

Cardiomyopathy

What is cardiomyopathy?

Cardiomyopathy (**car-dee-o-my-op-a-thee**) is a condition of the heart muscle. There are two types, primary and secondary. With the primary type, no other illness or heart disease is present. Secondary cardiomyopathy is a result of another illness. This sheet explains primary cardiomyopathy only.

The types of primary cardiomyopathy are described below:

Hypertrophic cardiomyopathy

This type of cardiomyopathy is the most common. The heart's left ventricle walls are hypertrophied (thicker than normal). This thickening makes the ventricle stiffer, which makes the heart work harder than usual. Some of the other names for this type of cardiomyopathy are:

- idiopathic hypertrophic subaortic stenosis
- hypertrophic obstructive cardiomyopathy

Most children diagnosed in infancy or childhood are noted to have a heart murmur. Many people with hypertrophic cardiomyopathy are not even aware they have it and are only diagnosed later in life.

Hypertrophic cardiomyopathy is sometimes found to be a genetic disease (passed on in families). Your child's doctor can talk to you more about this.

Dilated cardiomyopathy

In this type, the 4 chambers of the heart become dilated (bigger than normal). The heart does not pump blood as well as it should. Children will often tire easily and feel weak.

Restrictive cardiomyopathy

This is the least common type of cardiomyopathy. In this type, the ventricle walls become stiffer. This restricts the ventricle's ability to fill while in the relaxed phase of pumping. Sometimes children will feel tired and weak with activity or exercise, and may have chest pain.

How is cardiomyopathy diagnosed?

In order to make an accurate diagnosis, a number of tests are available that will help the doctor determine the type of cardiomyopathy. These tests may include:

- blood tests
- chest X-rays
- echocardiogram (ECHO) - a moving picture of the heart using sound waves
- electrocardiogram (ECG or EKG) - a recording of the heartbeat

What is the treatment?

There are a number of medicines that can be used to help treat this condition. Some of the medicines help the heart beat more efficiently. Others help keep the lungs free of extra fluid. Sometimes medicine is needed to prevent clotting of the blood. The doctors will talk to you about the medicines for your child and how they should be given.

Learn the names of all medicines your child is taking, what they do, side effects, and any precautions that need to be taken.

Have a schedule and give medicines on time (within 1 hour).

Keep medicines out of children's reach and sight.

It is **very** important for your child to continue to see the cardiologist and to take the prescribed medicine as directed.

How active can my child be?

Children with cardiomyopathy sometimes feel tired and will limit their activity themselves depending on how they feel. Activity may also be restricted depending on the medicines your child is taking. The doctor will talk to you more about this.

When should I call the cardiologist?

Call your cardiologist if:

- Your child is lethargic, working harder to breathe, has poor urine output or decreased perfusion.
- The medicines do not seem to be helping.
- Your child is vomiting the medicines.
- You have questions or concerns about the medicines.

What resources are available?

This disease can be hard to diagnose at first and it can be very frightening for parents and families as well as for the child. It is very important to treat your child as normally as possible. Many parents feel uncertain and even angry. Our social work staff can help with these feelings. Other resources include the following:

Children's has a **support group** for parents:

Parents for Heart of MN, Inc.

Attn: 32-P190

2525 Chicago Avenue S.

Minneapolis, MN 55404

www.parentsforheart.org

The **American Heart Association**

(952) 835-3300 has information about congenital heart disease.

Meld Special (612) 332-7563 is a free Twin Cities program that offers information and support for parents of children with chronic conditions. This program focuses on the "ordinary" tasks of raising a child as well as the impact of a chronic condition on raising children.

Pacer Center, Inc. (952) 838-9000 is a resource for parents of children with disabilities.

Your child may qualify for **financial help** because of his or her heart condition.

Children's social work staff can help you find out what financial resources are available. The nurse can help you contact them at your request.

Questions?

This sheet is not specific to your child but provides general information. If you have questions, please call your cardiologist.

For more reading material about this and other health topics, please call or visit the Family Resource Center library, or visit our Web site: www.childrensmn.org.

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