

The Heart Function Program



Children's Heart Centre

4480 Oak Street, Vancouver, BC V6H 3V4

604-875-2345 1-888-300-3088

www.bcchildrens.ca

What is Heart Failure?

For a child to grow and develop the heart needs to maintain normal pump function to provide adequate blood flow throughout the body. However, sometimes the heart of a baby or child may not function normally. The term "Heart Failure" is used commonly, that describes a heart that is not functioning properly. It does not mean that the heart has stopped working, but instead it means that it is not working as well as it should be.

What Causes Heart Failure?

The heart muscle becomes weak or damaged and cannot squeeze or pump properly. Some causes of muscle damage are:

- Viruses
- Problems with the coronary artery blood supply to the heart
- Genetic or inherited conditions (Cardiomyopathy)
- Heart rate that is too slow or too fast
- Certain drugs used to treat childhood cancers weaken heart muscle

Sometimes abnormal heart valves do not close properly and cause blood to leak backwards. If a valve does not open well the pressure can build up in the heart causing heart failure. Rarely, an infection such as strep throat can damage heart valves causing heart failure.

Over-circulation failure is usually caused by a problem with the structure or plumbing of the heart. In this case the baby or child is coping with too much blood is going to the lungs. This usually is a temporary condition that is often corrected with surgery.

What are the symptoms of Heart Failure?

The symptoms of heart failure can appear very quickly or can progress slowly. Symptoms may include any of the following:

- Abnormal breathing - rapid, noisy breathing (grunting), sucking in-between or below ribs (indrawing)
- Slow weight gain
- Poor appetite
- Trouble with feeding (vomiting)
- Abdominal pain
- Excessive sweating
- Tiredness
- Dizziness and fainting
- Chest pain
- Palpitations (feeling like the heart is beating too fast or hard)

How is Heart Failure Diagnosed?

Babies and children will usually need to be admitted to hospital to have the cause of the heart failure investigated, to have the required testing and to have the treatment plan organized. History and physical examinations are completed are completed by the team as wells as number of tests and bloodwork. Other hospital teams that can help with the diagnosis, for example

The Heart Function Program



Children's Heart Centre

4480 Oak Street, Vancouver, BC V6H 3V4

604-875-2345 1-888-300-3088

www.bcchildrens.ca

Genetics and Infectious Diseases, are often consulted.

Possible tests include:

- Echocardiogram (ECHO) -- ultrasound of the heart to look at the structure and function
- Electrocardiogram (ECG) – assess the heart's electrical activity
- Chest X-ray
- CT scan or Cardiac MRI – a more detailed look at the heart
- Heart Catheterization – obtain accurate data
- Blood tests – assess the heart function and other body systems
- Exercise stress test – evaluates the heart's response to exercise

How is Heart Failure Treated?

Your child's treatment plan will be very specific to them and be determined by the cause of the heart failure.

If the failure is caused by heart muscle weakness or "pump failure" medications are used. They include:

- **Enalapril or Captopril** -- one to lower blood pressure; making it easier for the heart to pump blood to the body (Enalapril used in children over 2 years of age and Captopril used in infants and children less than 2 years of age)
- **Carvedilol or Metoprolol** --beta-blockers -- helps reduce your child's heart rate which allows more time for

the heart to fill and pump blood more efficiently (e.g.)

- **Lasix**– removes excess fluid in the body and decrease the workload of the heart (e.g. Lasix)
- **Spironolactone** -- aldosterone-blocker – block hormones that cause stretching of the heart muscle and improve the squeeze of the heart
- **Aspirin** – reduces the risk of clot formation. It is used when blood flow is sluggish in the heart.
- **Digoxin** – slows the heart rate and improves the squeeze of the heart
- **Coenzyme Q10** – it is supplement that helps the heart muscle remodel and heal over time
- **Vitamin D** – important for bone health
- **Milrinone** – improves squeeze of the heart while at the same time relaxes the blood vessels in the lungs. This makes it easier for the heart to pump blood to the body. This drug is given continuously through an intravenous line (PICC line). The infusion is started in the hospital but in certain circumstances can be given at home.

Medications are used to help cope with the symptoms of heart failure but do not cure the heart failure. Hospitalization may be needed to start medication.

Most children respond very well to medications over time but if the team feels that the heart function is not improving there are several other options that might help. Sometimes a special pacemaker can improve the function of the heart by maintaining a normal coordinated heartbeat.

The Heart Function Program



Children's Heart Centre

4480 Oak Street, Vancouver, BC V6H 3V4

604-875-2345 1-888-300-3088

www.bcchildrens.ca

A mechanical pump may improve the function temporarily. In some cases your Cardiologist may discuss the need for a heart transplant.

If the failure is caused by structural problems or damaged valves your child may require surgery to repair the issue and reverse the failure. Your child may be put on medications such as Lasix, Spironolactone, and Digoxin which all help cope with the symptoms of heart failure but do not cure it.

As heart failure causes poor growth your child may also need nutritional supplements.

Life at Home

Nutrition and Diet:

Children in heart failure often require high calorie diets to help them catch up with weight or maintain normal weight for their age. The hospital dietician will make recommendations around the best nutrition for your child. Most children can take enough calories by mouth but some need a small tube inserted into their stomach that allows them to get extra calories. In general healthy diet with a variety of fruits, vegetables, whole grains, meats and dairy are very important.

Exercise and Activity:

Your child may become sick quickly or over a long period of time. It is likely that your child has become too tired to

participate in normal physical activity. Once they are stable on the right medication the goal is for your child to regain strength and return to their favorite physical activities and get back to having fun. It is very important to get some exercise every day. If your child has exercise restrictions they will be clearly written down for you and all care providers.

Monitoring at Home:

Every child will have different monitoring needs at home. Some children will have no need at all for monitoring. Your cardiac team will guide you and teach you what to look out for and what symptoms need to be reported to your nurse, pediatrician or cardiologist. Some examples of that you might be asked are:

- Record of weights
- Feeding patterns
- Fluid intake
- Number of wet diapers or pees in a day
- Breathing pattern
- Sweating
- Tiredness
- Exercise tolerance

These observations by you and your family will become just part of your regular routine and you should feel comfortable with observing and recording them easily.

The Heart Function Program



Children's Heart Centre

4480 Oak Street, Vancouver, BC V6H 3V4

604-875-2345 1-888-300-3088

www.bcchildrens.ca

Home Care:

In special cases your child might be eligible for care provided through the BC Provincial At Home Program or Nurse Support Services. Please ask your nurse if the supports in this program are available to you.

communicate plans with community care and be your link to the Cardiology team. Working with the Social Worker we will seek out possible supports that you and the family may require.

Remember that we are here to help in any way we can!

Who are the Professionals on my Child's Heart Function Team?

- Pediatric Cardiologist
- Cardiology Nurse Practitioner
- Cardiology Nurse Clinician
- Pediatrician or Family Physician
- Dietitian
- Social Worker
- Pharmacist
- Child Life Therapist
- Spiritual Care
- Administrative Clinic Staff
- Other potential Specialist
- **AND of course you the parents and family!**

No question is ever too small!

What does an outpatient clinic visit include?

- Routine test ECHO and ECG
- Possible bloodwork that is sometimes done before the visit
- Possible exercise test
- Possible Holter monitor to look at the heart's electrical activity over a 24 hour time period

What is the Role of my Nurse Clinician?

You and your child can expect that your Nurse Clinician will be your navigator through the diagnosis, admission to hospital and discharge home. Our goal is to support your family as you learn about your child's diagnosis and treatment plan. We want you to feel fully equipped and confident with the day to day care when you go home. We will attempt to coordinate appointments; tests and other outpatient follow up care. We will

You will meet with your Heart Function Nurse Clinician who will:

- Complete a medication review (take pictures of the bottles or bring all medications with you)
- Assess growth with weight and height
- Review nutrition and feeding plan
- Review exercise and activity levels
- Complete a nursing assessment
- Review immunizations
- Review emergency and school plans
- Review dental health and prevention of dental infection
- Review need for any additional social and information supports

The Heart Function Program



Children's Heart Centre

4480 Oak Street, Vancouver, BC V6H 3V4

604-875-2345 1-888-300-3088

www.bcchildrens.ca

Meet with your child's Heart Function Cardiologist who will:

- Do a physical exam
- Will review test results and findings
- Will discuss your concerns with you
- Will be decided on a treatment plan and follow-up
- Will send a clinic update letter to your child's team members

Be aware that some visits are lengthy so bring snacks and formula. Feel free to request the clinic letter from the visit for your records.

How is my Child's Progress Monitored?

We will look at several factors to monitor your child's heart function. These factors help to decide how often they need to be seen in clinic and if they need to have medications increased or decreased. The ECHO will give ongoing information on the function or strength of the heart muscle. The ECG and 24 hour Holter monitor looks at the electrical activity of the heart. The blood work gives information on how the whole body and other organs (kidney and liver) are coping with the heart failure and the medications that your child is on. A special blood test called a BNO will also help determine heart function and will be followed at regular intervals.

We will look at the growth and development and general condition of your child. In older children we can assess their exercise

tolerance with an Exercise stress test done in clinic. In younger children we look at their ability to keep up with their siblings or peer when playing and doing favorite activities.

How can Parents Prepare for Clinic Visits?

- Bring your medications with you or a picture and know if you need any prescription refills
- Bring your child's current immunization records
- Bring any home records if you have been keeping them
- Alert clinic if you have moved or have new contact information
- Have questions and concerns for your doctor or nurse written down



When to See Your Child's Doctor/Go to the Emergency If...

Your nurse will help develop an Emergency plan that is specific to your child's and family needs. This will be shared with all caregivers, community team members, daycares and schools.

If you have concerns during working hours please call the **nursing** office at **604-875-2345 ext. 7877** to speak to a nurse.

If your concerns are immediate during working hours and after hours please call **604-875-2161** and ask for the **Cardiology Fellow**.

In an **Emergency** please use **9-1-1**.

The Heart Function Program



Children's Heart Centre

4480 Oak Street, Vancouver, BC V6H 3V4

604-875-2345 1-888-300-3088

www.bcchildrens.ca

Heart Failure can happen to any child and family. This diagnosis is likely to turn your world upside down for a while. Our goal is that with proper medical care, education and supports things will improve for your child and family over time. There is much room for optimism as new treatments and medications become available to treat children with heart failure. We are here to support you and help your child live a full, active and happy life.