



Alberta Health
Services



STOLLERY
CHILDREN'S
HOSPITAL

Preparing for your Child's Heart Surgery



Information for Children Undergoing
Heart Surgery at the Stollery Children's Hospital

Stollery Congenital Heart Program
Revised March 2017

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Welcome

The Stollery Children's Hospital in Edmonton, Alberta, is a full-service pediatric hospital and centre for complex pediatric care and research established in 2001.

The Stollery is affiliated with the University of Alberta and housed within the Walter C. Mackenzie Health Sciences Centre along with the University of Alberta Hospital and Mazankowski Alberta Heart Institute.

The Stollery is Western Canada's referral centre for pediatric cardiac surgery. This booklet is designed to help you get ready for your child's heart surgery and to prepare you for your stay in hospital.

At the Stollery, we believe parents are partners on the health care team. We want you to be as informed as possible. Please ask us about things you do not understand and share your concerns. We encourage you to bring this booklet with you when you come to the hospital to assist you along your journey.



Understanding Your Child's Heart



Congenital heart defects (CHDs) are conditions that are present at birth and affect the structure of the heart and how blood flows throughout the heart and body. CHDs can vary from simple (such as a small hole between the

heart chambers) to complex (such as missing or poorly developed portions of the heart). CHDs can be diagnosed in pregnancy, during a routine ultrasound or after the baby is born. The heart is formed during the 8th week of pregnancy and any change in formation may result in a defect. Heart defects are among the most common birth defects and are present in 6-8 of every 1000 babies born in Canada; 1/3 of affected babies have a more severe cardiac defect. Roughly 60-80% of the most severe heart defects are now diagnosed before birth.



Acquired heart disease, which develops during childhood, includes cardiomyopathy, kawasaki disease, rheumatic fever and infective endocarditis. Kawasaki disease and rheumatic heart disease are the two

most common amongst children. **Cardiomyopathy** is the name for a weakened heart muscle. This may have several causes, including viral infection, and metabolic or genetic disorder. If your child's heart muscle is too weak to maintain normal blood flow it will affect how your child's organs function and result in serious complications

Cardiac Surgery at the Stollery

As the cardiac referral center for Western Canada, each patient referred to our Program for surgery is triaged at a multidisciplinary telehealth conference consisting of health care professionals across Western Canada.



In 2016, our program:

- Discussed over 1,000 patients at conference
- Performed over 750 procedures including cardiac catheterizations and all operations done by our congenital heart surgeons
- Completed 1,800 fetal echocardiograms and 10,000 pediatric echocardiograms

The Society of Thoracic Surgeons (STS) has a database of information that allows programs to benchmark against the 117 North American centers that perform congenital heart surgery. In 2016, the Stollery had the ninth highest volume of patients undergoing pediatric cardiac surgery in North America. Of the ten hospitals performing the most surgeries each year, the Stollery had the highest survival after complex pediatric cardiac surgery.

Where do I go from here?

Taking Care of Yourself

It is normal to feel overwhelmed or out of control when your child is diagnosed with a heart problem. Feelings of uncertainty about what will happen to your child, and feeling helpless to make them better, are often major causes of stress when your child is in the hospital.

Good communication with the health care team is an important way to reduce your stress levels.

Tips for communication

- Keep a journal and write down your questions. When the healthcare team makes their daily rounds you will be able to ask your questions, and then you can write down the answers.
- Ask the bedside nurse what time rounds will take place.
- Ask the bedside nurse at any time to speak to someone on the team about your child's care.
- Be open and honest with the team
- Be involved in your child's care as much as possible. The more you know and are able to do yourself for your child, the better it is for you and them.

Stress can make some individuals neglectful of their own health. Your child needs you to be at your best. We encourage you to take care of yourself by eating well, getting some rest, and delegating outside chores and responsibilities to others. Keep in touch with your friends and family so they can lend you their support. Be specific about your needs and what would, or would not, be helpful to you.



Taking Care of your Family

During a hospital stay, your day-to-day routine and family roles may be upset. This can sometimes cause friction at home with your spouse or other children. See the table below for some common experiences of children and families under stress.

Feelings

- Fear
- Anxiety
- Worry
- Frustration
- Sadness
- Physical and emotional fatigue
- Hope
- Relief

Thoughts

- What if...?
- Why?
- How will I get through?
- Its finally time
- I can't wait for it to be over

Behaviours

- Unable to sleep
- Restless
- Irritable
- Temper tantrums
- Crying
- Renewed faith in spiritual matters

Adapted from the WCCHN Family Satisfaction Survey, 2014

Taking Care of your Child



While in the hospital, your child will meet many, many people. They will face strange and sometimes painful tests. Sleep patterns are often disrupted. Your child may be irritable and bad-tempered for a few days after surgery. This is normal. It may take a few weeks for things to get back to normal. We encourage you to be with your child as much possible. If things are happening with your child in hospital that you do not understand, ask for explanations from the nurses and doctors caring for your child.

Waiting for Heart Surgery

What Can You Say To Your Child?

Please be truthful with your child and family: Honesty will encourage your child to trust in you and the staff. It is important that children learn that we are all on the same team.

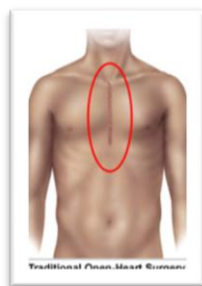
- Explain to your child, using age appropriate words, why they are coming to hospital
- Encourage them to trust the medical staff
- Reassure your child that everyone will be trying to make him/her well

The older kids are, the more time they might need to prepare themselves mentally for surgery.

- Preschool: Day prior to admission: “We are going to spend some time in the hospital over the next few days. The doctor will do an operation to make your heart work better.”
- School age children may know more about their heart problem and want a bit more information about a hospital stay. You might want to introduce the topic about a week before the scheduled surgery and ask if they have any questions.
- Older children and adolescents need more time to prepare themselves and want to have more input into the details, giving them some control over the process. They can make decisions about what items they want with them during their recovery, and who will come and visit. Tours are good for this age group to help them visualize where they will be and what they might look like.

Some examples of topics to discuss with your child are:

- What the incision will look like
- You could draw a picture of an incision on a doll or on their chest
- You can prepare them that they may have some pain and, if they do, they can ask for medicine to make it better



See the resources section for websites and books that can help you to prepare your child for heart surgery

Visit Your Dentist Before Surgery

Babies and children with teeth must see the dentist **before** their heart surgery. There is a form your dentist needs to fill out, and treatments/fillings must be complete before they come for surgery.

Remember:

- Some children may need antibiotics for dental cleanings and treatments. Check with your child's cardiologist if you don't know whether or not your child needs antibiotics.
- Take your dentist the letter we give you and bring the completed form back to us at your child's pre-admission clinic appointment. The dentist's office may also fax it to our Case Coordinator at 780-407-3598.
- If your child has seen the dentist recently (within 6 months of your child's surgery date), ask your dentist for a letter confirming that your child was seen and that the needed dental work was done. Again, you can either bring this with you to pre-admission clinic or fax it to the Case Coordinator (780-407-3598).



When to Call the Surgical Case Coordinator

Contact the Surgical Case Coordinator (by calling 780-407-7709) for any of the following reasons:

- If your child has had a respiratory illness at any time in the three weeks prior to surgery
- If any family member has even a minor cold or runny nose
- If your child was exposed to chicken pox, measles, mumps, or flu viruses in the three weeks before the heart surgery
- If your child has special medical needs or needs specific equipment for their stay
- If your child is started on antibiotics or blood thinner medicines, including aspirin, in the four weeks before surgery

If your child becomes ill while waiting for surgery, see your family doctor or pediatrician without delay. You should be aware that if your child is ill before or on the day of surgery, your child's surgery will be postponed.

When to Call the Family Doctor

Call your family doctor right away if your child has new symptoms or symptoms that are getting worse while waiting for surgery:



- A cold or cough
- A fever
- More short of breath than usual
- Trouble breathing when lying down



If Your Child is on Medication

- Children can continue to take most medications until the day of their surgery
- Aspirin and / or Persantine (Dipyridamole) should be stopped five days before surgery unless your cardiologist has told you not to
- If your child takes **Coumadin (Warfarin)** or **Low Molecular Weight Heparin**, contact a member of the Kid Clot Team (780-407-1070). This medication may have to be stopped several days before surgery.



What Should You Pack?

The hospital provides pajamas, diapers and food for your child. Please bring:

- ☐ Personal items like a toothbrush, toothpaste, comb, brush, shampoo, slippers, or a robe
- ☐ Some children like to wear their own pajamas or casual clothes that button up the front
- ☐ If your child has a favorite toy or blanket, please feel free to bring these too. They can be of great comfort to your child. Pictures or video of family and friends can also be helpful.
- ☐ For babies, please bring your own soothers, sleepers and special feeding utensils

Mark all items well with your child's name. The hospital is not responsible for personal items that are lost.

If you plan to stay at the hospital with your child, please bring as little as possible with you. Closet space is limited.

As per hospital policy, electrical appliances from home should not be used unless they are battery operated.

At the Hospital

Parking

Parking lots at the hospital are very busy. Leave home a early to be sure you arrive at your appointments on time.

Public parking can be found at:

The Public (East) Parkade	The Hospital's Zero Level
83rd Avenue and 112th	Underground Parkade at
Street (entrance off 83 rd)	the 114 th Street entrance

Weekly or monthly parking passes can be purchased from **The Hospital Parking Office:**

Room 0H1.01
Walter Mackenzie Centre
University of Alberta Hospital

Business Hours:

8:00 a.m. – 4:00 p.m.

Monday to Friday

(closed on holidays)

Phone: (780) 407-8890



- Parking passes are *not* refundable. Day passes can be credited toward a weekly pass, and weekly passes toward a monthly pass. If you leave before the pass expires you can donate the remainder by giving your pass to the ward social worker or the case coordinator to pass on to another family.
- Both parkades have daily maximum charges **but no in/out privileges**.
- The local transit system has many links leading into the University area including the LRT (train) which has a stop (Health Sciences/Jubilee Station) directly across the street from the Stollery Hospital entrance on 114 Street.



Dining

- The main cafeteria (level 1) is open to the public Monday - Friday from 8:30 am to 1:30 pm
- A snack bar (level 1) is open daily from 6:30 am to 10:30 pm
- Cafe Fantini (level 2) is open Monday - Friday from 7am to 2pm.
- Trendz Express and Health Trendz Café (Level 1) also serve snacks and light meals throughout the day
- There are many fast-food outlets and restaurants near the hospital



Smoking

Smoking in any form, including e-cigarettes, is not permitted on hospital premises



Banking

- There are three instant teller machines on the main floor of the hospital
- There is a CIBC bank on the corner of 82nd Avenue and 112th Street
- Other banks can be found along Whyte (82nd) Ave



Accommodation

If you live outside the Edmonton area:

- Ronald MacDonald House – Call them directly once a surgery date has been confirmed (780-439-5437)
- Check with hotels when booking to confirm current room prices. Many hotels in the area offer a discounted hospital rate. Ask for the WCCHN or hospital rate when booking your room. The case coordinator can email a confirmation letter to your

hotel to confirm that you should receive the discounted rate.

- There are a few RV Campgrounds within half an hour of the hospital. You may consider camping as an alternative accommodation if weather is good. There are discounts available at some local campgrounds.



Wi-Fi and Internet Access

Public computers with internet access and health resources are available to Stollery patients and guests in the Family Room (located on Level 4).

Self-register for an account on the “**healthspot**” wireless network, available in the following units and clinics:

1D1 Ambulatory Clinic
2E Oilers Ambulatory Clinic
NICU, PCICU and PICU
4C, 4D, 4E, and 4F2

To access the wireless network:

- Open wireless network settings on your mobile device and select “**healthspot**”
- Open your web browser and select “**don’t have an account? Click here to register**”
- Fill in the mandatory fields and select “**submit**”
- Record your username and temporary password and then use them to sign on
- A new username and password will be required after three days
- At the prompt, change your temporary password; please record your new username and password.
- For wireless troubleshooting, please visit the Family Room at 4H2.02

Getting Ready for Surgery

Pre-Admission Clinic (1C3 PAC)

The Surgical Case Coordinator will phone you with your PAC appointment. Usually this appointment is a day or two before surgery. Use the tear out checklist at the back of this booklet to record the date and time of your appointment.

The pre-admission clinic (PAC) is an outpatient clinic which prepares children and their parents for surgery. This clinic is located on the main floor inside the Stollery/University of Alberta Hospital. When passing the Stollery Bear with the Balloons, 1C3 PAC is on your left side. When you come from the LRT station and enter the hospital through the doors marked “Stollery Entrance”, 1C3 PAC is on your right side.

Helpful Tips:

- This appointment may take most of the day, so please come prepared. Bring toys, books and snacks for both you and your child.
- Please do not bring siblings to this appointment as this day is long and very busy.
- Please make every effort to be on time for your appointment.
- If you are from outside of the greater Edmonton area it is recommended that you arrive in Edmonton the day before your PAC appointment.
- Unless you have been told that your child must fast for a procedure, your child should eat breakfast before coming to the PAC appointment.
- Once the appointment is done, your child will go back with you to where you are staying for the night and return to the hospital on the day of surgery. You cannot eat in the waiting room of PAC as many

children are fasting for tests or procedures. Please check with your nurse first about leaving the unit for a nutrition break.

- If you don't understand English well, the case coordinator will organize an interpreter to attend this clinic with you.

During your PAC Visit

During your day in the Preadmission Clinic, you will meet many people and visit many places in the hospital. We will try and ensure that everything is completed as quickly and smoothly as possible. Please do not hesitate to ask your nurse in PAC for a short break if you feel your child needs one at any time.

Some of the people you will meet:

- A nurse who will discuss your child's general health history and what to expect before and after surgery. This is a good time to ask any questions about the nursing care your child will be receiving after surgery.
- A visit to the team in the **Cardiology Clinic (4C2)** for ECG and Echocardiogram
- Your child's heart surgeon to discuss with you the operation and answer any questions you may have.
- The anesthesiologist (the doctor who will sedate your child during the operation).
- The specialized nurse or resident (the doctor in training), who will do a more detailed history and physical examination of your child.

Some of the places you might go:

You will be taken on a tour of the Pediatric Cardiac Intensive Care Unit (PCICU) and/or the Cardiology Inpatient Unit (4C) depending on the type of heart

surgery your child is having. This is where your child will be transferred after finishing in the OR. This tour is optional, but it is highly recommended if this is your child's first heart surgery.

Some tests your child will require at PAC:

- Blood work
- A chest X-ray
- Echocardiogram
- ECG



You may also meet:

- The Cardiologist
- A Child Life Specialist
- The Social Worker
- The Physiotherapist
- The Kid Clot team
- Other healthcare team members who may be consulted to ensure the complete care of your child while in hospital

Because the Stollery is a teaching and research hospital, you may be approached during your PAC visit by a research coordinator from the University of Alberta. Participating in medical research is outside of your child's medical care and is completely optional. Please notify your PAC nurse if you are not interested in hearing about or participating in research.

Please be patient. We are unable to schedule definite times for any of the above persons or tests because all are based on availability of the team members. We will make every effort to have your day completed in a timely manner.

What to bring with you to PAC:

- Your child's medications in the original bottles, or a list of their medications with dosage
- Immunization records
- Dental letter
- Provincial healthcare card
- Guardianship papers, if applicable

Please tell us:

- If your child has any allergies
- If your child requires a special diet
- If you have any concerns about your child receiving blood or blood products during surgery

When you have all the information about your child's surgery, you will be asked to sign a consent form. If there is something that you do not understand, please do not hesitate to ask the doctor to explain it again. We suggest you write down your questions in advance and bring them with you. We want to be sure we answer them all.

The following can help to guide your questions for the doctors and medical staff. They were developed by the National Patient Safety Foundation to promote communication between staff and patients:



1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Some questions you might want to ask include:

How long will the surgery take?

Where will I meet my child after their surgery is finished?

How will I know when they are done?

What will my child look like when they come out?

Day before Surgery

The pre-admission clinic nurses will contact you the afternoon before surgery to tell you:

- What time your child's surgery is scheduled for
- What time your child must stop eating and drinking
- What time to come to the hospital in the morning
- Where to go on the morning of surgery

“NPO” means “nothing by mouth”. All children, even babies, will be NPO if they are going to have surgery or if they are having trouble swallowing properly.

Day of Surgery

Children are admitted to the hospital on the day of surgery. You may be asked to register with the Admitting Department, or to go directly to 1C3 Pre-Admission Clinic. Admitting is located on the main floor of the hospital, behind the glass elevators. Please look for the signs.



After registering with Admitting, you will return to the pre-admission clinic where you were on the day of your PAC visit. The nurses here will get your child ready for surgery.

Your child will:

- Change into a hospital gown and receive an identification band
- Have their blood pressure, pulse, and breathing rate checked and recorded
- Have numbing cream put on both hands or both feet for the intravenous line
- Get any pre-operative medication as ordered by the doctor
- Wait with his/her family for the operating room porter to take him/her to the OR

In The Operating Room

You may go with your child as they are transported to the operating room. You will be asked to put on booties overtop of your shoes, and a gown over your clothes, to prevent outside germs from coming into the clean environment of the operating room.

- A nurse will check your child's identification band against the chart.
- Your child will be moved onto the operating table.
- Monitors will be attached to record blood pressure, heart rate and oxygen saturations.
- The anesthetist will sedate your child and then you will be asked to step out. Your PAC nurse will have already told you how long the surgery is expected to take, and so you will know when it's time to head to the fish tank (in front of the Pediatric Intensive Care Unit) to meet your child once they are finished.



During the Surgery

After your child is sedated, a breathing tube is put in and hooked up to the breathing machine. Your child could be in the operating room for an hour or more just getting prepared before the actual operation begins.

Some things they do to prepare for the operation are:

- Place special IV lines into large veins in the neck and arteries in the wrist
- Put a tube into the bladder to keep it empty
- Put a tube down the nose and into the stomach to stop a child from vomiting

While the surgeon works, the anesthetist monitors breathing and gives any medications like antibiotics or blood pressure medications. If your child needs to be on the heart-lung machine during surgery, also called a heart bypass machine, a perfusionist will monitor the

machine until your child's heart and lungs can take over. The perfusionist is a specially trained technician who runs these machines.

When the surgery is finished steel wires will be used to wire the breastbone back together and steri-strips are used to close the skin.



A chest tube will be inserted to drain away any fluids that build up in the chest after surgery.



Pacing wires are attached to the heart and come out through the skin. These wires can be attached to a pacemaker to help get the heart back to a regular rhythm if the heart beat becomes irregular.

After Surgery

Once the surgery is complete, your child will be discharged from the OR. Your PAC nurse will have already told you where your child will be going to recover after his/her surgery. Specially trained nurses will care for your child immediately following surgery. Once your child is settled in the PCICU, the nurse will come out to the fish tank to meet you and bring you in to be with your child.

Intensive Care

PCICU (3A2) = pediatric cardiac intensive care unit
NICU (3A3) = neonatal intensive care unit

In the ICU:

- A special team of doctors (intensivists, neonatologists) work with the surgeons and cardiologists to provide expert care for your child.
- Residents and fellows assist the intensivists.
- The nurses in the ICU are specially trained to provide the advanced care your child needs to begin recovery following heart surgery.
- Only two visitors are allowed by the bedside at one time; others may sit in the waiting area.

Your child will spend some time on this unit before being transferred to the Pediatric Cardiac Inpatient Unit. How long a child spends on this unit depends on each individual child. Once your child no longer needs the support of the breathing machine, they usually can go to the ward.

The Pediatric Cardiac Unit (4C3, 4C4)

On this unit, the nurses will assist your child on the road to recovery. Your child's vital signs, surgical wound, and pain management will continue to be monitored. Pain management is a priority. Please discuss pain management with your bedside nurse if you are concerned.

On 4C:

- Staff nurses work 8 and 12 hour shifts. You will meet many nurses during your child's stay.
- The nurse in charge of the unit is the unit manager. If you have concerns about your child's care which your bedside nurse is not able to address, ask to speak to the unit manager or nurse in charge at any time.
- Parents or guardians can visit 24 hours a day. We hope you can take an active role in your child's care. Please note, only one parent can sleep at the child's bedside.
- Bedside television sets are available free of charge

Daily Rounds

Parents are encouraged to participate in daily rounds with the health care team. This is your chance to ask questions and receive answers. You will learn more about how your child is doing, as well as any tests, treatments, or procedures that may be needed.

For Breast Feeding Moms

There are breast pumps available for your use; one set of attachments will be provided to you for the length of your baby's hospitalization. Labels and bottles will also be provided. Unlabeled breast milk will be disposed of. There are freezers where your milk can be stored. Please talk to your bedside nurse.

Information for Family and Friends

- To prevent the spread of germs all visitors, including moms and dads, are asked to wash their hands with soap and water or hand sanitizer each time before and after being in their child's room.
- Family and friends can visit on 4C between 11:00 a.m. and 8:00 p.m.
- The ward has a quiet time every afternoon between 1:00 pm and 3:00 p.m. Doors will be closed and lights lowered to allow children recovering from surgery time to rest.
- Ask your nurse before bringing children to visit. Special permission may be needed for children under 12 years old.
- You are responsible for children who visit the hospital. The hospital cannot supervise visiting children.
- You must make your own arrangements for the care of your other children while your child is in hospital.
- For the safety of the child recovering from heart surgery, adults or children who are not feeling well are asked not to visit until they are well.



Privacy

In consideration of others, when in a shared room, you may be asked to leave when medical staff discuss the other patient. Thank you! Your cooperation is greatly appreciated.

The Treatment Team

The Stollery Children's Hospital is a teaching and research hospital. There will be many people caring for your child during and after your child's heart surgery.



Case Coordinator for Pediatric Cardiac Surgery

This RN will:

- Initiate contact with families before their child's admission to hospital
- Assist the team to best meet the needs of children and families during their stay in hospital
- Ensure the lines of communication between the family, surgical site team and referral site team remain open during your child's stay in hospital

Pediatric Cardiovascular Surgery

- The pediatric heart surgeons are Dr. Rebeyka, Dr. Al-Aklabi, Dr. Ross, and Dr. Freed
- The surgical team includes fellows, residents and interns who assist in caring for your child

Pediatric Anesthesia

- Pediatric cardiac anesthesiologists are specially trained to care for children during open-heart surgery.
- The anesthesiologists direct the operating room team and the perfusion team that run the heart bypass machine.
- The anesthesiologists monitor your child closely.

- They are responsible for all IV lines and the drugs, fluids and solutions that your child needs during surgery.
- The anesthesiologist will accompany your child to the ICU or recovery room after surgery.

Pediatric Critical Care



- While your child recovers in the PCICU, their most responsible physician is called a critical care intensivist
- These doctors have advanced training and experience in treating children who have very serious or complex medical requirements, and in particular those with congenital or acquired heart disease
- The Critical Care Intensivist will work closely with the doctors in Cardiology to ensure a smooth transition of care from ICU to the inpatient unit.

Pediatric Cardiology

- There are many pediatric cardiologists who work together and share in the responsibility of care for the cardiac children in hospital
- Each cardiologist is on inpatient service on 4C for a 1-2 week period of time
- After discharge from hospital, your usual cardiologist will resume your child's care

Nurse Practitioner (NP)

- Both the ICU and the cardiology unit have NP's who actively participate in patient care
- The NP is a nurse with specialized training, including a master's degree, in pediatric care.

- Your child will be assigned a primary NP or resident that will be your main point of contact from admission to discharge.
- The NP helps the doctors in the medical management and care of your child. They are specially trained for activities such as removal of chest tubes, drains, pacemaker wires and central lines. They also do IV starts and blood work. Please feel free to talk to the NP about your questions or concerns.

Dietitians

- In our program, we have two nutrition specialists who work with heart children and their families.
- They follow your child closely in hospital and after discharge if you child has any special dietary needs or requires tube feeding.
- Dietitians recommend the best foods and formulas for your child's health. Good nutrition is key in your child's recovery, growth, and development.
- The dietitian is only a phone call away if you have questions or concerns.

Pediatric Pharmacy



- A pediatric pharmacist makes hospital rounds each day and provides advice about your child's medications.
- The pharmacist is available to answer questions you may have about your child's medications.
- Discharge prescriptions can be filled at the Rexall Outpatient Pharmacy (Level 1, across from the snack bar).
- Some medications might not be available at your local pharmacy. Check with the pharmacist before leaving the hospital so that you can plan in advance.

Respiratory Therapy

- Respiratory therapists provide therapies and life-saving interventions for children who have breathing difficulties.
- They will follow your child through their stay, in the ICU and on the wards, if they need help with their breathing.
- They are also available to assess your child if you are concerned about their breathing.

Other Pediatric Consultants

- Other children's specialists may help us care for your child.
- The team will tell you when and why a specialist has been asked to see your child.

Children's Rehabilitation

- Physiotherapists provide treatments and exercises to help your child recover.
- The Speech and Feeding Team help if there are worries about your child's feeding and swallowing, or if your child spits up a lot.
- The Complex Therapies Team from the Glenrose Rehabilitation Hospital will see every child under the age of 2 months having open heart surgery.
- The Rehabilitation Team will see any child with multiple medical problems including a stroke.

Discharge Coordinator

The Discharge Coordinator is a nurse who assists the team, family and referring medical center to coordinate the discharge of your child either to home or to the referring hospital (if needed).

Support Services

Social Work

- Social workers are a part of the health care team and will be in contact with you while you are in hospital.
- A social worker can provide you with emotional support during your child's time in hospital.
- A social worker meets with families to assist with practical issues such as accommodation, transportation and finances.
- The social worker can connect you to community resources that may be helpful for your family.

Family Support for Children with Disabilities

Family Support for Children with Disabilities (FSCD) provides services to Alberta residents. For services in your home province, please contact your referring center.

Children less than 18 years of age with chronic medical conditions or developmental concerns may qualify for benefits (determined not by the diagnosis, but by the impact on your child's daily living needs).

You must make the call yourself to register your child's name. Please call the nearest FSCD office after speaking with our social worker to see if you qualify. We can provide you with the necessary medical information to apply for these support services.

Applications may take a several weeks to process.

Chaplains

- Nondenominational chaplains are available by request 24 hours a day.
- The chapel (on Level 5) is also nondenominational. It is available to patients and families 24 hours a day.

Child Life

The Child Life staff will help your child adjust to the hospital. Tools such as toys, games, and movies are used to teach, and to assist in a child's recovery. Children are encouraged, when they are able, to go to the playroom, teen room or "the Beach". The Beach, supervised by child life staff, is a large play area on Level 4. The Beach is available to all pediatric inpatients.



School (4H2)

- School activities help to give your child a more normal daily routine.
- School-age children can attend the Stollery School while in hospital where teachers will help them keep up with schoolwork.
- The hospital has two classrooms offering four, one hour classes per day. Classes run from 9am-3:30pm. Morning and afternoon breaks are provided, and children return to the unit at lunchtime.
- Patients who are unable to attend the Stollery School may participate in the bedside teaching program.

Recreation

The McMullen Art Gallery (Level 1)

- This gallery features art exhibits and music for both patients and visitors
- There is no entry fee
- Gallery hours vary and are posted at the door

The Patient Library (Level 4)

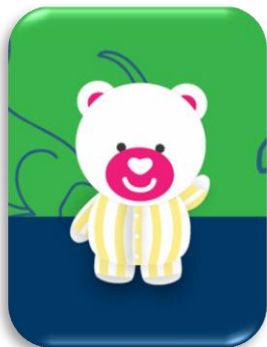
- Patients and families can visit this small public library located in the fourth floor atrium
- There is no charge to borrow a book and no library card is required

The Family Resource & Learning Centre (4H2)

- Child Health offers general health and safety advice for you and your family
- You can also find special information about many childhood diseases and illnesses, and common diagnostic tests
- It offers a place to relax as well as access to computers for complimentary use
- Hours: Monday to Friday, 9 a.m. – 4 p.m.
Extended hours are available for evenings and weekends depending on volunteer availability.



When You Leave the Hospital



Readiness for discharge is not determined by time, but by meeting a set of required criteria. Some children may take only a few days to meet discharge criteria. Others may require a week or more. Once your child meets the criteria specific to their age and condition, discharge from hospital can be considered.

Most children can go directly home after discharge from hospital. If you have come from another city for treatment and care, your child may be transferred back to the hospital nearest your home. In some cases, patients are required to stay in Edmonton after discharge until they have completed their post-operative clinic visit and the cardiologist feels it is safe to return home. Do not hesitate to ask your doctor or nurse if you have questions or concerns.

Discharge Instructions

- When you leave the hospital, you will receive an information sheet that tells you about your child's care at home. You will also be given a copy of the medical discharge report and the unit discharge instructions. Please bring these information sheets with you when you return to the Stollery for follow up at the Cardiology Outpatient Clinic, or when see your own doctor next.
- If your child is unwell, call right away. Do not hesitate to call your doctor or a nurse if you have any questions or concerns after discharge.

Medication

Children usually require medicine for awhile after they go home. You will be given a list of medications that have been ordered, and the necessary prescriptions, before you leave the hospital. Be sure to understand what medicine your child is taking and why. If you have questions, talk to your doctor, nurse or pharmacist.

Call your family doctor or cardiologist for refills **before** you run out of medication.

Some types of medications your child might receive:

Painkillers (Analgesics)

Analgesics (ex. acetaminophen, morphine) are given to treat pain. They may be used in individual doses or as a continuous infusion through an intravenous (IV) line. Your child's pain level will be assessed frequently by their bedside nurses.

Sedatives

Before and/or after surgery your child may be on sedation medications in order to prevent or decrease stress, movement, and anxiety. Sedation is often used when a ventilator is helping a child to breathe.

Blood Pressure Medications (Antihypertensives)

Beta Blockers

Beta blockers are used for treating high blood pressure, irregular or fast heart rates, and for some types of heart failure. These medications work by blocking some substances in the body that cause stress on the heart.



Calcium Channel Blockers

Calcium channel blockers are used for treating high blood pressure by relaxing the blood vessels and allowing for more blood to flow through. Sometimes they are prescribed to control how fast the heart is beating.

Angiotensin Converting Enzyme Inhibitors (ACE inhibitors)

ACE inhibitors are used to treat high blood pressure by stopping the enzyme responsible for raising blood pressure in the body.

Blood Thinners (Anticoagulants)

These medications work by preventing the blood cells from sticking together and forming clots. When your child is on anticoagulant therapy you should watch for signs of bleeding, and report them to your health care team. Watch for (at take seriously) red or black stools, dark red/brown urine, nose bleeds, large bruises, and bleeding gums.

Water Pills (Diuretics)

These medications work to get rid of extra fluid that is built up in the body by increasing the amount of urine the body produces. This can help with lung function and maintaining a normal blood pressure.

Acid Reducers (Proton Pump Inhibitor [PPI])

Medications used to decrease the amount of stomach acid and stop it from backing up into the esophagus (throat) causing heartburn.

Oxygen

Some children require extra support to make sure they are receiving enough oxygen for their body. Oxygen can be provided in different forms while in hospital. If your child is sent home on oxygen, you will be taught how to use oxygen at home prior to your discharge.

Hospital to Home

Follow up at the 4C2 Cardiology Outpatient Clinic

The clinic nurses at 4C2 coordinate your child's heart tests ordered by the cardiologist after discharge. They are excellent resources about the care of children with heart conditions. Each cardiologist has a designated nurse and you can call them directly if you have questions or concerns. If you are discharged from hospital back to your hometown outside of Edmonton, you will be followed by your home cardiology program.

Activity

The goal for the first weeks after surgery is to pace your child's recovery. Rest and activity periods should be balanced and spaced throughout the day. The breast bone, also known as the sternum, takes six to eight weeks to heal after the sternum is closed.

Activities should be limited to the following for eight weeks:

Infants and Small Children

- **Do not lift or pull your child by their arms.** Instead, **scoop them**, supporting their head, neck and bottom for the first few weeks after the sternum is closed.
- Do not enforce tummy time. If your child rolls onto their tummy by themselves, allow them to do so.
- No rough play
- Car seat and seat belts should be used at all times. Light padding in between the chest and the seatbelt/restraint system may be used but must not interfere with the restraint system.

School Age Children

- Children may return to school within about two weeks
- Do not let them lift, push or pull anything that weighs more than five to ten pounds. This includes their own body weight, and carrying a backpack or heavy books
- Hug a pillow when coughing, sneezing or laughing
- No rough play or contact sports; no climbing
- Do not have them use their arms to get out of bed, a chair or the car.
- Do not let them reach far behind their back (like when pulling pants up from behind).
- Do not let people pull their arms when helping them move. Have people assist from behind if needed.



Older Children

- Getting out of bed: To move from lying to sitting, log roll onto your side. Swing your legs off the edge of the bed and use your stomach muscles to sit up. Your physical therapist will show you how to get out of bed safely by either crossing your arms or hugging a pillow to remind you not to use your arms.
- When getting up from a bed, chair or toilet: Scoot forward to the edge, lean forward, tuck your feet underneath you and use your leg muscles to push up.

Teenagers

Driving:

- Do not drive for at least six weeks, or until your doctor says you may
- If you are sitting in the front passenger seat of a car, you must turn off the airbag. If you cannot turn it off, sit in the back seat.
- **Use your seatbelt.** For comfort, use your *heart pillow* between you and your seatbelt.

Sexual Activity:

- Sexual activity demands the same amount of energy from your heart as climbing 18 stairs at a normal pace.
- Once you are able to do this, then you can decide with your partner if you are ready.
- Do not put pressure on your chest until fully healed.
- Do not have sex after eating a heavy meal or drinking alcohol as these put more demands on your heart.
- Some medicine lessens your desire for sex, while others may interfere with sexual response. If you have concerns, talk to your family doctor.

Menstruation:

- Major illness, trauma, infection or **operations** can affect an otherwise normal menstrual cycle.
- You may get your period within days of surgery. Come to the hospital prepared with your own feminine hygiene products.
- It may take a month or two to fully revert back to your normal cycle.

Chest Care:

- Young ladies might find a sports bra without an underwire useful for pain management in the early post-operative period. Breast tissue pulling on the sternum can be uncomfortable for a few weeks after surgery, especially when up and about. A firm binder or support bra will be helpful.

Emotional Health:

- It is normal to feel overwhelmed, frustrated or as if you aren't getting better fast enough
- Many adults after heart surgery need anti-depressants to help them cope
- Talk to your family or to your doctor about how you are feeling

Conclusion

This is a lot of information. There may be times when you feel bombarded with *too* much information. Understand that it is okay to let others know that you need some time to absorb the information you have already received.

Feel the feelings.

Build on your strengths and supports.

And know that you are not alone.

Caring is what we do best.



Resources

Online

The Western Canadian Children's Heart Network:
<http://www.westernchildrensheartnetwork.ca/family-support-resources/resources>

The Children's Heart Society (Greater Edmonton Area):
<http://www.westernchildrensheartnetwork.ca/family-support-resources/resources>

Heart Beats Children's Society (Greater Calgary Area):
<http://www.heartbeats.ca/>

A colouring book for children about going for heart surgery, the people they will meet, and things they might experience:
https://my.clevelandclinic.org/ccf/media/files/Social_Work/SurgeryBookChildLife.pdf

The American Heart Association:
Numerous resources and printable information sheets, as well as general information about open heart surgery in children
www.heart.org
(Click on Cardiovascular Conditions of Childhood)

Books for Parents

"It's My Heart"

This resource book is for patients and families affected by congenital heart disease. In plain, understandable language, *It's My Heart* provides descriptions of congenital heart defects and acquired pediatric heart conditions. Along with explanations of various tests, surgical procedures, and treatments for congenital heart

disease, this book also contains helpful diagrams, a glossary of medical terms, and much more. *It's My Heart* was developed over a number of years by a dedicated group of doctors, nurses and parents in a collaborative effort spearheaded by The Children's Heart Foundation. (www.childrensheartfoundation.org)

"Matty's Heart"

This book prepares children for open heart surgery in a way that they can understand. Kids with Heart families have purchased these since they first became available and the children love it. It is also a great way to explain things to siblings, relatives, and teachers. This book is distributed exclusively by Kids With Heart National Association for Children's Heart Disorders. Can be purchased at www.kidswithheart.org

Books for Kids

"Matty's Heart Catheterization Coloring Book"

This book explains the heart catheterization procedure to children. It is also a coloring book which can help the child feel more comfortable when dealing with the situation. It can be purchased at www.kidswithheart.com

"It's My Heart"

This book was written by the Children's Heart Foundation for the purpose of assisting parents of children with congenital heart defects. It is an excellent resource for all parents who provide varying levels of care with their "heart child."

Books for Teens

“A Night Without Stars”

This book, designed for the adolescent facing open heart surgery, is a story of a 10 yr old girl who is facing open heart surgery and the fears she is dealing with. She meets a young boy, near her age, who is badly scarred from burns and he helps her to face her fears by sharing his experiences with her.

“The Beat Goes On”

This book is about living with a pacemaker or ICD that keeps your surgically repaired heart in beat. It takes the young adult with the congenital heart defect step by step through the following issues:

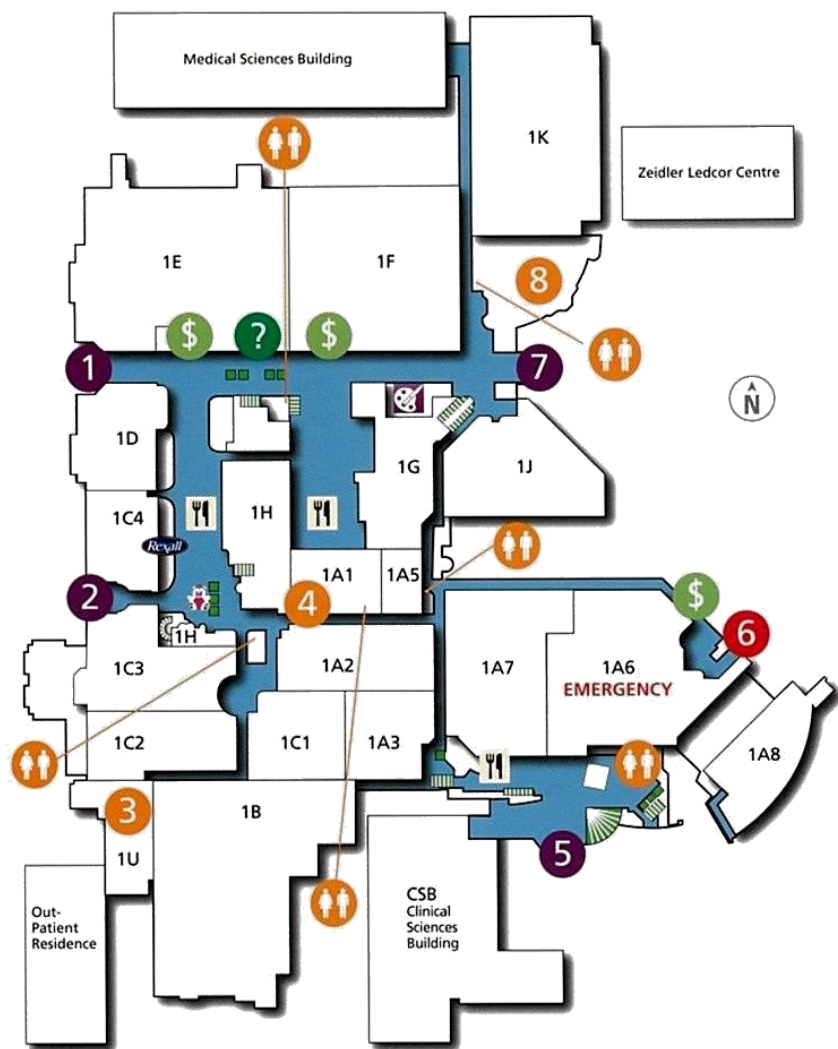
- 1) The heart and how it works
- 2) Abnormal heart rhythms
- 3) Types of devices and what they do
- 4) Caring for a device

The Beat Goes On answers a lot of the everyday questions about having a device that may leave some patients “off the beat”!

WALTER C. MACKENZIE HEALTH SCIENCES CENTRE

University of Alberta Hospital • Stollery Children's Hospital • Mazankowski Alberta Heart Institute

LEVEL ONE



Elevators/Stairs/ Escalator

Public Route

Washrooms

Information

1 114 St Entrance

2 Stollery Entrance

3 MRI

4 Admitting

5 Mazankowski Entrance

6 Emergency Entrance

7 112 St Entrance

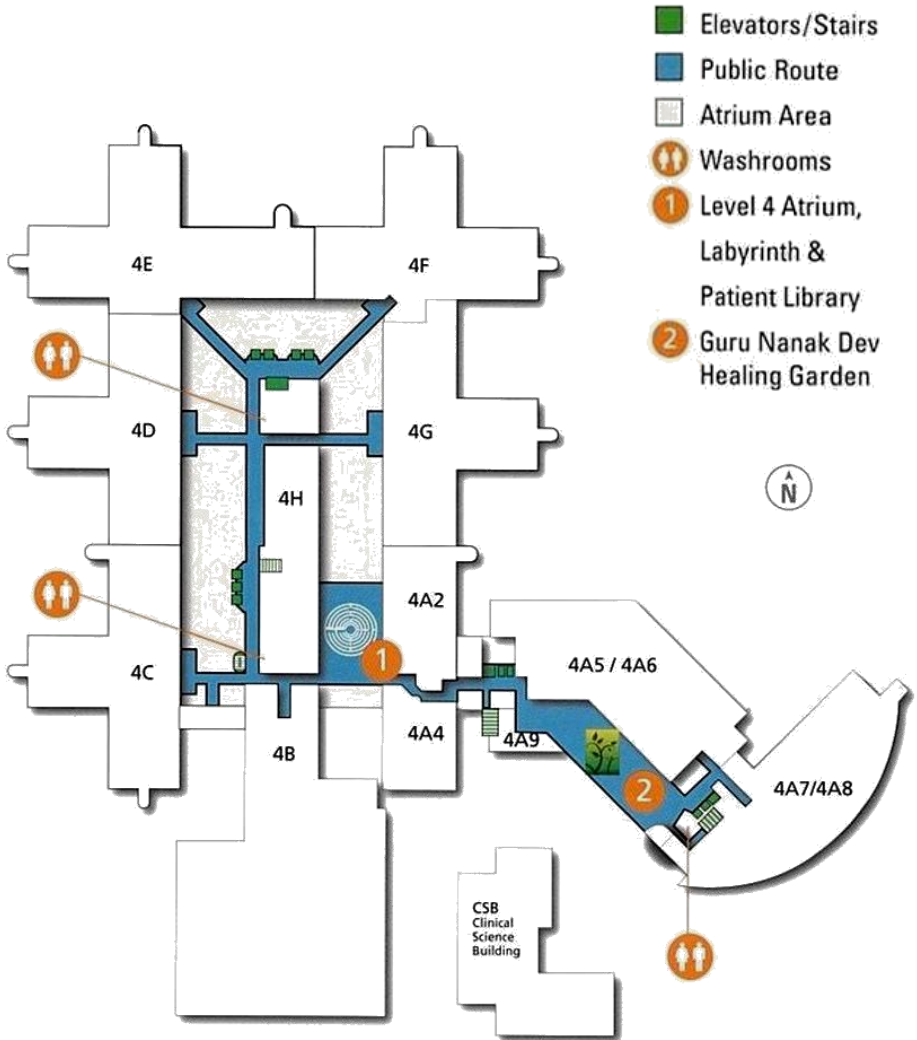
8 Bernard Snell Hall

\$ ATM

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LEVEL 4



Please Note: The Pedway to the East Public Parkade is located on Level Two of the Mazankowski Alberta Heart Institute

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support@carepages.com

Pediatric Congenital Heart Program Phone List Tear Off Sheet

	Phone
Surgical Case Coordinator	780-407-7709
Unit Manager (4C3)	780-407-7427
Cardiac Clinic Nurses	780-407-3307 780-407-3957
Offices of the Pediatric Cardiologists: Dr. Michal Kantoch Dr. Lisa Hornberger Dr. Joseph Atallah Dr. Angela McBrien Dr. Yashu Coe Dr. Jennifer Conway Dr. Edythe Tham Dr. Nee Khoo Dr. Carolina Escudaro Dr. Paul Kantor – Division Head Dr. Simon Urschel Dr. Tim Colen Dr. John Dyck Dr. Andrew Mackie Dr. Konstantin Averin	780-407-3963 780-407-3355 780-407-3964 780-407-8361
Offices of Pediatric Cardiac Surgeons: Dr. Rebeyka Dr. Ross Dr. Al Aklabi Dr. Freed	780-407-8033 780-407-8047 780-407-3929 780-407-3617

Clinic Appointments	4C2	780-407-3952
Program Social Worker		780-407-6877 780-407-1703
Discharge Coordinator (4C3)		780-407-1872
Dietitian		Inpatient: 780-407-8143 Outpatient: 780-407-6612
Pre Admission Clinic	1C3	780-407-6890
Cardiac Inpatient Unit	4C3 / 4C4	780-407-8421
PCICU	3A2	780-407-7525
NICU	3A3	780-407-6297
Cardiac Research Office (SCORE)		780-407-4427

Heart Surgery Checklist

Tear Off Sheet

To Do List	Date/Time/Details	Done ✓
Visit your dentist		
Book accommodation		
Call case coordinator or family doctor		
PAC Date: _____ Alberta Care Card Parent Photo ID Proof of Guardianship Medications Immunization Records		
Day before surgery What time your child must stop eating and drinking		
Day of surgery What time to arrive at the hospital: What time your child's surgery is scheduled for: Where to go on the day of surgery:		

Notes

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This material is for information purposes only. It should not be used in place of medical advice, instruction, and/or treatment. If you have questions, speak with your doctor or appropriate healthcare provider.