

COMPLICATIONS AND LONG-TERM CARE

Rejection

One new concern will be rejection.

Every transplant recipient experiences a rejection episode at some point. The recipient's natural defense system, the immune system, fails to recognize the transplanted heart as its own and tries to protect the body by rejecting the new heart.

When rejection occurs, it can be treated and reversed. To control rejection, additional drug doses or new medications may be given. For severe rejection, a hospital stay will be necessary. Whenever possible, however, the transplant team will make arrangements for treating rejection episodes at home by using a visiting nurse service.

It is very important to watch for signs of rejection in the recipient. These include:

- Fatigue
- Shortness of breath
- Irregular heart beats
- Low-grade fever
- Abdominal bloating in conjunction with ankle edema



It is very important to have the ability to recognize signs of rejection. If any symptoms are detected, the transplant coordinator must be notified at once. The telephone numbers for the heart transplant team are included in the directory in the front of this manual. Most of the time, a heart biopsy is necessary in order to detect rejection. Rejection is usually detected from a biopsy before the recipient becomes symptomatic, allowing treatment to start before the rejection progresses. Therefore, regular biopsies will be scheduled.

Long-Term Complications

Transplant Coronary Artery Disease (TXP CAD): This is a form of chronic rejection in heart transplant recipients and is the leading reason for re-transplant. It is a progressive process which becomes worse over time. The cause of this is not precisely known, but researchers think it may be related to the immune system or the medications.

The end result of the process is that the coronary arteries (the vessels that supply blood to the heart muscle) become narrow and thick. Thus, they cannot feed the heart very well. The symptoms are fainting and/or sudden death.

To monitor the progression of this process, the recipient will undergo coronary artery catheterization at least every two years. If disease is present, sometimes stents and/or balloons can be used to open blockages. Much of TXP CAD is at the ends of the arteries and cannot be reached by a catheter.

Limiting risk factors is important (for example: managing diabetes, hypertension (HTN), obesity, high cholesterol, avoiding smoke and smoking, and avoiding alcohol use).

Post-Transplant Lymphoproliferative Disorder (PTLD): Heart transplant recipients are more susceptible to cancer. In particular, white blood cell cancers called lymphomas or certain types of skin cancers. To monitor for lymphomas, we do annual chest x-rays and monitor for Epstein-Barr Virus (EBV). To prevent skin cancers, it is recommended to decrease exposure to the sun by wearing protective clothing and sunscreen.

Recognizing Infection

Because medications will be taken every day to suppress the body's natural defenses against bacteria and viruses, the recipient will be more susceptible to infections.

Be alert for signs of an infection, such as a cough, a fever (101.5 degrees F) or chills, shortness of breath, vomiting or diarrhea. Signs in infants may be increased irritability or fussiness, rashes, lethargy, poor feeding or lack of appetite.

Call the transplant coordinator at once if there may be an infection. The signs of infection and rejection are often the same. In either case, call the transplant coordinator if any of these symptoms are recognized.

Precautions should be taken to avoid sources of infection for the recipient. Keep them away from people with the flu or colds. Also, try to avoid other ways that germs are easily spread – in crowds, in cigarette smoke, and in dirty/dusty buildings.

Antibiotic Prophylaxis

Not everyone who has undergone heart transplantation requires antibiotics before a surgical procedure, dental procedure or deep cuts requiring stitches, to prevent against infection. We follow the American Heart Association prevention of bacterial endocarditis guidelines. It is not necessary to take antibiotics for minor scrapes, bruises or immunizations. If there are any questions regarding the need for antibiotics or a prescription for antibiotics before a procedure please do not hesitate to call the transplant coordinator.

Hygiene

Dental Care

Because many infections start in the mouth, dental care is very important. Here are some points that need to be done to promote good dental hygiene:

- Brush the teeth often – at least twice a day.
- Notify your nurse coordinator before making your child’s first dental appointment after the transplant. Your child may or may not need to take antibiotics before every dental procedure (examples: cleanings, fillings, and gum surgeries). A prescription can be called into your local pharmacy. Antibiotic prophylaxis (pre-medicine) is used until your child is on only one anti-rejection medicine (i.e., only Prograf).
- Your child should see the dentist every six months.
- Inform your dentist of your child’s transplant and the special medicines that your child takes.

Skin Care

- Make sure hair is washed frequently because hair holds bacteria and dust.
- Medications prescribed will make skin more fragile, and thus more susceptible for injury. If any injury does occur, cleanse the area and use clean dry bandages to prevent infection. If it takes an unusually long time to heal, or it becomes red, swollen or infected, notify the transplant coordinator immediately.
- Because your child is taking drugs that suppress the immune system, your child has an increased risk of developing skin cancer. We suggest that your child take precautions, including using sunscreen (SPF 15 or greater), hats and long sleeves (if tolerated). Your child should avoid tanning salons and repeated long unprotected exposure to the sun.

Eye Examination

It is recommended that your child is seen by an ophthalmologist (eye doctor) on a yearly basis after transplant. This is to monitor for any chronic eye changes that can be noted as a result of the anti-rejection medicines.

Physical Activity

The most important job for the recipient during the first few days after surgery will be to cough and breathe deeply to keep the lungs clear. Physical therapy will be directed toward conditioning and achieving a higher level of activity. In order to improve endurance and strength, daily walks and riding the stationary bicycle are necessary.

There will be an important change in the heart rate after transplant. There are nerves that connect the heart to the brain. When a person begins moving, the brain instructs the heart to beat faster and stronger to pump more blood to the muscles, but when a person has a heart transplant, the nerves are cut and the new heart is no longer directly connected to the brain.

However, the body has a back-up system. Blood contains chemicals that can also stimulate the heart to beat stronger and faster. The only difference is that it takes a few minutes to activate these chemicals. This means before starting a vigorous activity, the recipient will need to have a short “warm up” session to make the heart ready for exercise.

Children tend to pace themselves well and do only what they are capable of doing. They sit down when they are tired and play when they feel rested. Therefore, restrictions are not routinely placed on their activity. In most cases, a recipient can gradually begin returning to normal activity for his or her age.

After transplant, aerobic exercises will need to become a routine part of life. An aerobic exercise is an exercise that will maintain a target heart rate non-stop for at least 20 minutes. After completing any exercise, a “cool down” will be needed by stretching and allowing the heart rate to gradually return to normal. People who have had heart transplants tell us how good they feel when they continue regular exercises and are able to return to school or work even after months and/or years of limited activities.



Some heart transplant recipients choose to continue in an unmonitored, but supervised, exercise program. Exercise is a life-long pursuit. Each session should include a warm up, about 30 minutes of exercise and a cool down. The recipient should exercise at a level that requires some degree of effort, but never overexertion.

Home Environment

When the recipient first arrives home, try to restrict phone calls and visitors. Short walks and brief visits with small groups of family and friends are advised. We encourage walking immediately and to increase daily activity in a sensible fashion.

Transplant recipients should avoid crowds where ventilation is poor and where there may be people with colds. If this is unavoidable, then a mask is to be worn. Masks will also need to be worn when in the hospital. Do not allow visitors who are sick. If the recipient is exposed to an unusual illness (something other than a cold), call the transplant coordinator to discuss the situation.

Follow-Up Visits

Before discharge from the hospital, the recipient will meet with the transplant coordinator to schedule his/her return visit to the clinic.

As an outpatient, the recipient will undergo routine blood tests, cardiac biopsy, ECG echocardiogram, annual chest x-rays and periodic catheterization. Appointments in the Pediatric Cardiology Transplant Clinic will be frequent. Do not give Tacrolimus or Cellcept before the biopsy or clinic visits because blood work will be done that includes Tacrolimus and CellCept levels. Bring medications to give to the recipient after the blood is drawn.

The primary doctor will be contacted and written information will be provided to the doctor's office regarding the recipient's follow-up care.

Primary Care Follow-Up

It is a good idea to have a pediatrician, internist, general practitioner or family doctor see your child for routine medical issues other than his/her heart transplant. Always make sure you inform us if you change your child's personal physician, since we will be keeping in touch with him/her every time you come to the Heart Transplant Clinic or are in the hospital.

Be sure to inform your child's personal physician of all the medicines that your child is taking, since some drugs cannot be taken with immunosuppressive medicines. Your transplant coordinator can provide you and your physician a list of all medicines that interact with the immunosuppressive medicines.

Immunizations

Your child should NEVER receive immunizations that contain a live virus. If a live virus immunization is given, there is a potential risk that your child will contract that infection. The following immunizations contain a live virus and should not be taken:

- Small pox vaccine
- Oral polio vaccine
- MMR (measles, mumps and rubella)
- Varicella (chickenpox)
- Influenza (only nose spray type is live)

The following are acceptable immunization for your child to receive, but you should contact your nurse coordinator or doctor first:

- Tetanus
- Typhoid
- Diphtheria
- Pertussis (dT or DPT) (whooping cough)
- Polio (killed virus)
- Haemophilus Influenza Type B (HIB)
- Influenza (injected form only)
- Pneumovax
- Hepatitis B and A series
- Human Papilloma Virus (HPV)

It is necessary that your pediatrician have a copy of the immunizations that your child can receive. If a live virus immunization is given to your child after transplant, your child may get the infection that the immunization is trying to prevent.

Siblings and household contacts **should not** receive oral polio (Sabin) vaccine. Members of the household **can** get the MMR immunization, but varicella vaccine may have to be withheld. Please discuss the administration of the varicella vaccine to a household member with the transplant team before it is administered.

You Should Know

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Flu Shots and Pneumonia Shots

Transplant patients are encouraged to receive a flu shot every year and pneumonia shot every five years. Since high doses of anti-rejection medicines may lessen the effects of these vaccines, transplant patients are recommended to wait approximately three to six months after transplant before getting these or other vaccines.

School

Your child should be able to return to school or work within three months after transplant. Check with the transplant coordinator and school before his/her return to school. You should notify your child's school to make arrangements for home schooling once your child has been discharged from the hospital. Many times there are forms that need to be completed by the transplant coordinator/doctor that you obtain from your child's school.

Pets

Pets can be an important part of family life. Research has shown that pets help relieve stress and have positive physical and psychosocial benefits as well as possibly improving our quality of life.

Although animals do carry a number of diseases that can be transmitted to humans, few are life threatening. Some guidelines should be followed:

- Wash your hands after handling your pet, especially if you are going to eat, drink or handle any food.
- Your pet should have regular health visits to the vet and receive the required immunizations.
- Groom your pet on a regular basis. The nails of both the dog and cat should be trimmed on a regular basis to avoid scratches to you. If you do get a scratch, clean the wound with soap and water and apply antibiotic cream. If the scratch should become infected, seek medical treatment.
- All transplant recipients should avoid your pet's body fluids (urine, stool or vomit). If possible, have someone else clean up the accident or litter box. If necessary, use some gloves and clean the area with some disinfectant. Wash your hands with some antibacterial soap or hand sanitizer after the cleaning has been done.

- It is not recommended that a transplant recipient clean the litter box if at all possible. The litter and liner should be replaced frequently. The litter box should be cleaned at least every month with disinfectant soap or hot boiling water.
- Seek urgent medical treatment if your child should be bitten by any animal.
- Avoid having the pet lick your child on the face.
- Your child should avoid any stray or sick animal. Transplant recipients should avoid having an exotic animal as a pet (such as reptiles).

Drugs, Alcohol or Tobacco Products

It is the recommendation of the transplant team that **ALL** patients should refrain from using all forms of alcohol, street drugs, tobacco products or other potential harming drugs (such as huffing inhalants). The use of these products can lead to poor health and fatal damage to your body.

Medic-Alert Identification

It is recommended that your child wear a Medic-Alert bracelet or necklace. Your transplant coordinator will provide you with a form. The Medic-Alert Identification is ordered through the Kidney Foundation for a small fee. If your child would like one that is “fancier,” you can order this for them at a higher cost. The following information is needed:

- Child’s Name
- University of Michigan
- Heart Transplant
- Name of Transplant Cardiologist
- Phone number (734) 764-5176

You Should Know

Be sure to inform your child’s personal physician of all the medicines that your child is taking, since some drugs cannot be taken with immunosuppressive medicines.

