

Caring for Your Child After Heart Surgery



Department of Cardiology
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Transitioning to home after heart surgery can be both a happy and anxious time. We encourage you to see your health practitioner on a regular basis. This information is meant to answer some frequently asked questions, however do not hesitate to contact your health practitioner with concerns or additional questions.

Care of Your Child's Incision

- You will be given written instructions and shown how to do this before your child leaves the hospital.
- Check the wound for signs of infection. Look for redness, swelling, drainage, the wound edges coming apart or fever above 38° C.
- For babies and young children who may drool or spill food on the wound, clean the wound daily with the normal saline provided to you in the hospital. Keep it covered with a gauze dressing.
- For toddlers and older children gently wash the wound and chest tube sites at least once a day with a gentle soap and water. Dry thoroughly.
- It is normal to see bruising or swelling around the wound or bumpiness over the breastbone.
- Children can go back to showering once they are walking again.
- Your child can have a bath 10 days after the surgery as long as there are no signs of infection.
- Do not use lotions, creams or powders until the wound and chest drain sites are well healed and all the scabs have fallen off.
- Keep your child's hands clean and nails trimmed. Discourage your child from scratching or touching the wound by keeping the area covered with gauze.
- Have your child wear protective clothing or a sun block with a sun protection factor greater than 30 (SPF 30+) when the scar cannot be kept out of the sun. Surgical scars are more sensitive to sun damage than normal skin. These precautions should be taken as long as the scar looks pink. It usually takes a year before the scar returns to the normal skin colour.
- Contact the Nurse Practitioner at 604-875-2345 local 8968 if you notice:
 - Any signs of infection.
 - Dissolvable suture material, which looks like clear fishing line, poking through the skin.

Pain Management

- You can give your child acetaminophen, also called Tylenol®, for several days after surgery. Please contact the Nurse Practitioner to know how much to give and how often to give it.

Diet

Infants:

- Infants may feed on demand. You may find your baby takes shorter, more frequent feeds in the first few weeks following surgery.

- If weight gain is a concern for your baby, it is recommended to feed your baby at least every 3 to 4 hours. Ask your cardiology nurse clinician how long you will need to follow this.
- Limit each feed to 30 minutes so your baby has adequate time to rest.
- Your baby may need extra supplements to help them gain weight. Written information is available on preparation of feeds if required.
- Lactation Consultants are available if you have breastfeeding concerns. Call 604-875-2282.

Toddlers, School-aged Children, and Youth:

- Offer your child a regular diet unless otherwise instructed. Encourage a balanced diet of foods that promote healing.
- Some children may need more iron in their diet if their hemoglobin is low. Please check with your Pediatrician or Cardiologist if this is a concern.
- If constipation is a concern, encourage a diet rich in fruits, vegetables and other foods high in fiber. If this remains a problem and treatment is required, please contact your Pediatrician.

Behaviour

When a child goes home after surgery, parents sometimes notice he or she goes back to earlier childhood behaviors. This may include:

- bedwetting
- awakening during the night
- fussiness
- nightmares
- needing to be close to parents more often

These behaviors generally decrease within a short period of time.

Support your child during this stressful time, as well as set limits. If your child needs additional support, please contact the Nurse Practitioners.

Activity

Infants & Toddlers:

- Most children at these ages do not need restrictions from usual activities.
- When caring for your child:
 - For the first 2 to 3 weeks it may be uncomfortable to pick them up under the arms.
 - Tend to your baby's needs to prevent long periods of crying

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Preschoolers, School-age children, and Youth:

- Encourage your child to get dressed each morning, brush their teeth, join the family for meals and start to catch up on missed school work.
- Activity is restricted for 6 weeks to allow the wound to completely heal.
- Avoid rough play or activities associated with an increased risk of falling on the chest, such as bicycling, skating, climbing or contact sports. Walking and climbing stairs is not a problem. Ask about specific sports at your follow up appointment.
- Do not go swimming until the wound is well healed and there is no sign of infection. The earliest is 6 weeks after the surgery.
- Do not lift objects weighing more than 5 to 10 pounds (backpacks, younger siblings, or pets) for 4 to 6 weeks.
- Youth who have their drivers' licenses should not drive a car for 4 to 6 weeks. He or she may need his or her health status checked before driving again. Check with the cardiologist at your follow up appointment.

Immunizations

- Wait for at least 6 weeks after surgery before having your child immunized.
- You will be given a card that indicates which blood products your child received during surgery. You may need to wait up to 7 months before certain immunizations can be given. Usually, this only applies to the measles, mumps & rubella (MMR) vaccine and the chickenpox (varicella) vaccine. These vaccines are usually given at 12 months and 4-6 years of age. Ask your pediatrician or call the Children's Heart Centre if you have questions about specific immunizations.
- If your child is older than 6 months, the flu vaccine is recommended in the fall. Please discuss this with your pediatrician.
- If your child is less than 2 years they may be eligible to receive a monthly medication that helps prevent a serious respiratory viral illness called respiratory syncytial virus or RSV. This medication is called Palivizumab which is given monthly between November and April. Please discuss this with your cardiologist. For more information about RSV go to Information for Parents about respiratory syncytial virus or RSV: http://www.cw.bc.ca/library/pdf/pamphlets/CW95_RSV_2015.pdf

Returning to School and Day Care

- Most children are ready to return to school or day care about 2 weeks after leaving the hospital.
- Involvement in physical education activities may need to be adjusted.

Questions and Concerns



Call the Children's Heart Centre if your child has any of the following in the first 8 weeks after surgery:

- Increasing pale skin or cyanosis at rest
- Increasing tiredness or lethargy
- Significant decrease in appetite or food intake
- Significant weight gain or weight loss over a short period of time
- Severe nausea or vomiting
- Change in bowel patterns such as diarrhea or constipation
- Chest pain, particularly with exercise or activity
- Palpitations or pounding in the chest that may indicate an abnormal heart beat
- Anxiety or restlessness
- Fever above 38° C or a low grade fever that doesn't go away
- Overall, your child doesn't seem to be getting better

Important Phone Numbers

If you live outside the Lower Mainland call on the toll free line 1-888-300-3088 and then dial the local extension.

Cardiac Surgeons' Secretary:
604-875-2345 local 7313

Cardiac Pre-op Nurse Clinician:
604-875-2345 local 7877

Cardiac Nurse Clinician:
604-875-2345 local 7877

Partnership Nurse Clinician:
604-875-2345 local 7636

Cardiac Nurse Practitioner:
604-875-2345 local 8968.
The nurse practitioner can answer questions about going home after surgery

Cardiac Social Worker:
604-875-2345 local 7124

Child Life Specialist:
604-875-2345 local 7648

The Family Support and Resource Centre:
604-875-2345 local 5102

Preventing an infection of the lining of the heart called Infective Endocarditis

Infants and children who have had heart surgery are at a higher risk for infective endocarditis or IE for the first 6 months after surgery. Some children will remain at higher risk for longer than 6 months, including children with an artificial heart valve, a surgically constructed shunt or conduit, and/or a history of having infective endocarditis.

Take these steps to prevent Infective Endocarditis:

- Make sure your child flosses and brushes his or her teeth well everyday.
- Limit the number of sugary drinks.
- If your child has a bottle at bed time, fill it with water and not juice or milk.
- Have your child see the dentist regularly, once per year. Good dental hygiene reduces the risk of IE.
- If your child is having certain medical and dental procedures that increase the risk of getting IE, he or she may need a single dose of antibiotics before. Talk to your Doctor or Dentist about this when making your child's appointment

Check with the Cardiology Team as to whether your child needs to take these precautions beyond 6 months.

Post Pericardiotomy Syndrome or PPS

This condition can occur when heart surgery involves entering into a membrane which forms a thin sack around the heart called the pericardium. PPS sometimes occurs in children who have open heart surgery. It is temporary, and will generally go away on its own within 2 to 6 weeks. Sometimes children with PPS need treatments which may include medications such as aspirin, ibuprofen or steroids. Contact your child's Cardiologist if your child is experiencing any of the following symptoms:

- A fever after the first week following surgery
- General feelings of being unwell
- Feeling grumpy or irritable
- Shortness of breath
- Cough, chest and joint pain
- Decreased appetite or hunger