



# Your Child's Heart Surgery



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Here is a booklet to help you before and after your child's surgery.

- Read through it.
- Write down questions as they come up.
- Bring this booklet with you for your visits leading up to your child's surgery.

**At BC Children's Hospital we believe parents are partners on the health care team. We want you to be as informed as possible. Please ask about things you do not understand and share your concerns.**

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# Getting Ready for Surgery

## Your Healthy Child

Your child's surgery can only be done if your child is healthy. Here are some things to do to make sure that he or she is as healthy as possible.

### Teeth

- Some heart defects put children at risk for heart infections . Teeth and gums are an easy way for bacteria to enter the blood. **Make sure your child's mouth, gums, and teeth are healthy.**
- Surgery will be cancelled if your child has any unresolved dental issues that could lead to infection.
- Visit the Dentist THREE MONTHS prior to the proposed surgical date if your child has teeth.
- Have all dental work completed at least one month before the surgery.
- [http://www.cw.bc.ca/library/pdf/pamphlets/BC\\_CH1233AllChildrenCanGrewUpCavityFree.pdf](http://www.cw.bc.ca/library/pdf/pamphlets/BC_CH1233AllChildrenCanGrewUpCavityFree.pdf)



Call the Cardiac Pre-op Nurse Clinician at local 3002 if you are unsure whether your child needs antibiotics before dental work.

### Immunizations

- Please have immunizations up to date four weeks before your child's surgery date. Within the four

weeks prior to your child's surgery, do NOT give any immunizations. Wait until after surgery to "catch up."

- Synagis® (RSV prophylaxis) shots can be done at anytime.

## Illness



Call the Cardiac Pre-op Nurse Clinician at local 3002 if your child becomes ill or has any of the following approximately one month prior to the surgical date:

- Runny nose, cough, fever, diarrhea, vomiting, rash or ear infections
- Has contact with someone with chicken pox, measles, mumps or viruses.

Surgery could be cancelled if your child is sick depending on the symptoms, age of the child, type of surgery your child is having or other factors. This needs to be addressed as early as possible to ensure we can treat your child appropriately and minimize any surgery cancellations.

## Traveling To and Staying in Vancouver, for Families Who Live Outside Vancouver

Please make your travel and accommodation arrangements as soon as you know the date of the surgery. The following lists some organizations and services that may be useful.

### Traveling to Vancouver

The BC Family Residence Program can assist you with organization and funding for bus and air travel plus accommodations. You will need to provide the dates and the reason for travel, child's care card number, and the doctor's name. Call them at 1-800-465-4911 or 604-205-5989 or visit [www.bcfamilyresidence.gov.bc.ca](http://www.bcfamilyresidence.gov.bc.ca).

The BC Family Residence Program works with the following community partners. Each of these partners can be contacted directly.

- Northern Health Connections Bus.  
<https://nhconnections.ca/>
- The Shriners' Care Cruiser.  
[www.shriners.bc.ca/bus](http://www.shriners.bc.ca/bus)
- Hope Air.  
[www.hopeair.org](http://www.hopeair.org)
- Travel Assistance Program (TAP).  
[www.health.gov.bc.ca/tapbc/tap\\_patient.html](http://www.health.gov.bc.ca/tapbc/tap_patient.html)  
Helps with the cost to travel within the province. It must be for a special medical service, that is non-emergency, and that you cannot get in your home community. TAP helps fund the cost of travel by ground, air or ferry. Get the form from your local doctor's office.

## Staying in Vancouver

There are places you can stay that are close to the hospital. Visit <http://www.bcchildrens.ca/our-services/your-visit/planning-your-visit> for a full list of places to stay near the hospital.



Call Family Support and Resource Centre at BC Children's Hospital 1-800-331-1533 if you have other questions.

## Getting Your Other Family Members Ready

Many families find it helpful to make alternate arrangements for the care of their other children while in hospital. This way you can give your full attention to your child as he or she recovers.

## Coming to the Cardiac Pre-Admission Clinic

Expect to be at the clinic for 4 to 6 hours. Think about having another adult family member or friend care for your other children. We need to learn about your child from you. Brothers and sisters soon get bored and irritable if they need to wait for long periods of time. It is hard for you to care for them as well as take part in the clinic day activities.

Also consider bringing a support person along. You will get a lot of information. It is good to be able to talk about what you heard later.

### Make sure you bring:

- Immunization records.
- BC Health Care Card and hospital blue card (if you have one).
- A list of questions that you or your child has.
- A list of the information you want us to have about your child. You are the expert about your child.
- Notebook and pen for questions and answers. The pamphlet “Questions you may want to ask about your child’s upcoming surgery” can give some suggestions that parents think are important to ask.  
[http://www.bcchildrens.ca/General-Surgery-Site/Documents/BCCH1607\\_Questions%20You%20Can%20Ask%20Your%20Doctor\\_2011.pdf](http://www.bcchildrens.ca/General-Surgery-Site/Documents/BCCH1607_Questions%20You%20Can%20Ask%20Your%20Doctor_2011.pdf)

### We also suggest you bring:

- Toys
- Books
- A bag lunch or snacks and drinks for you and your child. Your child can have his or her regular meals and snacks (does not need to fast).
- Diapers and formula if your child is a baby
- Medications (if your child is on any)

# Day of the Cardiac Pre-Admission Clinic

## What you can expect:

- A chance to ask questions and talk about concerns.
- Talk with the surgeon and Cardiac Pre-op Nurse Clinician to discuss and understand the plan for surgery.
- Meet with other members of your child's team such as the Nurse Practitioner, the Anesthesiologist and the Child Life Specialist (depending on your child's age).
- Tour the areas of the hospital where you can wait while your child is in surgery and the wards where your child will be staying.

## What your child can expect:

- A physical exam by the Nurse Practitioner.
- A blood test. A special cream that numbs the skin called EMLA will be offered and put on before the blood test is done.
- An interactive play with the Child Life Specialist.
- A chest X-ray.
- An electrocardiogram, also called an EKG or ECG.
- An echocardiogram, also called an ECHO.
- Other testing that may be required prior to surgery.

## You will be given information about:

- When to arrive at the hospital on the day of surgery.
- Important things to do before the surgery such as:
  - Making sure your child has an empty stomach before surgery. This is called fasting and is very important. The surgery can be delayed if these instructions are not followed carefully.
  - Making sure your child is properly bathed and cleaned using a special scrub. This will be

given to you on the day of the pre-admission clinic appointment.

- The possible use of medicine to calm and relax your child before the surgery. This medicine is called a sedative which is given before the surgery so your child does not feel pain and is not aware during the surgery. For more information, see [http://www.cw.bc.ca/library/pdf/pamphlets/BCCH1572\\_YourChildsAnesthesiaForSurgery\\_2010.pdf](http://www.cw.bc.ca/library/pdf/pamphlets/BCCH1572_YourChildsAnesthesiaForSurgery_2010.pdf)
- The surgical procedure and the possible need for blood products. You will be asked to sign two consent forms. One is giving your consent for your child to have the surgery. The other gives your consent to give your child blood products if needed. For more information about heart surgery and blood products, visit: <https://www.childrenshospital.vanderbilt.org/services.php?mid=6455>
- For your child's recovery after surgery, it is very important that your child gets moving right away and does the breathing exercises to keep her or his lungs clear.

## Giving Your Child Medications

Give your child all his or her medicines until the day of surgery.

Ask your doctor or nurse if and when you should stop giving any of the following:

- Blood thinners such as:
  - Coumadin® or Warfarin
  - Plavix® or Clopidogrel
  - Aspirin™
  - Lovenox® or Enoxaparin

- Beta Blockers (such as Propranolol or Atenolol).
- ACE inhibitors (such as Captopril or Enalapril).



Call the Cardiac Pre-op Nurse Clinician at Local 3002 if you have any other questions.

## Preparing Yourself & Your Child

### Your role: Parents as Partners

You are the most important person on your child's team. You give your child special comfort, support, and encouragement. You can be with your child 24 hours if you choose. You are not a "visitor" for your child.

### Staying with your child

On the day of the surgery, be calm and positive while you wait with your child. You will be with your child until he or she goes into the operating room. If your child is anxious, a Child Life Specialist will be able to go with your child to the operating room. Please talk to the anesthesiologist if you have any questions.

The first place your child will go after the surgery is the Cardiac Intensive Care Unit, or CICU. While your child is there, you will be able to sleep in a parent cot beside your child. A maximum of two parents can stay overnight at one time in the CICU. We encourage you to take regular breaks. Eating well, taking walks and being in the fresh air will keep your spirits and energy up.

### When to start preparing your child

Use your child's age as a guide when you start talking and getting her or him ready for the surgery and hospital stay.

If your child is 2-3 years old, talk to him or her 2-3 days before the surgery. If your child is over three years old, begin talking to him or her about surgery a few weeks before.

Watch the BC Children’s Surgical Virtual Tour first and then decide which parts you would like to share with your child.  
[http://learn.phsa.ca/bcch/surgery/english/story\\_html5.html](http://learn.phsa.ca/bcch/surgery/english/story_html5.html)

## What to talk about

Talk about what will happen during the stay in the hospital to fix the heart. Be honest about what will happen. We sometimes hide the truth in order to protect our child from fear. Your child may be upset and angry, but the truth builds trust in what you say. Stay calm and matter-of-fact about the event. Your child will pick up from you that this is something he or she can manage.

### Talk about:

- What your child will see, hear and feel.
- What people will be there.
- Your own plans for staying with him or her at the hospital.
- What he or she might be asked to do such as “take a deep breath” or “hold out your hand to have cream rubbed into it”.
- Help your child to understand that things will be very different in the hospital. For example, the food, and bed, where she or he plays will be different. Tell them what will be the same such as having their toy or blanket and you.
- It is hard for children under five years old to understand “surgery”. We suggest you don’t focus too much on this.

- The Child Life Specialist will explain with the best words, and use play, to give your child ways of coping with any anxiety around the surgery.



If you want more advice you can call the Child Life Specialist at local 7648 or the Cardiac Pre-op Nurse Clinician at local 3002.

- Give your child a chance to tell you what she or he thinks will happen and take it from there.



If you need books or a video to help, call the Family Support and Resource Centre at local 5102 or visit: <http://www.bcchildrens.ca/our-services/support-services/resource-centre>

- Your child is not used to hospital routines. Some children find it hard to adapt. They may show this by acting out and/or not being able to fall asleep or stay calm. It's normal for children to feel grumpy or bad-tempered for a few days. The hospital staff understands this. We suggest you try to keep some limits on behaviour but make allowances for the situation. Tell your child that you are there to help when she feels sad or mad. Things will get back to normal in a few weeks.

## What to Pack\*

### For your child:

- Non-slip footwear
- Robe
- Pajamas that button up or your child can wear the hospital pajamas
- Casual clothes
- Toothbrush and toothpaste
- Hairbrush
- Any favourite items such as a toy, movie, iPad, blanket

### For a baby:

- Sleepers or t-shirts that fasten up in the front
- Soothers
- Cups, spoons, bottles
- Any favourite items such as toy or blanket

### For you:

- Pillow (optional)
- Personal items and all medications you may need

### The hospital has:

- Diapers
- Food for your child
- Bedding for child and parent
- Formula and bottles for babies

**\*Mark all items with your child's name.**

## What to Know and Tell Family and Friends about Visitors

- The Cardiac Intensive Care Unit only allows a minimum number of visitors at a time at the bedside during the day and only ONE parent stay with your child at night.

- Once your child is on the Children’s Heart Unit 6 West, any number of visitors is welcomed. However, keep in mind that your child may need extra rest. More than one parent can also stay with your child at night.
- Many children in hospital cannot fight infections. Please be sure that visitors with coughs and colds, or those that have been with someone who has measles, chicken pox and other childhood diseases, do not visit. One “not very sick” visitor can make many children very sick!
- You are responsible for children who visit the hospital. Visiting children may use the playrooms only when an adult is with them.
- While in hospital recovering from surgery encourage your child to get up walking at least twice a day. If you are able to buy bubbles or a pin wheel this is a fun way to get your child to take deep breaths and blow in order to get their lungs moving and working after surgery.

## **Surgery may be Postponed**

Sometimes things happen in the hospital that makes it necessary to change the date of surgery. They can include:

- Emergency surgeries taking away the use of the operating time
- The Cardiac Intensive Care Unit not having a bed

We will tell you as soon as possible if your child’s surgery must be postponed. We understand how upsetting this is. The safety of your child is our main concern. Surgery will not take place if we cannot provide the proper care before and after.

## **After the Surgery**

Going home after heart surgery can be both a happy and anxious time. We encourage you to see your family doctor or pediatrician on a regular basis.

Here are some answers to frequently asked questions:

### **How do I take care of the wound?**

You will be given written instructions and shown on how to do this before your child leaves the hospital.

### **How do I prevent infection?**

The best way to prevent infection is to keep the wound clean and dry.

### **Every day for 10 days:**

- 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.

### **When can my child shower or have a bath?**

- 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.

### **Also...**

- 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 Call the Nurse Practitioner at local 8968 for any questions, concerns or if you notice any signs of infection, dissolvable suture material, which looks like clear fishing line, poking through

the skin.

## How do I help my child with...

### **Pain**

You can give your child acetaminophen, also called Tylenol®, for several days after surgery. Please contact the Nurse Practitioner at local 8968 to know how much to give and how often to give it.

### **Behaviours**

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 at local 8968.

## **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 Nurse Practitioners 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.
- Helpful websites for infants and diet are at the end of the pamphlet.

### ***Toddlers, School-aged Children, and Youth:***

- Offer your child a regular diet unless otherwise instructed. Encourage a balanced diet of foods that promote healing.
- Helpful websites for toddlers, school-aged children and youth are at the end of this pamphlet.

- Some children may need more iron in their diet if their hemoglobin is low. Please check with your Pediatrician or Nurse Practitioner 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.

## **Activities**

### ***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.

### ***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 Synagis® 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/BCCH1542RSV\\_2009%20\(2\).pdf](http://www.cw.bc.ca/library/pdf/pamphlets/BCCH1542RSV_2009%20(2).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.

## Preventing Infective Endocarditis (IE)

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. IE is an infection of the lining of the heart. 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 IE:***

- 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 (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.

### ***How do I know if my child has PPS? Look for...***

- 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

### **Other Concerns**



Call the Children's Heart Centre if your child has any of the following in the first 6 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 if your child doesn't seem to be getting better

## More Resources for you

### People who can help:

If you live outside the Lower Mainland call the toll free line at 1-888-300-3088. Otherwise, call 604-875-2345 and then dial the following local extensions:

- Cardiac Surgeons' secretary at local 7313
- Cardiac Nurse Practitioners at local 8968.
- Cardiac Pre-op Nurse Clinician at local 3002
- Nurse Clinician in the Children's Heart Centre at local 7877
- Partnership Nurse Clinician at local 7636
- Cardiac Social Worker at local 7124
- Child Life Specialist at local 7648
- The Family Support and Resource Centre at local 5102

### Websites that can help:

- Information about BC Children's Hospital  
[www.bcchildrens.ca/YourVisit/default.htm](http://www.bcchildrens.ca/YourVisit/default.htm)
- Information about how the heart works  
<http://kidshealth.org/en/kids/heart.html>
- Treatment of heart conditions, ideas to prepare your child and yourself for surgery, and an overview of heart surgery  
[www.wcchn.congenital.org](http://www.wcchn.congenital.org)

## Diet

### Infants

- Breastfeeding Your Baby  
[http://www.cw.bc.ca/library/pdf/pamphlets/BCW732\\_BFYourBaby\\_2015.pdf](http://www.cw.bc.ca/library/pdf/pamphlets/BCW732_BFYourBaby_2015.pdf)  
OR  
<http://www.healthlinkbc.ca/healthfiles/hfile70.stm>

- Expressing Your Breast Milk  
[http://www.cw.bc.ca/library/pdf/pamphlets/BCW963\\_BreastMassageExpression\\_2015.pdf](http://www.cw.bc.ca/library/pdf/pamphlets/BCW963_BreastMassageExpression_2015.pdf)
- Other Helpful Breastfeeding Hints  
[http://www.cw.bc.ca/library/pdf/pamphlets/BCW982\\_HelpfulHints\\_2015.pdf](http://www.cw.bc.ca/library/pdf/pamphlets/BCW982_HelpfulHints_2015.pdf)
- Formula Feeding  
<http://www.healthlinkbc.ca/healthfiles/hfile69a.stm>
- Formula Feeding: Safely Preparing and Storing  
<http://www.healthlinkbc.ca/healthfiles/hfile69b.stm>
- Baby's First Foods  
<http://www.healthlinkbc.ca/healthfiles/hfile69c.stm>

### **Toddlers**

- Helping Your Toddler Eat Well  
<http://www.healthlinkbc.ca/healthfiles/hfile69d.stm>
- Meal and Snack Ideas for Your 1 to 3 Year Old  
<http://www.healthlinkbc.ca/healthfiles/hfile69e.stm>  
OR  
<http://www.bestchance.gov.bc.ca/you-and-your-toddler-0-36/>

### **School Age Children**

- <http://www.bcchildrens.ca/KidsTeensFam/HealthyWeights/For-Families/default.htm>

**Thank-you for reading this through!**

**We look forward to meeting you soon!**