizzy, loss of taste, 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.

**Angiotensin II receptor blockers** (ARB's) (Losartan) are used to open up your arteries. Side effects can include feeling tired or dizzy, and swelling.

**Beta Blockers** (Propranolol, Atenolol, and Carvedilol) block the effects of the chemicals in your body that can make your heart work too hard. Side effects can include shortness of breath, slow heartbeat, feeling tired or dizzy, and swelling. They also help control heart beats that are not normal.

**Diuretics** (furosemide Lasix®) 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.

## **Spironolactone (Aldactone®)**

This medicine is a water pill 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, 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 maintains good heart function. The lungs and the heart work together. If the lungs aren't working well this causes the heart to try and work harder. Breathing treatments or BiPAP may be recommended to help make it easier for your heart to pump.

## **Nutrition**

Healthy eating helps your 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 muscular dystrophy you will be seen in the Adult Heart Failure Clinic.

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 4/2018. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#6856