

PEDIATRIC HEART TRANSPLANT DISCHARGE TEACHING MANUAL



This book is based on the work of the transplant team at the University of Alberta Hospital, Stollery Children's Hospital, Variety Children's Heart Centre, Seattle Children's Hospital, and Sick Kids Hospital. By working together we make the children's journey better. PREPARED BY THE UNIVERSITY OF ALBERTA, STOLLERY CHILDREN'S HOSPITAL HEART TRANSPLANT TEAM December 15, 2015.

TIME TO GO HOME	3
WHAT DO I HAVE TO BEWARE OF AFTER TRANSPLANT?	3
Early Complications	3
Long Term Complications	5
PREPARING FOR LIFE AFTER TRANSPLANT	6
REJECTION	7
HOW ARE CARDIAC BIOPSIES DONE?	8
HOW DO YOU TREAT REJECTION?	8
INFECTION	10
HOW CAN I AVOID INFECTION?	10
WHAT TYPES OF ORGANISMS CAUSE INFECTION?	11
MEDICATION	16
MANAGING YOUR MEDICATIONS	18
ANTI-REJECTION MEDICATIONS	19
TACROLIMUS (PROGRAF)	20
MYCOPHENOLATE MOFETIL (CELLCEPT)	20
PREDNISONE (DELTASONE)	21
MANAGING MEDICATION SIDE EFFECTS	22
MEDICATIONS FOR PREVENTING AND TREATING INFECTION	24
DRUGS THAT PROTECT THE HEART	26
DRUGS THAT PROTECT THE DIGESTIVE SYSTEM	26
WHAT CAN I BUY AT THE PHARMACY WITHOUT A PRESCRIPTION?	27
HERBAL MEDICINES	28
HOW DO WE GET BACK TO NORMAL?	28
SPECIAL WARNING TO PARENTS OF CHILDREN	35
WHO HAVE HAD TRANSPLANTS	35
SPECIAL ADVICE FOR TEENS	36
FOLLOW UP PLAN	37
WHAT CAN I EXPECT AT A CLINIC VISIT?	37
BLOOD PRESSURE MONITORING	37
BLOOD TESTS	38
TESTS FOR BLOOD COUNT	39
TEST FOR BLOOD CLOTTING	39
TESTS FOR ELECTROLYTES (DISSOLVED MINERALS)	39
TESTS FOR MEDICATION LEVELS	40
TEST FOR KIDNEY FUNCTION	40
TESTS FOR LIVER FUNCTION	40
HEART FUNCTION TESTING	40
RADIOLOGY TESTING	41
REGISTRY AND FOLLOW-UP OF COMPLEX PEDIATRIC THERAPIES PROGRAM	41
ANNUAL ASSESSMENT	42
TRANSITIONS	43
DEVELOPMENTAL GUIDELINES	44
MEDICATION MANAGEMENT TOOL	45
SAMPLE SCHEDULE	47
HOW TO REACH US	48
WHEN SHOULD I CALL THE TRANSPLANT TEAM?	48
IMPORTANT PHONE NUMBERS	49
RESOURCES AFTER TRANSPLANT	51
SUGGESTED READING LISTS AND WEB SITES	51
Index	53

Austin's Story

Eleven days after Austin was wheeled into the operating room to receive his new heart, he walked out the doors of the hospital, discharged, to begin his new normal. It was a steep learning curve at first but I feel that our transplant team prepared us well to transition home. We used the education that was provided to establish priorities and routines that would ensure that we were doing everything we could be to keep Austin's beautiful new heart healthy. For a time it felt like our lives revolved around clinic visits, pediatrician appointments, blood draws, speech therapy, occupational therapy, physiotherapy etc. but I wouldn't have traded any of it for the alternative.



TIME TO GO HOME

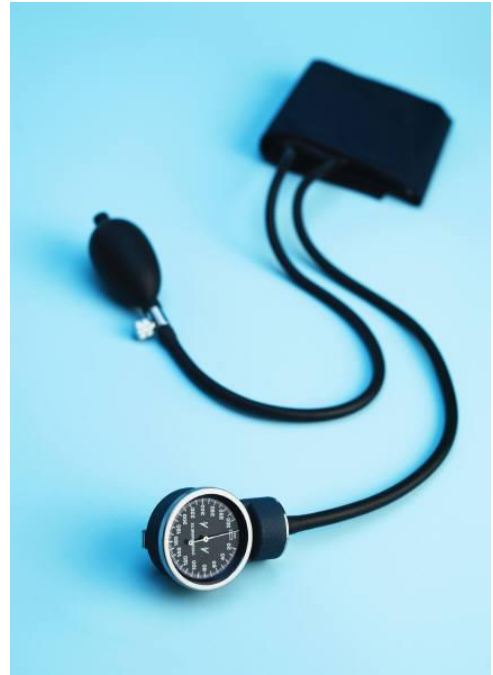
This booklet will help to guide you through life after transplant. Now that you or your child has a new heart you want to keep it healthy. Learning about your transplant and the medical plan will help you to take better care of yourself or your child and lead a healthier, more active life. It is very important that you ask questions and become an expert about the new heart. Your transplant team will help you to do this.

WHAT DO I HAVE TO BEWARE OF AFTER TRANSPLANT?

Early Complications

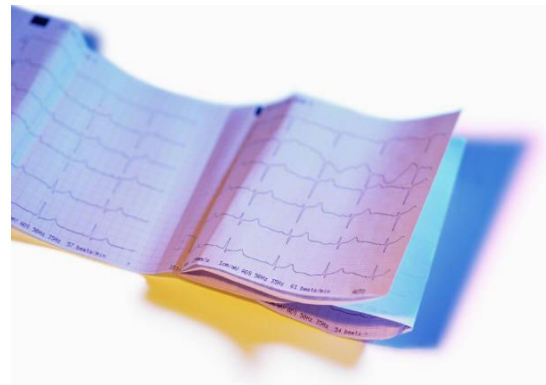
Wound healing: Check your child's incision and other wound sites daily. If there is any unusual redness, swelling, pus, drainage, or pain contact your doctor's office. No swimming until the incision is well healed.

High blood pressure: High blood pressure (hypertension) is common after a transplant. Some of the medicines we give to stop rejection will cause the blood pressure to be increased. It is very common for the child to be on an anti-hypertension medicine. We might ask you to take your child's blood pressure every day, at the same time, while resting or sitting still. It is best to do this in the morning as part of your morning routine. If you are taking the blood pressure on a leg (usually a child under the age of 5 yrs), have your child lie down. The child's heart should be at the level of the blood pressure cuff for the best number.



Heart rate issues: A transplanted heart is not attached to nerves like your own heart. This means the brain can't tell the heart when to speed up or slow down. The transplanted heart will be guided by the normal hormones in the blood stream that increase or decrease with activity and emotion.

Some recipients will require a permanent pacemaker. If this is needed, it will be placed before your child leaves the hospital.



Fluid build-up: Steroids (Prednisone) have a side effect of retaining water in the body. Surgery will also cause the body to hang on to extra water. It is very common your child will need a water pill (diuretic) to help get rid of the extra water. This medicine may or may not be long term. It is more of an issue in the first few days to weeks after transplant. Diuretic medicines can also get rid of minerals in the body along with the water such as magnesium, potassium, and chloride. Your child may need supplements of these minerals while receiving diuretic medicine.

Long Term Complications

Kidney Damage: This is a common problem after transplant. Up to 57% of children after heart transplant have kidney damage. There are many factors that contribute to kidney damage: poor circulation before or around the time of transplant, high blood pressure, medications, and infections. Preventing infections will help to prevent kidney damage. The best thing you can do to help protect the kidneys is to stay hydrated. That means you need to drink water and other fluids until your urine is colourless and odourless. The dietitian can help you figure out what your fluid goal should be for every day but a general guideline is:

- 10kg (22 lbs) =1000ml/day
- 15kg (33 lbs) =1250ml/day
- 20kg (44 lbs) =1500ml/day
- 45kg (100lbs) =2000ml/day

Vomiting and diarrhea will lead to dehydration so early intervention is necessary. Fluids lost through vomiting or diarrhea should be replaced with an electrolyte solution like pedialyte, or pedialyte popsicles.

Check all new medications with the transplant team.

Post Transplant Lymphoproliferative Disease (PTLD): This is a problem that any transplant patient can develop. It is a type of blood cancer. If PTLD develops, we will cut back on the anti-rejection medicines. It seems odd, but the medicines we use to keep away rejection, can also make some types of cancer cells start to grow. If your child is diagnosed with PTLD, we often will involve the Cancer or Oncology Doctors to help manage the problem. Patients who are Epstein Barr Virus (EBV) negative at the time of transplant but receive a heart from a donor who is positive are at a higher risk of developing PTLD.

Diabetes: Diabetes can develop after transplant. Although rare in young children, it is seen in teens and young adults. Tacrolimus and Prednisone can both increase the risk of developing diabetes after transplant. You are at risk if you have a family history of type 2 diabetes. You may need to be on insulin or you may just need to watch your diet carefully. If you



do become diabetic any change in your prednisone will change the sugar levels (glucose). Physical activity helps to reduce this side effect of tacrolimus and prednisone.

PREPARING FOR LIFE AFTER TRANSPLANT

It is important to remember that transplantation is about swapping a fatal or unmanageable diagnosis for one that is manageable with the expectation of a good life. You still need to manage your health needs.

The transplant coordinator will review the following topics with you now that you are ready to be released from the hospital:

- ♥ Rejection
- ♥ Infection
- ♥ Medications
- ♥ Follow-Up Plan
- ♥ How to reach the Transplant Team
- ♥ Resources

Austin's Story

At this point a transplant is not a cure and I wouldn't be honest if I didn't say that I have moments when that provokes a great deal of fear and anxiety in me. With that said, in those moments I know that I have to adjust my perspective, not borrow worry and just enjoy each and every day for the blessed gift that it is. I continually make a conscious decision to choose hope over fear. As I've read before "Life doesn't have to be perfect to be beautiful." I agree - despite being difficult at times, life is very, very beautiful.



REJECTION

Your body knows what belongs to you and what does not. This is part of what your HLA system does for you. Your immune system knows your transplanted heart is new to you and will try to destroy it. This is known as rejection. The doctors 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.

Acute rejection occurs when your body's natural defenses become stronger than the anti-rejection drugs and begins to attack your new heart. We find rejection in the heart by looking for changes in heart function in the Echo, EKG, and especially in cardiac biopsies. Read more about the Echo and EKG in the Testing section of this book.

What are the symptoms of acute rejection?

- Higher or lower resting heart rate than normal
- Lower blood pressure than normal
- Sudden weight gain
- Nausea, vomiting, discomfort in the abdomen (stomach)
- Fatigue or decreased energy level
- Dizziness
- Shortness of breath
- Fever



We look for acute rejection with a cardiac biopsy

HOW ARE CARDIAC BIOPSIES DONE?

This procedure is done in the cardiac catheterization lab with general anesthesia. It is a day surgery procedure. This means you, or your child, will go home the day of the biopsy if all goes well. The timing of biopsies all depends on how your child is doing and what the last biopsy showed. Usually you would have 3 during your first year after transplant with one every year until you are three years out.

You will be lying on your back on a special stretcher. The doctor will insert a small needle into the vein in your groin or neck. A catheter or tube will be threaded through the needle into your veins. The pressure inside the heart and the cardiac output can be measured. Then a device called a biopptome is put down the tube. It has little clippers on the end that are used to take a small sample of heart tissue. The size of the sample can be up to 0.2 cm in diameter and they will take up to 6 pieces. That tissue is then put under a microscope. The doctors are looking for cells that invade the heart muscle to destroy it.



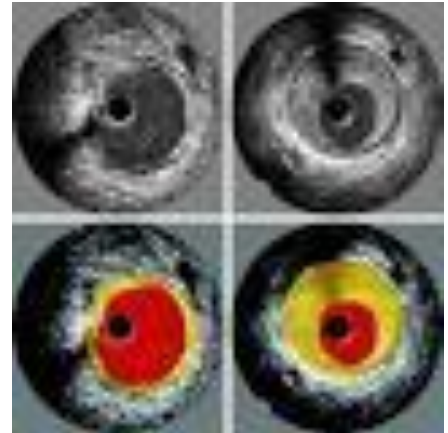
HOW DO YOU TREAT REJECTION?

It depends on the severity of rejection. There is a scale that is used to measure rejection. The scale is 0-4. 0 and 1 are not treated. If you are a 2 you might just need your medications changed to treat it and prevent rejection from happening again. We treat moderate to severe acute rejection (3-4) with intravenous steroids.

Chronic rejection is the type of rejection that occurs slowly over time and can develop when you forget to take your medicine. *Coronary Artery Disease (CAD)*: This is also called “hardening of the arteries”. This is a problem that is caused by fat build-up inside the coronary arteries. The coronary arteries are blood vessels that supply the heart muscle with blood. The fatty deposits block normal blood flow and cause a heart attack. People with CAD feel chest pain (called angina) when the oxygen supply to the heart is too low. Blockages normally build up in sections of the coronary arteries. A procedure called a balloon angioplasty can be used to open up the clogged artery.

Transplant CAD is different and is referred to as Cardiac Allograft Vasculopathy (CAV). The entire coronary artery becomes narrowed, not just a section. Balloon angioplasty will not help this problem as it involves the entire artery. Heart transplant patients can have a heart attack and not even know it since their heart cannot feel pain. The cardiologist will do a dye study (angiogram) at regular intervals, with the heart biopsy, to look at the coronary arteries.

CAV is thought to be evidence of chronic rejection in the heart recipient. The body's immune system attacks the inside wall of the blood vessel causing scarring and narrowing of the artery. There is no standard treatment for this problem once it occurs, however there are some new medicines which may be able to help prevent this problem before it starts. We encourage you and your child to develop and maintain a heart healthy diet and active lifestyle to prevent CAV. Your dietician and physical therapist can teach you more about this during your hospital stay.



After 5 years the risk of rejection is only 6% as long as you take your meds regularly. How will you manage?

INFECTION

Infection is a common complication after transplantation. As you have already learned, your suppressed immune system has less ability to fight bacteria and viruses that cause infection. The doctors use medications to prevent infection (prophylaxis) and to treat infections (therapy).

Children are less likely to have been exposed to a large variety of organisms and so have no prior immunity. They also tend to need to be in hospital longer than adults and so are exposed when they are most fragile to the many organisms in the hospital.

What are the symptoms of Infection?

- ♥ Increased temperature (higher than 37.5C while on Prednisone, 38.5C otherwise), chills, and/or shivering
- ♥ Pain, swelling, redness, and heat in any area of the body
- ♥ Feeling very tired, achy, or weak
- ♥ Vomiting, diarrhea
- ♥ Frequent, painful urination, change in color, amount or odor of your urine
- ♥ Cold symptoms, green sputum, shortness of breath
- ♥ Sores on yours lips, mouth, or face

HOW CAN I AVOID INFECTION?

Organisms that cause infection are everywhere. On your skin, in your body, on surfaces you touch, in the air you breathe, and the food you eat. However, there are only a small number of organisms that cause illness. Organisms can enter your body from an injury to your skin or through body cavities exposed to the environment such as your nose or mouth. Ensuring your body is healthy by eating a good diet, getting adequate rest, exercising regularly, and regular dental care also help prevent infection.

Because immunosuppression medications interfere with a patient's natural immune system, you need to protect yourself from infection after the surgery by taking the following precautions:

- ♥ Wash hands often.

Washing your hands should take at least 20 seconds, enough time to sing the happy birthday song twice or the ABC song once. Make sure you rub all surfaces of your hands and between fingers.

- ♥ Keep hands away from face and mouth.

When you touch your face or mouth you carry germs from the surfaces around you to your respiratory tract.

- ♥ Stay away from people with colds or other infections.
- ♥ Ask friends to visit only when they are well.
- ♥ Practice good dental hygiene

See the dentist every 6 months and brush your teeth every day. Cavities are caused by bacteria so you are at an increased risk for poor dental health.



www.lucylearns.com

- ♥ Wash hands after coughing or sneezing, and throw tissues into the garbage immediately.
- ♥ In the first few weeks after transplant avoid crowds in places like stadiums and malls.
- ♥ If someone in the patient's family becomes ill with a cold or flu, have that individual follow some normal precautions (use separate drinking glasses, covering their mouths when coughing, etc.)
- ♥ Avoid working in the soil for 6 months after the transplant. Thereafter, wear gloves.



- Areas most frequently missed during hand washing
- Less frequently missed
- Not missed

(Adapted from Taylor L (1978), An evaluation of handwashing techniques - I, Nursing Times, 12 January, pp 54-55)



WHAT TYPES OF ORGANISMS CAUSE INFECTION?

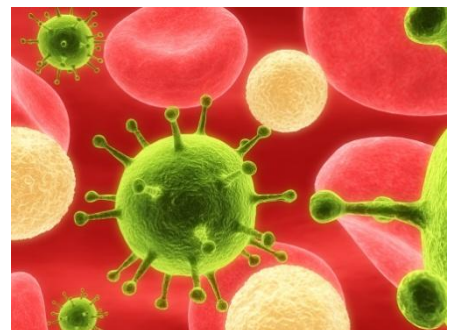
Even with our best efforts to stay healthy, we still get infections. The following is a description of the types of organisms that cause infection. You will also learn about the most common infections that occur after a transplant. You may be worried about these organisms and the risk of infection. Remember that common sense is the best approach to caring for you. Report any symptoms of infection to the Transplant Team, follow the infection control suggestions, and relax. Even though you are immunosuppressed, your body can still fight and control infection, especially with a little help from you and your Transplant Team.

Bacteria

Most bacteria are harmless or natural helpers to our bodies. We have bacteria that live in and on our bodies that help us to stay healthy. Bacterial infections occur when harmful bacteria become established. We also get infections in our bodies when our natural bacteria moves to a place it should not be. For example, your natural skin bacteria are healthy on the outside of your body, but can make you very ill if it becomes established inside. Bacterial infections are treated with antibiotics. There are many different kinds that are effective against only some bacteria. We will select the best antibiotic for the type of bacteria and infection you have.

Viruses

Viruses are common organisms that cause stomach flu, the common cold, influenza (flu) and many childhood illnesses. Most viral infections last only a short time. However, some viruses remain in our bodies forever they are known as resident viruses. For example, the virus that gave you chicken pox remains in the nerve roots of the spine and can cause shingles in adulthood. Herpes simplex, the cold sore virus resides in the nerves of the face, causing flare-ups of new sores. These “resident viruses” can be problematic after transplant, especially in the early months after your surgery when the immunosuppression levels are high. The following provides more detailed information about specific viruses we are concerned about.



Varicella Zoster

This virus causes chicken pox during the initial infection and shingles later in life. If you have not had chicken pox, it is important to notify the Transplant Team as soon as you know someone you have been around in the previous two weeks develops the infection. We will arrange for a shot of antibodies against the virus (VZIG) which may help prevent you developing chicken pox. The antibodies last about six months.

If you develop shingles, we will treat the illness. Shingles usually starts with a burning pain in your back, followed by a break out of very painful, fluid filled blisters. Notify the Transplant Team immediately of symptoms. Early treatment is important.

After your transplant, do not get vaccinated against chicken pox. The vaccine has live, but very weakened chicken pox viruses. Since you are immunosuppressed, even the weakened chicken pox viruses can cause infection.

Herpes Simplex

This virus causes painful sores on the mouth and genitals. They can spread to other parts of the body if left untreated. The sores usually start with a burning, itchy feeling, development of redness and swelling develops, followed by a fluid-filled vesicle, then a painful sore. The sores usually take about two to three weeks to heal. Notify the Transplant Team as soon as you develop the sores so that we can start treatment.

Cytomegalovirus (CMV)

This is a very common virus that causes severe flu-like symptoms. Most people eventually contract the virus, but are unaware that the “flu” was a CMV infection. This virus flares up again in people who are immunosuppressed. Your donor organ can also infect you. The virus may cause muscle pain, weakness, tiredness, respiratory symptoms, diarrhea, nausea, vomiting, hepatitis and a variety of other symptoms. We monitor your blood work and provide preventative medications if you or your donor is positive for CMV.

Epstein-Barr Virus (EBV)

EBV is commonly referred to as “mono” or “the kissing disease”. Like CMV, this virus is contracted eventually by most people, usually in the teen years. It causes a flu-like illness and most people are not aware that they had it. Some individuals become very ill (infectious mononucleosis) with severe fatigue, sore throat, headache, hepatitis, possibly a rash, painful muscles, fever, and achiness. You can become infected by your donor organ if have not already had the virus. If you are

negative for EBV, but your donor was positive, we monitor your blood work for the virus and use preventative medications.

West Nile Virus

Mosquitoes can carry West Nile Virus and pass it on to people when they bite them. For most people the likelihood of contracting the virus is minimal but it depends on the numbers of infected mosquitoes. Less than 1% of people with a normal immune system who are infected with West Nile Virus become seriously ill. However, transplant recipients are at a much higher risk of becoming seriously ill. It is very important to protect yourself from mosquito bites during mosquito season. You can do this by avoiding being out at dusk and dawn, wearing light clothing including long sleeves and pants, and by using mosquito repellent containing DEET. All of the transplant recipients who have developed symptoms of West Nile Virus have complained of fever, stomach upset, diarrhea, headache and other nervous system symptoms. Should you ever develop a fever, it is extremely important to follow up with your local emergency department.



Human Papilloma Virus (HPV)

HPV has been linked to gynaecological cancers in women. Your risk of developing cervical, vulva, anal and for men penile cancer is increased if you are infected with this virus. It is the most common sexually transmitted infection (STI) in North America with over 20 million people in the US infected. Decrease your risk by being immunized and using a barrier method such as a condom to prevent transmission.

Fungus

Fungi also cause infections in our body. "Athlete's foot" is an example of a fungus that causes infection. Yeast infection in the mouth caused by an over growth of this naturally occurring fungus sometime occurs after transplant. It is commonly called "thrush". Symptoms include a sore mouth and white spots on the insides of your cheeks and on your tongue. You should examine your mouth daily before you brush your teeth. As long as you are taking steroids you will receive medication to prevent the infection. Once home, if you develop symptoms, we will treat the infection.

We have a type of fungus that lives in our lungs called pneumocystis jirovecii. Given the opportunity, this may cause pneumonia (PCP). For the first six months after your transplant when immunosuppression is highest, we will give you medication to prevent the development of pneumonia from this organism.

80% of patients have some kind of infection in the first three months. What can you do to keep yourself safe?

N O D T S Y F S C O

D

N P R H

M R J M S R T U Z A T O E E G

O S Y K V E S M K N I V O H M

C W E L L G F I A I O D E L L

L S I E S R X L G C D A R K B

I I O N G U P O E T R N T A Y

N Y G O F S W R T T D M E W C

I G X F N E J C S T E C E Y Y

C N N A T Y C A T D L E S J K

T N R E J E C T I O N L R E C

O T S F N Y P C I K K L U E Q

D O C T O R I L H O U C N G T

R R S P L N A T I Q N E J S G

S J X T E R U S S E R P E W Z

B M K L O L H T A R E T A W F

BLOOD
 CARDIAC
 CELLCEPT
 CLINIC
 DOCTOR
GET
 HEART

INFECTION
 KIDNEY
 MEDICINE
 NURSE
 PRESSURE
 RECOVER
 REJECTION

SOON
 SURGERY
 TACROLIMUS
 TEST
 TRANSPLANT
 WATER
WELL

Austin's Story

Medications, fluid intake, physical activity, healthy eating, proper hand washing and watching for signs of infection and rejection will always be a part of life for Austin so as he gets older, we are using a teach, help, support process to help him be more involved in his care so that one day he will be confident and comfortable managing it on his own.



MEDICATION

You will be on a number of medications when you leave the hospital. At home, you will continue taking most of the medicines you began taking in the hospital after the transplant surgery, especially the anti-rejection medications. This medication called immunosuppression or anti-rejection drugs is to help protect your new organs from your own immune system. You will probably have to take one or more of these drugs for the rest of your life, in addition to other medications. You will have antibiotics to help protect you against infection. You will need medication to protect your stomach from ulcers caused by other medication. Your body may need some help for a while getting rid of water or keeping up essential nutrients like potassium and magnesium or iron.

We want you to be an expert in the medication you are expected to take. You must know your dose and what times you take it and what it does for you. It will help if you keep a list of your medications with you at all times and bring it to your

doctor visits. The pharmacist and coordinator will teach you these things while you are in hospital in addition to helping you through this manual. Keep track of medication changes in the space provided at the back of the discharge binder. Once the 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 number of new medication before you go home and have to do it by yourself.

The child and parent should talk to his physician, pharmacist, transplant nurse, and/or coordinator to understand fully:

- ♥ the name and purpose of each medication
- ♥ when to take each medication
- ♥ how to take each medication
- ♥ how long to continue taking each medication
- ♥ principal side effects of each medication
- ♥ what to do if your child forgets to take a dose
- ♥ when to order more medication so it doesn't run out
- ♥ how to order or obtain medications
- ♥ what to avoid while taking medications



It is important to keep a
current list of your
medication to show all your
doctors

Many parents take responsibility for their child's medication. It is the parent's task to decide when and how the child should start taking responsibility for taking their own medication. Allow your child to participate and encourage them as a first step to put the medication in their mouth themselves, then pour the medication, and then remember to take the medication. You may continue to prompt your child for some time but children in Junior High, depending on how well they function, should be able to take the medication themselves and accept

responsibility for it. Adolescence is a time of seeking independence and rebelling against authority. Some young adults stop taking their meds at this time. Most who do, do not understand why they are taking this medicine in the first place. It is important as you give responsibility to children that you teach them what they need to know to become responsible. Independence doesn't mean you can't check in with your child.

MANAGING YOUR MEDICATIONS

Right drug:

- ♥ Always check the bottle carefully to ensure you are taking the right medication.
- ♥ Learn both names of your drugs.
- ♥ Do not memorize colors and shapes as the appearance of drugs can vary between manufacturers.



Right dose:

- ♥ Know the number of milligrams (mg) you are taking of each medication.
- ♥ When you pick up prescriptions from the pharmacy, double check the label as the strength of the pills/liquid may be different from what you had last time.

Right time:

- ♥ Medications need to be taken at the right times. You risk getting rejection if you do not take your drugs within half an hour of the scheduled times. That is half an hour before or half an hour after your regularly scheduled time is OK, anything else and you are taking a risk.
- ♥ Think about ways to make medication taking part of your routine at home. Choose a time that works best with your schedule, time it around meal times or other rituals that occur in your home.

Right way:

- ♥ It is important to take medications according to the directions on the bottle.

Travel:

- ♥ Always bring an extra supply of all of your medications whenever you are travelling. You never know when the airlines will be on strike!
- ♥ Pack your medications in carry-on luggage.

Storage:

- ♥ Medications should be kept in a dry place at room temperature unless told to refrigerate.
- ♥ Never leave your medications in the car as it may freeze or overheat.

Pharmacy:

- ♥ It is best to use the same pharmacy for all your medications. If that is not possible then make sure your pharmacist knows ALL medications you are taking.

ANTI-REJECTION 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 to have, however, they also have effects that are not desired. These are called side effects and can vary in their strength from person to person. Some side effects can be more serious than others. These are the more common side effects. It is important that you know what they are and what you can do to protect yourself. Expect to be on two types of immunosuppression forever, usually prednisone is weaned between three and six months post-transplant.

Increased risk of infection:

- ♥ Hand washing is the best prevention
- ♥ Do not visit people with cold or flu symptoms.
- ♥ Get an flu shot every year and the pneumococcal vaccine twice in your lifetime (Contact your local Public Health Unit)
- ♥ Practice safe sex, use condoms!
- ♥ Report signs and symptoms of infection right away

Increased risk of cancer:

- ♥ Use sunblock with a minimum SPF of 30, apply 15-30 mins before going outside
- ♥ Wear hats, avoid sunbathing, and avoid the hottest time of the day (11 am – 3 pm in summertime)
- ♥ Have any unusual skin growths examined right away
- ♥ Do not smoke

TACROLIMUS (PROGRAF)



Tacrolimus acts directly on white blood cells to reduce their ability to identify foreign cells.

Always take Tacrolimus after blood is drawn

(bring the medication to the lab with you)

NEVER take with grapefruit juice or grapefruit

(read labels of multi-juice products)

- ♥ Must be taken 12 hours apart, 8 am and 8 pm during initial post-transplant phase, may change by 30 minutes per day to fit personal routines once follow up is decreased
- ♥ Can be taken with food or on an empty stomach – be consistent
- ♥ Light destroys the drug. Take pills within 15 minutes of removing from foil
- ♥ Drug can only be obtained at hospital pharmacies. Out of town patients must make arrangements with outpatient pharmacy to have the drug shipped.

Side effects: See [Managing Side Effects](#) for details of common side effects.

Kidneys, Blood Pressure, Skin Changes, Nausea, Vomiting, and Diarrhea, Diabetes

Nervous System:

- ♥ Can cause headaches, tremors, and confusion. Symptoms usually improve over time.
- ♥ If you are having severe headaches notify your transplant coordinator
- ♥ Some recipients report that simple stretching exercises can temporarily relieve tremors.

Muscle pain:

- ♥ Some people experience sore muscles, weakness, and tingling, the symptoms are usually associated with high doses
- ♥ Report your symptoms to you transplant coordinator.

MYCOPHENOLATE MOFETIL (CELLCEPT)

Mycophenolate mofetil reduces the number of a special type of white blood cell that is very active in producing rejection.

- ♥ Taken twice daily, 12 hours apart
- ♥ Always take with food to reduce the risk of ulcers and stomach upset
- ♥ Keep tablets in the foil packages until ready to take.
- ♥ Not recommended during pregnancy.

Side Effects:

Nausea, Vomiting, and Diarrhea, Low Blood Counts



PREDNISONE (DELTASONE)

Prednisone stops your white blood cells from sending chemical messages that start an immune response.

- ♥ *Always take with food to avoid getting ulcers*
- ♥ Never stop taking Prednisone suddenly, as you could become very ill. Your transplant team will reduce the dose gradually.



Side effects:

Blood Pressure, Nausea, Vomiting, and Diarrhea, Diabetes, Muscle weakness, Skin Changes, Hair Growth

Water and salt:

- ♥ Ankle, abdominal and scrotal swelling can occur.
- ♥ Medication may be prescribed to help reduce the swelling.

Osteoporosis:

- ♥ Long-term use of Prednisone (steroids) can result in loss of calcium from your bones
- ♥ Calcium pills and/or bone building medication will be prescribed if yearly bone scans prove it necessary.
- ♥ Weight-bearing activity like walking helps strengthen your bones.
- ♥ Do not play contact sports if diagnosed with osteopenia or osteoporosis.

- ♥ Do not smoke or drink alcohol, this increases the risk
- ♥ Eat/Drink a diet which contains adequate amounts of calcium and vitamin D.

Appearance Changes:

- ♥ You may develop a round puffy face and/or a hump on your back between your shoulders.

Mood Changes:

- ♥ Mood swings are common.

Sleep Disturbances:

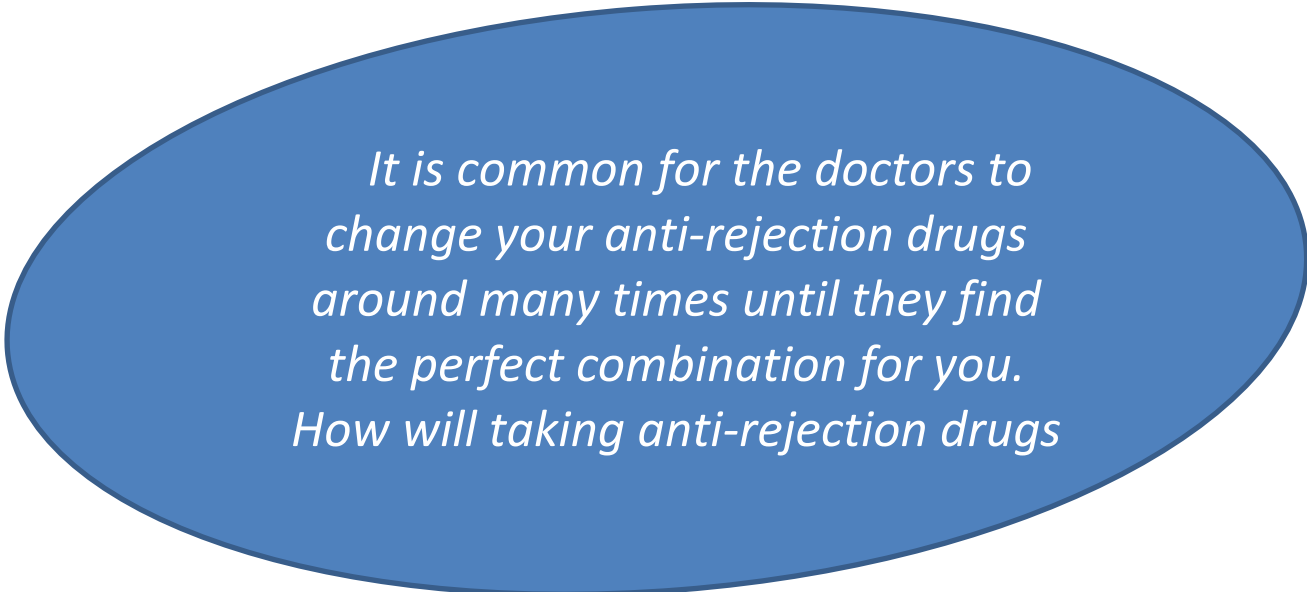
- ♥ Take your Prednisone in the morning.
- ♥ Sleeping pills can be prescribed if necessary.

Blurred Vision:

- ♥ Blurred vision is common at first, do not obtain or fill eye prescriptions for at least six months after your transplant

Increased Appetite:

- ♥ You will feel very hungry and may gain weight if you do not follow dietary guidelines.



It is common for the doctors to change your anti-rejection drugs around many times until they find the perfect combination for you. How will taking anti-rejection drugs

MANAGING MEDICATION SIDE EFFECTS

Kidneys: (Tacrolimus, Cyclosporine, Septra, Valcyte, Ganciclovir)

- ♥ Drink 3 liters of fluid every day (adult size people, dietitian will advice for smaller children)
- ♥ Water is best, try keeping a sports bottle with you all day to help increase water intake

Blood Pressure: (Tacrolimus, Prednisone)

- ♥ You may need some medication to control your blood pressure
- ♥ If you need to monitor your blood pressure at home, keep a record on the monitoring sheet provided and bring it with you to clinic. See Follow-Up section for information about ordering your BP Cuff and stethoscope.
- ♥ Stop risk factors for hypertension such as obesity, high cholesterol, high salt intake and tobacco use.
- ♥ Follow a diet high in fruits and vegetables, limits salt, sugar and fat, and uses adequate amounts of potassium, calcium and magnesium.
- ♥ Regular physical activity reduces hypertension.

Skin Changes: (Tacrolimus and Prednisone)

- ♥ Oiliness and acne are common
- ♥ Keep your skin clean.
- ♥ Wash areas of oily skin several times a day < wash gently and do not rub the skin.
- ♥ Use a soap which removes oil, but does not dry the skin
- ♥ Avoid moisturizing soaps or harsh antibacterial soaps
- ♥ Do not pick pimples since this can result in infection and scarring.

**Nausea, Vomiting, and Diarrhea:** (All, Cellcept particularly for diarrhea)

- ♥ Take your medications with food if you experience nausea
- ♥ If vomiting or diarrhea persist longer than 24 hours contact your coordinator or family doctor

Diabetes: (Tacrolimus and Prednisone)

- ♥ Some people develop increased blood sugars for a period of time
- ♥ You may need to learn how to administer insulin and manage you blood sugars at home.

- ♥ Blood sugars are monitored before meals and before bedtime.
- ♥ Regular physical activity reduces high blood sugar

Muscle weakness: (Prednisone, Diltiazem)

- ♥ People may experience weakness and lose some muscle mass
- ♥ Physical activity and a healthy diet can reduce these effects.

Hair Growth: (Prednisone, Cyclosporine)

- ♥ Excess hair growth on face and body can occur
- ♥ Hair removal creams or devices may be used to control unwanted hair growth
- ♥ An esthetician may be able to give you some advice on how to control the hair growth and protect your skin

Low Blood Counts: (Cellcept, Septra, Valcyte, Ganciclovir)

- ♥ Your other blood cell counts (red cells, hemoglobin, and platelets) may also decrease due to bone marrow suppression.
- ♥ Your blood counts will be monitored on a regular basis.

Headache: (Acyclovir, Fluconazole, Diltiazem)

- ♥ Mild pain relievers such as Tylenol, taken as directed, may be appropriate - talk to your Transplant Coordinator.
- ♥ Try sleeping or resting quietly in a dark room to relieve symptoms
- ♥ Report severe or persistent headaches to your doctor immediately, especially if the headache is accompanied by changes in vision, fever, nausea, vomiting or a stiff neck.

MEDICATIONS FOR PREVENTING AND TREATING INFECTION

Co-trimoxazole (Septra, Bactrim)

Co-trimoxazole, is part of the family of medications commonly called “sulfa drugs.” It is used to prevent pneumonia from pneumocystis jervoci. You will take the medication for six to twelve months after your transplant.

- Taken once daily at the time you prefer, do not take at night



Side effects:

Nausea, Vomiting, and Diarrhea, Low Blood Counts, Kidneys

Ganciclovir (Cytovene)

Ganciclovir will be used to prevent and/or treat CMV and EBV infection. This IV form will be used when you are unable to take pills, once on pills you will be switched to Valganciclovir.

Valganciclovir (Valcyte)

Valganciclovir may be used to prevent and/or treat CMV and EBV infection.

Valcyte is a pill. If you need intravenous (IV) therapy you will receive Ganciclovir instead. Usual treatment is 100 days.



Side Effects:

Low Blood Counts, Kidneys

Sore veins: (Ganciclovir)

- ♥ The intravenous needle and the medication can cause redness, swelling, heat, pain and hardness in a vein.
- ♥ If the problem is severe a central line {PICC} will be inserted. It will remain in place until your Ganciclovir therapy is completed.

Acyclovir (Zovirax)

This medication is used to prevent and/or treat herpes infections of the mouth, skin, and genitals as well as shingles outbreaks.

- ♥ Most effective if started when sores first develop.
- ♥ Acyclovir may be given intravenously during an active chicken pox infection.

Side Effects:

Nausea, Vomiting, and Diarrhea, Headache

Nystatin (Nilstat)

Nystatin helps prevent yeast infection in your mouth.

- ♥ The medication must be swished throughout your mouth, then swallowed. Parents of younger children can use a swab to swish around the mouth. Do not put down the feeding tube.
- ♥ It is taken after each meal, and before bed. Do not eat or drink anything for 30 minutes after your dose.

Side Effects: no significant side effects

DRUGS THAT PROTECT THE HEART

Furosimide (Lasix)

Lasix is a water pill or diuretic. This medication works in the kidney to increase how much urine you make. This helps to get rid of extra water in your body. It is common to need some help getting rid of extra fluid after transplant.

Side Effects:

Electrolyte imbalance: when you are getting rid of all that water the salt balance in your body can get upset. We will monitor your electrolytes closely when you are on a water pill.

DRUGS THAT PROTECT THE DIGESTIVE SYSTEM

Because some medications can cause ulcers in the stomach and upper intestine, a patient may need to take other medications to help protect his digestive system. The transplant team will prescribe these drugs when necessary.

ANTI-ULCER MEDICINES

ZANTAC, PREVACID, PANTOLOC, LOSEC and SULCRATE are medications used to prevent and sometimes treat ulcers of the stomach of upper intestine.

Side effects:

These include, but are not limited to, headache, nausea, vomiting, diarrhea, constipation, and gas.

WHAT CAN I BUY AT THE PHARMACY WITHOUT A PRESCRIPTION?

Over the counter medications have to be used with caution as many interact with your immunosuppression drugs. You can safely use plain Tylenol. Do not use other Tylenol combinations such as medicine for colds or arthritis pain. If you have nausea, Gravol can be safely used as directed. All forms of cold medications should be avoided as they come in many drug combinations and several of these drugs interact with immunosuppression. NSAIDs, or Non-Steroidal anti-inflammatory Drugs should not be taken. These drugs can cause kidney damage or stress when used with your immunosuppression or anti-rejection drugs. Examples of these drugs are Advil, Ibuprofen, Motrin and ASA (aspirin). In special situations your transplant physician may order an NSAID for you, but you will be monitored carefully.

****NOTE****The most important thing to remember about using over the counter medications is that if you still feel ill after taking these drugs, you must contact your family doctor or your transplant coordinator. This is important because you may have a health problem that might be treated better in a different way.

DOSING FOR TYLENOL

Children 11-12 yrs may have 480 mg of Tylenol every four hours. Children over 12 can have 650 mg of Tylenol every four hours.

Weight In Pounds	Weight in Kilos	Age	Dose in mg	Infant Drops 80mg/ml	Chewable Tablets 80mg each
6-11	2.5-5.4	0-3 mths	40	0.5 ml	-
12-17	5.5-7.9	4-11 mths	80	1 ml	-
18-23	8.0-10.9	12-23 mth	120	1.5 ml	-
24-35	11.0-15.9	2-3 yrs	160	2.0 ml	2
36-47	16.0-21.9	4-5 yrs	240	3.0 ml	3
48-59	22.0-26.9	6-8 yrs	320	-	4
60-71	27.0-31.9	9-10 yrs	400	-	5

HERBAL MEDICINES

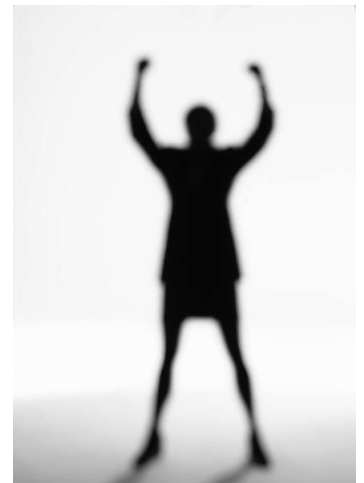
The transplant team does not recommend any herbal supplements. Herbal medicines are poorly investigated and have no regulations governing how they are prepared or dispensed. This means there may be important drug interactions with your anti-rejection medications.

There are some herbal medicines we know do cause problems for transplant recipients. We know that St John's Wort will decrease your tacrolimus levels and increase the risk of rejection. Heart transplant patients have died after taking St John's Wort.

Echinacea and other immune boosters are not a good idea; we want your immune system to be low as that is what keeps your heart safe from rejection.

HOW DO WE GET BACK TO NORMAL?

What are the emotional effects of transplant? This is a time of great change in your life. It is normal to be overwhelmed by the scale of transplantation and its effect on your life, your family and your future. Some people become very emotional for a time; you may experience many feelings that are confusing or overwhelming; this is normal, hang in there. The hospital stay can be very upsetting for children. It will upset their routine and change their sleep patterns. Routine is especially important to young children. They will benefit from getting back to familiar routines after discharge. During their hospital experience they faced strange and sometimes painful tests and meet many new people. It is normal for them to be irritable and bad-tempered after this experience, especially if their stay in the Pediatric Intensive Care Unit (PICU) has been a long one. It may take some time after you go home for things to get back to "normal". The members of the transplant team are available to you to answer your questions.



Austin's Story

Austin experienced some anxiety throughout his hospital journey but it actually got worse about one year post transplant (he was prone to some anxiety even pre diagnosis) but it is now well managed and he enjoys a very high quality of life. He is proud of his journey and enthusiastic to show off his scars. He has shown resilience in the face of adversity and has a positive attitude about his future.



How important are diet and exercise after transplant? Nutrition and exercise remain an important part of your daily life.

Nutrition: The dietitian will be spending time with you talking about nutrition and therapists from the hospital will be giving you advice about keeping active. Attending to these details will keep you and the new heart on the right track.

Very often young children need to be fed by tube and fall behind on their developmental milestones when they are critically ill. Time, patience, the dietitian and the occupational therapist or speech pathologist will help with feeding issues to move your child along the road to recovery.

Food safety is an important issue after transplant. The risk of contracting a food borne illness is higher for the transplant recipient as with all over bacterial and viral illnesses. Raw food is the highest risk. All vegetables and fruit should be washed and stored in the refrigerator and raw and undercooked meat is to be avoided. Below is a copy of the recommendations from Canada's Food Guide and on the next page is a chart by the US FDA outlining what foods should be avoided and what are safe choices to eat.

	Children			Teens		Adults			
	2-3	4-8	9-13	14-18 Years		19-50 Years		51+ Years	
	Girls and Boys			Female	Male	Female	Male	Female	Male
Vegetables and Fruit	4	5	6	7	8	7-8	8-10	7	7
Grain Products	3	4	6	6	7	6-7	8	6	7
Milk and Alternatives	2	2	3-4	3-4	3-4	2	2	3	3
Meat and Alternatives	1	1	1-2	2	3	2	3	2	3

Common Foods: Select the Lower Risk Options

Type of food	Higher Risk	Lower Risk
Meat and Poultry	<ul style="list-style-type: none"> Raw or undercooked meat or poultry 	<ul style="list-style-type: none"> Meat or poultry cooked to a safe minimum internal temperature (see chart on p. 10)
<p><i>Tip: Use a food thermometer to check the internal temperature on the "Is It Done Yet?" chart on page 10 for specific safe minimum internal temperature.</i></p>		
Seafood	<ul style="list-style-type: none"> Any raw or undercooked fish or shellfish or food containing raw or undercooked seafood e.g., sashimi, found in some sushi or ceviche. Refrigerated smoked fish Partially cooked seafood, such as shrimp and crab 	<ul style="list-style-type: none"> Previously cooked seafood heated to 165 °F Canned fish and seafood Seafood cooked to 145 °F
Milk	<ul style="list-style-type: none"> Unpasteurized (raw) milk 	<ul style="list-style-type: none"> Pasteurized milk
Eggs	<p>Foods that contain raw/undercooked eggs, such as:</p> <ul style="list-style-type: none"> Homemade Caesar salad dressings* Homemade raw cookie dough* Homemade eggnog* 	<p><i>At home:</i></p> <ul style="list-style-type: none"> Use pasteurized eggs/egg products when preparing recipes that call for raw or undercooked eggs <p><i>When eating out:</i></p> <ul style="list-style-type: none"> Ask if pasteurized eggs were used
<p><i>*Tip: Most pre-made foods from grocery stores, such as Caesar dressing, pre-made cookie dough, or package d.eggnog are made with pasteurized eggs.</i></p>		
Sprouts	<ul style="list-style-type: none"> Raw sprouts (alfalfa bean, or any other sprout) 	<ul style="list-style-type: none"> Cooked sprouts
Vegetables	<ul style="list-style-type: none"> Unwashed fresh vegetables, including lettuce/salads 	<ul style="list-style-type: none"> Washed fresh vegetables, including salads Cooked vegetables
Cheese	<ul style="list-style-type: none"> Soft cheeses made from unpasteurized (raw) milk, such as: <ul style="list-style-type: none"> — Feta — Brie — Camembert — Blue-veined — Queso fresco 	<ul style="list-style-type: none"> Hard cheeses Processed cheeses Cream cheese Mozzarella Soft cheeses that are clearly labeled "made from pasteurized milk"
Hot Dogs and Deli Meats	<ul style="list-style-type: none"> Hot dogs, deli meats, and luncheon meats that have not been reheated 	<ul style="list-style-type: none"> Hot dogs, luncheon meats, and deli meats reheated to steaming hot or 165 °F
<p><i>Tip: You need to reheat hot dogs, deli meats, and luncheon meats before eating them because the bacteria Listeria monocytogenes grows at refrigerated temperatures (40 °F or below). This bacteria may cause severe illness, hospitalization, or even death. Reheating these foods until they are steaming hot destroys these dangerous bacteria and makes these foods safe for you to eat.</i></p>		
Pâtés	<ul style="list-style-type: none"> Unpasteurized, refrigerated pâtés or meat spreads 	<ul style="list-style-type: none"> Canned or shelf-stable pâtés or meat spreads

Exercise: After discharge from the hospital, it is important for older children and teenagers to learn how to start activity slowly to allow time for hormones like adrenalin to be released to tell the heart to speed up. If the child starts with a burst of running right off the bat, the heart may have to play “catch-up” with the child. It can be frustrating to the child who can’t keep up with other children. The reason you need to warm up before activity is because during the heart transplant the nerves that tell your heart to speed up and slow down are cut and cannot be repaired. This is called denervation. The hormone messengers are helpful but slower to affect the heart rate. The physical therapist will teach you more about this.

When Do I Write My Thank You To The Donor Family?

You can write to the donor family when you are ready. Anyone in the family is welcome to write to offer thanks or expressions of sympathy at their loss. We recommend that you wait until 2 or 3 months after surgery so you have time to think about your experience. Please do it before the first year passes you by.

Should Children Be Immunized After Transplant?

Yes, but not until at least six months after transplant then you can continue the immunization schedule as recommended by Public Health. After transplant you should never have vaccines that contain “live virus”. These are the MMR (measles, mumps, rubella), Varivax (Varicella or chicken pox), and OPV (oral polio) vaccines. After transplant it is dangerous to have vaccines that contain live viruses as that vaccine may cause the illness to occur. Please discuss immunization with the transplant team before you go.

Family members (such as brothers and sisters) may receive the MMR and Varivax vaccinations. They may NOT receive the oral polio vaccine, as there is a chance the disease can be transmitted. However, most children now receive the polio injection instead of the oral vaccine.



Influenza: Do get the “flu shot” every year and the pneumococcal vaccine. We highly recommend that your entire family receive the influenza vaccine on a yearly basis. Children under the age of 6 months do not receive this vaccine (it doesn’t work well under that age). The newer nasal flu spray should not be given to transplant children. We would

prefer that nobody in the family gets it either. The spray contains a weak form of live virus that can cause illness in immunosuppressed people.

When can we go to the Dentist?

Wait until 6 months after transplant. Make sure your dentist knows you have had a heart transplant. You will probably need antibiotics before any invasive procedure, including extensive dental cleaning.

Are we allowed to have pets after transplant?



Yes but you do have to be careful. Your children must avoid handling animal waste. They cannot clean bird cages or fish or reptile tanks or cat litter. It is OK to have a dog or cat but dogs must be taught not to lick the face and the transplant recipient cannot be responsible for cleaning up messes. Teach your child not to touch poo.

Should my child have a medic alert bracelet?

Yes, a medic alert bracelet or necklace is a good idea. It is most useful when you are not available to answer questions in an emergency. There are some heart medications and antibiotics that should not be given without close monitoring after heart transplant. Medications that interact with the immunosuppression your child is on. Make sure the paperwork you fill out includes the following information:

Heart Transplant Recipient

Allergies

Immunosuppressed – list your drugs

University of Alberta Hospital Transplant Program [780] 407-8822



**When can I go back to school or daycare?**

You can go back to school or daycare after about 3 months with the doctors OK, you might want to start with half days and see how it goes.

Are there any restrictions to activity?

Do not lift/push/pull more than very light weight for at least 6 weeks after transplant, this includes any backpacks and grocery bags. Do not sit behind an airbag for at least 6 weeks.

Babies and toddlers should be lifted under their legs or bottoms, do not lift them holding their chest or pull them to a sitting position by pulling their arms for at least six weeks.

When can I play hockey?

Check with the doctor before resuming contact sports, usually not for 3-6 months or longer. The breast bone has to heal well before you can risk being hit or falling down. Non contact physical activity and sports play will begin while attending physical and occupational therapy.

Austin's Story

As a family, we enjoy a normal lifestyle. We go to professional hockey, soccer, baseball, and lacrosse games. We go to parks, parties, movies, and many other attractions and events. We've been to Disneyland, to different cities around Alberta and we are looking forward to travelling more one day. Austin is a sports fanatic and loves to watch and play almost any type of sport. He also likes to play video games, read, do art projects, and play with marbles, Lego, Knights and Star Wars figures. In so many ways he is a "normal" ten-year-old boy. His heart transplant and stroke are a part of his experience but don't completely define him.



SPECIAL WARNING TO PARENTS OF CHILDREN WHO HAVE HAD TRANSPLANTS

Ask the school nurse or other official to notify you immediately about any communicable diseases (for example measles and chicken pox) that may be circulating in your school. If your child has contact with chicken pox call the transplant nurse as soon as possible as they may need a special antibody to help prevent them catching it. Someone who is not immune suppressed could handle the slight case of the illness with ease. A transplant patient will not.

When can we go on a holiday? Always let the doctor and the Transplant Coordinator know when you are traveling. We ask that you not leave the country for one year after transplant and you must beware of crowds for the first 3-6 months when you are the most immunosuppressed.

SPECIAL ADVICE FOR TEENS

Driving: You cannot drive for at least three to six months, check with your transplant doctor. You have to inform Motor Vehicles and your insurance that you have had a transplant, they may require a form to be filled out by your doctor.

Sexuality: Protect yourself from sexually transmitted infections – you are at risk! Check with the transplant cardiologist as some forms of birth control work better with immunosuppression than others. Notify the transplant coordinator immediately if you become pregnant.

Are Cigarettes and Alcohol OK after transplant? No, not only is smoking a known cause of cancer, it causes your blood vessels to shrink every time you inhale. This lowers the amount of blood going to your new heart, which can cause damage over time. Drinking alcohol can cause damage to your liver. Avoid alcohol.



As a parent of a child with a transplant we ask that you do not subject them to second-hand smoke, you will be risking their lives.

Can I get my ears pierced?

Yes, but you must wait for at least one year after transplant or one year after a rejection episode. You must be off prednisone and on a level maintenance dose of immunosuppression. Check with the doctor in clinic at your annual visit if this is something you want. You must follow the directions for cleaning to prevent infection very carefully.



FOLLOW UP PLAN

WHAT CAN I EXPECT AT A CLINIC VISIT?

Clinic visits are weekly for one month after discharge, then the doctor will decide at each visit when you should be seen again. At each clinic visit, you will be weighed, have your height measured, and have vital signs taken.

- ♥ At most visits, an EKG and Echocardiogram (ECHO) will be done.
- ♥ The Transplant Nurse will talk with you to see how things have been going at home and review all of your medications and doses.
- ♥ The Transplant Cardiologist will do a physical exam and discuss any possible changes that need to be made.
- ♥ Review of home blood pressure monitoring if needed, or the nurse will do your blood pressure in clinic.

If you have questions between clinic visits and they do not need immediate answers, write them down and bring the list in with you. You can always call and talk with one of the nurses in between visits if you need to. Good communication between you and your transplant team is essential.



BLOOD PRESSURE MONITORING

Some patients need to monitor blood pressure at home. The doctor and transplant coordinator will let you know if this is a requirement for you. We recommend the Welch Allyn Spot Blood Pressure Monitor. The transplant coordinator or clinic nurse will order them for you, please discuss with them. Approximate cost of equipment is \$1100.00.

What blood work will be done?

In the beginning you will have a blood test twice a week. As you get healthier the amount of blood work will be decreased. A usual blood test monitors blood count, clotting, kidney function, electrolytes, and medication levels in the patient's blood. Other tests may be ordered as necessary.

- ♥ Blood cholesterol will be tested every 6 months until 1 year after transplant and the once a year after that.
- ♥ CMV and EBV have their own schedules. Your coordinator will explain them to you.

BLOOD TESTS

Blood tests are a part of life after transplant. They are very important to your medical management. It is extremely important you follow our requests in having the blood draws performed. We follow blood levels of certain medicines such as



Tacrolimus (Prograf), Cyclosporine (Neoral), and/or Sirolimus (Rapamune). If the blood level is too high, the medicine can affect other body organs and their function. If the blood level is too low, your child is at risk for rejection of the heart.

Blood draws may be obtained either at the hospital or at a lab near your home. In the early days after transplant, you will be seen at the Transplant Clinic on a regular basis. Until your medicines are stable, we may request all blood work to be drawn at the Hospital. Later, we can arrange for the blood work to be obtained at a laboratory near your home.

The transplant coordinator will let you know when to have the blood work drawn. It is your responsibility to make sure this is done on time. If the blood work is not drawn at the hospital, please call the nurse to let us know it was done. It takes a few days for the results of blood levels of medicine to be done. The nurse will call you if any adjustment of medication is required; if you don't hear from us it means all is well. However, if you are concerned or there are ongoing issues and you have not heard from the clinic more than 5 days after the blood test was done, please call the heart transplant coordinator at: (780) 407-3394.

TESTS FOR BLOOD COUNT

***WBC** tells if the patient's white blood cells have increased (usually a sign of infection) or decreased (indicating a lower defence against infection).

***HGB** measures the haemoglobin, which is the amount of red blood cells in the blood. Red blood cells carry oxygen to all parts of the body. When a patient's Hgb is low, he may feel tired or have little energy.

TEST FOR BLOOD CLOTTING

***PLT** measures the level of platelets. Platelet cells form a blood clot when the body is injured. Low platelet levels may cause someone to bruise easily and to bleed for a longer time when injured.

TESTS FOR ELECTROLYTES (DISSOLVED MINERALS)

***Ca** measures calcium, which is necessary for strong bones and teeth, blood clotting, and heart and nerve function.

***P04** measures phosphate, which works closely with calcium to strengthen bones.

***Mg** measures magnesium, which is necessary for normal function of muscles and for blood clotting.

***K** measures potassium, which is needed for normal heart and muscle function.

***Na** measures sodium, which helps maintain the balance of salt and water in the body.

***Glu** measures glucose, levels of sugar in the blood; some medications may produce a diabetes-like condition in which blood-sugar levels are too high.

TESTS FOR MEDICATION LEVELS

Drug levels measure Tacrolimus, Cyclosporine, and Sirolimus (Rapamycin) in the blood. These blood levels must be checked regularly to avoid levels that are too high or too low. High levels could lead to toxicity or over-immunosuppression and high infection rates, and low levels may lead to rejection.

NOTE: The normal range will differ for each person, depending on the combination of anti-rejection medications and the length of time since the transplant.

TEST FOR KIDNEY FUNCTION

*Creatinine and BUN tell how well the kidneys work by measuring levels of creatinine and blood urea nitrogen (BUN), waste products normally removed from the blood by the kidneys.

TESTS FOR LIVER FUNCTION

These tests tell us how well the liver is working.

***Bili** measures the level of bilirubin, a normal by-product when the red blood cells break down. The liver removes bilirubin from the blood and gets rid of it in the bile. When the liver is not functioning normally, bilirubin levels can increase, often causing jaundice - yellow skin and eyes.

***Alk Phos** measures alkaline phosphatase, which is made in the bones, liver, pancreas, and intestines and removed from the blood by the liver.

***AST, ALT, and GGTP** test enzymes that are made in the liver.

HEART FUNCTION TESTING

Echo and EKG

Your child has probably had these many times by now.

An Echo is an ultrasound of the heart; young children may have to be sedated. It is important that they be as still as possible so we can get the best picture.

An EKG looks at the electrical activity of the heart, it measures the rate and rhythm of the heart beat.

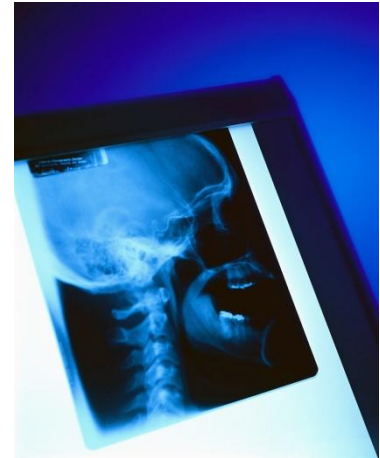
RADIOLOGY TESTING

CXR

- ♥ A chest X-ray will be done on occasion when you come to clinic.

GFR scan

- ♥ To be done at 12 months post transplant, then once a year.
- ♥ Needs an IV and takes 3 hours to complete



REGISTRY AND FOLLOW-UP OF COMPLEX PEDIATRIC THERAPIES PROGRAM

The Complex Pediatric Therapies Follow-up Program based out of the Glenrose Rehabilitation Hospital in Edmonton, AB is involved in the long-term evaluation and follow-up of selected young children who have received new specialized treatments often requiring care in the Pediatric Intensive Care Unit (PICU). Our purpose is to provide long-term follow-up and service for children within Western Canada to assist in the prevention of childhood problems that may occur and to also help to improve care for future children and benefit the health and education systems. Understanding more about the effects that illnesses and their required care have on children's development will help to achieve this purpose.

The Complex Pediatric Therapies Follow-Up Program provides assessments throughout Western Canada in existing developmental/neonatal follow-up clinics. Various professionals carefully evaluate the children for progression in their development. As the child's health improves and they grow and develop in all areas, the program provides assessments that confirm their skills or assist them if required.

For young children the program helps them reach early developmental milestones. For older children the program can assist with school placement and learning as needed. The length of the visit will be determined by the development and age of the child. The other clinic settings are in Calgary, AB; Regina and Saskatoon, SK; Winnipeg, MB; and Vancouver, BC.

For additional information please contact:
Gwen Alton RN, MN
Coordinator
780 735-7999 ext 15630
Pager 780 445-6706
Gwen.alton@albertahealthservices.ca

Austin's Story

Very early in the transplant journey, Austin was put under general anesthetic for the first time in his life, to have a PICC line inserted. The anesthesiologist had a grave conversation with us beforehand and was not optimistic that it would go well because Austin's heart was so weak. We were told that Austin could come back from the procedure on ECMO, or worse. We resignedly signed consent knowing it was necessary. We prayed while we waited anxiously for the procedure to be over. We were elated when Austin returned to the unit in stable condition after an uncomplicated procedure! It was official - we were harnessed in and gripping tightly to the rails on the roller coaster ride that we wouldn't get off for several more months. In hindsight, I wish that I could have heeded the advice of the compassionate doctor who told us that there would be good days and bad days and to enjoy the good and try not get too upset on the bad.



ANNUAL ASSESSMENT

Once per year, around the date of the anniversary of your transplant we will ask you to do a number of tests to make sure your heart is functioning well, look for early signs of rejection, monitor your bone health and kidney function. There will also be extra blood work that we will ask you to get done.

The annual testing will include:




- ♥ Blood work
- ♥ Biopsy
- ♥ Clinic Visit
- ♥ Bone Density/Bone Age >age 5 years
- ♥ Echo, EKG
- ♥ GFR or Cystatin C
- ♥ Coronary Angiograms or stress testing
- ♥ Exercise Testing starting age 6

TRANSITIONS

The transition period is how we describe the time when you change from a child to an adult. This usually begins about age 12 and continues until you are about 22 years of age. During this time the staff in the clinic will be talking to you about more grown up topics like taking responsibility for medication, sexual health, independence and career planning. Your transplant can affect all these things.

Most children's hospitals do not look after youth after the age of 18. After 18 years of age it is expected that you will be cared for by a physician who looks after adult heart transplant recipients. We understand that this might be a difficult change for you and your family but if we have done our job in preparing you for the adult world you should make that transition smoothly.

	Birth to 3 years old	4-7 years old	8-11 years old	12-14 years old	17 years old
General	<p>Take short breaks from your child to renew your energy</p> <p>Apply for special funding/drug plan if possible</p> <p>Be a role model to help your child develop healthy eating habits</p> <p>Give your child choices</p> <p>Bring a favourite toy to the hospital</p>	<p>Increase the level of difficulty of the choices you give your child</p> <p>Teach your child the consequences of his behaviours and choices</p> <p>Begin thinking about your child's future</p> <p>Let your child play out their hospital experiences with puppets or dolls</p>	<p>Let your child make mistakes</p> <p>Teach your child to speak up for themselves and express wants and needs</p> <p>help your child recognize his special talents and interests</p> <p>Recognize your child's increasing need for independence</p>	<p>Advocate for yourself</p> <p>Ask questions if you don't understand</p> <p>Talk about sexuality with someone you trust</p> <p>Look for older role models</p> <p>Talk with health-care providers about how you feel about your condition or care</p>	<p>Ensure continuation of special funding/drug plan</p> <p>Become a mentor for younger children</p> <p>Begin to think of yourself as a role model</p> <p>Discuss dating issues with your parents and peers</p>
School	<p>Read to your child</p> <p>Talk with other parents</p> <p>Take your child to playgrounds, parks and playgroups, and community activities</p> <p>Invite families with children your child's age to your home to play</p> <p>Encourage your child to interact with staff</p>	<p>Let your child learn what they like to do by introducing them to a variety of activities</p> <p>Host birthday parties</p> <p>Let your child play at others' houses without you, and invite kids to your house.</p>	<p>Encourage hobbies, leisure and physical activities</p> <p>Help your child make friends</p> <p>Support your child's participation in community activities without parents where possible</p>	<p>Join teams and clubs at school</p> <p>Get involved in activities outside of school (camp, sports)</p> <p>Hang out with friends</p> <p>Choose who you would like to share the details of your medical condition with.</p> <p>Consider joining a peer support group</p>	<p>Participate in community programs for adults that match your interests</p> <p>Keep in touch with friends from high school or camp and make plans with them</p> <p>Join teams or committees at your school</p>
Self-care	<p>Teach your child everyday skills, such as brushing his teeth and hand washing</p>	<p>Teach your child skills related to their medical condition</p> <p>Be creative when assigning household chores to your child</p> <p>Maintain a record of your child's health</p> <p>Celebrate your child's academic achievements</p> <p>Teach your child how to use 911</p>	<p>When you take your child food shopping discuss diet needs and read labels together</p> <p>Teach your child their personal information such as address, phone number, etc</p> <p>Involve your child in preparation of medication (use proper name and reason for med)</p> <p>Help your child reduce stress through activities such as art, exercise, music or journal writing</p>	<p>Set up your own health care routines, such as taking medications and getting blood work done</p> <p>Learn more about your special dietary needs when cooking with your family</p> <p>Start to find your way around the community</p> <p>Plan ahead to fit your health-care routines into your life</p>	<p>Plan and prepare meals in accordance to your diet needs</p> <p>Practice budgeting and banking skills</p> <p>Keep a record of tests procedures and medications</p>
Education		<p>When registering your child for school, discuss health care needs with the teacher</p>	<p>Let your child do homework on their own as much as possible, wait for them to ask for your help</p> <p>Begin asking your child what they want to be when they grow up and encourage discussion about the future</p>	<p>Take part in meetings about your education and keep a record</p> <p>Get to know your school guidance counselor</p> <p>Talk about career interests and being to set goals (College)</p> <p>Find volunteer work or a part-time job</p> <p>Be able to explain your condition to teachers who need to know</p>	<p>Going to College or university?</p> <p>Register with the special needs office even if you feel fine</p> <p>Looking for work? Go for career counseling, shadow someone at their job, attend a job fair</p> <p>Research your medical condition.</p> <p>Make contact with others who have already transitioned to the adult service</p> <p>Review your college/university workload, is it too much?</p>
Medical	<p>Develop good relationships with your child's health-care team</p> <p>Learn about your child's heart condition and transplantation</p> <p>Keep a record of your child's medical history including medications and diet</p> <p>Ensure immunizations are up to date (beware live vaccines)</p> <p>Plan ahead for travel, including getting extra medications.</p>	<p>Teach your child the name of their medical condition (Heart Transplant Recipient)</p> <p>Teach your child about their medical needs and how to make them part of daily life</p> <p>Prepare your child for clinic appointments using play acting or drawing</p>	<p>Ask your child what they know about heart transplant and fill in the gaps in their understanding</p> <p>help your child to talk directly with the health-care team</p> <p>Prepare for clinic visits one week before appointments</p> <p>Encourage your child to visit kid friendly websites like www.transplantkids.uk.co or www.aboutkidshealth.ca/justforkids</p>	<p>Discuss eventual need for adult health-care providers</p> <p>Attend part of your medical appointments by yourself, prepare a list and ask questions</p> <p>Start to make your own medical appointments and keep a record of your medical history, such as current weight and blood pressure</p> <p>Create or update you own Health Passport</p>	<p>Visit an adult health care centre</p> <p>Discuss birth control, pregnancy or fatherhood, drugs, alcohol and smoking with your health-care provider</p> <p>Get a summary of your medical record</p> <p>Update your Health Passport</p> <p>Know who to call in an emergency</p> <p>Transfer to an adult facility</p>

MEDICATION MANAGEMENT TOOL

Children reach developmental milestones at different chronological ages. The following growth and development milestones are provided to assist in developing an individualized child health plan that incorporates the child as fully as their abilities allow. Children with cognitive/developmental delays should be encouraged to participate to the best of their abilities.

Age	Characteristics	Relevant Points	Example of Child Participation
0 - 5	♥ variable	♥ Younger preschooler – unable to assist with medication plan ♥ older preschooler will be able to assist with some aspects of the medication plan	♥ Younger, parent does all ♥ Older, child may squirt medicine into their mouth
5 - 7	♥ can follow rules, directions ♥ wishes privacy ♥ developing manual dexterity	♥ finds it difficult to leave activities ♥ will be able to assist with some aspects of the medication plan	♥ start to learn to take pills rather than liquid medicine ♥ put own medicine in mouth
8 - 9	♥ may be able to tell time ♥ beginning to understand safety ♥ self confidence increasing	♥ fine motor control improving ♥ more independent ♥ developing good health habits	♥ help fill dosettes on the weekend ♥ ask child what time is it? Oh it must be time for medication, lets do it together.
10 - 13	♥ good coordination ♥ able to look after own needs ♥ wants independence ♥ needs ownership in decision making	♥ May begin planning and doing own procedures in care ♥ involve in plan development	♥ Make a plan together about who will take responsibility for dosettes, setting alarms, reminders about prescription refills
14 - 15	♥ gains maturity and control ♥ needs autonomy ♥ able to problem solve	♥ needs independence ♥ Needs to fit in with peers ♥ involve in care plan	♥ Need to teach your child how to get prescription filled, how to ask for prescription refills, how to track same. Will still need reminders but needs to take on responsibility for medication management ♥ This is a difficult age as if they do not understand the reasons for medication, they will not take it ♥ Need to agree to a plan that works with their routine
16 - 19	♥ depth in reasoning ♥ reasons deductively ♥ comprehensive problem review ♥ more emotionally stable	♥ Independent ♥ Any assistance required may be related to special health challenges	♥ Allow your child to ask and answer questions at the doctors office about medication ♥ Ask them what help they want with medication management.

Overall Guidelines:

- ♥ Encourage normalcy
- ♥ Maintain confidentiality
- ♥ Practice honesty
- ♥ Involve the child
- ♥ Keep preschool/school routine disruption to a minimum
- ♥ Allow child to assume responsibility for their care as developmentally and physically appropriate

**Adapted from B.C. Ministry of Health for AHS in Guidelines for Child/Student Focused Medication Management in Preschool/School Settings
March 2009**

SAMPLE SCHEDULE

	MONDAY	TUESDA Y	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
6 am	On Tuesday it is time to get up and go to the hospital. Have breakfast now or at 8am, take all meds except immunosuppression. If your baby in on continuous feed overnight it might be time to stop. If nothing else sleep in until med time at 8am.						
7:30 am	Blood work in the outpatient lab in the Maz, 2 nd floor or Edmonton Clinic main floor on Tuesday before clinic. Take your immunosuppression after your bloodwork, have breakfast now if you didn't earlier.						
8 am		Heart Tx clinic at the Maz					
11 am	If your child is on tube feeds it may be time for a bolus, bring your stuff to clinic just in case						
noon	Eat lunch every day. Good nutrition is important for healing. Talk to the dietitian if this is a problem.						
1- 3 pm	Lie down and rest. TV is not restful. Read or day dream, listen to music but be quiet.						
4 pm	Time for a little exercise. Start with 10 minutes and work your way up to 20 minutes of walking. For mom's of infants, you can play and work on developmental exercises. Talk to your physiotherapist or OT.						
6 pm	Supper time. Try to eat. Immunosuppression changes your taste buds. Try small frequent meals every two hours if this isn't working.						
8 pm	Medication- it is important that you take it at regular intervals, every day to prevent rejection.						
10 pm	Time to go to bed to sleep so you can start all over again in the morning. Younger children may need to go to bed immediately following their 8pm medications. See table below for sleep needs in the different age groups.						

Age of Child	Recommended Hours of Sleep www.webmd.com
1-4 weeks	15-18 hours per 24 hrs for 2-4 hour periods, no day/night cycle.
1-4 months	14 ½ -15 ½ hours per 24 hrs, 4-8 weeks only awake for two hours at one time, then transition to 3 daytime naps
4-8 months	14-15 hours per 24 hrs, includes 3 naps (9, 12, 3) decrease to 2 naps at 6mths with earlier bedtime.
9-12 months	10 hours at night plus two naps, morning and afternoon, up to 2 hrs each
1-3 years old	12-14 hours per 24 hrs, includes two naps until ~21months, then one nap after noon
3-6 years old	10 ¾ -12 hours per 24 hrs, includes one nap for the 3-5 yr old, varying from 1-3 hrs.
7-12 years old	10-11 hours per night
12-18 years old	8 ¼ – 9 ½ hours per night

HOW TO REACH US

To reach the team, call the Heart Transplant Outpatient Coordinator from 8am to 4pm at (780) 407-3394. Please leave a detailed message and you will be contacted. If the matter is urgent and it is after 4pm and before 8am, call (780) 407-8822 and ask for the Transplant Coordinator on call.

If the situation is an EMERGENCY, call 911 and take an ambulance to the Hospital.

WHEN SHOULD I CALL THE TRANSPLANT TEAM?

You should call the Transplant Center for the following reasons:

- ♥ Sudden weight gain of 2-3 pounds over 24-48 hours
- ♥ Increase or decrease in blood pressure (more than 10-15 points difference)
- ♥ Increase or decrease in heart rate (by 10 points)
- ♥ Temperature increase of one degree or more over the normal range
- ♥ Nausea or stomach pain that lasts longer than 24 hours
- ♥ Vomiting (especially if it occurs more than once such as with the stomach flu)
- ♥ Diarrhea (more than 3-4 loose stools in 24 hours)
- ♥ Decrease in urine output or less frequent wet diapers
- ♥ Fatigue or increased naps
- ♥ Irritability (especially in the case of infants)
- ♥ Shortness of breath or difficulty breathing
- ♥ Swelling around your child's eyes, hands, and/or feet
- ♥ Dizziness, feeling faint, or "black out" spells
- ♥ Irregular heart rate or palpitations
- ♥ Exposure to chicken pox or other contagious diseases
- ♥ Cough with yellow or green mucus

For after office hours or on the weekends, call the Transplant Coordinator On-Call through the main switchboard. (780-407-8822)

The list above can all be symptoms of rejection, infection, or be nothing more than a childhood virus. However, it is better to be safe than sorry. Having a bout of the childhood stomach flu may mean hospitalization for a child after a heart transplant. This is because missing a few days of medicine from throwing up can lead to severe rejection.

If you are not sure about calling us or not, then just do it!



IMPORTANT PHONE NUMBERS

University of Alberta Hospital Stollery Children's Hospital Heart Transplant PHONE: (780) 407-3394 ,
FAX: (780) 407-8981

Out patient Coordinator:

Name: Phone:

Pediatrician:

Name: Phone:

Cardiologist:

Name: Phone:

Social Worker:

Name: Phone:

Physical therapist:

Name: Phone:

Dietitian:

Name: Phone:

Pharmacist:

Name: Phone:

Occupational therapist:

Name: Phone:

Child Life Specialist:

Name: Phone:

RESOURCES AFTER TRANSPLANT

SUGGESTED READING LISTS AND WEB SITES

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.

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 well a couple of years post transplant

To the Edge and Back: My Story from Organ Transplant Survivor to Olympic Snowboarder (2004) by Chris Klug (Author), Steve Jackson (Contributor)

Pennies, Nickels & Dimes (1999) by Elizabeth Murphy-Melas (Author), Anthony Pouncey (Illustrator). For age 4-8, A girl raises money for her liver transplant.

Now Caitlin Can: A donated organ helps a child get well. (2004) by Ramona Wood (Author) Caitlin needs a kidney transplant but this story of recovery after transplant is a good one for age 4-8.

Precious Gifts: Katie Coolican's Story. Barklay and Eve Explain Organ and tissue Donation Paperback – March 6, 1999

by Karen L. Carney (Author): the true story of six year old Katie Coolican, this sensitively written and illustrated book will help children and adults understand the process of organ and tissue donation.

The Bounce Back Book published by the Alberta Mental Health Board is about encouraging resiliency (the ability to bounce back) in your children from infant to school age. Find it online at <http://www.albertahealthservices.ca/1739.asp>

www.transplantkids.co.uk this is a great website for kids, colorful, good explanations and stories from other kids who have had transplants.

www.transweb.org is based at the University of Michigan and has a full time editor responsible for maintaining the web site.

www.organ-donation-works.org is the website for the Canadian Transplant Association. This group is responsible for the transplant games that are held in Canada and also participate in the world games. If you are interested in meeting other people with transplants and you are interested in participating in sports activities this is a group you should get involved with. Children over age 5 are welcome to join in the fun.

www.transplantliving.com maintained by the United Network for Organ Sharing and supported by Roche Pharmaceuticals this has extensive information for transplant recipients.

www.transplantexperience.com sponsored by Astellas who makes one of the transplant drugs. Lots of information for transplant recipients.

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.

Index

A

Acyclovir · 25
 Advil, · 27
 alcohol · 36
 alkaline phosphatase · 40
 anti-rejection · 7, *See* Immunosuppression
 ASA · 27
 aspirin · 27

B

bilirubin · 40
 birth control · 36
 blood pressure · 4, 23, 37
 blood test · *See* Bloodwork
 bloodwork · 38
Bloodwork · 37
 Blurred vision · 22

C

calcium · 39
cancer · 19
 chicken pox · 25, 35
 Clinic · 37
 CMV infection · 13
 contact sports · 34
 Creatinine · 40

D

daycare · 34
 denervation · 32
 Diabetes · 5, 20, 21, 23
 diarrhea · 23
 dietician · 9
 dietitian · 29
 diuretic · 26
 Diuretic · 4
 drive · 36

E

EBV · 13
 Echo · 41
 EKG · 41
EMERGENCY · 48
 exercise · 29

G

Ganciclovir · 25
GFR · 41
 glucose · 39
 Graval · 27

H

haemoglobin · 39
 hair growth · 24
 headaches · 20
 herpes · 25
 High blood pressure · 4
 hungry · 22

I

Ibuprofen · 27
 immunization · 32
 immunosuppression · 10, 19
 infection · 10, 19
 prevention · 10
INFECTION
 CAUSES OF · 12

L

LOSEC · 26

M

magnesium · 39
 medic alert · 33
 medication · 17
 Motrin · 27

N

Nutrition · 29
 Nystatin · 25

O

Osteoporosis · 21
 Over the counter medications · 27

Discharge Information

P

pacemaker · 4
Pediatric Intensive Care · 28
pets · 33
phosphate · 39
PICU · 28, *See* Pediatric Intensive Care
platelets · 39
pneumonia · 14
Post Transplant Lymphoproliferative Disease · 5
potassium · 39
Prednisone · 21
pregnancy · 21
PTLD · *See* Post Transplant Lymphoproliferative Disease
puffy face · 22

R

rejection · 7, 9
symptoms of · 7
treatment of · 8

S

school · 34
Septra · 24
sleep patterns · 28
Sleeping pills · 22
smoking · 36
sodium · 39
sore muscles · 20

T

Tacrolimus · 40
tingling · 20
traveling · 35
Tylenol · 27

U

ulcers · 26
urea · 40
urgent · 48

V

vaccines · 32
Valganciclovir · 25
vomiting · 23

W

water pill · 4, *See* Diuretic
weekends · 48
white blood cells · 39

Z

ZANTAC · 26