

The cardiologist may recommend surgery for your child to repair the CHD and make your child's cardiovascular system as normal as it can be.

For some children it may be possible to repair the heart completely with a single surgery. This is called a "definitive repair". For other children who are more ill or who have more complex problems, surgery may be needed to relieve a problem or help the child gain weight before definitive surgery.

This is called "palliative" surgery. Some children only receive palliative surgery. Some children with complex CHDs require more than one surgery to get the best result.

This section describes what to expect before and after surgery.



"I have to say, it is extremely difficult to be taking her back into the hospital, even though we have known since she was born that this is only one of many operations that she will need. We will hope and pray that after her surgery she will be that much stronger and more than ready to conquer new things."

PARENT

Before surgery

PREPARING FOR SURGERY

Who makes the decision about surgery?

Before surgery, the team will talk to you about it and talk to your child if he or she is old enough to be included. They will talk about the best type of surgery and the best time for it to take place.

After reviewing your child's health status, diagnostic test results, and other information, the health care team (cardiologists, surgeons, radiologists, nurses and other specialists) recommends an operation. The information you and your child give them about your child's current health status is a very important part of deciding when a surgery should happen.

Will we get a chance to meet the surgical team?

Your cardiologist will contact you with the final decision about surgery. The surgeon's office will then contact you to set the date and to make an appointment for your family to meet with the surgeon and other team members. If possible, you should arrange this meeting several weeks before the surgery so that you can get answers to your questions.

At the meeting, the surgeon will discuss:

- the reason for the surgery,
- the risks and benefits of having the surgery performed,
- what the surgical procedure involves,
- how long the hospital stay will be.

You will be encouraged to ask any questions and discuss concerns. In addition, you will probably be asked to sign the consent for surgery.



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TIPS FOR SUCCESS

REPEAT INFORMATION BACK TO MAKE SURE YOU UNDERSTAND IT CORRECTLY. FOR EXAMPLE:



IF THE SURGEON HAS JUST EXPLAINED THE TYPE OF SURGERY TO YOU, YOU COULD SAY, "SO WHAT YOU ARE PLANNING TO DO IS..."



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What is an "informed consent"?

An important part of the meeting is signing a document called an "informed consent". An informed consent is a document that says you have been told about the type of surgery and the risks involved, that you understand this information, and that you agree to the surgery. Be sure to read the consent completely before signing.

In some provinces, children of 11 years or older may be legally able to sign the consent. Each child needs to be assessed individually for his or her competency. Some patients or their parents may feel uncomfortable with this (depending on the child). In this case, the parents or legal guardians may ask to provide consent for the procedure.

Who should come to the meeting?

Families often report feeling overwhelmed by the amount of information they receive during the appointment. It may be helpful to have a family member or friend go with you to the meeting to help you remember and make sense of the information you are given.

We encourage you to bring your child to the meeting if he or she is old enough to understand the information. This will give your child a chance to ask questions and be involved. Infants and young children do not need to attend this meeting.

How should we prepare for the meeting?

Some families do not feel comfortable asking about the procedure. However, it is not possible to give an informed consent without a good understanding of what will happen to your child.

You will feel more prepared if you do some research to learn about the procedure. In the

time leading up to the meeting, you will likely think of several questions and concerns you would like to discuss with the team. We recommend that you write them down so you feel as prepared as possible for the meeting. It is a good idea to write down the answers during the meeting so you can review them later.

Here are examples of questions you may want to ask:

- What will this surgery do for our child if it is successful?
- What is the best we can hope for? What is the worst that might happen?
- Is there anything that could be done instead of the operation that would get the same results?
- What will happen if we do nothing?
- How much time do we have to make a decision?
- Why is it better to do the operation now rather than later?
- What are the most common complications and how often do they occur?
- What is the most serious complication and how often does it occur?
- How often do complications occur at other centres, and how does your centre compare?
- What are the possible risks and complications of the anaesthetic, if any?
- Who will perform the operation? What experience has the surgeon had with this type of procedure? How successful have others been?

In some emergencies, you may not have time to ask anything. You and the health care team will have to act immediately.

Questions adapted from: *Family Issues, BC's Children's Hospital Newsletter for Families*. Spring/Summer Issue, 2001, p. 3.

What are the risks of surgery?

The risks involved in your child’s surgery depend on whether it is “open-heart” or “closed-heart” surgery. Open-heart surgery means that a **heart-lung machine** (often called “cardiopulmonary bypass”) is needed. Closed-heart surgery does not use a heart-lung machine.

Although heart surgery for babies and children has improved a great deal over the past twenty years, it still carries some risk. There are two types of risk—morbidity (complications during or following surgery) and mortality (loss of life). The level of risk depends on the procedure your child needs. The surgeon will talk to you about the specific risks for each procedure.

In general, complications after open-heart surgery are rare - they occur in about 1-3% of cases (1 to 3 of every 100).

The most common complications include:

- bleeding after surgery,
- heart rhythm problems,
- a permanent pacemaker may be needed in the future,
- infection, which may be minor or severe.

Following open-heart surgery, children may get an inflammation (irritation) of the sac that surrounds the heart, called the pericardium. There may also be a build-up of fluid around the heart and lungs. This is an inflammation, not an infection. It is known as **Post Pericardiotomy Syndrome (PPS)**, and it happens in about 2-30% of patients (2 to 30 of every 100). The symptoms of PPS are fever, general malaise (feeling unwell), and irritability (feeling bad-tempered and easily upset). PPS is commonly treated with oral aspirin or steroids.

The risk of kidney damage, liver damage, or stroke following open-heart surgery are now extremely low (generally less than one in every hundred cases).

The risk of complications following closed-heart surgery is much lower than for open-heart surgery.

Will my child need blood products, and are they safe?

Your child may need blood or blood products for surgery, especially if it is open-heart surgery. For example, when the heart-lung machine is used in babies and small children, blood products are used to fill the machine’s tubing. If other fluids are used instead, the child’s blood can become diluted and the cells of the body do not get enough oxygen.

At some centres, parents may be able to arrange blood donations specifically for their child - referred to as “directed blood donation”. Older children may even be able to donate their own blood for heart surgery. This is called “autologous” blood donation. Ask your cardiac surgeon about options for your child. If blood products are needed, the cardiac surgeon will discuss the risks of the various products.

If you have spiritual beliefs about the use of blood products, please discuss your concerns with your health care team.



OPEN-CLOSED

OPEN-HEART SURGERY MEANS THAT A HEART-LUNG MACHINE (OFTEN CALLED “CARDIOPULMONARY BYPASS”) IS NEEDED



CLOSED-HEART SURGERY DOES NOT USE A HEART-LUNG MACHINE



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NEEDED TESTS

CHEST X-RAY AND
ELECTROCARDIOGRAM
(ECG)



OXYGEN
SATURATION



ECHOCARDIOGRAM



RECENT DENTAL
EXAM TO ENSURE
HEALTHY TEETH



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**PRE-SURGICAL ASSESSMENT
AND PREPARATIONS**

**What can we do to prepare our
child for surgery?**

Once you know that your child needs heart surgery, you need to make sure that your child's teeth are healthy. Dental cavities and abscesses increase the risk of an infection such as bacterial endocarditis (see page 2-14) after surgery. Surgery may have to be delayed until dental work is done.

Surgery is usually done only if your child is in the best of health.

You need to tell your cardiologist and cardiac surgeon:

- if your child has been in contact with any communicable diseases (chicken pox, whooping cough, etc.) within the two to three weeks before surgery,
- if your child has had any type of illness in the week before surgery.

Communicable diseases are a risk for both your child and other children who are in hospital. Surgery may have to be delayed if your child has a cold or other illness. If your child needs urgent surgery, a delay may not be possible, and the cardiac team will discuss their recommendations with you.

**How long will our child be in
hospital before surgery?**

If your child's health is stable and the surgery is not urgent, your child probably won't have to be admitted to hospital until the day of the surgery.

What will happen at day clinic?

Most hospitals now have day clinics, or Pre-Admission Clinics, where routine tests can be done. These tests ensure that your child is fit for surgery.

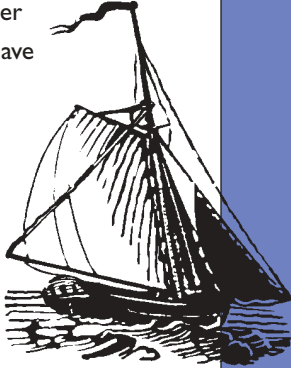
At the day clinic, they will:

- check to see if your child is well enough for surgery,
- ask if you have any questions or concerns,
- give you a chance to tour the areas of the hospital where your child will be staying,
- talk about how to help your child prepare emotionally for the surgery,
- give you instructions about fasting (how many hours your child should not eat or drink prior to surgery), bowel preparation, and when to arrive at the hospital,
- give you information about plans for sedation before and the anaesthetic during the operation,
- do a general physical assessment and medical history of your child (come prepared to answer questions about your child's health problems, allergies, and the medications he or she is currently taking),
- talk about recovery after the operation, particularly about getting out of bed and moving around and breathing exercises (to keep the lungs clear).

You can also expect the following tests to be done during the clinic day if they have not been done recently:

- chest X-ray and electrocardiogram (ECG) (see pages 15-2 and 15-5),
- blood analysis or bloodwork (see page 15-1),
- oxygen saturation (see page 15-14),
- echocardiogram (see page 15-4).

The day clinic visit usually takes 4 to 6 hours. It is a good idea to bring snacks or other supplies necessary to help you get through the day. After the appointment, you can return home or to the place you are staying while awaiting your child's surgery, and return to the hospital the morning of surgery.

	<p>What should we do during the surgery?</p>	<p>SIBLINGS</p> <p><i>We recommend that you don't bring young siblings to the hospital the morning of surgery as this can be stressful for the parents, siblings, and the child going for surgery.</i></p> 
<p>THE DAY OF SURGERY</p>		
<p>How will we know when and where to go?</p>	<p>During surgery, which may take from 3 to 7 hours, you may choose to go home if it is close by, or wait in a parents' lounge or waiting area. If you leave the waiting area, make sure the team knows how to contact you for updates on your child's condition and to let you know when the surgery is over.</p> <p>To ensure that you can be reached, you should:</p> <ul style="list-style-type: none"> ■ tell a staff member where you are going and your phone number at that location, ■ check whether there are pagers available for parents to use, ■ check whether cellular phones can be used inside the hospital, ■ get the name and phone or pager number of a staff member you can contact if you have questions during your child's operation. 	
<p>The hospital admissions department or clinic nurse will tell you (well before surgery) where you should bring your child on the morning of surgery.</p> <p>Surgery sometimes has to be rescheduled to protect your child's health (for example, if the expert team members needed for your child's care are not available) or to save another child's health (for example, if the child requires emergency surgery). Surgery is rescheduled according to priority of need, so be prepared to be patient.</p>		
<p>What will happen before our child goes to the operating room?</p>		
<p>When you arrive at the hospital, you and your child will go to a waiting area.</p> <p>During this time:</p> <ul style="list-style-type: none"> ■ you can stay with your child until it is time to go to the surgical room, ■ EMLA cream may be applied to your child's hand to numb the skin so that an IV can be inserted in the surgical room, ■ your child may be given some sedating medicine, ■ some centres will let you go into the surgical room with your child. 		



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BEFORE SURGERY

AN ENDOTRACHEAL TUBE WILL BE PLACED DOWN THE NOSE TO HELP BREATHING



AN ARTERIAL LINE WILL BE PLACED IN ONE OF THE ARTERIES OF THE WRIST



AN IV WILL BE PLACED IN A LARGE VEIN IN THE NECK



A URINARY CATHETER WILL BE INSERTED INTO THE BLADDER



A NASOGASTRIC TUBE WILL BE INSERTED DOWN ONE OF THE NOSTRILS INTO THE STOMACH



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IN THE OPERATING ROOM

What will happen before the operation starts?

It takes about an hour to prepare your child for surgery. An IV line for the anaesthetic will be inserted shortly after your child goes into the operating room. Once the anaesthetic is working, your child will not be aware of any other events until he or she is recovering in the Intensive Care Unit.

After the anaesthetic is started, several standard procedures are generally done before the surgery:

- A tube called an endotracheal tube will be placed down the nose (or sometimes the mouth) into the windpipe to help with breathing during and after surgery. The tube is connected to a ventilator, or breathing machine. The ventilator does the work of breathing for your child and keeps the right amount of oxygen in the bloodstream.
- A small plastic tube (catheter) called an arterial line will be placed in one of the arteries of the wrist. The arterial line will be used to measure blood pressure during and after surgery, and will also be used to draw blood samples after surgery.
- Another IV will be placed in a large vein in the neck (or occasionally the groin) to give medications or blood products.
- A drainage tube called a urinary catheter will be inserted into the bladder to measure urine output.
- Another tube called a nasogastric tube or NG tube will be inserted down one of the nostrils into the stomach to make sure that the stomach is empty during surgery and to allow feeding after surgery.

These tubes and equipment will also be needed as your child recovers in the Intensive Care Unit. The staff will tell you which equipment and supports your child needs after surgery.

What will happen during the surgery?

Once all of the equipment is in place, the surgeon will start the operation. If your child is having an open-heart procedure, the incision will be over the breastbone (sternum) in the front of the chest. If your child is having a closed-heart procedure, the surgeon will tell you about the surgical approach and where the incision will be made.

Open-heart surgery

To do open-heart surgery, the surgeon opens the heart and usually has to stop the heart to do the precision repair. During this time, the heart-lung machine does the work of the heart and lungs by sending oxygen-rich blood through the body. The machine takes the blue, oxygen-poor blood from the entrance of the heart and sends the blood through the heart-lung machine where oxygen is added. It then returns the blood to the main artery of the heart (the aorta), which takes the oxygen-rich blood to the body. The heart-lung machine can also cool the blood to protect your child's organs during surgery.



The heart is stopped with a special medication (called cardioplegia) during the time the surgeon needs to do the repair. Once the repair is done, the child will be gradually weaned off the heart-lung machine so that the child's own heart is doing the work of pumping the blood after surgery. The child's breathing usually needs the help of the ventilator for several hours to several days, depending on the type of surgery and how quickly the child recovers.

In small infants and young children, the skin will be closed after surgery but the breastbone may be left open to allow for the swelling of the heart after surgery. The breastbone will be sewn together a few days later once the swelling has gone down and your child's condition is stable. When you first see your child after surgery, a gauze dressing will cover the incision.

For some children, the surgeon may also place a small catheter in the abdomen, under the belly button, to help the kidneys get rid of extra fluid. This is called peritoneal dialysis. This tube is removed when the kidneys are working well, usually a few days after surgery.

For some types of open-heart surgery, it is common for the electrical system of the heart to become bruised or swollen. This can result in unusual heart rhythms—the heart may beat too fast or too slow, or the top and bottom chambers may beat in an uncoordinated way. If this is a concern, the surgeon will place pacemaker wires onto the outside part of the heart muscle at the end of the surgery. These tiny wires are then pulled through the skin and sit next to the incision, ready to be connected to a temporary external pacemaker if there are any concerns about the heart rhythm.

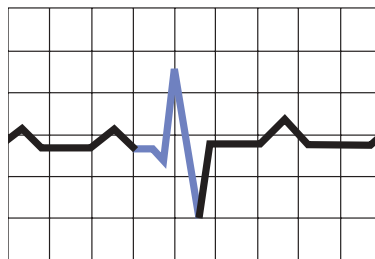
The external pacemaker is an additional support that is often needed temporarily to regulate the child's heart rhythm during the first few days after cardiac surgery. In most cases, once the swelling and bruising of the

heart have subsided, the child's own regular heart rhythm starts again and the temporary pacemaker wires are easily removed. Wires can be removed as easily as stitches. In rare cases, the child's own regular heart rhythm does not resume after several days and a permanent pacemaker may need to be inserted before the child goes home. Before surgery, your cardiologist and surgeon will provide information specific to your child about the possibility of requiring a permanent pacemaker.

Chest tubes for open and closed-heart surgery

Following heart surgery, most children need chest tubes (also called chest drains) that drain the air, fluid and blood away from the heart as it heals. These chest tubes are placed in the operating room before the child enters the Intensive Care Unit.

As many as three chest tubes may be needed after surgery, depending on the type of surgery. Chest tubes are connected to a drainage box and a suction system to encourage air or fluids to drain. This suction makes a soft bubbling noise. The staff watches the tubes closely after surgery to make sure that they are still connected and unclogged, and that fluids are replaced if needed.



EXTERNAL PACEMAKERS

The external pacemaker is an additional support that is often needed temporarily to regulate the child's heart rhythm during the first few days after cardiac surgery.



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“Everything has a beep, and I panicked every time anything made a noise. But a lot of those alarms are just reminders to nurses and not a warning. I calmed down once I figured that out.”

PARENT

“When they said she was paralysed I freaked. I forgot that they meant by the drugs... I cried with relief when they reminded me that's what it was.”

PARENT



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AFTER THE SURGERY

After heart surgery, most children go to the Intensive Care Unit (ICU) to recover. This section describes what to expect when you first see your child in ICU, offers some suggestions on how you can be involved in your child's care, and explains the importance of taking care of yourself during this overwhelming time.

The Intensive Care Unit

Your child's stay in ICU may be a few days or longer, depending on the type of surgery (open-heart or closed-heart) and any other medical conditions your child has. In the ICU, your child will be closely watched and cared for during the critical time that follows heart surgery.

The first glimpse of your child may be a very difficult and emotional moment for you. While you will likely feel relieved that the surgery is over, the sights and sounds of ICU may overwhelm you. This section will give you some ideas of what to expect in the busy ICU. To help you prepare, you may want to ask whether it is possible to tour the ICU and meet some of the staff before surgery.

What will our child look like?

Just after surgery, your child will be surrounded by machines and people.

Your child will be lying quite still and be very sleepy because of:

- pain medication to make your child comfortable,
- medication that paralyses your child's muscles for a short time so the heart does not have to work as hard.

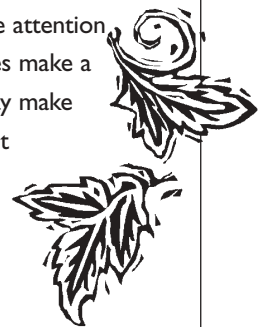
Some parents are frightened when the child doesn't move.

You may notice some swelling of your child's face, eyes and hands. This swelling is common after heart surgery, and will go away gradually.

Here are some other things you may see:

- a large dressing on your child's chest to cover the incision and protect it from infection,
- IVs for fluids and drugs (see the medications starting on page 9-5, for information on the IV medications your child may be receiving),
- a cardiac monitor, which shows heart rate and rhythm, blood pressure, breathing rate, oxygen saturation, and other information,
- a ventilator (a machine that breathes for your child through a tube into your child's throat),
- one to three chest tubes to drain air, fluid, or blood from around your child's heart,
- temporary pacemaker wires to help regulate the heart rate,
- a cooling blanket to control fever and decrease the work of the heart (most children get a fever after heart surgery).

Many of the machines attached to your child have alarms which attract the attention of the ICU staff. The machines make a lot of beeping noises that may make you feel nervous until you get used to them.



What can we expect in the first few hours and days after surgery?

At first, there will be a lot of activity around your child's condition as nurses and doctors stabilize your child. Once things settle down, there will be room for you to sit beside your child.

You can tell things are improving when your child slowly starts to wake up and move around. Your child will gradually need less medication to support the heart, and will no longer need the ventilator for breathing. As your child improves, the lines and wires will be taken out, and he or she will be able to sit up and take sips of water or suck on a Popsicle®.

Your child may have ups and downs on the road to recovery. Several parents have described feeling like they are on a roller coaster. The ICU staff will continually monitor your child, respond to changes, and be alert to possible complications.

The ICU nurses and doctors will keep you informed about how your child is doing and answer your questions whenever possible. There may be times when they need to attend to your child's or another child's needs and may not be able to answer your questions for a few minutes.

Who will be caring for our child?

The intensive care unit team cares for your child and consults with the cardiologist and surgeon as needed (see *Who's Who on your Health Care Team* in the Glossary).

You will see new faces every day. When you arrive, ask who will be caring for your child that day and what procedures or treatments are planned.

During rounds (when the team visits all of the children in the ICU), be prepared for a large crowd. There may be as many as 15 people at

your child's bedside. You may be asked to leave during rounds to ensure that information about other patients remains confidential. If you need to speak with your child's doctors, ask the nurse about arranging a time that works for both of you.

How can we care for our child in an ICU?

You may find it difficult having a child in ICU. You may feel that you are no longer part of the team, or that you are no longer able to parent your child. Remember that parents play an important role in helping their children recover.

One way to help is to give the team information—you know more than anyone does about your child.

For example, tell the staff:

- whether your child is right or left-handed so that IVs can be placed in the opposite hand,
- how your child is likely to react in certain situations, and anything that has helped make such situations easier,
- what kind of distraction is most helpful during uncomfortable procedures,
- whether your child likes bandaids removed quickly or slowly.

You can also advocate for your child—ask for anything you think your child needs, or make suggestions that you think may be helpful.

"We kept a diary of events and the staff's names, and found that to be very helpful."

PARENT

"It was important to us that we be able to participate in the care of our child as much as possible. At first this was very little; but eventually we could change her diaper, give her a bath and hold her during procedures. I think the nurses really appreciate parents who take an active role in the care of their child."

PARENT



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“She loves to keep watch on everyone in the room, play with her little photo album, and has discovered that she loves the Barney videos.”

PARENT

VISITING HOURS

OUR VISITING HOURS ARE:

OUR VISITING RESTRICTIONS ARE:



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Ask your nurse about ways that you can participate in your child’s care.

Ways to help your child include:

- bathing and hair washing or combing,
- diaper changes,
- turns (changing your child’s position),
- back rubs,
- kisses, hugs, and hand holding,
- reading stories,
- praising your child during and after procedures,
- speaking or singing softly to your child even when he or she appears to be asleep —your child may be able to hear you.

You may also want to:

- play tapes of soft music or lullabies,
- record yourselves, siblings, or grandparents reading a story to be played for your child when you are not there,
- bring a favourite toy or teddy,
- bring favourite videos for your child to watch, or tape up pictures of your child and family around the bedside,
- tape up “art” drawn by your child’s siblings or friends,
- tell stories or make up a fantasy adventure with your child.

Remember that you can offer love and emotional support in a way that no one else can.

Visiting the ICU

Parents are not seen as “visitors” but are important members of the team helping your child get well. You can usually be with your child as often as you would like. However, crises occur often in an ICU, although not necessarily to your child. There may be times when you are asked to step outside.

You can also invite other family members or special people in your child’s life (for example, godparents or close family friends) to visit.

However, think carefully about whom you invite, because:

- very sick children need rest and calm, and the more people there are, the more noisy and stressful the environment may be,
- when a lot of people gather around a bedside, it may become difficult for staff to respond to a child who suddenly needs urgent care,
- young children may find the ICU a scary place to visit.

If your child has young sisters or brothers who want to visit, please arrange for their visit with your child’s nurse, who can help you prepare them.

Hand-washing

Sick children can easily catch other illnesses.

To help reduce the risk to your child:

- wash your hands well each time you come into the ICU, and after changing diapers,
- remind all visitors to wash their hands,
- if you are not feeling well, talk to your child’s nurse about ways to protect your child from catching your illness,
- tell the nurse if a visitor has been in contact with anyone who has chicken pox or other infectious diseases.

Bedside space

ICUs are usually crowded spaces, filled with machines and monitors. There may be little room for balloons and toys. Ask your nurse what you may bring in for your child. There is usually room for a few favourite teddies and blankets.

Taking care of yourself

The stress of the ICU environment may wear you out. It is hard to predict how long your child will be in the ICU, so it is important to look after yourself.

You can take care of yourself and help your child by:

- taking breaks and taking turns with other family members or your partner,
- eating nourishing food—don't try to survive on coffee!
- sleeping when possible,
- taking walks occasionally; you need a break and the exercise will feel good,
- taking a break with a friend who is a good listener,
- making sure you drink plenty of water and eat well, especially if you are a breast-feeding mother.

Some parents feel guilty about not being at the hospital all the time, although they know how important it is to get rest and take care of themselves. Try for a balance of visiting and resting that works for you. This is very important if your child is in the ICU for more than a week.

It is difficult to predict how busy the ICU will be and nights can be as busy and noisy as days. If possible, arrange a quiet place to sleep outside the unit—plan to go home from time to time if you live nearby, or ask about accommodations near the hospital. If you wish to stay at the bedside, please ask the nurse about possible sleeping space.

Be realistic about your expectations for yourself. No one can “do it all”. See *Coping with Stressful Times*, page 6-1, for more suggestions.

What do we tell friends and extended family?

People often want to help when a child is ill, and may think that visiting is the best way to show their concern. However, visitors can be tiring for you and your child. Many people are pleased to be asked to help in practical ways, knowing that it will give you less to worry about.

Make a list of things that need to be done at home, and ask friends and family members what they would be willing to do. In particular, think of things that will help keep your other children's lives as normal as possible, such as making their meals and taking them to and from school and activities.

Other ideas for help include:

- putting meals in your freezer for the days when you are too tired or stressed to cook,
- taking your toddler out for a day,
- doing laundry,
- picking a contact person who is willing to give updates to friends,
- setting up a family website where people can share information and provide support.



“These few days while I have just sat at the bedside have been the most exhausting days of my life. I don't know how I will keep going.”

PARENT

“My friends say they want to help, but I don't know what to tell them.”

PARENT



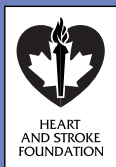
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“I can’t tell you how shattered I was when the child in the next bed died. We always knew this was possible, but it brought home to us that this was possible for our child too.”

PARENT

CAUTION!

CELLULAR PHONES MUST BE TURNED OFF WHILE IN THE HOSPITAL, AS THEY MAY INTERFERE WITH EQUIPMENT.



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ICU Realities

The ICU is set up to care for children who have serious health problems. It can be extremely upsetting to watch another child struggle, or to see other parents coping with the death of their child. If you are having difficulty, speak with your child’s nurse. The hospital may have a social worker, psychologist, or volunteer available to help you through the difficult times.

Privacy

Your privacy and the privacy of other families are protected by the ICU team. Because of this, staff will not discuss the other children with you. However, you are welcome to offer friendship and support to other parents. Some parents will be grateful for the chance to talk, while others may be uncomfortable with it.

ECMO or ECLS life support

Some children need a special kind of life support called ECMO or ECLS while they are in ICU. ECMO (extracorporeal membrane oxygenation) or ECLS (extracorporeal life support) are the same thing. ECMO is used for critically ill children whose heart and lungs are not able to work well. This support uses a heart-lung machine similar to the one in the operating room to do the work of the child’s heart or lungs and allow them time to heal. At first, the ECMO machine does most of the work of the heart or lungs, but its work is gradually decreased as the body recovers.

If your child needs ECMO, two large tubes (cannulae) will be inserted in a vein and artery, usually in the neck or the groin. The machine

takes the blue blood out of the right side of the heart and pumps it through the artificial lung (oxygenator) and returns it, warmed and filtered, to the body. During this time, your child is on the ventilator (breathing machine) to prevent the lungs from collapsing. Your child is kept very still to prevent the tubes from being pulled out.

While on the machine, your child’s blood is thinned to prevent clotting. When ECMO is stopped, clotting generally returns to normal within a few hours.

Babies and children can be on ECMO for several days to a week. Frequent blood tests are needed to determine when they are ready to be weaned off the machine.

What will we need while our child is in ICU?

What you will need depends how far away from the hospital you live. Some things to consider include:

- a place to stay,
- a pager—the ICU may have a “parent pager” that you can use to take a break or to get errands done and still keep contact with the ICU team,
- microwave for meals,
- locker for personal belongings,
- breast pumps.

Record information specific to your centre in *Section 4: Visiting the Hospital*.

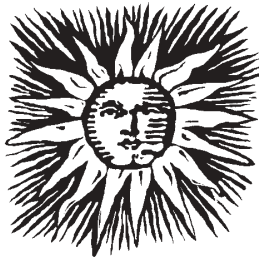
When will our child be ready to move out of ICU?

Your child will likely be ready to move out of ICU when:

- he or she is breathing without the ventilator,
- blood pressure and heart rhythms are stable,
- chest tube bleeding is under control.

Your child may be transferred to a step-down or transitional care unit for a few days, and then to the ward to recover fully.

Sometimes children need to go back to the ICU if there are complications. If this happens, it will be a disappointing time for everyone. Readmissions to the ICU are usually only for a few days and are required to ensure the appropriate level of care is provided to your child.



Leaving the ICU

When your child moves from the ICU to the step-down unit or onto the ward, you might expect that it would be easier to deal with than the ICU. Many parents think that the emotional strain will be eased because their child is recovering. However, you may find the ward more stressful than the ICU because the one-to-one care your child has received in the ICU is no longer available, leaving you feeling more responsible for your child’s care. The thought of taking your child home may be frightening and you may feel unprepared.

You may already be exhausted by the ICU experience, yet still have new people to meet and a new system to learn.

These feelings are normal, and there are steps you can take to ease the transition:

- visit the step-down area before your child gets there, and find the locations of facilities such as parent bathrooms and microwaves,
- begin preparing to go home on Day 1 —start learning what you need to know as soon as possible,
- learn who the nurses are and how to call them if you need them,

“On Sunday she was so punky I could imagine her walking, skipping, running, and even heading off to school. Today she is far less zippy. I must keep in mind that it is truly one day at a time. What a crazy roller coaster ride.”

PARENT

“I was thrilled this afternoon when she opened her gorgeous little eyes and reached out her hand to stroke my face. What renewed faith I felt. Our little buddy has gone through far too much for a little 9-month-old, but she bounces back so amazingly well.”

PARENT



Finding answers. For life.

**Celebrate leaving the ICU—
it is a huge step forward on your child’s road to recovery.**

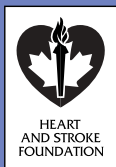
After Intensive Care

“The doctor told us today that Katie would probably have to go home on oxygen for a while. We have no problem with that: as long as Katie is stable and appears ready for going home.”

PARENT

“She came home on Saturday, much to everyone’s delight. She got her first full night’s sleep in almost 6 weeks. She was all smiles today and obviously is quite happy to be home.”

PARENT



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Going home

Discharge from hospital is a happy time, but it can also be a very stressful time for families and children. You can ease the stress by preparing early.

As soon as your child is recovering well, start to ask questions about going home, such as:

- when can we leave?
- what medications should we know about?
- what signs of a wound infection or other problems should we look for at home?
- what care does our child need at home?
- when can our child go back to daycare/school?
- when can we resume our child’s immunization schedule?

Getting information early and in small pieces will help you remember it and increase your confidence when you leave. Ask for information to be written down to take home. Have a place to put the information once you get home, such as the fridge door or by the telephone. Pass this information on to family members, baby-sitters, and other caregivers so everyone knows where it is.

What do we need to know to care for our child at home?

Complications can happen up to 6 weeks after surgery. The nurse will give you specific information about caring for your child.

You will need to know about the following:

- wound care and signs of infection,
- bathing,
- activity levels,

- medications,
- pain control,
- diet and constipation (from codeine and other pain medications),
- Post Pericardotomy Syndrome (PPS), which includes irritability, fever, chest pain, loss of appetite, and shortness of breath.

What can we expect when our child returns home?

When you bring your child home from hospital after surgery, you may feel anxious about taking on full responsibility for your recovering child. You will have medications to give and other tasks such as checking your child’s wound.

Most parents are exhausted at the end of a hospital stay. It is helpful if friends can cook meals or stay with the children so you can run errands or sleep during the day if you are likely to be up at night. Your sleep routines may be disrupted, and you may find it difficult to sleep although you are exhausted. Try to sleep when your child does, even if it is during the day.

Siblings may be more demanding than usual because they have not had your attention. They may feel jealous of the child who took so much of your time while in hospital.

Not only are most parents tired at this time, they often react to the stress of the hospital. Although you may feel relief that the surgery is over, you may relive the anxious moments you had. You may feel overwhelmed even as you and your child recover from the experience. These are normal reactions, and it can be helpful to find someone to talk to about them.

Some parents feel pressured to return to work as soon as they get home. Remember

that it is not just your child who has gone through an exhausting time—you need time to recover, too.

As your child gradually recovers, he or she will likely become more active, eat more, and drink more. Your child may also have nightmares and go through a cranky stage. It is easy for a child's behaviour to get out of control as a result of the unusual circumstances and extra attention of a hospital stay. It is important for the whole family, both now and in the future, to set clear limits on your child's behaviour. Children respond well when they know exactly what is expected of them. Be sure to have the clinic nurse's phone number handy for questions that come up at home.

As a result of being in the hospital, some children may lose recent skills such as toilet training, crawling, or walking. This may be frustrating for both you and the child, but the skills will return as your child continues to recover at home and normal routines are established.

What kind of follow-up should we expect?

Follow-up care from the hospital will be arranged before your child's discharge. These appointments are a time to ask any questions that arise after you leave the hospital.

The community health nurse may be involved in your child's discharge planning, and is often a good source of information and contacts. Additional resources such as parent support groups and infant development programs may be available in your area (see *Additional Supports and Resources*, page 12-1).

If your child was receiving home care or other community-based services before the hospital stay, you may need to let the agency know that the child is home and discuss the need for ongoing services.



"The nurse and pediatrician called me at home to go over her 'at home' feeding program and adjusted her feeding to suit both her needs and mine - for that I was very happy!"

PARENT

"I stopped by the unit today after our appointment. I really think it is important for the staff to see their little patients during the good times too."

PARENT

Follow-up schedule

Appointment with the cardiac surgeon, Dr. _____

Date _____

Time _____

Place _____

Appointment with the cardiologist, Dr. _____

Date _____

Time _____

Place _____

Appointment with the pediatrician/family doctor, Dr. _____

Date _____

Time _____

Place _____



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