Heart Transplant for Children at the Stollery Children’s Hospital

Prepared by your Transplant Team

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INTRODUCTION

We hope that this handbook will help to answer your questions about heart transplant in children. The purpose of this book is to introduce you and your family to the University of Alberta Hospital and Stollery Children's Hospital Heart Transplant Program. Here you will find information about the process of heart (cardiac) transplantation that will help you to prepare for the journey ahead.

Your doctor has referred you to this program because your child has heart disease. The most common reasons a child needs a heart transplant is because of a complex heart defect (congenital heart disease) present from birth or because of poor heart function as a result of abnormal heart muscle (Cardiomyopathy). You can either be born with abnormal heart muscle or it can be caused by a virus. There are other reasons to have a heart transplant; your doctor will discuss these with you if necessary.

Your first visit, called the referral visit, is arranged to provide you with more detailed information about heart transplantation. This information is to help you and your family decide whether transplantation is the best option for you. If so, you will then move on to the assessment or work-up phase, to collect more information about you and to determine if there are any factors that would make the surgery or recovery more difficult you.

Heart Transplantation is not suitable for everyone nor is it a cure. It involves replacing a damaged heart with a healthy one to prolong, and improve the quality of your life. It requires a lifetime commitment to taking medications and to ongoing follow-up tests and appointments.

Your transplant coordinator and physicians will spend time with you and your support person to answer all of your questions, explain more about transplantation, and to help you make the right decisions.
What is the main problem?

The main problem is that your child’s heart isn’t working properly. Without enough oxygen to the brain and other organs, they will begin to suffer and eventually die. Often we have other options like surgery, medications and treatments to choose from but if these things are no longer working to help you, or your child, to get better then transplant might be the only hope for long life.

Transplant means that we take out the heart that is not working and replace it with another heart. We get other hearts from people who have passed away and their families have chosen to donate their organs. They cannot be frozen or stored so we must use the heart right away. That means you will have to wait on a list until the best heart for you becomes available. This is a very precious gift, one that should not be taken lightly, and one that must be looked after carefully for the rest of your life.

What do I need to do?

It is very important that you take good care of the heart, now and for the rest of your life. Becoming part of the team that is responsible for your health is the best thing that you can do. Being an active participant, asking questions, working to make sure that you have the best care is all part of the team work.

We will ask you to have blood tests often, after a while they will be every few months but in the beginning it is a lot. You have to see the doctor every week, then every month, never less than every 4 months for the rest of your life. The most important thing is that you take your medication as ordered every day.

Why is it important for me to do this?

The person who knows the most about you and your health, or your child’s health, is you. You need to be part of the team making decisions about your health. Transplant is not a cure; you are trading the possibility of death for a type of chronic illness. If you do not pay attention to your continued good health by having blood work, attending clinics or taking your medication your health will suffer. It will seem after a few years that you are doing well and perhaps we are exaggerating the need for continued surveillance but the long term complications of transplantation are best dealt with early, before physical symptoms occur, this means we catch signs in your blood work or during clinic visits that you might not notice right away. The long term complications include kidney disease, rejection, infection, cancer, growth delays due to hormonal imbalance, poor bone health and diabetes.

If you do your part and pay attention to your health, and we watch for signs of complications in your blood work and during clinic visits, we can work together for a happy and healthy future for you.
TRANSPLANT PROCESS

What steps must we go through to get to Transplant?

There are generally six phases that are part of the transplantation process.

Referral

Your cardiologist or family doctor referred you for possible transplantation assessment. During this first visit you will meet the Transplant Cardiologists (heart doctors), Clinic Nurse, and Coordinators. Please bring your support person/people to this visit.

Learning that you may need a heart transplant is very stressful. Children need their parents to be present for much of the time in hospital. A support person for the parent is useful, it can be anyone you choose who will be there to assist and support you during all phases of the process. This person should be able to provide you with the physical and emotional support you need. It is important to have this person is with you for the teaching during the assessment phase. Then they can spell you off in hospital, or even once you are home, because they know what you know.

You could choose someone such as your spouse, another family member, or a good friend. Choose someone who knows you well and is willing to make the long-standing commitment to you. They will be needed to encourage you, listen to your
concerns, and help you cope. Also, they will help you learn the medications, learn new routines, keep appointments, and assist you during your child’s recovery.

During the first visit with the transplant team, your child’s health history will be reviewed and the baby or child will be examined. The doctor may discuss several options with you, including:

♥ Changes in your child’s medications
♥ A surgeon may be consulted to determine other surgical options
♥ Other options, such a mechanical cardiac assist, may be discussed (Refer to VAD section for further explanation)
♥ Putting off the decision about transplant because your child is still too well or because there may be some potential for improvement with time or with other treatments.

The risks and benefits of transplantation will be discussed along with the commitment transplantation requires. If it is felt that you have a condition that can be best treated with heart transplantation and you have no other obvious reasons not to go ahead with transplant, then you may go on to a full assessment. You will have your questions answered and then you will have time to decide if a transplant is the right choice for you.

**Assessment**
The purpose of the assessment is:

♥ Confirm diagnosis and rule out complicating factors such as:
  ♦ Very high pressures in your child’s pulmonary arteries (arteries that carry blood from the heart to the lungs).
  ♦ Blockages in blood vessels to your child’s brain or other parts of their body,
  ♦ Liver, kidney or lung disease.
  ♦ History of cancer
♥ Rule out infections
♥ Determine baseline health status
♥ Determine if a heart transplant is the best option for your child

A Transplant Coordinator will arrange for all appointments and tests.

The majority of assessments are done as an inpatient over a period of about 5 days. If you live outside of Edmonton, arrangements can be made for you to stay near to the hospital at the Ronald McDonald House or a hotel depending on finances.
During the assessment phase, you and your family will meet many of the team members. The team includes doctors, transplant nurse coordinators, social workers, dietitians, physiotherapists, occupational therapists, pastoral care, and secretaries. Each member has a particular interest and expertise.

The transplant team needs to know what your understanding of the disease process, your lifestyle, and your goals are. We will discuss your feelings toward transplantation, the strength of your emotional support, any financial concerns, and any concerns about treatment after transplant.

These are done to assess how your heart disease has affected the rest of your body. They may help identify any problems, which may increase risk of transplantation, or may need special treatment before and after transplant.

Pediatric Heart Transplant Assessment Testing Outline

Based on your child’s age and health status, these lists may not be fully inclusive or exclusive, please use as a guideline only.

CONSULTS:

♥ Pediatric Occupational Therapist for developmental assessment
♥ Transplant Dietician
♥ Transplant Psychiatrist
♥ Infectious Diseases
♥ Immunology Specialist (If history of penicillin allergy)
♥ Endocrinology
♥ Transplant Social Worker
♥ Transplant Pulmonologist
♥ Transplant Cardiologist
♥ Nephrology
♥ Dentistry A dental exam is required as long as your child has teeth and any outstanding dental work should be done prior to transplant

*Please note, if coming from out of province, there may be a cost involved to have dental work done in Edmonton. If possible, please have completed in your home province.

♥ Transplant Coordinator
♥ Other consults as necessary

BLOODWORK:

♥ Blood type and screen
♥ Tissue typing
♥ Microbiology/Virology
♥ Blood cultures
♥ Routine bloodwork and hormonal screening
OTHER LABORATORY INVESTIGATIONS:
♥ Height and weight
♥ Sputum for bacteria, fungus, and acid-fast bacilli
♥ Rectal swab for VRE (Vancomycin Resistant Enterococcus) screening
♥ Nasal swab for MRSA (Methicillin Resistant Staphylococcus Aureus) screening
♥ Urine tests (urinalysis, urine culture, 24 hour urine collection)

RADIOLOGICAL STUDIES:
♥ Chest x-ray
♥ Ultrasound of kidneys, ureter, and bladder
♥ Ultrasound of abdomen
♥ CT chest
♥ Bone age
♥ Bone Density studies (>5 years of age)
♥ GFR

CARDIAC INVESTIGATIONS:
♥ Echocardiogram
♥ 12 Lead Electrocardiogram (ECG)
♥ 24 hour holter monitor
♥ Cardiac catheterization (if required)

PULMONARY INVESTIGATIONS:
♥ PFT’s if > 5 years of age (Pulmonary function tests)

OTHER TESTING:
♥ You will need to go to your public health center to have an update of all immunizations, bring your records to the assessment
♥ Vaccinations as recommended by infectious diseases
♥ TB (Tuberculosis) Skin test (unless prior history of TB or positive reaction)
♥ Other testing as necessary or recommended by consultants
♥ If candidate for ABO incompatible transplant, additional bloodwork and consults required.

Please contact your transplant coordinator if you have any questions or concerns about any of the above testing, or if you would like further explanation. Your coordinator will arrange a teaching session with you as part of the assessment for transplant.
How does my child get on the list?

It will take time for all the information to be collected and reviewed. Once this is done, your case will be presented to the entire transplant team at our regular Wednesday conference. Most of people you meet during your assessment will be present at the meeting. The transplant team reviews information from consultations, examinations and tests. They then decide whether a heart transplant is your best option. If you are accepted for transplantation, the Transplant Coordinator will contact you for:

♥ Continued follow-up in the pediatric cardiology clinic closest to your home

♥ Answering your questions and providing additional teaching

♥ Preparing you for the call and for the procedure

♥ Once you are active on the heart transplant list your status will need to be updated at least every six months. The coordinator will arrange these appointments and notify you

Waiting List

Waiting times can vary widely due to:
♥ lack of organ donors
♥ health status
♥ antibody status
♥ blood group

This can be a very difficult time for families who wait for weeks, months, or years. When you are listed, it is important that a cell phone number, home number or pager number is listed for us to contact you at any time. You must carry a phone or pager with you at all times, especially if you are not home. Transplant can happen at any time. There is usually no warning that a suitable heart will become available but when it is, you will be required to get to the hospital quickly.

Your job while waiting is to:

♥ keep your child as healthy as possible. The more stable you are before transplant the quicker you will recover.
It is important for children to maintain a healthy weight; loss of weight might indicate worsening heart function.

If your child gets a cold, flu, fever, infection, etc, see your family doctor and contact the coordinator.

It is important to have someone contact the transplant office if you are admitted to hospital, as a new illness may affect the decision about whether, and when, you would be transplanted.

SAVE MONEY - you have to pay your bills at home plus bills in Edmonton for a minimum of two months.

Develop a telephone fan out for family and friends- you call one person, they call two friends etc. This way news about your child’s transplant and recovery can be communicated quickly. Some families use facebook or carepages to communicate with friends and family while in the hospital.

Learning ways to manage your stress is especially important at this time.

How can I manage stress during the waiting period?

Most people find the waiting period to be very stressful. If you are experiencing symptoms of stress, you are not alone. To help you through this period, here are some things other people have found helpful.

- Know and understand your child’s condition
- Discuss your child’s condition with informed people
- Be realistic about your child’s situation
- Find support
- Continue with your normal daily routines
- Enjoy some private time
- Keep positive
- Seek professional help
- Find a local Support Group
- Talk to patients who have been through transplantation
- Learn stress management techniques from our Occupational Therapists

If you are still experiencing difficulties coping with your illness or have difficulty finding support for yourself or your child contact the transplant coordinator or social worker. They can guide you to finding the right kind of support. We have a psychologist who frequently sees patients from our program and who may be quite helpful in dealing with these stresses.
How should I prepare my child for transplant?
Tell your child the truth, as much as they will understand, before they come to the hospital. You will find a list of recommended books in the resources section of this manual. Most are easily bought online at Amazon or Borders. Your child might find reading about the experiences of another child with transplant helpful. Encourage them to trust the medical staff. It is important that children believe that we are all on the same team. The older your kids are the more time they might need to prepare themselves mentally for transplant.

Some examples of topics to discuss with your child are:
- Tell them what the incision will look like
- Draw a picture of an incision on a doll or on their chest
- Tell them they may have some pain but if they have pain they can ask for medicine to make it better
- Tell them that the doctors and nurses are on their side and helping to make them better

What should we bring to the hospital?
The hospital will provide pajamas, diapers and food for your child.

Bring personal items; toothbrush, toothpaste, comb or brush, shampoo, slippers and a robe. If your child would like to wear his or her own pajamas, he or she may do so. Bring your child’s favorite toys, books or music. Pictures of family are also a good idea. Mark all personal items with your name.

For babies, bring their own bottle and nipples from home, along with their favorite soother. One parent can stay with the child in their room, except when in the Intensive Care. Bring your own toiletries but please remember there is a limit to the amount of storage space available. You will be responsible for your own food.

Once you receive the call that an organ is available for you, you will not have much time to prepare. Here is a checklist to help you when you get the call.
- Pack a small suitcase in advance including slippers and loose clothing. Have a list ready for items you will need to pack at the last minute.
- Bring a small amount of cash in case you need to take a taxi to the hospital and have some loose change available for phone calls. You can’t use your cell phone on the hospital wards but you can use it in the main areas of the hospital.
- Designate someone to look after your household responsibilities like watering the plants, caring for pets, picking up mail, and paying bills.
- Make a list of people you will need to notify and their phone numbers. Use this to create a fan out plan – where you will call 1 person who will call 2 people and, they, in turn will call 2 people until everyone is aware. You may be asked to stay off the
phone for a period of time once you receive the initial call, therefore, the less you have to do the better.

- Bring a book or some magazines, your mp3 or ipod, CD player, and maybe a favorite reminder of home. The more you feel at home and have things to do, the faster the recovery will seem.
- Consider getting a calling card if you are from a distant town or city within Alberta or from another province. Check with your cell phone provider for plans with cheaper long distance rates.

**How does the transplant team match donor hearts to recipients?**

There are several factors that the Transplant Team considers when matching donor hearts with recipients on the waiting list:

1. **Blood Group**

   All patients are categorized according to blood group. There are four blood types: A, B, AB, and O.

   Usually anyone receiving an organ transplant must receive an organ from a donor of the same or compatible blood type to avoid severe rejection. An example of a compatible typing is an O blood type donor heart that may be given to any blood group recipient, and a blood type AB recipient can receive a heart from any donor. However, infants and children up to about age 2 can receive hearts from donors of incompatible blood types because they have not yet developed certain antibodies that would lead to acute rejection. This is called **ABO Incompatible Transplant**.

   This type of transplant was pioneered in Toronto by Dr. West, who is now based here at the Stollery Children’s Hospital. Since 1995 a number of these transplants have been done very successfully. The number of infants dying on the list waiting for transplant has dropped dramatically since the introduction of ABO incompatible transplants.

   ![Blood Group Diagram](Image from wikimedia commons)
2. **Height and Weight**

   There needs to be some similarity in size between the donor and the recipient.

3. **Degree of Illness or Status**

   This is also referred to as the *status* of the recipient. Here is a brief overview of our status listing criteria. Your child’s listing status will be discussed with you.

   **Status 0** - Patient temporarily on HOLD
   **Status 1** - Patient at home
   **Status 2** - Patient in hospital or health care facility in stable condition
   **Status 3** - Patient has a ventricular assist device and is at home, OR Intravenous Inotropes and in hospital
   **Status 3.5** - On ventricular assist device in hospital OR high dose inotropes and not a candidate for an assist device
   **Status 4S** - High PRA (>80%) or having 3 prior positive crossmatches
   **Status 4** - Patient in ICU requiring mechanical, ventilatory or circulatory support, OR a ventricular assist device in a patient < 8 kg

   The patient who is sicker, or has a higher status, will receive the organ first. This is determined through continuous communication with your own heart specialist and the transplant team. If you are hospitalized, please notify the team. Your status will change accordingly.

   If your condition has deteriorated to a critical point, *status 4*, the Transplant team will place the request nationally. This means that matching organs from anywhere in Canada will be offered first to our program for you.

4. **Length of Waiting**

   If all other factors are the same, length of time on the waiting list may determine who receives the transplant. Organs are not matched by sex, ethnicity, age, or religion.

   ****REMEMBER**
   *It is only the number of hearts donated to the program that determines how many transplants are done.*

**What can I know about the donor?**

Currently in Canada it is illegal for you to know who the donor was and where they come from. However, we recognize the need for you to express your thanks to the donor family. Once your child has recovered from the transplant surgery (and when you feel ready), you will be encouraged to write an anonymous thank-you letter to your
donor family. Please give this letter to the coordinator who will read it to ensure you are not identifying yourself. If you wish we will be happy to help you to write your letter. This letter will be passed on to the donor coordinator on the donor side who will then locate the family and give it to them. The donor family is not obliged to write back, but if they do, the same process will be used.

Try to remember that it is not important who your donor was, but that their family very generously gave you the gift of life amidst their tragedy and loss.

Transplant

Transplant day is here! This is a very exciting time and feels like you are at the end of a long and hard race, but really this is just the beginning of a new adventure with transplant. There is a lot of hard work ahead. This is still a day to celebrate and dream big.

Usually you will receive a call from the transplant coordinator and are asked to come to the hospital with very little notice. Once at the hospital your child will be admitted to the Stollery Children’s Hospital. They will receive some medication by mouth to settle their stomach and start immunosuppression. More blood work is needed at this time to make sure your child is stable before surgery and to see if any further medication is needed for the operating room. All patients are asked to bathe using antibiotic soap to clean the surgical area. At this time you will be asked to sign consent for surgery. Once the procedures are complete you will wait in the room until the operating room staff call and ask for your child.

What is consent?

Consent means that you agree that your child needs a heart transplant, that somebody has told you all the risks and benefits of the transplant, what could happen without surgery, what could happen after surgery, and the most likely outcome.

There are sometimes theoretical concerns about donor organs. Health Canada calls these “exceptional release” items.

What is exceptional release?

Health Canada has strict requirements for assessment and testing of organ donors. In some cases there may be assessments and tests that cannot be completed for various reasons. The term “exceptional release” means that an organ intended for transplant has not met all the requirements for assessment and testing as defined by Health Canada.
Some examples include:
  - No family member available to provide information regarding the donor’s travel history, previous blood transfusion or previous surgery.
  - A blood test result was not available at the time of organ offer.

Exceptional release is also required when an item of concern related to the donor has been identified.

Some examples include:
  - Donor with remote history of low risk cancer
  - Donors who test positive for a particular virus
  - Donors with high risk sexual or substance abuse behavior which may put organ recipients at a higher risk for contracting certain infections.

Will I be offered an organ under exceptional release?
You will be offered an organ under exceptional release only when the physician decides that the organ is suitable for transplant. Your physician will decide to accept the organ for transplant based on his or her clinical judgment and with your best interest in mind. The physician will assess the potential risks involved in using the organ for transplant. He/she will also assess the risk of not accepting the organ based on your health and organ availability in the future. **However, the decision to proceed with transplantation is yours.**

How will I be informed?
You will not receive an organ under exceptional release without your knowledge and consent. The transplant coordinator on call or the transplant physician or surgeon will give you information about the risks of proceeding versus not proceeding with the organ transplant and answer your questions. You will receive this information over the telephone if you are waiting at home for your transplant, if your child is hospitalized either the coordinator or physician will speak to you. You have the right to ask to speak to your physician before proceeding.

Do I have to sign consent?
Once you have decided to proceed with transplant, you will be required to sign a consent form for organ transplant under exceptional release. You will sign this consent in the hospital prior to your surgery.
Dry Run

It is possible that you will be called in for transplant, sign consent, be prepared for the operating room but then be discharged from hospital without a heart transplant. This is called a dry run. Surgery is cancelled because the heart is not acceptable for transplant; the heart is not as healthy as it seemed based on the early test results, once the surgeon has it in his hands. Once your child is discharged from hospital the cost of returning to your home, if you do not live in Edmonton, is your responsibility.

What happens in the hospital after Transplant?

Patients normally spend between 3-7 days in the pediatric intensive care unit (PICU), they go to the PICU directly from the operating room once the transplant is done. They still have a breathing tube in their nose or mouth, down into their lungs and a machine is breathing for them. This machine is called the ventilator. The process of having the tube put into their lungs is called intubation. Once the tube is removed (extubation) your child can be moved back to the ward.

Kids often also have a tube into their stomach called a naso-gastric tube or ng tube. This can be used for feeding once the bowels start to move. Until then they are fed fluids, sugar and salt by IV. Your child will have many IV lines including one into their neck or groin that goes into one of the large blood vessels directly connected to the heart. These central lines are used for special monitoring, blood work and special types of IV fluid.

Children may have a tube into their bladder, called a foley catheter, to drain urine for a few days. We try to take out many of these tubes as soon as possible as each tube increases the risk of infection.

Expect to stay 2-4 weeks on the regular nursing unit before you can be discharged from hospital. The length of stay depends on how well your child recovers. Older children tend to recover faster than babies but there are no rules when it comes to complications and infections.

While on the ward you will learn about life after transplant. The transplant coordinator, dietitian and pharmacist will spend time at the bedside teaching you the things you need to know to keep your child healthy at home. Because this is a very stressful time, and many things are happening, it is not unusual to need to hear these things many times. When you come to see us in clinic we will keep talking about life after transplant.
Outpatient Life

It is normal to spend up to 3 months in Edmonton, from the time of transplant, depending on the type and number of complications your child has and where you live. If you are far from a large centre you will be asked to stay longer than if you live in Calgary or Vancouver, Saskatoon or Winnipeg. The important things to have right before discharge to your home community are good medication levels, your child recovered from surgery and gaining weight, and that you are comfortable with the care your child needs.

The major worries after transplant are Rejection and Infection. Your body knows what belongs to you and what does not. Your immune system knows the transplanted heart is new to your child and will try to destroy it. We control this natural response with anti-rejection medications called immunosuppressants. These drugs act by weakening this response to protect your new heart. However, when you are immunosuppressed you are at greater risk of developing infection and cancer. Our body knows that infections and cancers do not belong and is normally able to destroy the things that cause them. It is important to balance the amount of anti-rejection drugs you take to prevent rejection while keeping your natural defenses strong enough to protect you from infection and cancer.

Your child will probably have to take two or more antirejection drugs for the rest of their life, in addition to other medications. Anti-rejection drugs or immunosuppression are the most important drugs you take after your transplant. They protect your heart from your immune system. Every drug has effects that you want; however, they also have effects that are not wanted. These are called side effects and can vary in their strength from person to person. Some side effects can be more serious than others. It is important that you know what the common side effects are and what you can do to protect yourself. Long term effects of these drugs can include diabetes, kidney disease, high cholesterol, high blood pressure, acne, hair loss, weight gain and diarrhea. Despite this long list of complications taking the medication is better than not taking the medication and suffering a massive rejection and losing your child to graft failure.

You need to be an expert in the medication your child is expected to take. You must know the dose and what time to take it and what it does. The pharmacist or coordinator will teach you these things while you are in the hospital in addition to helping you through this manual. Once the pharmacist or coordinator has reviewed the medications with you, you will be expected to start giving them yourself, with the nurses’ help, while you are still in hospital. This will help you to get used to
the new medication before you go home and have to do it by yourself.

**What happens at clinic?**

You will attend clinic once a week when your child is first discharged. Your clinic visits will become less frequent as your child’s overall health improves. Eventually you will be seen in the pediatric clinic 3 or 4 times a year.

**What should I do when I go home?**

After transplantation you will continue to improve. How well you do is up to you. To assist your recovery you must follow a few basic rules:

- Follow the instructions of our doctors and transplant coordinators.
- Eat a balanced diet and ensure you maintain a healthy weight
- Find a healthy balance between exercise and activity, following the guidelines provided by your therapists and doctors.
- Do not drink alcohol
- Do not smoke
- When traveling always carry enough medication for unexpected delays.
- When going out into the sunshine, wear a hat and sunscreen, do not get sunburnt. The medications necessary to prevent rejection of your liver will increase the risk of skin cancer from exposure to sunlight or ultraviolet radiation in tanning booths.
- Take good care of your teeth. See a dentist regularly. Before major dental work, call your doctor.

**WHO ARE THE PEOPLE ON THE TRANSPLANT TEAM?**

The Transplant Team is a group made up of doctors, nurses, social workers, physiotherapists, occupational therapists, dietitians and pastoral care personnel. Together with you, the team will work to find the best solution for your particular circumstances. During your transplant journey you will see the following team members:

**Transplant Surgeon**

There are two surgeons who perform pediatric heart transplants at the Stollery Children’s Hospital.

**Pediatric Transplant Cardiologist**

There are two pediatric transplant cardiologists in the Heart Transplant program at the Stollery Children’s Hospital. One of these physicians will meet with you and your support person to discuss your medical condition. A physical examination is required.

**Transplant Coordinator**

The transplant coordinator is a registered nurse with expertise in the area of heart transplantation. You are assigned a coordinator when the referral is made. That person will teach you how to care for your general health and will answer most of your
questions about transplantation. Your coordinator is involved in all aspects of your care and is your primary contact with the heart transplant program.

**Clinical Nurse Specialist**
This is an advanced practice nurse who specializes in pediatric transplant. A CNS has expertise in patient care, family and staff education, and family support.

**Social Worker**
The Social Worker provides emotional support and resource counseling to you and your family. The Social Worker can assist you in coping with the changes experienced by you and your family as a result of your illness or the transplant.

**Dietitian**
The dietitian will meet with you and your support person to review what you normally eat and counsel you on how to improve your nutrition before the transplant.

**Heart Failure Team**
You may also meet the doctors in the heart failure team. They are experts in supporting the heart with medication and in some circumstances mechanical devices. It may be that your child will require an “artificial heart” while you wait for transplant. This happens in extreme heart failure and will be discussed with you at length by the heart failure team before proceeding.
INFORMATION ABOUT YOUR HEART

How does the heart work?

The heart is a hollow muscle about the size of a fist. Its job is to pump blood throughout the body. The heart has four chambers divided into left and right sides and works as a double pump.

The left side pumps blood full of oxygen to your brain, organs, tissues, and muscles. As the blood is circulated it delivers nutrients and oxygen, and assists in the removal of waste products.

The right side of the heart receives the blood that comes back from the body and pumps it to the lungs. In the lungs the blood receives a fresh supply of oxygen. The blood is then returned to the left side of the heart where it is pumped throughout the body again. This cycle repeats itself 50-100 times a minute.

How does heart failure affect my health?

A healthy heart pumps blood to all parts of your body in a matter of seconds. Heart failure happens when the heart can no longer pump forcefully enough to supply blood to the muscles and vital organs. This can cause tiredness and muscle weakness. It may also cause your blood pressure to be low and this can cause dizziness or lightheadedness. The blood that should be pumped out of your heart backs up and causes fluid to collect in the lungs and other parts of your body. This is why you may experience shortness of breath and swelling in your abdomen, legs, and feet.
People with heart failure may have enlarged hearts, which can be seen on a chest x-ray. As a weak heart struggles to pump out all its blood, the muscle fibers of the heart stretch. Over time, this extra stretching leaves the heart with larger, weaker chambers.

**What is a Ventricular Assist Device (VAD)?**

This is a type of mechanical heart. There are a couple of devices that can be used in children. The VAD team will discuss all the details of these devices with you and choose which would be best for the size of your child.

We have been using VAD at the Stollery Children’s Hospital for several years with great success. Children can wait for transplant with the VAD, some children must wait in hospital but others are able to go home with the device. This could be a year or longer. Children are able to play, think, move, breath and eat better with the mechanical heart than they do with their failing heart. VADs are used when the risk other organ failure, or death, becomes a concern or to improve quality of life while waiting for heart transplant. There are some risks associated with using these devices but these will be discussed with you by the VAD doctor as they differ from device to device.

**TRANSPLANT HISTORY**

The Heart Transplant program at the University of Alberta Hospital and Stollery Children’s Hospital began in 1985. Our center is involved in various types of organ transplants, including heart, combined heart/lung, double lung, single lung, living related lobar lung transplants, liver, kidney, pancreatic islet cell, pancreas, and intestinal transplantation. We provide these options to adults, teens, children, and infants.

We are also a leading center in research. Scientific developments have moved transplantation from an experimental procedure to an accepted treatment option. The artificial heart has come a long way in the past few years and specialists at this hospital can make a variety of mechanical support devices available to those in heart failure. It has been used successfully to keep patients well until a donor heart can be found for transplant. We now know that we can use hearts from children with different blood types in infants thanks to research done in Toronto and continued here.

Of those receiving a heart transplant today, 90-95% will survive at least a year and 80-85% will survive at least five years, and 70 - 75% will survive at least 10 years. There have been heart transplant patients who have survived more than 25 years. We are very proud to be able to offer transplantation as a treatment to children who suffer from life threatening heart disease.
RESOURCES

Heart & Soul: Your guide to living with congenital heart disease. Author: Heart And Stroke Foundation. This binder is an excellent source of information about congenital heart disease, all the tests that are done, all the information you might need, very comprehensive. Ask your cardiology clinic nurse for a copy.

Now Caitlin Can. Author: Ramona Wood. A children’s story book about a little girl who needs and gets a kidney transplant, told from her older brother’s perspective. Good story showing all the steps to transplant.

Pennies, Nickels & Dimes. Author: Elizabeth Murphy-Melas. About a girl needing a liver transplant, she and her friend have a lemonade stand to help raise money for her liver transplant. Again reviews all the steps of transplant.

Gracyn’s Song Author: Kris & Gracyn DenBesten. The story of Gracyn DenBesten who developed cardiomyopathy at age 9, went on the Berlin Heart to wait for a heart transplant. She is now health and well a couple of years post transplant

www.transplantliving.com a website with good information about transplant

www.transplantkids.co.uk a kid friendly website in England

www.mymedschedule.com a website where you can design and print out a number of varieties of medication lists including wallet size and monthly schedules.

How do I contact the transplant team? The main switchboard for the hospital can put you through to any member of the team’s office number. That number is 780-407-8822. This is also the number used to contact the transplant coordinator on call on nights and weekends if you have an urgent concern.

Your main contact before transplant will be your transplant coordinator. You will meet many members of the team during the assessment. Collect all of their business cards and keep them with this folder. Any member of the team is happy to speak to you and answer questions or concerns at anytime throughout your journey with us. Your coordinator can help you to connect with the rest of the team as you wish.

In Patient Transplant Coordinator:
Kristin Simard, BScN, RN (780)407-3732 (office) Kristin.Simard@albertahealthservices.ca
Shannon Nethersole, BScN, RN (780)407-8172 (office) Shannon.Nethersole@albertahealthservices.ca