

# **Caring for Children with Cardiac Conditions in a Community Program**

**Unified Referral and Intake System (URIS)  
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Manitoba Health ° Manitoba Family Services ° Manitoba Education and Advanced Learning

CARDIAC CONDITIONS

**This document was developed in consultation with health care professionals in the areas of cardiology and community health. The Unified Referral and Intake System (URIS) wishes to acknowledge the contribution of the following individuals.**

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## INTRODUCTION

The Unified Referral and Intake System (URIS) is a joint initiative of the provincial Departments of Health, Family Services and Education and Advanced Learning. URIS supports community programs in the care of children with specific health care needs. Community programs that are eligible for URIS support include schools, licensed child care facilities and agencies providing respite service.

URIS provides a standard means of classifying the complexity of health care needs and establishes the level of qualification required by personnel to support children with these health care needs. Health care needs that are classified as 'Group B' can be delegated to non-health care personnel who receive training and monitoring by a registered nurse. For children with 'Group B' health needs (e.g. cardiac condition), the nurse provides the following support:

- develops and maintains a written health care plan;
- provides training to community program personnel that are responsible for the child; and
- monitors community program personnel that receive training.

A child is eligible for URIS Group B support if he/she is diagnosed with a cardiac condition and is at risk for related complications. When a child has been discharged from the cardiologist's care and is no longer at risk for complications related to their cardiac condition, URIS Group B support is not required.

This document provides standard clinical information that is relevant to the care of children with cardiac conditions during attendance in a community program setting. Supplemental documents are also provided to assist the nurse in the development of health care plans and training and monitoring of community program personnel.

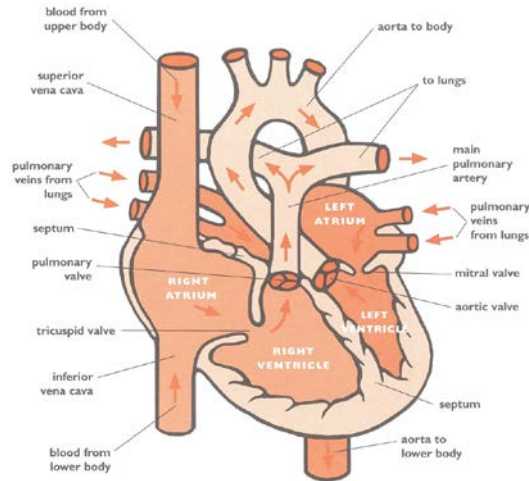
## CLINICAL INFORMATION

The following information is considered best practice in community program settings and is the basis for all cardiac condition information contained in this document and its supplements.

### How the heart works

The heart has 4 main parts

- Septum – muscular wall which divides the right and left sides of the heart
- Chambers (2 on each side)
  - Atria - upper chambers which collect blood
  - Ventricles - lower chambers which pump blood to the body
- Valves that open and close when the heart beats
- Great vessels
  - aorta - takes blood to the body
  - pulmonary artery - takes blood to the lungs



The heart is a strong muscular pump that collects oxygen-poor blood and pumps it to the lungs to get oxygen. The heart then pumps the oxygen-rich blood out to the organs, tissues and cells of the body, delivering oxygen and nutrients to every cell and removing carbon dioxide and waste products made by the cells. The heart itself needs a continuous supply of oxygen and nutrients to function, which it receives from the blood that is pumped through the coronary arteries.

- The right atrium receives oxygen-poor blood.
- The right atrium contracts which opens the tricuspid valve and blood moves to the right ventricle.
- The right ventricle contracts which opens the pulmonary valve.
- The pulmonary artery carries oxygen-poor blood to the lungs.
- Oxygen-rich blood returns to the heart through the pulmonary veins to the left atrium.
- The left atrium contracts which opens the mitral valve and oxygen-rich blood moves to the left ventricle.

- The left ventricle contracts which pushes the aortic valve open.
- Oxygen-rich blood moves through the aorta into smaller arteries throughout the body.

The heart pumps blood to the lungs and body by a sequence of organized contractions of the four chambers. The sinus node, the heart's "natural pacemaker", discharges regular electrical signals that cause the right atrium to contract. This signal then moves into the junction between the atria and ventricles, passing through the atrioventricular node (A-V node). The A-V node delays the signal slightly and then passes it into the ventricles which causes them to contract.

### **Congenital heart defects**

A congenital (existing at birth) heart defect happens when the heart or the blood vessels near the heart do not develop normally before birth. Many congenital heart defects slow down or block the blood flow in the heart or in the blood vessels near the heart. Other congenital heart defects cause blood to flow through the heart in an abnormal way which makes the heart work harder. Congenital heart defects vary in severity. Congenital heart defects are present in approximately 1% of live births and are the most frequent congenital malformation in newborns.

### **Stenosis**

Stenosis is narrowing or obstruction that partly or completely blocks the flow of blood. Obstructions can occur in heart valves, arteries or veins. The three most common forms are described below.

- With *pulmonary stenosis*, the pulmonary valve which lets blood flow from the right ventricle to the lungs is narrowed. As a result, the right ventricle must pump harder than normal to overcome the obstruction.
- *Aortic stenosis*, is a narrowing of the left side of the heart that delivers blood to the body. This narrowing can produce a strain on the left pumping chamber.
- With *coarctation of the aorta*, the aorta is pinched or constricted, which obstructs the flow of blood to the lower part of the body and increases blood pressure above the constriction.

### **Septal defects (holes in the heart)**

When a baby is born with an opening between the septum, blood flows from the left chambers to the right chambers of the heart instead of flowing normally to the rest of the body. This may cause the heart to become enlarged. This defect is commonly referred to as a "hole in the heart." The two most common forms are described below.

- *Atrial septal defect (ASD)* is an opening between the left and right atria. This allows some blood from the left atrium that has already been to the lungs to return to the right atrium.
- *Ventricular septal defect (VSD)* is an opening between the left and right ventricles. This allows some blood from the left ventricle that has already been to the lungs to return to the right ventricle.

In most cases, septal defects close naturally or are repaired early in the child's life and therefore are not at risk for related complications. If a septal defect has been resolved and the child is not at risk for related complications, URIS 'Group B' support is not required. Consultation with the child's physician may be required to confirm the need for URIS 'Group B' support.

### Complex Congenital Heart Defects

When blood pumped to the body contains less than normal amounts of oxygen, it results in cyanosis, a blue discoloration of the skin. Infants with cyanosis are often referred to as 'blue babies'. These defects are repaired during early infancy and the child will no longer be cyanotic.

- *Tetralogy of fallot* involves four defects that cause cyanosis including:
  - ventricular septal defect (VSD);
  - a narrowing at the pulmonary valve which can block the flow of blood from the right side of the heart to the lungs;
  - a more muscular right ventricle; and
  - an aorta that lies directly over the lower chambers of the heart which allows oxygen-poor blood to flow into the aorta.
- With *transposition of the great arteries*, the position of the pulmonary artery and aorta are reversed. The aorta is connected to the right ventricle so most of the blood returning to the heart from the body is pumped back out without first going to the lungs to refresh with oxygen. The pulmonary artery is connected to the left ventricle so most of the blood returning from the lungs goes back to the lungs again. Some type of opening (e.g. atrial septal defect, ventricular septal defect) also exists between the right and left chambers of the heart.
- *Ebstein's anomaly* affects the valve on the right side of the heart which limits the amount of blood going to the lungs. This may cause cyanosis which varies according to the amount of valve affected.

### Single Ventricle Defects

With single ventricle defects, the ventricles may be smaller, underdeveloped, or missing a valve. These defects are treated with the Fontan procedure.

- With *hypoplastic left heart syndrome (HLHS)*, the left side of the heart is underdeveloped. The aorta and left ventricle are too small and the holes in the artery and septum do not properly mature and close. Blood coming back to the heart from the lungs has to go through an atrial septal defect and blood reaches the aorta through a hole in the septum. Hypoplastic heart syndrome can also occur on the right side.
- With *pulmonary atresia/intact ventricular septum*, the pulmonary valve does not exist. The only blood that receives oxygen when it enters the heart is the blood that is diverted to the lungs through openings that normally close after birth.
- With *tricuspid atresia*, the tricuspid valve has failed to develop so blood cannot flow from the right atrium to the right ventricle. The right ventricle also does not

form fully and is too small. As a result, blood passes through a hole in the atrial septum from the right atrium to the left atrium and mixes with blood coming back from the lungs. Tricuspid atresia is a serious but rare condition.

### **Arrhythmias**

Arrhythmias are abnormal heart beats. They may be completely harmless or life-threatening. Arrhythmias may be related to a congenital heart defect or may occur after surgery. Some arrhythmias are brief and do not significantly affect the overall heart rate or rhythm and treatment may not be required. Other arrhythmias may cause the heart rate to be too slow, too fast or the heart rhythm to be irregular (e.g. Long Q-T syndrome). Arrhythmias are identified by an electrocardiogram (ECG or EKG) that shows the major waves of the electrical signals in the heart. The first wave is the electrical activity on the atria (P wave). The second wave records the electrical activity of the ventricles (QRS wave). The third wave records the heart's return to the resting stage (T wave).

Children with arrhythmias may experience episodes of bradycardia, tachycardia and/or syncope. Bradycardia is a heart rate that is "too slow" to meet the body's needs. Tachycardia is a fast heart rate, usually more than 220 beats per minute. Syncope is a temporary loss of consciousness which can be caused by a rhythm disturbance in the heart.

Arrhythmias that are more common in childhood are included in this document. If a child has an arrhythmic condition that is not described below, it is recommended to consult with the child's physician when developing the health care plan.

#### **Supraventricular tachycardia**

Supraventricular tachycardia (SVT) is the most common tachycardia in children that involves both the atria and ventricles. It is not life-threatening for most children and is often referred to as a "nuisance" disease. The occurrence of tachycardia is not predictable and is not caused by specific events such as increased physical activity.

For SVTs only, vagal (or valsalva) maneuvers can be used to assist in slowing down the heart rate. Vagal maneuvers can be accomplished by closing the mouth and nose while "attempting" to breathe out or blowing through a blocked straw. For babies, applying a bag of ice to their forehead or putting them in a cold shower may help in slowing down the heart rate.

#### **Ventricular tachycardia (VT)**

Ventricular tachycardia (VT) is a fast heart rate that starts in the ventricles. VT is uncommon but can be potentially life-threatening because the ventricles pump blood out to the body.



### Heart block

Heart block can be congenital or acquired after open-heart surgery or other procedures. The electrical signal that normally travels from the atria to the ventricles is either delayed or stopped. It can be either a complete block where no electrical signal reaches the ventricles or incomplete block where some of the impulses reach the ventricles. When this occurs, another "natural pacemaker" in the ventricles takes over but sends signals at a slower rate. If these signals are not fast enough or reliable, an artificial pacemaker is implanted. A child with heart block may experience bradycardia.

### Long Q-T syndrome (LQTS)

Long Q-T syndrome (LQTS) is a less common condition that usually affects children or young adults. When the heart contracts it sends out an electrical signal that can be recorded on an electrocardiogram (ECG) and produces a characteristic waveform that is designated by letters P, Q, R, S and T. The Q-T interval represents the time for electrical activation and inactivation of the ventricles. If this interval takes longer than normal, the child is diagnosed with long Q-T syndrome. The prolonged Q-T interval may occur during physical activity, intense emotion or when startled. LQTS may be treated with medication, surgery or implanting an internal cardioverter defibrillator. Children with LQTS are at a higher risk of episodes when they are swimming and should always swim with a responsible adult who is capable of rescuing them and who is no further than an arm's length away. A child with LQTS may experience tachycardia and syncope.

### Wolff-Parkinson White syndrome

The heart has an extra pathway in the electrical system of the heart which causes the electrical signal to arrive too early at the ventricles. A child with Wolff-Parkinson White syndrome should always swim with a with a responsible adult who is capable of rescuing them and who is no further than an arm's length away because of the potential for life-threatening arrhythmia to occur. A child with Wolff-Parkinson White Syndrome may experience tachycardia and syncope.

### **Genetic Cardiac Conditions**

Cardiomyopathy is a disease in which the heart muscle loses its ability to pump blood effectively. There are 3 categories of cardiomyopathy including dilated , hypertrophic, and restrictive cardiomyopathy. Typically, children are most affected by dilated or hypertrophic cardiomyopathy.

#### Dilated (congestive) cardiomyopathy

Dilated cardiomyopathy is the most common and is characterized by an enlarged and stretched heart muscle and chambers. The heart cannot meet the body's oxygen demands so it preserves blood flow for vital organs (e.g. brain) and reduces blood flow to other body parts (e.g. muscles). A child with dilated cardiomyopathy may experience tachycardia and syncope.

### Arrhythmogenic right ventricular cardiomyopathy (ARVC)

ARVC is a rare type of cardiomyopathy that occurs when the muscle tissue in the right ventricle dies and is replaced with scar tissue. This process disrupts the heart's electrical signals and causes arrhythmias. ARVC usually affects teens or young adults and can cause sudden cardiac arrest. Treatment may include medication, surgery and implanting a pacemaker or internal cardioverter defibrillator. A child with ARVC may experience tachycardia and syncope after physical exercise.

### Hypertrophic cardiomyopathy (HOCM)

HOCM occurs if heart muscle cells enlarge and cause the walls of the left ventricle to thicken. This causes obstruction of blood flow from the left ventricle. It can occasionally cause the right ventricle to thicken as well, making it difficult for blood to leave the heart. These changes can raise blood pressure in the ventricles and blood vessels of the lungs as well as disrupt the heart's electrical signals. HOCM is often hereditary. Strenuous and competitive sports may be restricted as the sudden cardiac arrest may occur during very vigorous physical activity. A child with HOCM may experience tachycardia and syncope.

### **Acquired cardiac conditions**

Cardiac conditions that occur from infections are acquired.

### Kawasaki's disease

Kawasaki's disease causes swelling of the blood vessels and may affect the coronary arteries that carry blood to the heart muscle. In most children, the damage is minor and does not last long. However, it can weaken the walls of the coronary arteries and result in aneurysms which is ballooning of the blood vessel wall. Kawasaki's Disease is treated with medication and the child is usually prescribed blood thinners. Most children recover completely from Kawasaki's Disease.

If a child has Kawasaki's Disease and has coronary aneurysms, URIS Group B support is required. If a child with coronary aneurysms has chest pain, it may be caused by a ruptured aneurysm.

If the child complains of chest pain

1. Contact the parent/guardian immediately.
2. If the parent/guardian or emergency contact cannot be reached, call 911/EMS.

The parent/guardian should also be notified if the child is exposed to chicken pox as the child may be at risk for developing Reye's Syndrome.

### Rheumatic fever

Rheumatic fever is a disease most often caused by bacteria and involves swelling of body tissues such as joints and heart. Rheumatic fever symptoms are the result of an allergic reaction between the bacteria and the body tissues. It can involve the whole heart or parts of it such as the valves or heart muscle. If the heart muscle is involved, it

usually happens early in the course of the infection and the heart muscle usually recovers. Heart valve damage may not be apparent right away. A child with rheumatic fever may be prescribed blood thinners.

### Pulmonary hypertension

Pulmonary hypertension is a rare disorder of high blood pressure in the blood vessels that line the lungs. Because the vessels of the heart and lungs are connected, this raised the blood pressure in the heart and forces the heart to work harder than normal. If the heart cannot push hard enough against the lung pressures, it can lead to heart failure. Congenital heart defects and lung disease are common causes of pulmonary hypertension. Treatment for pulmonary hypertension may include treating or repairing the underlying cause and medications. Children with pulmonary hypertension can become tired easily, experience shortness of breath, have decreased activity level and are prone to fainting. They are often prescribed blood thinners and may have activity restrictions.

### Treatment

Treatments for cardiac conditions may include medication, definitive surgery (e.g., VSD repair), palliative surgery (e.g. Fontan procedure) or implantation of a pacemaker or internal cardioverter defibrillator (ICD).

### Fontan procedure

The Fontan procedure directs oxygen-poor blood to the lungs while the ventricle pumps the oxygen-rich blood to the body. It is often the last procedure in the series of surgeries to repair single ventricle defects. A child with a Fontan procedure has only one pumping chamber that pumps blood to the body and blood flows passively to the lungs.

A child with a Fontan does not have activity restrictions but they should be allowed to self-regulate their activity level as they may not have the same activity tolerance as their peers. A child with a Fontan procedure may be prescribed blood thinners.

### Heart transplant

A child with a heart transplant will be on anti-rejection medication. Some of the side effects include headache, tremors, mood and behavior changes, confusion, tingling of hands and feet. The parent should be informed if the child experiences any of these side effects

The following precautions are recommended for a child with a heart transplant.

#### *Sports*

- The child should have a 5 minute warm up before vigorous exercise and 5 minute cool down period after vigorous exercise. The child's new heart is "denervated" which means the nerve that provided communication between the brain and heart was disconnected during transplant surgery. This nerve increases the heart rate during exercise. If exercise is started to quickly, the child may experience shortness of breath and fainting.

- The child may require frequent breaks during exercise as they may not have sustained energy for up to one year after the transplant.
- The child should be allowed to stop exercising if they feel unwell at any time.

### *Preventing infections*

- The child should be encouraged to wash his/her hands frequently.
- The child should avoid close contact with people who have respiratory illness and avoid exposure to persons with tuberculosis.
- The parent should be informed if there are cases of communicable disease including measles, mumps rubella or chicken pox in the community program.
- The parent should be informed if the child has a fever or flu symptoms (nausea, vomiting, diarrhea, unexplained pain).

### *Food/drink*

- The child should have a water bottle with them as they need to drink at least two liters of water daily.
- Do not give the child food or drink with grapefruit (e.g. mixed juices) as it interacts with anti-rejection medication.
- The child should avoid raw/undercooked eggs, meat, seafood, raw seed sprouts, soft cheeses and unpasteurized milk.
- When serving the child hot dogs, turkey franks and deli meats, they should be thoroughly cooked.
- When serving the child fruits and vegetables, they should be peeled and thoroughly washed.

### *Environment*

- The child should avoid activities that generate a large amount of dust. The child should wear gloves and mask if dust is generated.
- The child should avoid gardening/farming for the first year after transplant.
- The child should avoid cleaning animal cages or litter boxes.
- The child should avoid pigeon/bird droppings, chicken coops, caves, stray animals and mice droppings.
- The child should avoid contact with reptiles, chicks, ducklings, hedgehogs and monkeys.
- The child should avoid pets, especially cats, that are less than 1 year of age.

### Pacemaker

The sinus node, the heart's "natural pacemaker", discharges regular electrical signals that cause the heart to beat. A pacemaker is a battery operated device that may be used to maintain normal heart rhythm when the sinus node is affected. A pacemaker may be needed if the heart rate is abnormally slow, there is a problem with the regular discharge of electrical signals or the sinus node is not working.

The pacemaker has a pulse generator which is a small unit with a computer that generates the electrical signal. It is implanted in the upper chest or abdomen. Wires with electrodes transmit the electrical signal from the pulse generator to the heart muscle. These electrical signals cause the heart muscle to contract.

Pacemakers are built with protective shields so the majority of items that a person comes into contact with will not affect the pacemaker. However, devices that generate, transmit or use electricity may affect the normal operation of the pacemaker. It is recommended to use devices that are in good working condition and to maintain a minimum distance, if recommended, between the device and pacemaker. Some devices that could interfere with the function of the pacemaker include metal detectors, store security gates/entrances and machines that emit strong magnetic/electrical fields. The *Electromagnetic Compatibility for Pacemakers/ICDs* table (see below) provides information on devices that may interfere with the function of the pacemaker.

After the pacemaker is implanted, the child should not carry a backpack on the side that the pacemaker is located for six weeks. A light pack can be worn over both shoulders. The child may return to regular physical activity after six weeks. Sports in which the pacemaker is likely to be hit forcefully should be avoided (e.g. dodge ball, football, hockey, boxing, wrestling). It is the parent's responsibility to determine the level of physical activity that is appropriate for their child. If the community program is uncertain about the child's participation in a specific activity, the parent/guardian should be consulted prior to the activity.

A child with a pacemaker may experience bradycardia and syncope.

#### Internal cardioverter defibrillator (ICD)

An internal cardioverter defibrillator (ICD) may be implanted if a child has a life-threatening arrhythmia. It is a battery-powered device implanted in a pouch under the skin of the chest or abdomen. It is the size of a pocket watch. It has wires that go to the surface of or inside the heart and keep track of the heart rate. If an abnormal heart rhythm is detected, the device delivers an electric shock to restore a normal heart rhythm.

After the ICD is implanted, the child should not carry a backpack on the side that the ICD is located for six weeks. A light pack can be worn over both shoulders. The child may return to regular physical activity after six weeks. Sports in which the ICD is likely to be hit forcefully should be avoided (e.g. dodge ball, football, hockey, boxing, wrestling). When swimming, the child should be partnered with a buddy in the event they experience an irregular heart rhythm in the water. Bungee jumping should be avoided as the forces experienced can damage the ICD leads. Laser tag should be avoided as the magnetic vest can interfere with the function of the ICD. It is the parent's responsibility to determine the level of physical activity that is appropriate for their child. If the community program is uncertain about the child's participation in a specific activity, the parent/guardian should be consulted prior to the activity.

The majority of items that a person comes into contact with will not affect the normal operation of the ICD. However, devices that generate, transmit or use electricity may affect the normal operation of the ICD. It is recommended to use devices that are in good working condition and to maintain a minimum distance between the device and the ICD. Some devices that could interfere with the function of the ICD include metal detectors, store security gates/entrances and machines that emit strong magnetic/electrical fields. The *Electromagnetic Compatibility for Pacemakers/ICDs* table (see below) provides information on devices that may interfere with the function of the ICD.

If the ICD delivers a shock

1. Put the child in the recovery position (lying on left side).
2. Ensure child's safety.
3. If the child is responsive and received one shock, contact the parent/guardian.
4. If the parent/guardian or alternate contact cannot be reached, call 911/EMS.
5. If the child is not responsive or received more than one shock, call 911/EMS.

If the ICD is not working properly, the child may experience tachycardia or syncope. If this occurs, call 911/EMS.

## Electromagnetic Compatibility for Pacemakers/ICDs

<b>No known risk</b>  If the item is used as intended and in good working condition there is no known risk.	<b>Minimal risk</b>  Maintain at least a 6-inch distance between the item and the pacemaker	<b>Special considerations</b>  Maintain at least the recommended distance between the item and the pacemaker
<b>Household items</b> <ul style="list-style-type: none"> <li>• Battery charger (for household batteries)</li> <li>• Casino slot machine</li> <li>• CD/DVD or VHS player</li> <li>• Dishwasher</li> <li>• Electric blanket</li> <li>• Electric guitar</li> <li>• Garage door opener</li> <li>• Heating page</li> <li>• Hot tub</li> <li>• Ionized air filter</li> <li>• Iron</li> <li>• Kitchen appliances – small &amp; large</li> <li>• Massage chair/pad</li> <li>• Medical allergy necklace</li> <li>• Microwave</li> <li>• Radio/iPod</li> <li>• Remote control</li> <li>• Salon hair dryer</li> <li>• Shaver – battery powered</li> <li>• Tanning bed</li> <li>• TV</li> </ul>	<b>Household items</b> <ul style="list-style-type: none"> <li>• Cordless headphone sending unit (TV/Stereo)</li> <li>• Cordless telephone – from antenna and charging base</li> <li>• Electric golf cart – from motor</li> <li>• Electric kitchen appliances – hand-held</li> <li>• Electric shaver – corded</li> <li>• Electric toothbrush charging base</li> <li>• Hair dryer – hand-held</li> <li>• Home wireless electronics – from antenna</li> <li>• Magnetic therapy products</li> <li>• Radio-control items – from antenna</li> <li>• Sewing machine/serger – from motor</li> <li>• Small magnet (household magnet)</li> <li>• Speakers</li> <li>• Treadmill – from motor</li> <li>• Vacuum cleaner – from motor</li> </ul>	<b>Household items</b> <p>12 inch distance</p> <ul style="list-style-type: none"> <li>• car-motorcycle – from components of ignition system</li> <li>• electric fence</li> <li>• electric pet containment fence</li> <li>• transformer box (green box in yard)</li> </ul> <p>2 foot distance</p> <ul style="list-style-type: none"> <li>• beach comber metal detector – from search head</li> <li>• Induction Cooktop Stove</li> </ul> <p>NOT RECOMMENDED</p> <ul style="list-style-type: none"> <li>• AB Stimulator</li> <li>• Electric Body Fat Scale</li> <li>• Magnetic Mattress Pad/Pillow</li> </ul>
<b>Office equipment</b> <ul style="list-style-type: none"> <li>• Copy machine</li> <li>• Desktop/laptop computer</li> <li>• Fax machine</li> <li>• GPS</li> <li>• Low voltage residential power lines</li> <li>• Metal detectors archway</li> <li>• Pager – receiver only</li> <li>• Printer</li> <li>• Scanner</li> <li>• Theft detection systems</li> </ul>	<b>Office equipment</b> <ul style="list-style-type: none"> <li>• Airport screening wand</li> <li>• Amateur radios, Ham radios, Marine Radios, Walkie Talkies – 3 watts or less – from antenna</li> <li>• Cell phone – 3 watts or less – from antenna</li> <li>• On Star Technology – from antenna</li> <li>• Security Badge Wall Scanner</li> <li>• Wireless Communication Items (computer, headsets, modem, Palm Pilot, router)</li> </ul>	<b>Office equipment</b> <p>12 inch distance</p> <ul style="list-style-type: none"> <li>• Amateur radio, Ham Radio, marine Radio, Walkie Talkie – between 3-15 watts – from antenna</li> <li>• Citizens band (CB) Radio – 5 watts or less –from antenna</li> </ul> <p>2 foot distance</p> <ul style="list-style-type: none"> <li>• Amateur Radio, Ham Radio, marine Radio, Walkie Talkie – between 15-30 watts – from antenna</li> </ul>
<b>Industrial equipment</b> <ul style="list-style-type: none"> <li>• Calipers – battery powered</li> <li>• Flashlight – battery powered</li> <li>• Laser level</li> <li>• Soldering iron</li> <li>• Stud finder</li> </ul>	<b>Industrial equipment</b> <ul style="list-style-type: none"> <li>• Circular Saw – skill saw</li> <li>• Drills – battery and electric</li> <li>• Grinder (hand-held)</li> <li>• Hedge trimmer – electric</li> <li>• Lawn mower – electric</li> <li>• Leaf blower – electric</li> <li>• Reciprocating saw</li> <li>• Router</li> <li>• Sander</li> <li>• Screwdriver – battery powered</li> <li>• Soldering Gun</li> <li>• Weed Whacker – electric</li> </ul>	<b>Industrial equipment</b> <p>12 inch distance</p> <ul style="list-style-type: none"> <li>• car battery charger – 100 amps or less</li> <li>• Gasoline Ignition Systems – from component of ignition system</li> <li>• Gasoline powered tools – from components of ignition system</li> <li>• Generators – 20 kW or less</li> </ul> <p>2 foot distance</p> <ul style="list-style-type: none"> <li>• Bench mounted/free standing tools – for motors 400 horsepower or less (air compressor, drill presses, grinder, pressure washer, table saw)</li> <li>• Jumper cables</li> </ul> <p>NOT RECOMMENDED</p> <ul style="list-style-type: none"> <li>• Chainsaws</li> <li>• Welding equipment</li> </ul>

## **Activity restrictions**

Most children with cardiac conditions can participate in physical activities without restrictions. However, some children may not be able to participate in competitive sports where there is strenuous training and prolonged physical exertions (e.g. football, hockey, wrestling, soccer, basketball).

The Variety Heart Centre uses the following categories to determine the levels of recommended activity for a child with a cardiac condition.

- May participate in the entire education program, including varsity competitive sports without any restrictions.
- May participate in the entire physical education program EXCEPT for varsity competitive sports where there is strenuous training and prolonged physical exertion such as football, hockey, wrestling, soccer and basketball. Less strenuous sports such as baseball and golf are acceptable at varsity level. All activities during the regular physical program are acceptable.
- May participate in the physical education program EXCEPT for restrictions from all varsity sports and from excessively stressful activities such as rope climbing, weight lifting, sustained running and fitness testing. MUST be allowed to stop and rest when tired.
- May participate ONLY in mild physical activities such as walking, golf and circle games.
- RESTRICTED from the entire physical education program.

It is the parent's responsibility to determine the level of physical activity that is appropriate for their child. If the community program is uncertain about the child's participation in a specific activity, the parent/guardian should be consulted prior to the activity.

## **Infective endocarditis**

Infective endocarditis (IE) is an infection caused by bacteria that enters the bloodstream and can affect the heart lining, heart valves or blood vessels. Endocarditis can lead to permanent damage to the heart. The bacteria that causes endocarditis can usually be found in the mouth, digestive tract and urinary tract.

IE is not common but children with certain cardiac conditions are at greater risk of developing it. Some medical and dental procedures can increase the chance of IE because the procedure may cause bleeding which allows bacteria to enter the blood.

If a child with a cardiac condition is being transported to the hospital for any medical emergency, ensure that EMS personnel are aware that he/she has a cardiac condition so procedures can be implemented to prevent IE, if required.



## **Blood thinners**

If a child with a cardiac condition is prescribed a blood thinner, he/she is at risk for prolonged bleeding. Therefore, participation in contact sports such as football, hockey, wrestling, full contact soccer, lacrosse, downhill skiing, boxing, rugby may be restricted. It is the parent's responsibility to determine the level of physical activity that is appropriate for their child. If the community program is uncertain about the child's participation in a specific activity, the parent/guardian should be consulted prior to the activity.

A child who is prescribed blood thinners should not be given aspirin or non-steroidal anti-inflammatory drugs. If the child is prescribed aspirin, the parent should be notified if the child is exposed to chicken pox.

## **External bleeds**

External bleeds are treated with standard first aid.

### *Cuts and scrapes*

1. Put on gloves.
2. Clean the skin.
3. Apply firm continuous pressure until the bleeding stops.
4. Apply a band-aid or dressing.
5. Encourage ice.
6. Contact the parent/guardian for instructions if bleeding has not stopped after 20 minutes. If unable to contact parent/guardian or emergency contact, call 911/EMS.

### *Nose bleeds*

1. Put on gloves.
2. Encourage the child to gently blow his/her nose to remove mucous and unstable clots. Once the bleeding has stopped, encourage the child to NOT blow his/her nose again for as long as possible (at least 1-2 hours)
3. Position the child in a sitting position with their head slightly forward.
4. Apply firm continuous pressure for a minimum of 10 minutes or until bleeding stops. Use a cold cloth if possible.
5. Contact the parent/guardian if bleeding has not stopped after 20 minutes.
6. If unable to contact the parent/guardian or emergency contact, call 911/EMS.

### *Bleeding in the mouth*

1. Put on gloves.
2. Apply firm continuous pressure (when applicable) until the bleeding stops. Use a cold cloth if possible.
3. Encourage popsicles or ice.

4. Encourage the child to spit out rather than swallowing the blood as it can upset their stomach.
5. Contact the parent/guardian if bleeding has not stopped after 20 minutes.
6. If unable to contact the parent/guardian or emergency contact, call 911/EMS.

### *Joint and muscle bleeds*

The child may be reluctant to use a limb or it may feel tight. It will gradually swell, feel hot to touch and become painful. Bleeding most commonly occurs in ankles, knees and elbows. Muscle bleeds can occur anywhere in the body.

1. Have the child rest. Keep the child still to avoid further injury.
2. Apply ice to injury. Do not apply ice longer than 20 minutes and keep a cloth layer between the ice and bare skin.
3. Elevate the injury body part.
4. Contact the parent/guardian. If unable to contact parent/guardian or emergency contact after 15 minutes, call 911/EMS.

### *Bruising*

Visible bruising is usually not serious. Small bruises usually resolve on their own. However, if a child complains of ongoing pain at a bruised site, inform the parent/guardian.

### Internal Bleeds

Bleeding into the head, eye, neck, chest or abdomen may be life-threatening and requires immediate medical attention.

All *head injuries* must be considered serious as there is a risk of a brain hemorrhage. Possible signs of internal bleeding in the head may include loss of consciousness, drowsiness, dizziness, irritability, lethargy, nausea and/or vomiting, dilated or unequal pupils, headache, confusion and/or unsteady gait.

An *injury to the eye and/or surrounding area* could potentially result in an eye-threatening injury (e.g. loss of vision). Possible signs of internal bleeding in the eye include pain and/or swelling.

*Neck bleeding* is serious because of the potential to block the airway. Any injury to the neck area as well as a child's expressing pain and tenderness should be attended to quickly. Possible signs of internal bleed in the neck area include pain, swelling, difficulty swallowing and/or difficulty breathing.

*Injuries to the chest* may be very painful if there is bleeding into the muscles between the ribs. Possible signs of internal bleed in the chest include pain, difficulty breathing, coughing up blood, pale skin and/or lack of energy

A blow to the *stomach* is serious because of the potential injury to vital internal organs.

Possible signs of internal bleed in the abdomen include pain in abdomen or lower back, nausea, vomiting, blood in the urine and/or black or bloody stool.

If the child suffers a significant injury to the head, eye, neck, chest or abdomen with or without showing signs of internal bleeding

1. Call 911/EMS.
2. Do not move the child, unless the child is in an unsafe place.
3. Notify the parent/guardian.

### **Congestive heart failure**

Congestive heart failure (CHF) occurs when the heart is unable to pump an adequate amount of blood to meet the body's needs. It does not mean that the heart will stop or that a heart attack will happen. CHF can take several days or weeks to develop. CHF can be caused by congenital heart defects, arrhythmias or diseases that weaken the heart muscle.

### **Signs of congestive heart failure**

Signs of congestive heart failure are more noticeable in babies when they are feeding and in children when they are exercising and playing actively.

- Sweating during quiet time
- Persistently rapid/labored breathing
- Shortness of breath
- Rapid heart rate or irregular heart rate
- Chest pain
- Nasal flaring
- Blueness on or around the mouth, eyes, ears, and/or finger tips
- Listlessness (tired and unwilling to do normal activities)
- Inability to stop coughing
- Skin becomes increasingly pale or blue
- Suddenly tired

### **Responding to congestive heart failure**

1. Have the child rest.
2. If symptoms do not improve, contact the parent/guardian.
3. If symptoms do not improve and you are unable to reach parent/guardian or emergency contact within 5-10 minutes, activate 911/EMS.
4. Place the child on the floor in recovery position (lying on left side).
5. Keep the airway open. Loosen any tight restrictive clothing.
6. Stay with the child until EMS personnel arrive.
7. Inform EMS that the child has a cardiac condition.

If the child has noisy gurgled breathing, which may be caused by fluid build-up in the lungs, call 911/EMS.

## **Loss of consciousness**

### **Sudden cardiac arrest**

A child that is diagnosed with a cardiac condition is at risk for sudden cardiac arrest. Most cardiac arrests occur when the heart's electrical system malfunctions, producing an abnormal rhythm. Some cardiac arrests are caused by extreme slowing of the heart's rhythm. Cardiac arrest may be reversed if CPR is performed and an automated external defibrillator (AED) is used to restore a normal heart rhythm. It is highly recommended that community program personnel trained in CPR and use of an AED are available when a child with a cardiac condition attends the community program.

### **Syncope**

Syncope is a temporary loss of consciousness, described as passing out or fainting. Cardiac conditions such as HOKM, Wolff Parkinson's White Syndrome, Long QT Syndrome, CPVT and ARVC can cause syncope. Syncope caused by a rhythm disturbance in the heart usually occurs without warning and the loss of muscle tone is almost immediate and complete. It often occurs during exercise.

If the child does not regain consciousness within 1 minute

1. Call 911/EMS.
2. Implement CPR and the use of an artificial external defibrillator (AED), if available.
3. Notify the parent/guardian.
4. Inform EMS that the child has a cardiac condition.

## **Tachycardia**

Tachycardia is a fast heart rate, usually more than 220 beats a minute. In addition to a rapid heartbeat, the child may experience fatigue, dizziness, lightheadedness, chest pain, shortness of breath, upset stomach or weakness.

If tachycardia occurs (i.e. heart rate is too fast to count)

1. Have the child rest.
2. If symptoms do not improve contact the parent/guardian.
3. If the parent/guardian or emergency contact cannot be reached, call 911/EMS.
4. Stay with the child until EMS personnel arrive.
5. Inform EMS that the child has a cardiac condition.

For SVTs only, vagal (or valsalva) maneuvers can be used to assist in slowing down the heart rate. Vagal maneuvers can be accomplished by closing the mouth and nose while "attempting" to breathe out or blowing through a blocked straw. For babies, applying a

bag of ice to their forehead or putting them in a cold shower may help in slowing down the heart rate. Vagal maneuvers can be attempted for up to 20 minutes before contacting the parent/guardian.

1. Have the child rest and perform vagal maneuvers .
2. If symptoms do not improve after 20 minutes, contact the parent/guardian.
3. If the parent/guardian or emergency contact cannot be reached, call 911/EMS.
4. Stay with the child until EMS personnel arrive.
5. Inform EMS that the child has a cardiac condition.

### **Bradycardia**

Bradycardia is a slow heart rate, usually less than 40 beats per minute. The child may experience a decreased level of activity, weakness, paleness and/or dizziness with bradycardia.

If the child experiences any of the symptoms:

1. Contact the parent/guardian.
2. If symptoms do not improve in 20 minutes and you are unable to contact parent/guardian or emergency contact, call 911/EMS.
3. Stay with the child until EMS personnel arrive.
4. Inform EMS that the child has a cardiac condition.

## HEALTH CARE PLAN

When a community program receives URIS Group B support for children with URIS 'Group B' health care needs, a written health care plan is developed and maintained by a registered nurse minimally on an annual basis. The development and implementation of the health care plan should reflect the principles of inclusion, normalization and independence.

- A child with a cardiac condition is foremost a child within a family, child-care facility, classroom or other community program.
- The environment should be changed to support the child, not the child changed to suit the environment.
- Interventions should be as non-intrusive as possible and be delivered in a manner that respects the child's dignity and privacy as well as the normal routines and patterns of the community program.
- The parent/guardian and child have rights and obligations and should be encouraged to actively participate in decisions affecting them.

Consultation with the parent/guardian and community program is required to develop a health care plan that is relevant to the child's needs and appropriate within the community program setting. For some children, the management of their cardiac condition within the community program may not require any specific interventions at community program however the management may be complex and require consultation with health care professionals who are involved with the child.

When a child has multiple health care needs, all relevant information should be integrated into one comprehensive health care plan. The format should be user friendly and include information that is required to manage the child's cardiac condition in a safe and appropriately manner during attendance at the community program

The health care plan should be kept in a location that is secure and accessible. Community program personnel that are responsible for the child should be aware of its location. The health care plan should accompany the child on excursions outside the facility.

### **Content**

The following information is included in the cardiac condition health care plan. The *Cardiac Condition Health Care Plan* contains this information and is included as a supplement to this document.

### **Demographic information**

- Child's name
- Birth date
- Community program name
- Parent(s)/guardian(s) name and phone number(s)

- Alternate emergency contact name and phone number(s)
- Cardiologist name and phone number
- Family physician/pediatrician name and phone number

Medical information

- Medical diagnoses and other relevant conditions
- Known allergies
- Availability of Medic-Alert® identification
- Prescribed medications
  - If medication is administered at home, the name of medication is required
  - If medication is administered at the community program, drug name, dose, location, time and route of administration is required

Cardiac condition information

- Type of cardiac condition
- History (e.g. when diagnosed, surgeries)
- Current status
- Precautions, if any
- Restrictions, if any

Emergency situations and required actions

- Congestive heart failure
- Loss of consciousness
  - Sudden cardiac arrest
  - Syncope, if relevant to the child (see table below)
- Bradycardia, if relevant to the child (see table below)
- Tachycardia, if relevant to the child (see table below)
- Responding to bleeds, if the child is prescribed a blood thinner

<b>Cardiac condition</b>	<b>Syncope</b>	<b>Bradycardia</b>	<b>Tachycardia</b>
Supraventricular tachycardia			X
Ventricular tachycardia			X
Heart block		X	
Long Q-T syndrome	X		X

Wolff-Parkinson White syndrome	X		X
<b>Cardiac condition</b>	<b>Syncope</b>	<b>Bradycardia</b>	<b>Tachycardia</b>
Dilated cardiomyopathy	X		X
Arrhythmogenic right ventricular cardiomyopathy (ARVC)	X		X
Hypertrophic cardiomyopathy (HOCM)	X		X
Child with a pacemaker	X	X	
Child with an ICD	X (911 emergency)		X (911 emergency)

### Documentation

- Template for recording interventions and actions performed by the nurse and/or community program personnel (e.g., communication, actions taken)
- Signatures & dates
  - Nurse signature & date(s) of health care plan development/review
  - Parent/guardian signature & date

### **When child has supraventricular tachycardia (SVT)**

When the child has SVT, the health care plan also includes the use of vagal maneuvers when responding to episodes of tachycardia. The *Cardiac Condition Health Care Plan – Supraventricular tachycardia* contains this information and is included as a supplement to this document.

### **When child has a pacemaker**

When the child has a pacemaker, the health care plan also includes the information listed below. The *Cardiac Condition Health Care Plan – Pacemaker* contains this information and is included as a supplement to this document.

- Syncope
- Bradycardia
- Precautions
- Electromagnetic compatibility for pacemakers/ICDs

### **When child has an internal cardioverter defibrillator (ICD)**

When the child has an ICD, the health care plan also includes the information listed below. The *Cardiac Condition Health Care Plan – ICD* contains this information and is included as a supplement to this document.



- If the ICD delivers a shock
- Tachycardia due to ICD not working properly
- Syncope due to ICD not working properly
- Precautions
- Electromagnetic compatibility for pacemakers/ICDs

### **When child has had a heart transplant**

When the child has had a heart transplant, the health care plan also includes the information listed below. The *Cardiac Condition Health Care Plan – Heart Transplant* contains this information and is included as a supplement to this document.

- Responding to side effects of anti-rejection medication
- Precautions

### **When child has Kawasaki's disease and is at risk for coronary aneurysms**

When the child has Kawasaki's Disease and is at risk for coronary aneurysms, the health care plan also includes the information listed below. The *Cardiac Condition Health Care Plan – Kawasaki's disease* contains this information and is included as a supplement to this document.

- Responding to chest pain
- Exposure to chicken pox
- *Blood Thinner Emergency Response Plan*

### **When child is prescribed blood thinners**

When the child with a cardiac condition is prescribed blood thinners, the following information is to be included in the health care plan. The *Blood Thinner Emergency Response Plan* contains this information and is included as a supplement to this document.

- Responding to external bleeds
- Responding to internal bleeds

## TRAINING

When a community program receives URIS 'Group B' support, training is provided to community program personnel by a registered nurse. Training is provided minimally on an annual basis. The training of community program personnel should reflect the principles of adult learning.

- The learning needs of participants should be identified and integrated into the training session.
- Information should be applicable to the participants' responsibilities and focus on what is most useful to them.
- Adults have accumulated a foundation of life experiences and knowledge and need to connect learning to this knowledge base.
- An organized training session with clearly defined elements assists participants in identifying and attaining learning goals.

It is recommended that all community program personnel that may be responsible for a child with a cardiac condition attend the training session. As an example, community program personnel that may be responsible for a child with a cardiac condition in a school may include teachers, teaching assistants, school administrators, office staff, substitute teachers, bus drivers and lunch room supervisors. The community program is responsible to ensure personnel that may be responsible for a child with a cardiac condition attend the training session. It is recommended to keep a written record that indicates community program personnel in attendance and date that training occurred.

Adequate time should be scheduled for training to ensure community program personnel obtain the knowledge and skill necessary to safely respond to the needs of children who have a cardiac condition within their facility. The amount of time required to train community program personnel will vary depending on factors such as the existing knowledge of community program personnel, number of persons attending the training session and the format of training resources used (e.g. PowerPoint, Worksheet).

To ensure service is provided in an efficient manner, training should be scheduled when all community program personnel that may be responsible for the child can attend. If an adequate number of community program personnel did not attend the training session, additional training should be scheduled. If subsequent training sessions are also poorly attended, alternate strategies should be discussed with the community program to ensure training is provided in an efficient manner.

When the community program has not received training, a child with a cardiac condition may attend the community program. In such situations, the community program's standard policy for medical emergencies is implemented, as required.

## **Content**

The following clinical information and child specific information is included in the training session.

### **Standard clinical information**

- How the heart works
- Types of cardiac conditions
- Treatment of cardiac conditions
- Activity restrictions
- Infective endocarditis
- Emergency situations
  - Congestive Heart Failure
  - Loss of consciousness
    - Sudden cardiac arrest
    - Syncope, if relevant to child
  - Tachycardia, if relevant to child
  - Bradycardia, if relevant to child
- Pacemaker, if relevant to child
  - Precautions
  - Syncope
  - Bradycardia
  - Electromagnetic compatibility
- Internal cardioverter defibrillator, if relevant to child
  - If the ICD delivers a shock
  - Syncope
  - Tachycardia
  - Precautions
  - Electromagnetic compatibility
- Heart transplant, if relevant to child
  - Side effects of anti-rejection medication
  - Precautions
- Responding to bleeds, if child is prescribed blood thinners
  - Internal bleeds
  - External bleeds

### **Child specific information**

- Type of cardiac condition
- Activity restrictions
- Additional information specific to child

## **Training Resources**

The following resources may be used for training purposes and are included as supplements to this document. If alternate resources are used, it is the responsibility of the nurse to ensure its content is consistent with the clinical information included in this document.

- *Cardiac Condition Handout* includes only information that is relevant to all cardiac conditions.
- *Cardiac Condition PowerPoint* includes information that is relevant to all cardiac conditions (slides 1-10) and then information that is relevant only to specific cardiac conditions (slides 11-17). When a training session includes information that is relevant only to specific cardiac conditions, it is recommended to rearrange the slides so that only relevant information is included.
- The *Cardiac Condition Worksheet* (Word and PowerPoint version) is recommended for community program personnel that have previously attended a cardiac condition training session. The Microsoft Word version may be better suited for individuals or small groups. The Microsoft PowerPoint version may be more suitable for large group settings.

## MONITORING

Monitoring of trained community program personnel by a nurse is required to ensure that the knowledge and skill necessary to safely care for children with cardiac conditions has been retained. Monitoring is required minimally on an annual basis.

The frequency and timing of monitoring is based on the professional judgment of the nurse as well as the complexity of information taught, maturational issues and the skill demonstrated by community program personnel. Some monitoring strategies are listed below.

- Community program personnel complete the *Cardiac Condition Training Session Evaluation Form* after attending the training session. It is included as a supplement to this document.
- Community program personnel complete the *Cardiac Condition Worksheet* after attending the training session.

## REFERENCES

**American Heart Association website.** [www.heart.org](http://www.heart.org)

**Heart & Soul. Your Guide to Living with Congenital Heart Disease.** Heart and Stroke Foundation

**Your Child has a Pacemaker,** 2004. Pritchett & Hull Associates.

**The Beat Goes On,** 2007. Pritchett & Hull Associates.

Houston, Kate. **Arrhythmogenic Right Ventricular Cardiomyopathy, An Information Booklet for Parents,** 2008. The Canadian SADS Foundation

Houston, Kate. **Long QT Syndrome, An Information Booklet for Parents,** 2008. The Canadian SADS Foundation

## RESOURCES

The following list includes resources that may be relevant to community programs in the care of children with cardiac conditions. The purpose of these agencies/organizations may not be consistent with the purpose and content of this manual.

**American Heart Association**

[www.heart.org](http://www.heart.org)

**Hospital for Sick Children**

[www.sickkids.ca](http://www.sickkids.ca)

**Western Children's Heart Network**

[www.westernchildrensheartnetwork.ca](http://www.westernchildrensheartnetwork.ca)

**Canadian Congenital Heart Alliance**

[www.cchaforlife.org](http://www.cchaforlife.org)