

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" 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?

Your child may have an underlying structural heart defect or the heart muscle may be abnormal becoming weak or damaged and cannot squeeze or pump properly. Some causes of muscle damage are:

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

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 may need to be admitted to hospital to have the cause of their heart failure investigated, for testing and to have the treatment plan organized. History, physical examinations and testing are completed are completed by the medical team. Other hospital teams that can help with the diagnosis, for example Genetics and Infectious Diseases, are often consulted.

Possible tests include:

- Echocardiogram (ECHO): an ultrasound of the heart to look at the structure and function
- Electrocardiogram (ECG): to assess the heart's electrical activity
- Chest x-ray
- CT scan or Cardiac MRI: a more detailed look at the heart
- Heart catheterization: obtain information about heart structure and pressures in the heart.
- Blood tests: to assess the heart function and other body systems such as the kidneys and liver.

- Exercise stress test: to evaluate the heart's response to exercise

How is heart failure treated?

Your child's treatment plan will be very specific to them and will 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:

- **Ace Inhibitor:** (Enalapril or Captopril) Lowers blood pressure; making it easier for the heart to pump blood to the body.
- **Beta Blocker:** (Carvedilol, Metoprolol) Reduces your child's heart rate which allows more time for the heart to fill and pump blood more efficiently.
- **Diuretic:** (Lasix) Removes excess fluid in the body and decrease the workload of the heart.
- **Aldosterone blocker:** (Sprinolactone) Blocks hormones that cause stretching of the heart muscle and improve the squeeze of the heart.
- **Anticoagulation:** (Aspirin) reduces the risk of clot formation.
- **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 manage the symptoms of heart failure but do not 'cure' the heart failure; however they can allow children to feel better while we wait to see if the heart will recover. 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. 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.

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

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calories by mouth but some need a small tube inserted through their nose or directly into their stomach that allows them to get extra calories. In general a 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. 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.

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.

Who are the professionals on my child's heart function team?

- Pediatric Cardiologist
- 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!**

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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 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!

No question is ever too small!

Your child's outpatient clinic visit might include:

- Routine tests including ECHO and ECG.
- Bloodwork may be done before the visit.
- Exercise test.
- Holter monitor to look at the hearts electrical activity over a 24 hour time period.

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.

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 decided on a treatment plan and follow-up
- Will send a clinic update letter to your child's team members

Some visits are lengthy so bring snacks and formula; always plan to be here for two to four hours. Feel free to request the clinic letter from the visit for your records.

How can parents prepare for clinic visits?

- Bring your medications with you or a picture and know if you need any prescription refills.

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- 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**.

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.