After the Heart Transplant

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Life After the Heart Transplant

Right after your child is discharged from hospital, they will need to have frequent follow-up appointments at the heart transplant clinic. These can be emotionally and financially draining, but the transplant team will work with you to help your child's follow-up care go as smoothly as possible.

Your child's appointments will be less frequent after the first few months and especially after the first year. Eventually, the appointments will more easily fit into a normal family schedule.

As you read this section, please remember that every child is different. Also, different transplant centers have their own routines for follow-up after a heart transplant.

Note, too, that schedules and tests may change for many different reasons. For instance, some tests are only done in patients of a certain age, weight or height. Your heart transplant team members will explain why they are doing a certain test or procedure in your child at a specific time.

Clinic Visits and Routine Testing

Clinic visits and routine tests are intended to track your child's health and development after their heart transplant and identify any problems as early as possible.

This section outlines some tests heart transplant patients may undergo, but remember every patient and every transplant program is different. Your transplant team will explain the routine in your center and the plan for your child's specific situation and health concerns.

Clinic Visits

Immediately after their transplant, your child will usually visit the clinic once or twice a week. Over time, these visits will become less frequent once your child does not have any problems. Many centers eventually cut down appointments to once every six months for patients who are doing well.

Laboratory (lab) Tests

Most transplant patients have regular blood, urine or other lab tests. Common things tested include:

- White blood cell count, to show any possible infection or side effects from transplant medications.
- Level of waste products, such as creatinine and blood urea nitrogen in the blood, to show how well the kidneys and liver are working.
- "Levels," which is short for how much immunosuppressant medication stays in a patient's bloodstream and for how long. High levels could be toxic or suppress the immune system too much, and low levels may cause a patient to reject the new heart.
- Amount of glucose (sugar), or lipids (cholesterol and other fats) in the blood. Some transplant medications can make them too high.
- Signs of any recent viral infections.
- Level of HLA antibodies in the blood, to check if there is a risk that the body might start to reject the donor heart.

Heart Tests

Echocardiogram (Echo)

Your child will have had echocardiograms before the transplant (see p. 13). This test is an ultrasound of the heart. It uses sound waves to:

- Check the size, shape and movement of the heart and its valves.
- See how well the heart pumps blood.
- Identify if there is any fluid in the sac around the heart (known as pericardial effusion).

Sometimes your child will have a special type of echocardiogram called a stress echo. This involves making the heart "stressed" or excited by having a patient do exercise or take special medication. An echo is then carried out to see how the heart functions when it is working vigorously. The results are compared to the heart's function when it is resting.

Right Heart Cath (RHC)

This is short for right heart catheterization. The test checks the pressure in the right side of the heart and the lungs and is often done at the same time as a biopsy (see p. 76).

The test involves guiding a catheter (a thin, hollow tube) through the chambers of the heart and into the blood vessels of the lungs. Different centers have different schedules for this procedure.

Left Heart Cath (LHC)

A left heart catheterization is usually done to check for any narrowing or blocks in the coronary arteries. The arteries are blood vessels that feed oxygen-rich blood to the heart (see transplant coronary artery vasculopathy, p. 77). The test also measures pressures in the left side of the heart.

During the test, a catheter will be inserted into the artery in the groin or arm and passed up to the aorta and the left side of the heart. Dye will be injected to outline the coronary arteries and look for any abnormalities. Different centers have different schedules for this procedure.

Electrocardiogram (EKG or ECG)

This test involves placing 12 electrodes on the chest to assess the rhythm of the heart.

Other Tests and Procedures

Your transplant team will explain any other routine tests are done in your center. They may include:

- Exercise stress testing.
- Glomerular filtration rate (GFR), to see how well the kidneys are working.
- Bone mineral density, to assess bone strength.
- Twenty-four-hour ambulatory blood pressure monitoring, to check blood pressure at regular intervals during your child’s everyday routine.
- Developmental assessments.

Transplant Medications

The key to maintaining a successful heart transplant is following medication instructions correctly for the rest of your child's life. Skipping medications will lead to rejection of the heart or to decreased life of the heart. It is important medications are given as prescribed by the transplant team.

At first you may feel overwhelmed with the new medications and the information about them. But, over time, it will become routine for you and your child to follow the medication instructions.

Your transplant team's goal is to make sure you are familiar with all of the medications your child will be taking before you leave the hospital. We want you to become responsible for giving the medications, and your child needs to become more involved in taking the medicines as they get older.

Types of Transplant Medications

Most transplant patients take three types of medications:

- Immunosuppressants.
- Anti-infection medications.
- Other medications.

Immunosuppressants

Immunosuppressants (also known as anti-rejection medications) help to prevent the body from attacking the new transplanted heart. Immunosuppressants do this by suppressing, or weakening, the immune system, which usually fights infection and tries to destroy anything it doesn't think should be in the body.

Your child will take immunosuppressants for the rest of their life, but, over time, their doctor may prescribe a lower dose.

Anti-Infection Medications

Your child has a higher risk of developing certain infections because they are taking immunosuppressants. Anti-infection medications work to prevent or fight infections so your child can stay as healthy as possible while they get used to their new heart.

Patients normally take anti-infectants only during the first year after transplant. Sometimes they may also take them after being treated for a rejection episode, as this is when your child is usually given more immunosuppressants.

Other Medications

Other medications are usually used to control side effects caused by the transplant medications or the surgery itself. Side effects include high blood pressure, stomach pains and blood clots.

If your child does well, without side effects, the team will likely stop these medications.

Understanding Your Child's Medications

Because you are responsible for giving your child their medicine, it is very important you talk with your pharmacist or your child's doctor or nurse to understand:

- The name of each medicine and why your child needs it.
- When to take each medicine.
- How to take each medicine.
- How long your child will be on each medicine.
- The possible side-effects of each medicine.
- What to do if a dose is missed.
- How and when to order medications to prevent missed doses.

Guidelines for Taking Medications

Below is a list of basic guidelines that apply to many medications.

Each medicine your child needs has its own rules. Please refer to the specific medication page in this manual, and ask the pharmacist, doctor or nurse for any other information.

Giving Medications and Reporting Side Effects

- Always give medication at the same time every day and in the same way (with or without food), including weekends.
- Never skip a dose! Skipping doses increases the chance the heart may stop working properly.
- Do not stop or change any dose of your child's medications without speaking to your transplant team.
- Never give your child over-the-counter, herbal (natural) or homeopathic medications or any medications prescribed by another doctor without talking to your transplant team first. Many medications interact with transplant medications, leading to unpleasant side effects or preventing the transplant medications from working properly.
- Call your transplant team right away if your child has side effects from any medications.

Storing Medications

- Store transplant medications out of reach of small children or animals.
- Store medications in a cool and dry place, but make sure to check the label first to see if you should keep them at room temperature or put them in the refrigerator.
- Never keep transplant medications above a stove or oven or in the bathroom. The heat or humidity from these places can damage them.

Refilling Prescriptions

- Always call your pharmacy for refills a few working days before the medications run out.
- When your child misses doses of their medicine, there is a greater chance that the heart will stop working properly.

Travel

- Always keep the transplant medications with you when traveling. You risk not having your child's medications if you check them in and the luggage gets lost. Medication can also be damaged from being stored at freezing temperatures in the storage area.

Eating and Drinking

- Never let your child eat or drink grapefruit or grapefruit juice. This includes any fruit related to grapefruit, such as pomelo, and any mixed fruit juices containing grapefruit juice. Grapefruit juice can interact with some transplant medications and raise the levels of immunosuppressants in the blood.

Hygiene

- Always wash your hands before and after giving your child medications.

Why It Is Important to Stick to One Brand of Medicine

Medications always have two names: the chemical name and the brand name from the manufacturer. The same medications can be produced by different manufacturers. Each brand may have a different strength.

For example, one type of immunosuppressant is tacrolimus. This is the chemical name, but Prograf® is the brand name given by Astellas, the company that makes it.

Other companies also make tacrolimus as well and may offer it in different strengths. In addition, your child's body may handle medications from other manufacturers differently.

These differences in brands can affect the amount of tacrolimus remaining in your child's blood stream. If the amount is too low, the heart could be rejected; if it is too high, your child could have more side effects from the medications.

As a result, it is important to know the brand name and strength of your child's medicine and to keep using the same brand.

Make sure you tell your transplant center if the brand name or strength of the medicine changes, as your child's blood levels may need to be re-checked.

The following pages in this section are meant as a guide and contain the most important and common information you may need about transplant medications.

Every child is different. Your child may need medications not listed here.

Be assured your child's transplant team will only choose medications they feel will be the best for your child.

If you have any questions, ALWAYS call your transplant team to discuss them.

Immunosuppressant Medications

Induction Immunosuppression

These are strong medications used to suppress, or weaken, the immune system at the time of the operation and for the first few days afterwards. They help to prevent rejection for days to weeks until your child can recover from the surgery and start taking enough of the medications by mouth they will need for the rest of their life.

Not every transplant center uses induction immunosuppression medications.

Generic name	**Alemtuzumab**
Brand name	**Campath®**
What it does	Prevents the body from rejecting the transplanted heart.
What it looks like	Prepared in a syringe (needle) or intravenous (IV) bag.
How it is given	Injected into your child's vein.
Most common side effects	• Fever, chills, aches (during the infusion). • Blood pressure and heart rate (during the infusion). • Lower platelet counts. • Lower white blood cell counts.
Other important information	Most children will take some medications, such as acetaminophen (Tylenol®) or diphenhydramine (Benadryl®), before the dose to prevent or lessen reactions during the infusion.

Generic name	**Anti-Thymocyte Globulin (rabbit)**
Brand name	**Thymoglobulin®**
What it does	• Prevents your child's body from rejecting the transplanted heart at the time of transplant. • Treats serious rejection at any time after transplant.
What it looks like	Prepared in a syringe (needle) or an intravenous (IV) bag.
How it is given	Injected into your child's vein over several hours for 1 to 14 days.
Most common side effects	• Fever, chills or aches (during the infusion). • Changes in blood pressure and heart rate (during the infusion). • Difficulty breathing (during the infusion). • Rash. • Lower platelet counts [platelets help stop bleeding]. • Lower white blood cell counts [white blood cells help fight infection].
Other important information	Most children will take some medications, such as acetaminophen (Tylenol®) or diphenhydramine (Benadryl®), before the dose to prevent or lessen reactions during the infusion.

Generic name	**Basiliximab**
Brand name	**Simulect®**
What it does	Prevents the body from rejecting the transplanted heart.
What it looks like	Prepared in a syringe (needle).
How it is given	Injected into your child's vein on the day of transplant and for four days after the transplant.
Most common side effects	• Fever or chills (while the dose is being given). • Changes in blood pressure and heart rate (while the dose is being given). • Allergic reaction (rare).

Generic name	**Methylprednisolone**
Brand name	**Solumedrol®**
What it does	A corticosteroid that: • Prevents your child's body from rejecting the transplanted heart at the time of transplant. • Treats rejection at any time after the transplant.
What it looks like	Supplied in vials (small bottles) and prepared in a syringe (needle) or intravenous (IV) bag.
How it is given	• Injected into your child's vein. • Once your child is taking food by mouth, they may continue with it in a tablet or liquid form.
Most common side effects	• Increased blood pressure. • Higher blood sugar levels. • More appetite (hunger). • Weight gain. • Edema (puffiness). • Higher cholesterol. • Mood swings, irritability. • Difficulty sleeping. • More sweating (more often at night). • Mild headache. • Slow wound healing.
Other important information	High doses of methylprednisolone are usually given over a few days at the time of transplant or if your child has a rejection episode.

Maintenance Immunosuppression

These are the medications that your child will take every day for the rest of their life to prevent rejection of the donor heart (see p. 74).

There are different types of maintenance immunosuppressants. Your transplant doctor will choose the ones that are best for your child.

Generic name	**Azathioprine**
Brand name	**Imuran®**
What it does	Prevents the body from rejecting the transplanted heart.
How it is given	• Give once a day, at the same time, every day. • Give with food or without food, but give it the same way every day. • Giving with food can lessen stomach upset (such as nausea).
Most common side effects	• Nausea (upset stomach), vomiting (throwing up). • Reduced appetite. • Low platelet counts [platelets help stop bleeding]. • Low white blood cell counts [white blood cells help fight infection]. • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]. • Mild headache. • Dizziness. • Hair loss. • Rash.

Generic name	**Cyclosporine**
Brand name	**Gengraf®, Neoral®, Sandimmune®**
What it does	Prevents the body from rejecting the transplanted heart.
How it is given	• Give at the same times every day, usually 12* hours apart (*8 hours apart for some children). • Give either with food or without food. Give it the same way every day, since changes in food intake can affect how much cyclosporine passes from your child's stomach into their bloodstream. • Neoral® and Sandimmune® are different drugs. **Never** swap one for the other. • Make sure that you always have the same brand of cyclosporine. Call your transplant team if you notice that the capsules or liquid cyclosporine look different from what your child normally takes.
Most common side effects	• Decreased magnesium in the blood. • Increased potassium in the blood. • Increased blood pressure. • Increased blood sugar (some children develop diabetes). • Damage to the kidneys (usually if blood levels of cyclosporine are too high). • Tremors (shakiness of the hands or feet). • Upset stomach, vomiting (throwing up) or diarrhea (watery stools). • Increased fine body hair growth. • Tender or enlarged gums.
Other important information	• **Never** give your child grapefruit juice or any juices containing grapefruit. These products raise the cyclosporine level in your child's bloodstream. This can lead to more side effects. Read the labels of mixed fruit juices (front and back!) carefully. • **Never** let your child eat grapefruit (even when mixed in a fruit salad) or any fruit grown from grapefruit, such as pomelos or tangelos.

Generic name	**Mycophenolate**
Brand name	**Cellcept® (mycophenolate mofetil), Myfortic® (mycophenolate sodium)** **Several generic products are also available.**
What it does	Prevents the body from rejecting the transplanted heart.

What it looks like	Mycophenolate mofetil (Cellcept®) and mycophenolate sodium (Myfortic®) are different drugs with different dosing instructions. **Never** swap one for the other.
	• Mycophenolate mofetil comes in:
	  • 250mg capsules (usually orange and blue).
	  • 500mg tablets (usually purple).
	• Suspension (liquid).
	• Mycophenolate sodium (Myfortic®) comes in:
	  • 180mg tablets (light green).
	  • 360mg tablets (light orange).
	• Other brands of mycophenolate can look different.
	• Always use the same brand. Call your transplant team if you notice the mycophenolate looks different from what you normally give your child.

How it is given	• Give mycophenolate at the same times every day, 12 hours apart. • Give mycophenolate with food or without food. Give it the same way every day, since changes in food intake can affect how much mycophenolate passes from your child's stomach into their bloodstream. • Giving mycophenolate with food may lessen stomach upset (such as cramps or diarrhea).
Most common side effects	• Stomach cramps, diarrhea (watery stools). • Nausea (upset stomach), heartburn or vomiting (throwing up). • Low platelet counts [platelets help stop bleeding]. • Low white blood cell counts [white blood cells help fight infection]. • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]. • Mild headache. • Risk of malformations in an unborn fetus (teenage girls should take precautions to avoid getting pregnant while taking).

Generic name	**Prednisone / Prednisolone**
Brand name	**Deltasone®, Orapred®, Pediapred®**
What it does	Prevents the body from rejecting the transplanted heart
How is it given	By mouth
Most common side effects	• Increased blood pressure. • Higher blood sugar levels. • Upset stomach, vomiting (throwing up) or diarrhea (watery stools). • Increased appetite (hunger). • Weight gain. • Edema (puffiness). • Mood swings, irritability. • Difficulty sleeping. • More sweating (more often at night). • Mild headache. • Acne (pimples). • Slow wound healing. • Stretch marks. The following are effects of **long-term use**: • Weaker bones. • Slower growth (height). • Cataracts (a gel-like glaze over the eye(s)).

Generic name	**Sirolimus**
Brand name	**Rapamune®**
What it does	• Prevents the body from rejecting the transplanted heart. • May slow down the progress of a heart condition (called cardiac allograft vasculopathy) that can occur over time after the transplant.
How it is given	• Give once a day, at the same time, every day. Some children take it twice a day if they are on a high dose. • Give with food or without food, but give it the same way every day. Food does not have a big effect on how much sirolimus passes from your child's stomach into their bloodstream.
Most common side effects	• Upset stomach, vomiting (throwing up) or diarrhea (watery stools). • Mild headache. • Mouth sores or ulcers. • High cholesterol and/or triglyceride levels. • Low white blood cell counts [white blood cells help fight infection]. • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]. • Low platelet counts [platelets help stop bleeding]. • High blood pressure. • Delayed wound healing. • Acne. • Increase in liver function (transaminases) tests. • Leg cramps. • Lung inflammation (swelling).
Other important information	• Avoid grapefruit juice or any juices that contain grapefruit. These products raise the sirolimus level in your child's blood, which can lead to more side effects. Read the front and back labels of mixed fruit juices carefully. • Avoid all grapefruit products (by itself or mixed in a salad) and any fruit grown from grapefruit such as pomelos or tangelos. • Sirolimus may cause reversible sterility in males. • Precautions should be taken to prevent pregnancy while taking sirolimus.

Generic name	**Tacrolimus**
Brand name	**Prograf®** **Several generic products are also available**
What it does	Prevents the body from rejecting the transplanted heart.
How it is given	• Give at the same times every day, usually 12* hours apart (*eight hours apart for some children). • Give either with food or without food. Give it the same way every day, since changes in food intake can affect how much tacrolimus passes from your child's stomach into their bloodstream.
Most common side effects	• Decreased magnesium in the blood. • Increased potassium in the blood. • Increased blood sugar (some children develop diabetes). • Increased blood pressure. • Damage to the kidneys (if blood levels of tacrolimus are too high, but long term damage is also possible). • Shakiness of the hands/feet (tremor). • Upset stomach, vomiting (throwing up) or diarrhea (watery stools). • Mild headache. • Seizures (if blood levels of tacrolimus are too high). • Leg cramps. • Hair loss.
Other important information	• Avoid grapefruit juice or any juices containing grapefruit. These products raise the tacrolimus level in your child's blood, which can lead to more side effects. Read the front and back labels of mixed fruit juices carefully. • Avoid all grapefruit products (by itself or mixed in a salad) and any fruit grown from grapefruit such as pomelos or tangelos. • Always use the same brand. Call your transplant team if you notice the tacrolimus looks different from what you normally give your child.

Other Immunosuppressants

Generic name	**Cyclophosphamide**
Brand name	**Cytoxan®**
What it does	Treats certain cases of post-transplant lymphoproliferative disorder (PTLD) (see p. 84).
How it is given	Injected into your child's veins over several hours. Depending on the situation, your child may receive only one dose of cyclophosphamide or one dose every few weeks.
Most common side effects	• Changes in blood pressure and heart rate (during the infusion). • Nausea, vomiting, cramping, or diarrhea (watery stools) • Bladder problems. • Lower white blood cell counts [white blood cells help fight infection]. • Lower platelet counts [platelets help stop bleeding]. • Rash. • Hair loss.
Other important information	Your child will be given extra IV fluids before, during, and after cyclophosphamide doses to protect their kidney and bladder.

Generic name	**Rituximab**
Brand name	**Rituxan®**
What it does	• Treats certain types of post-transplant lymphoproliferative disorder (PTLD) (see p. 84). • Treats antibody-mediated rejection (see p. 75).
How it is given	Injected into your child's veins over several hours. Depending on the situation, your child may receive only one dose of rituximab or one dose every few weeks.
Most common side effects	• Fever, chills, muscle aches (during the infusion). • Changes in blood pressure and heart rate (during the infusion). • Difficulty breathing (during the infusion). • Headache, dizziness. • Change in blood sugar. • Rash. • Lower platelet counts [platelets help stop bleeding]. • Lower white blood cell counts [white blood cells help fight infection].
Other important information	Most children will also take some medications, such as acetaminophen (Tylenol®) or diphenhydramine (Benadryl®), before the rituximab dose to prevent or ease reactions during the infusion.

Medications to Prevent and Treat Infections

Generic name	**Acyclovir**
Brand name	**Zovirax®**
What it does	Prevents and treats infections caused by certain types of viruses.
How it is given	Given by mouth. To prevent kidney problems, your child should drink plenty of water or other fluid (unless the doctor has told your child to drink less).
Most common side effects	• Upset stomach. • Vomiting (throwing up) or diarrhea (loose stools). • Mild headache. • Dizziness. • Reduced kidney function (shown by higher levels of a waste product called creatinine in the blood); may also cause kidney damage.

Generic name	**Atovaquone**
Brand name	**Mepron®**
What it does	Prevents a certain type of lung infection called pneumocystis jiroveci pneumonia (PCP).
How it is given	Given by mouth. Can be mixed in small amounts of orange juice or milk if your child cannot tolerate the taste or texture by itself.
Most common side effects	• Fever. • Headache, dizziness. • Inability to sleep. • Nausea, vomiting, stomach cramping, diarrhea (watery stools).

Generic name	**Clotrimazole**
Brand name	**Mycelex®**
What it does	Prevents and treats mouth or throat infections caused by certain types of yeast or fungus.
How it is given	Given by mouth.
Most common side effects	Nausea or vomiting.

Generic name	**Cytomegalovirus immune globulin (CMV-IVIG)**
Brand name	**Cytogam®**
What it does	Prevents and treats CMV (cytomegalovirus) infection with other medications.
How it is given	Injected into your child's vein; infusion lasts several hours.
Most common side effects	• Change in heartbeat, blood pressure or breathing rate (during the infusion). • Aches. • Nausea or vomiting.

Generic name	**Dapsone**
Brand name	**Avlosulfon®; may also be called by its short form, DDS**
What it does	Prevents a lung infection called pneumocystis jiroveci pneumonia (PJP, previously PCP).
How it is given	Given by mouth.
Most common side effects	• Nausea (upset stomach) or vomiting (throwing up). • Loss of appetite. • Difficulty sleeping. • Headache.

Generic name	**Fluconazole**
Brand name	**Diflucan®**
What it does	Prevents and treats infections caused by some yeasts or fungus.
How it is given	Given by mouth
Most common side effects	• Upset stomach. • Vomiting (throwing up). • Diarrhea (watery stools). • Mild headache. • Dizziness. • Liver problems.

Generic name	**Gancyclovir**
Brand name	**Cytovene®**
What it does	Has been used to prevent and treat two viral infections in transplant patients: • Cytomegalovirus (CMV). • Epstein Barr virus (EBV).
How it is given	Given by mouth or injected into your child's vein.
Most common side effects	• Mild headache. • Lower platelets [platelets help stop bleeding]. • Lower white blood cell counts [white blood cells help fight infection]. • Lower red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]. • Reduced kidney function (shown by higher levels of a waste product called creatinine in the blood); may also cause kidney damage. • Upset stomach, vomiting (throwing up), or diarrhea (watery stools).

Generic name	**Nystatin**
Brand name	**Mycostatin®**
What it does	Prevents thrush, a type infection caused by a fungus. Thrush can occur in the mouth and throat. If not treated, it can spread to the esophagus (food tube) and further into the body. Thrush often looks like a white, sometimes furry coating on your child’s tongue or white spots on the inside of the mouth. Your child’s voice may also be hoarse.
How it is given	• By mouth - your child swishes it around their mouth for a minute before swallowing it. • Your child should not eat anything for 20 minutes after taking the dose.
Most common side effects	• Upset stomach. • Vomiting (throwing up). • Diarrhea (watery stools). • Cavities (if teeth are not brushed regularly – see below).
Other important information	• Nystatin contains sugar. To prevent cavities, your child should brush their teeth for 20 to 30 minutes after taking it. • If your child does not like the taste of nystatin, your pharmacist can flavor it.

Generic name	**Pentamidine**
Brand name	**Nebupent®, Pentam®**
What it does	Prevents and treats a certain type of lung infection called pneumocystis jiroveci pneumonia (PJP, previously PCP).
How it is given	Inhaled through a mask or given intravenously.
Most common side effects	When inhaled: • Cough, tightness in the chest. • Bitter taste in the mouth. Both forms: • Low white blood cell counts [white blood cells help fight infection]. • Low platelets [platelets help stop bleeding]. • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body].
Other important information	If your child is receiving inhaled pentamidine, they may also inhale a medication called 'albuterol' or 'salbutamol' before the pentamidine to prevent coughing and chest tightness.

Generic name	**Sulfamethoxazole-Trimethoprim (SMX-TMP)**
Brand name	**Bactrim®, Septra®, Cotrimoxazole®**
What it does	Prevents a certain type of lung infection called pneumocystis jiroveci pneumonia (PJP, previously PCP). It contains two antibiotics: • Sulfamethoxazole. • Trimethoprim. Your child cannot take this medication if they have an allergy to: • Sulfonamides or "sulfa" drugs. • Trimethoprim.
How it is given	Can be given daily, every other day, or three times a week.
Most common side effects	• Upset stomach, vomiting (throwing up) or diarrhea (watery stools). • Mild headache. • Rash. • Increased sensitivity to the sun. • Low white blood cell counts [white blood cells help fight infection]. • Low platelets [platelets help stop bleeding]. • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body].
Other important information	Because SMX-TMP makes your child's skin more sensitive to the sun, your child needs to wear sunscreen regularly when outside.

Generic name	**Valgancyclovir**
Brand name	**Valcyte®**
What it does	Prevents and treats two viral infections in transplant patients: • Cytomegalovirus (CMV). • Epstein Barr virus (EBV).
How it is given	• Give once or twice a day at the same time each day. • Give with plenty of fluids. • Give with food to help more of the medication pass from your child's stomach into their bloodstream.
Most common side effects	• Mild headache. • Lower platelets [platelets help stop bleeding]. • Lower white blood cell counts [white blood cells help fight infection]. • Lower red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]. • Reduced kidney function (shown by higher levels of a waste product called creatinine in the blood); may also cause kidney damage. • Upset stomach, vomiting (throwing up) or diarrhea (watery stools).

Vitamins and Supplements

Generic name	**Multi-Vitamin**
Brand name	**Once-A-Day®, Centrum®, AquaDEKs®, Poly-Vi-Sol®, Tri-Vi-Sol® (many other brands)**
What it does	Helps to prevent low vitamin levels that can be caused by some medications or a diet low in vitamins and minerals.
Most common side effects	• Stomach pain. • Upset stomach. • Nausea and vomiting.

Generic name	**Calcium**
Brand name	**Oscal®, Tums® (calcium carbonate), Citracal® (calcium citrate), NeoCalGlucon® (calcium glubionate)**
What it does	• Helps to build strong bones and teeth.
Most common side effects	• Stomach pain. • Constipation. • Gas. • Nausea and vomiting.

Generic name	**Iron**
Brand name	**Femiron®, Ferretts®, Palafer® (ferrous fumarate), Ferate®, Fergon® (ferrous gluconate), Feosol®, Fer-In-Sol® (ferrous sulfate)**
What it does	• Helps to correct blood anemia (low red blood cell counts).
Most common side effects	• Constipation. • Dark-colored stools. • Stomach pain and cramping. • Nausea and vomiting.
Other important information	Iron supplements may turn your child's stools very dark. Do not be alarmed if this happens.

Generic name	**Magnesium**
Brand name	**Mag-Ox® (magnesium oxide), Magonate® (magnesium gluconate), Milk of Magnesia® (magnesium hydroxide), magnesium sulfate**
What it does	Increases low magnesium levels that can be caused by some medications or a diet low in vitamins and minerals.
Most common side effects	• Stomach upset. • Cramping. • Diarrhea.

Generic name	**Potassium**
Brand name	**K-Effervescent® (potassium bicarbonate), Klor-Con® (potassium chloride), Phos-K® (potassium gluconate, potassium phosphate)**
What it does	Increases low potassium levels that can be caused by some medications or a diet low in vitamins and minerals.
Most common side effects	• Stomach pain. • Diarrhea. • Gas. • Nausea and vomiting.

Other Common Medications

Infection-control

Generic name	**Intravenous Immunoglobulin (IVIG)**
Brand name	**Many brand names**
What it does	• Gives your child immunoglobulins, which are important in fighting infection. • Treats a special type of rejection called antibody-mediated rejection (see p. 75).
How it is given	Injected into your child's vein; infusion lasts several hours.
Most common side effects	• Fever, chills, aches (during the infusion). • Blood pressure and heart rate (during the infusion). • Difficulty breathing (during the infusion). • Rash.

Diuretics

Class	**Loop Diuretics ("water pills")**
Brand (and generic) names	**Lasix® (furosemide), Bumex®, Burinex® (bumetadine), Demadex® (torsemide)**
What they do	• Help to decrease swelling by removing extra fluid from the body. • Can also lower blood pressure.
Most common side effects	• Increased amount of urine (pee). • Dizziness. • Low blood pressure. • Low electrolyte and mineral levels in the blood. • Decreased hearing (rare).

Class	**Potassium-Sparing Diuretics**
Brand (and generic) names	**Aldactone® (spironolactone), Dyrenium® (triamterene)**
What they do	• Decrease swelling by removing extra fluid from the body without decreasing potassium levels. • Can also lower blood pressure.
Most common side effects	• Increased amount of urine (pee). • Increased potassium levels in the blood. • Diarrhea. • Nausea and vomiting. • Low blood pressure.

Class	**Thiazide Diuretics**
Brand (and generic) names	**HCTZ (hydrochlorothiazide), Diuril® (chlorothiazide)**
What they do	• Decreases swelling by removing extra fluid from the body • Can also lower blood pressure.
Most common side effects	• Increased amount of urine (pee). • Dizziness. • Low blood pressure. • Low electrolyte and mineral levels in the blood.

Class	**Thiazide-Like Diuretics**
Brand (and generic) name	**Zaroxolyn® (metolazone)**
What it does	• Decreases swelling by removing extra fluid from the body. • Can also lower blood pressure.
Most common side effects	• Increased amount of urine (pee). • Dizziness. • Low blood pressure. • Low vitamin and electrolyte levels in the blood.

Anti-Hypertensives (Blood Pressure Medications)

Class	**Angiotensin Converting Enzyme (ACE)-inhibitors**
Brand (and generic) names	**Lotensin® (benazepril), Vasotec® (enalapril), Prinivil®, Zestril® (lisinopril), Capoten® (captopril), Monopril® (fosinopril), Accupril® (quinapril), Altace® (ramipril)**
What they do	Lower blood pressure and treat symptoms of heart failure.
Most common side effects	• Dizziness. • Low blood pressure. • Cough. • Increased potassium levels in the blood. • Face, tongue or neck swelling. • Risk of malformations in an unborn fetus (teenage girls should use precautions to prevent pregnancy).
Other important information	Call your doctor if your child develops: • any face, tongue or neck swelling. • a cough that is bothersome and does not go away.

Class	**Angiotensin Receptor Blockers (ARBs)**
Brand (and generic) names	**Cozaar® (losartan), Atacand® (candesartan), Diovan® (valsartan), Benicar®, Olmetec® (olmesartan)**
What they do	Lower blood pressure and treat symptoms of heart failure.
Most common side effects	• Dizziness. • Low blood pressure. • Increased potassium levels in the blood.
Other important information	Avoid diets high in potassium (salts, bananas, tomatoes, potatoes, nuts and fruit juices).

Class	**Dihydropyridine Calcium Channel Blockers (CCBs)**
Brand (and generic) names	**Norvasc® (amlodipine), Procardia® (nifedipine), Plendil® (felodipine), Nimotop® (nimodipine), DynaCirc® (isradipine)**
What they do	Lower blood pressure.
Most common side effects	• Lower leg swelling. • Dizziness. • Tiredness. • Low blood pressure. • Anxiety.

Class	**Non-Dihydropyridine Calcium Channel Blockers (CCBs)**
Brand (and generic) names	**Cardizem® (diltiazem), Verelan® (verapamil)**
What they do	Lower blood pressure and may help regulate abnormal heart beats.
Most common side effects	• Dizziness. • Headache. • Low blood pressure. • Lower leg swelling. • Abnormal heart beats (extra beats or skipped beats).

Class	**Vasodilators**
Brand (and generic) name	**Apresoline® (hydralazine)**
What they do	Lower blood pressure and treat symptoms of heart failure.
Most common side effects	• Dizziness. • Low blood pressure. • Increased heart rate. • Leg swelling. • Flushing. • Mood changes.

Brand (and generic) name	**Catapres® (clonidine)**
What it does	Lowers blood pressure and can help attention disorders.
Most common side effects	• Dizziness. • Low blood pressure. • Abnormal heart beats. • Mood changes. • Skin irritation where the patch is applied. • Nausea and vomiting.

Class	**Beta-Adrenergic Blocking Agent (beta-blockers)**
Brand (and generic) names	**Tenormin® (atenolol), Toprol®, Lopressor®, Betaloc® (metoprolol), Trandate® (labetalol), Inderal® (propranolol), Coreg® (carvedilol), Betapace® (solatol), Corgard® (nadolol)**
What they do	Lower blood pressure and help control abnormal heart beats.
Most common side effects	• Dizziness. • Low blood pressure. • Slow heart beat. • Lower leg swelling. • Mood changes. • Fatigue. • Blurred vision.

Statins (Cholesterol and Lipid-Lowering Medications)

Class	**HMG-CoA Reductase Inhibitors "Statins"**
Brand (and generic) names	**Lipitor® (atorvastatin), Zocor® (simvastatin), Lescol® (fluvastatin), Mevacor® (lovastatin), Pravachol® (pravastatin)**
What they do	• Decrease the amount of bad cholesterol and lipids in the blood. • Can also help prevent and slow down the progress of cardiac allograft vasculopathy (see p. 77).
Most common side effects	• Abdominal (belly) discomfort. • Increases in liver function tests. • Muscle pain and fatigue.
Other important information	Call your doctor if your child develops any severe muscle pain or if your child's urine becomes dark brown.

Anti-Arrhythmics (Medications to Regulate Heart Beat)

Class	**Anti-Arrhythmics**
Brand (and generic) names	**Lanoxin® (digoxin), Pacerone®, Cordarone® (amiodarone), Rythmol® (mexiletine, propafenone), Tambocor® (flecainide), Tikosyn® (dofetilide)**
What they do	Treat abnormal heart beats.
Most common side effects	• Dizziness. • Abnormal heart beats. • Low blood pressure. • Nausea and vomiting. • Blue/gray skin appearance (amiodarone). • Abnormal liver function (amiodarone). • Lung scarring (amiodarone). • Abnormal thyroid function (amiodarone). • Blurred or yellow/green vision (digoxin).

Anti-Ulcer Medications

Class	**Proton Pump Inhibitors (PPIs)**
Brand (and generic) names	**Nexium® (esomeprazole), Losec®, Prilosec® (omeprazole), Prevacid® (lansoprazole), Pantoloc®, Protonix® (pantoprazole)**
What they do	Prevent and treat heartburn, indigestion and stomach ulcers.
Most common side effects	• Dizziness. • Diarrhea. • Nausea and vomiting.

Class	**Histamine Antagonists**
Brand (and generic) names	**Zantac® (ranitidine), Pepcid® (famotidine), Axid® (nizatidine)**
What they do	Prevent and treat heartburn, indigestion and stomach ulcers.
Most common side effects	• Dizziness. • Nausea and vomiting. • Low platelet counts. • Abnormal heart beats. • Mood changes.

Brand (and generic) names	**Carafate® (sucralfate), Mylicon®, Gas-X® (simethicone)**
What it does	• Coats the throat and stomach to treat and prevent ulcers. • Simethicone helps to control gas.
Most common side effects	• Dry mouth. • Stomach pain. • Constipation.

Anti-Platelet Medications

Generic name	**Acetylsalicylic Acid (ASA)**
Brand name	**Aspirin®**
What it does	Thins the blood and prevents blood clots.
Most common side effects	• Easy bleeding. • Easy bruising. • Stomach upset.

Generic name	**Dipyridamole**
Brand name	**Persantine®**
What it does	Prevents blood from clotting.
Most common side effects	• Easy bleeding. • Easy bruising.

Medications to Prevent and Treat Blood Clots

Generic name	**Enoxaparin**
Brand name	**Lovenox®**
What it does	Prevents and treats blood clots.
How it is given	Given as a subcutaneous injection (a 'needle' just below the skin) once or twice a day.
Most common side effects	• Easy bleeding. • Easy bruising.

Generic name	**Warfarin**
Brand name	**Coumadin®**
What it does	Prevents and treats blood clots.
Most common side effects	• Easy bleeding. • Easy bruising.

Immunizations

When Will My Child Get Their Immunizations After Transplant?

It is very important that your child get their immunizations (vaccines or “shots”) after a heart transplant to prevent infection.

Children with heart transplants can usually start or continue their routine vaccines four to six months after their transplant. It is best to wait until then, as the immunizations may not work properly if they are given sooner. This is because a child has a much weaker immune system right after the transplant due to their immunosuppressant medications.

Every child’s situation is unique, however, and some children may need to wait longer before they get their shots. The transplant team will work with your pediatrician or family doctor to make sure your child is immunized properly and will tell you the best time to start or continue immunizations for your child.

Different Vaccine Doses or Schedules

Your child may need different doses or schedules of some vaccines depending on their health post-transplant. Some school and community vaccination programs may not be able to provide a different vaccine dose. In this case, your family doctor or pediatrician will need to give these to you instead. Talk to your transplant team about what is needed for your child.

“Live Vaccines”

Your child should not have “live vaccines” after transplant because of the risk of getting the illness that the vaccine is supposed to prevent.

Common live vaccines are:
- Chickenpox (varicella).
- Rotavirus.
- Measles/mumps/rubella (MMR).
- Influenza drops into the nose (influenza nasal mist).

Other family members and your child’s classmates can safely get the chickenpox, rotavirus and MMR vaccines.

Some schools or activity programs may need a letter explaining why your child has not had live virus vaccines. Your family doctor or pediatrician or the transplant team can provide this letter.

You can read more about chickenpox and other common infections on pages p. 80 to p. 85.

Flu Shots

Most transplant teams recommend influenza vaccine, also called the “flu shot,” for transplant patients and their families every year. After heart transplant, children and household members should get the injectable (needle) flu vaccine and not the nasal spray.

Vaccines and Travel

Traveling away from home may mean your child needs extra immunizations. It is best to get specific advice about this from the transplant team or a travel clinic.

Rejection

Rejection is the body's normal reaction to something it thinks does not belong there. Your child's immune system keeps them healthy and works by protecting the body from attack by foreign things such as germs (bacteria or viruses) and cancer cells.

Your child's immune system will try to reject their new heart because it recognizes it is different from the rest of the child's body. Your child will be taking immunosuppressant medications (see p. 43) for the rest of their life to prevent rejection of their heart.

Different types of rejection are possible, including acute cellular rejection (caused by the white blood cells in your body) and antibody-mediated rejection (caused by proteins called antibodies that recognize "foreign" things in your body). Your transplant team will explain these to you.

Can Rejection Happen at Any Time?

Yes it can, but it is most common during the first year after transplant. It will happen if your child misses medications, so it is very important to take medication as prescribed by your doctor. Most of the time, rejection is treated by giving your child extra medication by mouth. Most rejection events are mild, and your child may not have any outward signs that they will feel or you will see.

Many children have some rejection early after a heart transplant, but it is less common after the first year. In time, as your child's body gets more used to the new heart, the signs of rejection are generally fewer or milder. As long as your child takes their immunosuppressant medications as instructed, rejection is much less likely.

How Can the Transplant Team Identify Rejection Without any Outward Signs?

There are different types of rejection, and some can be difficult to diagnose. The transplant team will monitor your child for signs of rejection by doing certain regular tests (see below). These tests will depend on your child's age and risk factors for rejection.

Different things can affect your child's risk of rejection. The heart transplant team will determine the risks for your child and explain them to you. The risk of rejection can change over time.

What Are the Common Signs of Rejection?

Rejection symptoms can often be described as heart failure combined with the flu, but it is unlikely you will be the first to notice the signs of rejection in your child. Rejection is usually noticed in the results of your child's tests before your child shows any symptoms.

However, the following are some signs of rejection. Tell the transplant team immediately if you notice or if your child complains of:

- Fever.
- Fatigue.
- Shortness of breath.
- Stomach upset.
- Irritability.
- Palpitations (faster heart beat).
- Dizziness.
- Swelling or significant weight gain.
- Changes in your child's usual heart rate or blood pressure.

How Can I Help to Prevent Rejection?

- Give your child's medications exactly as directed by the heart transplant team.
- Do not miss any doses of medications.
- Bring your child to all clinic appointments, follow-up tests and blood tests.
- Check with the heart transplant team before giving your child any over-the-counter medications, including herbal (natural) medications. These medications can sometimes interfere with the immunosuppressant medications.
- Check with the heart transplant team before giving medications prescribed by another doctor.
- Call the transplant team about any concerning changes in your child's health.

What Types of Tests are Used to Diagnose Rejection?

One of the best ways of diagnosing rejection in your child's new heart is by doing a heart biopsy (see description below). This is also known as an endomyocardial biopsy, or EMB.

Sometimes other, less invasive, tests give us clues about rejection. These include echocardiograms (echos), electrocardiograms (ECGs), 24-hour Holter monitor testing and a blood test called BNP.

The results of these tests help the heart transplant team decide if there is any sign of rejection. Some centers will use these tests first before moving ahead with biopsies.

Heart Biopsy

Heart biopsies can find signs of rejection even though your child does not show any outward symptoms or signs. The heart biopsy is recognized as the most effective test for diagnosing rejection in a heart transplant patient and deciding the effectiveness of rejection treatment.

Biopsies are most often done in the cardiac catheterization lab ("cath lab"), though some are done in the echo lab under echocardiography guidance.

A pathologist looks at a small sample of heart tissue under a microscope for signs of rejection. The results from this study are reported back as a number under the **heart biopsy grading scale** outlined below.

Grade 0 (No Acute Rejection):	No features of acute rejection or cell damage on the biopsy tissue (heart tissue samples). There is no need to change your child's medications.
Grade 1 R (focal, Mild Acute Rejection):	A mild immune system response usually with not a lot of cell damage. This is often described to families as "no or mild rejection." At least one piece of the biopsy tissue is involved, but there is usually no need to change your child's medications.
Grade 2 R (Moderate Acute Rejection):	A greater immune system response, with more cell damage. At least one piece of biopsy tissue is involved. Grade 2 R usually requires treatment, which can include: • Increasing your child's maintenance immunosuppressant medications. • Switching to different maintenance immunosuppressant medications. • Giving a steroid "bolus" over three days (by mouth or through an IV – see p. 46 and p. 50). • Using stronger immunosuppressant medications.
Grade 3 R (Diffuse, Borderline Severe Acute Rejection):	An even greater immune system response and inflammation usually within multiple pieces of biopsy tissue. This means the cells of the child's heart are damaged. Swelling, hemorrhage (bleeding) and vasculitis (inflammation of blood vessels) can also be present. Usually a 3 R result requires your child be admitted to hospital, where they will receive steroids through an IV. Your child may also receive other anti-rejection medications if the rejection is not responding to the steroids or is causing your child to be unstable.

Antibody-Mediated Rejection: There are other features on a biopsy that may lead to suspecting or diagnosing antibody-mediated rejection. Although rare, some children, before transplant, have antibodies in their blood that could attack the new heart.

The treatment for antibody-mediated rejection is the same as for a Grade 3 R rejection, but often stronger medicines (such as rituximab or alemtuzemab) need to be added. Sometimes a procedure called plasmapheresis or apheresis needs to be done to remove the antibodies from the blood. If these things are necessary, your transplant team will explain them to you.

How Often Are Heart Biopsies Done?

Routine biopsies begin one to four weeks after transplant and will often be more frequent in the first year. They become less frequent as time goes on, as long as your child does not have frequent episodes of rejection.

Ask your transplant center for their biopsy schedule, as some centers biopsy less frequently.

For example, infants sometimes only have a heart biopsy if other tests show there are signs of rejection. Additional biopsies can be performed if your child is clinically unwell or if the team suspects rejection.

What Happens During the Biopsy?

Most biopsies take about an hour and are done while your child is an outpatient (they do not stay in the hospital overnight). Your child usually has two to four hours of recovery time before they are allowed home.

A heart biopsy will involve the following steps.

1. Your child is taken to the cardiac catheterization lab. They are given different levels of sedation or anesthesia (medicine to calm them or send them to sleep) based on your center's protocol (rules) and your child. You can discuss this with your transplant team.

2. A catheter, or tube, is threaded through a large vein in the neck or groin into the right chamber of the heart (see illustrations below). Through this tube, a wire with a pincher on the end is threaded into the heart, where it removes five to eight pieces of heart muscle, each no bigger than a pin point. Removing these pieces does not usually damage the heart.

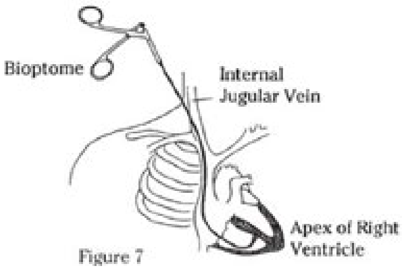

Figure 7

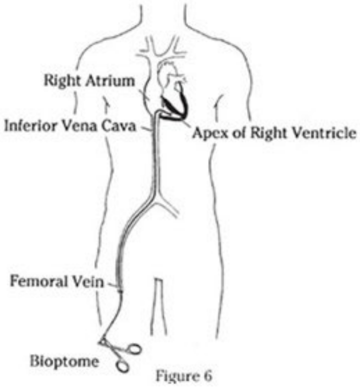

Figure 6

3. After the specimens (tissue samples) are taken, the doctor removes the catheter and applies pressure to control any potential bleeding. A Band-Aid® is then put on the insertion site.
4. The biopsy samples are sent to a pathologist (see p. 15), who examines them under a microscope and decides if the transplanted heart has any signs of rejection (see p. 73).

Possible Complications of Heart Biopsy

Complications from a heart biopsy are rare but can include:

- Bruising or bleeding at the site where the catheter was inserted into the body.
- Damage to the blood vessel used for the biopsy or to nearby nerves.
- Damage to a valve in the heart.
- Abnormal rhythms (heart beats).
- Perforation (tearing) of the heart, with collection of blood around the heart.

Transplant Cardiac Allograft Vasculopathy (CAV)

One type of rejection is cardiac allograft vasculopathy (CAV). This happens when the coronary arteries (small blood vessels that carry blood) thicken and narrow, making it harder for blood to get to the heart. This causes parts of the heart muscle die when they do not get enough oxygen.

This problem can happen at any time after transplant, but the exact cause is not known. It is typically a long-term complication and continues to be the major reason people eventually die or need another heart transplant.

How Is CAV Diagnosed?

CAV is often difficult to diagnose. Adult patients with blocked coronary arteries have chest pain, but this often does not happen to patients after transplant because the heart does not have any nerve signals.

There are, however, other signs or symptoms that may make your transplant doctor wonder if your child has developed CAV. A number of tests, described below, can give some clues. (Remember every transplant program has its own protocol for routine testing, and this will be explained to you.)

Coronary Angiography

Most children will undergo a dye test to look at the size and shape of the coronary arteries at various times after transplant. While this test is good at looking for bigger coronary vessels it does not always show changes in the smaller blood vessels. Sometimes this test does not show changes until they are quite advanced.

Intravascular Ultrasonography (IVUS)

In some centers and in bigger children, an ultrasound probe going through the blood vessels in the leg can look at the coronary arteries. This technique can sometimes detect changes in the blood vessels earlier than coronary angiography.

Exercise Testing (Stress Test)

Children after transplant may have some form of exercise testing. This test usually requires the child to ride a bike or walk or run on a treadmill. Their heart is connected to an ECG monitor at the same time to monitor their heart rate and rhythm. A breathing test can also be used to see how well your child uses oxygen during exercise.

If certain changes are picked up by the ECG during the exercise test, they may draw attention to the possibility of CAV and prompt the transplant team to arrange more tests.

Non-Invasive Studies

Other screening tests that may be done at your center include exercise echocardiography, dobutamine stress echocardiography or stress MIBI.

These studies look for changes in how the heart works or how the walls of the heart move. They can help the transplant team decide if enough blood is getting to the heart muscle during exercise.

Preventing CAV

CAV can happen at any time after transplant, even into adulthood. In some cases, nothing can be done to stop CAV from developing. However, a number of things thought to be helpful include:

- Regular exercise.
- Following a healthy diet.
- Taking medication regularly and not missing any doses.
- Maintaining a normal body weight.
- Going for regular tests for high blood pressure, high cholesterol and diabetes (high blood sugar), and treating them if they happen.
- Not smoking.

Treating CAV

At the moment, despite efforts by many researchers, there is no cure for CAV. If your child develops CAV, there are a number of medications that will be started to:

- Try and slow down the narrowing in the coronary arteries.
- Prevent blood clots from forming in the small coronary arteries.

In some cases, your child may have surgery to open up the blocked arteries. Your child will be closely monitored and in more severe cases may need to limit their activity. In very severe cases, your child may need another heart transplant.

Infections and Diseases

Infections are a concern because of the immunosuppressant medications your child is taking to prevent rejection.

Your child will get normal childhood infections (runny noses and coughs, ear infections, sore throats, vomiting and diarrhea) and they will usually get better. In general, you can take care of these infections as with any other child who has not had a heart transplant. If you have any concerns, you can see your family doctor or pediatrician.

Some infections are more serious in a child who is on immunosuppressant medications after a heart transplant. Your child's transplant team will teach you about these infections after your child's surgery. Your child's blood tests will check for some of these infections a few times every year.

How Do I Help My Child Avoid Getting Infections?

- Practice good hand-washing for everyone who lives at home. Hand-washing is especially important before preparing food and after diaper changes or going to the bathroom.
- Ask friends and relatives who are sick to avoid visiting until they are better.
- Wash hands well after contact with animal body waste (for example after cleaning up after a family pet).
- *If you have been told to do so,* tell the heart transplant team if your child is in contact with someone who has chickenpox. We will explain how and when to do this.
- Maintain general wellbeing by getting enough rest, eating healthy food, drinking enough fluids and keeping active.

What Signs of Infection Should I Watch for?

Contact your pediatrician or family doctor if your child is sick with any of these signs or symptoms:

- Fever.
- Runny nose and cough.
- Sore throat or sore ears.
- Pains in the stomach.
- Vomiting.
- Diarrhea.
- Feeling of burning or pain when peeing.
- Sores on the lips and around the mouth.
- Rashes.

As in all children, your child will likely get many of the colds and flus caused by viruses "going around" every year. We expect that your child will recover well from these infections.

Serious Viral Infections

Some kinds of viral infections may put children with heart transplants at risk. These include:

- Chickenpox (varicella).
- Herpes simplex virus (HSV).
- Cytomegalovirus (CMV).
- Epstein-Barr virus (EBV).

If your child gets one of these viruses, they will likely be monitored more closely and they may be treated for them.

Chickenpox (Varicella)

Chickenpox is a disease caused by the varicella virus. People with chickenpox develop an itchy rash that looks like insect bites at first before developing into fluid-filled blisters that may break open and crust over. Chickenpox can also cause fevers, headache, abdominal (belly) pain, muscle aches and a general feeling of "unwellness" or irritability.

Chickenpox used to be very common, with most people getting the disease in childhood. A vaccine has made chickenpox much less common in many countries, including the United States and Canada, but it is still possible for children in these countries to catch the disease.

A child who has had a heart transplant is at risk for getting chickenpox if they have not had it or have not had the varicella vaccine. A blood test is performed before a child is listed for heart transplant to see if they are protected against chickenpox. If they are, the blood test will show antibodies in the blood.

What Happens if My Child Is at Risk for Chickenpox?

If your child is not protected from chickenpox through a previous infection or a vaccine, you will need to make sure that you instruct relatives, friends, teachers and caregivers to tell you if your child has been exposed to chickenpox while in their care.

You will also need to avoid contact with people who have shingles. This is a painful rash that is also caused by the varicella virus. Contact with someone with shingles can cause chickenpox in a child.

Being exposed to chicken pox is not an emergency. There are normally a few days before the virus takes hold. During this time, your child's doctors can arrange for your child to get medication if they need it (see information below). You can contact your heart transplant team during regular working hours to discuss the exposure.

What Medications May My Child Get if They Were Exposed?

If your child is exposed to someone with chickenpox or shingles, they may need varicella antibodies (by a needle) to help prevent getting chicken pox.
This medication needs to be given within four days of exposure to chickenpox to have the best chance of helping.

Even if a child receives this medication, it is still possible they may catch the virus. Chickenpox can develop between 10 and 21 days after someone is exposed to a person with the disease.

What if My Child Develops Chickenpox After Being Exposed to It?

If your child develops spots you think may be chickenpox, they will need to see the family doctor or pediatrician and inform the heart transplant team. Your child may need to receive the anti-viral medication acyclovir either by mouth or IV (see p. 54). If there are signs the chickenpox rash is quite severe or if the virus appears to be affecting other organs, your child may need to be treated in hospital.

If My Child Has Chickenpox After Transplant, Will Their Symptoms Be More Severe?

In general, even in a transplant patient, chickenpox usually causes the same signs and symptoms we see in other children: mostly fever and a skin rash. Rarely, chickenpox can affect other body organs and potentially can make the patient very sick.

If your child gets chickenpox, you will need to take them to your family doctor or paediatrician, and you will need to tell the heart transplant team. The team will decide if your child needs treatment for chickenpox with anti-viral medication.

Can My Child Have the Chickenpox Vaccine After the Heart Transplant?

Health experts review and update vaccine recommendations every year. In 2013, the answer is it is **not recommended**. The chickenpox (varicella) vaccine is a live vaccine, meaning it could actually give your child chickenpox instead of protecting them from it.

If this recommendation changes over time, or if a new vaccine option becomes available, your transplant team will discuss it with you.

Can My Other Children Get the Chickenpox Vaccine?

It is safe for brothers and sisters to get the chickenpox vaccine. Adult family members who have not had chickenpox may also want to discuss vaccination with their family doctor.

Herpes Simplex Virus (HSV)

Herpes simplex virus types 1 and 2 are a family of viruses that can cause blisters and sores in different areas of the body.

- Herpes simplex virus type 1 (HSV-1) generally causes cold sores in the mouth or on the lips. It can be passed from one person to another through saliva or sores on the skin of an infected individual.
- Herpes simplex virus type 2 (HSV-2) is linked with genital sores. It is usually passed during sexual contact with an infected individual.

Children who have had a heart transplant can acquire both types of herpes virus, but cold sores due to HSV-1 are more common. The sores may be painful and filled with fluid. In more serious cases, they can be linked with symptoms such as fatigue, fever or body aches.

How Can HSV Be Treated?

There is no cure for HSV, but treatment can relieve HSV symptoms. Painful cold sores can be treated with a topical ointment (a lotion or gel applied directly to the sores) or, in more severe cases, a medicine called acyclovir (see p. 54).

If children experience a lot of pain from the cold sores, and the pain affects their ability to eat and drink normally, they may need to be admitted to the hospital for further treatment.

Cytomegalovirus (CMV)

Cytomegalovirus (CMV) is another member of the herpes virus family. Like Epstein-Barr virus (see below), it is very common; between 50 and 90 percent of adults have been infected with CMV. Usually, CMV infection causes no symptoms in healthy children and adults. However, even then, CMV can stay in the body for a very long time after the initial infection.

Due to the effects of your child's immunosuppressants, CMV is an important cause of disease after heart transplant. CMV already present in your child (without any symptoms), may become active or CMV may be passed to your child as a new infection through the transplanted heart or in other ways.

CMV infection after transplant may cause a wide range of symptoms, including:

- Fever.
- Joint pain.
- Reduced white blood cell counts.
- Pneumonia.
- Gastritis (severe stomach upset).

Because of the wide variety of symptoms, this virus must be considered as a possible cause for any unexplained infection in someone who receives a transplant.

How Is CMV Diagnosed?

CMV is most commonly diagnosed through blood tests that can detect even very tiny quantities of CMV in the blood. Occasionally, blood tests may be "negative" (no CMV is found) if the body has limited the infection to one region of the body. In these cases, the transplant team may need to order tests of specific tissue (such as an intestinal biopsy) to confirm the diagnosis.

How Is CMV Treated?

CMV is treated differently before and after symptoms appear.

To stop symptoms appearing, it is treated for several months after transplant surgery with:

- Immunoglobulins through an IV (see p. 55).
- Anti-infectant medications such as gancyclovir or valgancyclovir (see p. 56 and p. 60).

If symptoms are already present, a child usually needs higher doses of anti-infectant medications over a specific time.

Epstein-Barr Virus (EBV)

Epstein-Barr virus (EBV) is a member of the herpes virus family. It is very common, and most adults in the United States have been exposed to it by the time they turn 40.

In most people, EBV causes a viral illness that is either asymptomatic (has no symptoms) or mild. At most, the infected person may have a sore throat or flu-like symptoms. EBV also causes mononucleosis or “mono” in teens and young adults. Once a person has an EBV infection, the virus stays in their body for the rest of their life, although usually with no problems.

For transplant patients, EBV infection increases the chance of developing post-transplant lymphoproliferative disorder (PTLD) (see below), a condition that can lead to cancer. This can occur after a new infection or if a dormant virus (one that has remained in the body after a previous infection) becomes active again.

The link between EBV and PTLD means that transplant doctors often check their patients’ EBV status over time, usually through blood tests. These look for the virus itself or check if the body is making antibodies to EBV (a sign of a new or previous EBV infection depending on the type of antibody detected).

How Is EBV Treated?

Treatment of EBV depends on the results of the tests.

- No treatment is needed if neither EBV nor EBV antibodies are present in the blood.
- If there are antibodies but no EBV, a patient is usually monitored over time.
- If there is evidence of EBV in the patient’s blood, sometimes transplant doctors may lower the dose of immunosuppressants to allow the body to clear the virus on its own.
- Drugs to treat EBV are available, but often they are not effective or have side effects.

Post-transplant Lymphoproliferative Disorder

Post-transplant lymphoproliferative disorder (PTLD) is a complication occuring in about 10-15 percent of heart transplant patients.

PTLD is usually associated with a viral infection after transplant. The virus can make a person’s lymph glands larger. A normal immune system would get rid of these cells, and they would not cause cancer, but in transplant patients, the immunosuppressants prevent the immune system from clearing them. Over time, there is a risk that the enlarged lymph glands will turn into lymphoma (a malignant tumor, or cancer).

PTLD can cause flu-like symptoms, pneumonia, vomiting and/or diarrhea. Many non-PTLD illnesses cause similar symptoms. If your child develops these symptoms, the transplant team will usually monitor them and decide if more tests are needed to check for PTLD.

What Type of Viral Infections Can Lead to PTLD?

The most common virus associated with PTLD is Epstein Barr virus (EBV) (see above).

Often the heart transplant team tries to protect against CMV or EBV by using anti-viral medications, but these are usually only continued for a few months after transplant when the immunosuppressant medications are at their highest (see p. 43).

Most transplant teams will routinely measure the amount of virus particles in the blood to see if there has been an infection. If the test shows a new infection or the reappearance of an old one, the transplant doctor may reduce the dose of immunosuppressant medications for a short time to allow a patient’s body to clear the virus on its own.

How Is PTLD Diagnosed?

The diagnosis of PTLD is often made in several steps. If the transplant team suspects PTLD after evaluating a patient’s symptoms and doing a physical exam, they may order other studies, such as x-rays, CT scans or PET scans to look for other evidence of it. If enlarged lymph nodes are seen in these scans or x-rays, a doctor will take a biopsy of the lymph nodes to make a diagnosis.

If PTLD is diagnosed, the transplant team will usually decrease the immunosuppressant medications and may begin giving anti-viral medications.

Some children who have a new PTLD diagnosis need to be assessed by an oncology team and may have chemotherapy.

Fortunately, when it is identified in time, PTLD can be treated successfully. However, children who are treated will need to have follow-up appointments for the rest of their lives to check for the return or relapse of PTLD.

Kidney Issues

Immediately after a heart transplant, the kidneys can often take a while to start working properly. Some patients even need dialysis for the first few days. Usually, however, their kidney function returns to normal.

Some transplant medications have the unfortunate side effect of causing kidney damage, usually over many years. This may create the need for a special diet, more medications or, in rare cases, dialysis or a kidney transplant.

Because of the concern about kidney function, it is very important that your child drink enough water after a heart transplant, especially in the heat.

- School age children should drink at least one liter (four eight-ounce cups) of water a day.
- Teenagers need 1.5 to two litres (6-8 eight-ounce cups) of water a day.

Encourage your child to always have a bottle of water they can drink from and refill throughout the day at school and during after-school activities.

Hypertension

Hypertension (high blood pressure) is a common issue after a heart transplant. It is important to treat the high blood pressure to prevent further kidney disease and heart disease.

Many children need medication to lower high blood pressure soon after a transplant. This medication can often be cut down or stopped months or years after the transplant. However, high blood pressure can come back later in life. This is often related to the immunosuppressant medications a patient is taking and their effect on the kidneys.

Following a Healthy Lifestyle After Transplant

Physical Activity and Exercise

Exercise and physical activities are part of a heart healthy lifestyle and we encourage regular activity in all transplant patients. Regular exercise is a crucial part of keeping your child strong and healthy, as it:

- Helps them develop socially.
- Develops their motor skills (such as hand-eye co-ordination and movement).
- Boosts their overall fitness.

We encourage you to enroll your younger child in developmental play groups and community activities. Older children can take part in recreational and organized sports and join school or community teams. Encourage your child to try new activities so they can find things they really enjoy.

Exercise Training

For the first eight weeks after transplant, your child should avoid strenuous activities, such as high-intensity aerobics, lifting or climbing.

After this time, your child can take part in exercise training. A physical therapist (see p. 15) can help them regain the muscle strength they lost while waiting for and recovering from surgery. This therapist can also help increase your child's endurance (their ability to exercise for longer without increasing their heart rate).

Exercise training after a transplant is not geared at reaching a certain heart rate as a measure of exercise intensity. Instead, your child's transplant team will focus on a range of good exercise practices and checks, for example by:

- Having your child work towards an extended warm-up and cool-down (see below).
- Monitoring intensity using an RPE (rating of perceived exertion)
- Teaching your child a range of stretching and ROM (heart **r**ate, **o**xygen uptake and **m**etabolic equivalents) exercises.

Exercising Safely After Transplant

After transplant, your child should spend at least 10 minutes warming up and cooling down before and after any physical activities. Their heart rate is now controlled by hormones (such as adrenaline) because the nerves connected to their heart were cut when their old heart was removed.

During exercise, the body produces adrenaline, but the new heart may take a few minutes to detect this. A warm-up period allows the heart to beat faster in response to increased levels of adrenaline. A cool-down period allows the body to gradually return to normal and the heart rate to slow down.

During exercise, your child's heart rate may be limited by their medications or by the ability of adrenaline to stimulate it. The best way to work out the intensity of the exercise is to assess your child's breathing. For exercise to be effective and safe, a transplant patient should be breathing faster than normal but should not be gasping for air or even short of breath.

Exercise and physical activity should always be done at a level your child can tolerate. Neither your child nor their coaches should push your child beyond their abilities. Remember, too, that your child must take plenty of fluids during exercise to stay hydrated and take breaks or rest periods when needed.

Taking Part in Organized Sports

Most children who receive a heart transplant return to a relatively normal and age-appropriate lifestyle after six months. They are able to take part in team sports and other active pursuits if they wish.

Children who want to take part in *competitive* sports, however, should talk to their transplant team, especially their cardiologist. Further tests will be recommended, including exercise testing (see below). Your child will also need to follow a number of post-transplant exercise recommendations.

In general, a child with a heart transplant can take part in all competitive sports that are suitable for their exercise ability if:

- Their tolerance for exercise is normal for their age.
- There is no evidence of CAV (narrowing of the heart's blood vessels, see p. 77).

The special issues involved with managing transplant patients make it very important you consult with your child's transplant team, especially their cardiologist, before deciding if your child can start, or continue, competitive sports after surgery. Your transplant team can explain things to you.

Exercise Testing

If your child is aged six or older, they will often have an exercise stress test in the first six to 12 months after their transplant. If they are aged five or under, exercise testing will start around the age of six.

An exercise test involves having the patient walk on a treadmill or ride a stationary (not moving) bicycle for as long as they are able while their heart function and blood pressure are monitored.

The results of the stress test can help the transplant team to monitor for CAV (see p. 77) and assess your child's physical fitness, especially for taking part in competitive sports. If there are problems or concerns during the stress test, the transplant team may follow up with other tests.

Heart-Healthy Eating

Eating Well After Transplant

After a heart transplant, your child's appetite will be different than before. They may have more energy to eat and should tolerate meals better.

The dietician on your child's transplant team will assess and monitor your child to develop a nutritional plan. Each child's plan is different but, in general, children should learn to choose healthy foods and appropriate portions and minimize "junk" foods. In addition, food should be cooked and stored properly to prevent food-borne illness.

Supports to Gain Weight and Feed by Mouth

For children who are very underweight before their heart transplant, the first 12-18 months after transplant are the most important time for them to "catch up" in weight and height.

Underweight infants and very young children often need fortified (strengthened) breast milk or formula with extra calories. Older children may need calorie-rich foods or extra tube feedings.

As these children develop normally, they will no longer need extra calories. Their nutrition plans will then be adjusted to reflect a more age-appropriate food intake and feeding pattern.

Some young children who were very sick before transplant might find it difficult to take food by mouth. If this applies to your child, an occupational therapist can assess them and recommend treatments to improve their feeding and swallowing so they can eat safely and efficiently. Often the dietician and occupational therapist will work together to enhance your child's feeding, growth, and development.

Following a Heart-Healthy Diet

Following transplant, children should follow heart-healthy food guidelines. These include:

- Eating fruits and vegetables.
- Choosing whole grains, lean meats and alternatives, low-fat dairy products, and unsaturated oils.
- Limiting foods that are high in salt, sugar and saturated fat and low in nutrients.

Some immunosuppressant medications, especially steroids, can make children very hungry, increase their cholesterol levels and cause them to gain weight. To reduce the risk of high cholesterol and excess weight gain, have healthy foods and snacks available for your child. Consider options such as fruit, chopped vegetables, low-fat yogurt or milk and cereal.

Your child's dietician can offer more advice.

Handling Food Safely

Transplant patients are at higher risk for developing infections, including those that come from incorrectly prepared or stored food. As a result, it is important to make sure that the food your child eats is safe.

You can reduce foodborne illness following four easy steps.

1. Clean
   - Wash your hands and all surfaces, utensils, and cutting boards:
     - Before beginning to prepare food.
     - After touching pets, coughing or sneezing, changing diapers, touching the phone, touching garbage or using the washroom.

2. Chill
   - Refrigerate or freeze all perishable food within two hours of buying it.
   - Set your fridge to 4°C (40°F).
   - Marinate and defrost food in the fridge, not on the kitchen counter top.

3. Separate
   - Keep raw foods and their juices separate from other food in the fridge and when preparing them.

4. Cook
   - Use a food thermometer to tell if food is cooked properly.
   - Reheat leftovers to 74°C (165°F).

Fluids

Drinking plenty of fluids, especially water, is also very important after your child's heart transplant, especially to protect the kidneys. The heart transplant team will tell you how much water your child should drink every day to keep their kidneys healthy.

Remember, your child must avoid anything related to grapefruit. Grapefruit and grapefruit products raise the levels of tacrolimus, cyclosporine or sirolimus in your child's blood (see p. 47). This can lead to more side effects.

Your child needs to avoid:

- Drinking grapefruit juice or any juices that contain grapefruit.
- Eating grapefruits or any fruits grown from them, such as pomelos and tangelos.
- Having fruit salads or mixed fruit juices containing grapefruit or grapefruit juice.

Read the front and back labels of mixed fruit juices carefully to make sure they do not contain grapefruit.

Your child's dietician will be happy to answer any questions or concerns you have about your child's nutrition, growth or feeding.

Your Child's Behavior, Emotional Well-Being and School Performance

If you, your family or a member of your child's school or transplant team expresses any concerns about your child's mood, behavior or school performance, your child may be referred to see a psychologist or neuropsychologist.

A neuropsychologist is a professional who has been trained to work with children and teens to understand how an illness can affect their behavior and how their brain works. They can also help young people deal with some of the stresses of dealing with end-stage heart disease and transplant.

A child is usually referred if:

- Your family or your child's transplant team have any concerns about your child's development (for example poor performance in physical therapy or occupational therapy tests).
- Your child is struggling at school (for example with reading, spelling or math).
- There are concerns about your child's language skills, attention or memory.There are changes in your child's thinking abilities or brain imaging scans.
- Your child has missed a lot of school.

Assessment in Relation to School Performance

If your child is being assessed because of their school performance, the neuropsychologist will look at your child's thinking skills, academic performance, memory, language, visual processing, speed and dexterity, attention and emotional control.

If there is any problem that could affect your child's education (such as a learning disability), the neuropsychologist will diagnose it and/or recommend different forms of treatment.

With your family's consent, the neuropsychologist can also talk to your child's school to co-ordinate learning and health needs and recommend specific educational supports that could help.

Assessment for Emotional Support

If your child is being assessed for emotional support and therapy, they will be seen alone (if they are old enough) and with you. Depending on the child's age, they, or you, will be asked about how they have been feeling and about their mood, relationships, involvement in school, social and recreational activities, sleep, appetite and any other worries or changes in their life.

The neuropsychologist may also ask your child, your family or your child's teachers to fill out some questionnaires to get an idea of how everyone thinks your child is doing.

Sometimes, the psychologist may diagnose a specific mental health difficulty such as depression or anxiety. It may then be helpful for your child to see a psychologist or a mental health therapist (or counselor) for a number of sessions. They can listen to your child, help them understand why they feel this way and give some ideas about things your child can do, or say, to help change the way they feel. They may also discuss these ideas with you or with other important people in your child's life (such as their teacher) so everyone understands and can work together to help your child.

In some instances, medication might be recommended for older children and teens. Those in this age group may also need to see a psychiatrist or adolescent medicine doctor for assessment and monitoring.

Issue	Neuropsychology role	Other services involved
Possible Cognitive (Thinking) Difficulties	Full evaluation, consultation on results and recommended treatments.	Occupational therapy – provides cognitive screening and can refer for a full evaluation if needed.
Difficulties Sticking to Treatment	Evaluation to identify possible causes for poor adherence.	Nursing, social work, or psychiatry to treat any underlying emotional reasons.
Emotional or Behavioral Concerns	Evaluation, usually including emotional and behavioral screening.	Social work or psychiatry.
Attention Difficulties	Assessment and, if appropriate, diagnosis of ADHD.	Psychiatry involved in managing medications, if needed.
School Liaison	Can inform and update the school about impact of the medical condition on school attendance and performance.	Social work, among others.

Commonly Asked Questions

How Long Will the New Heart Last?

It is not clear how long a new heart will function well in a child. Survival has improved greatly over the last 20 years, with most children have a good chance of surviving into adulthood. This depends on the age of your child when they have a transplant. In 2013:

- More than 50 percent of infants survive with a transplanted heart until 20 years after their transplant.
- More than 50 percent of children survive until 15 years after their transplant.
- More than 50 percent of teenagers survive until 12 years after their transplant.

However, it is difficult to know exactly how long a transplanted heart will last. This uncertainty can be a source of stress for parents and older children.

There are many reasons a child can develop heart failure after a heart transplant. The most common ones include rejection (p. 74) and transplant coronary artery vasculopathy (CAV, p. 77). Other reasons include non-specific allograft failure, which means the new heart function decreases without any clear reason why. This is a type of rejection that still needs to be better understood.

To give your child the best chance of success with a new heart, make sure:

- They take their medications as prescribed.
- They follow a heart-healthy lifestyle (by eating the right foods and getting enough exercise that is suitable for them).
- You keep all of your follow up appointments at the transplant center.

Despite all of this, it is still possible a new heart will unexpectedly fail. If the reason for this is known, the heart transplant team will explain it to you.

In cases of heart failure, your child may need to be treated for rejection or put on heart failure or heart rhythm medications. They may even need to be assessed or relisted for another heart transplant. These things will be explained to you by your heart transplant team if it happens to your child.

When Can My Child Return to School or Other Daily Activities?

As your child recovers from the transplant and has more energy, encourage them to take part in all normal family activities. There is no specific time children are expected to stay home; each child’s situation is unique. Please talk to your transplant team about what is best for your child.

Before your child returns to school, talk to the school about the best way to continue class work. Your child’s teacher may provide some work or, in some areas, tutors can be arranged.

Children can play outside, go for walks and see friends. If relatives or friends are sick, it is best to ask them to visit once they are well. Other ways to keep your child healthy include regular hand-washing, which will help to prevent spread of infections. Children returning to school (or work if they are in their teens) might find it useful to carry hand sanitizer and anti-bacterial wipes with them to clean any work surfaces.

It is very important your child's teachers (or co-workers) realize a transplant patient is healthy and no longer ill when they receive the new heart. As such, they should treat the patient as normally as possible. The transplant team will help with your child's return to school or work once your child is ready.

Does My Child Need a Special Skin Care Routine?

Transplant patients generally don't need special skin care, unless they develop an unusual skin condition or rash (see below). Showering and bathing with regular soap is generally okay, but mild soap and lotion after bathing are recommended if the skin is dry.

A number of children will have dry skin or eczema after their transplant. This can be cared for by having regular baths with hydrating oil, using Vaseline® on damp skin and, if necessary, using cortisone cream from your family doctor or pediatrician. The eczema can sometimes be so severe that your child may need to see a dermatologist or take medications.

Immunosuppressants prescribed after transplant can increase the risk of certain viral skin conditions, such as warts or herpes. Teens who have had a transplant may also be at increased risk of acne, which is already common in teenagers, due to steroids.

Will Medications Affect My Child's Hair?

If your child is on prednisone, the texture of their hair is likely to change, possibly becoming dryer or coarser. Your child's hairdresser will probably suggest a good conditioner to help with this. Chemical treatments like highlights, hair dye, permanents and straightening can increase hair breakage. Your child should avoid these until their prednisone dosage is lowered.

Medications also may cause more facial hair. A hair-removal cream can be used, but the instructions should be followed carefully to avoid skin irritation. Teens may also try bleaching, waxing or electrolysis.

What Type of Dental Care Should My Child Have After Transplant?

Regular dental care and check-ups are important for transplant patients.

- Dental problems such as abscesses or mouth pain can lead to or be signs of serious infection because your child's immune system is weaker.
- Some transplant medications can cause gum problems.
- Tell your child's dentist that your child has had a transplant.

Right after transplant, your child's teeth and gums should continue to be cleaned every day. Preventative care is more important than ever.

The American Heart Association currently recommends heart transplant patients do not need antibiotics before dental procedures. There are exceptions to this, so check with your child's transplant team to be certain. Your child will usually only need antibiotics if dental work is needed within the first six months after transplant.

Can My Child Go Out in the Sun as Usual?

Transplant patients are more likely to develop skin cancers, so it is extremely important that you protect your child's skin.

- Avoid the sun between 10 am and 2 pm; this is when ultraviolet rays are the strongest.
- Have your child wear protective clothing outdoors, including a hat.
- Encourage your child to sit or play in shaded areas.
- Apply sunscreen and lip balm daily to uncovered areas of your child's body. Remember to re-apply sunscreen every few hours—more often if your child is swimming or sweating—because it wears off.
- Use skin products with at least SPF 30.
- Check your child's skin for abnormal spots (irregular moles or growths) and report them to your doctor.

What if My Teen Wants to Get a Tattoo or Piercing?

There are differences in what programs recommend about tattoos and piercings. Please talk to your own transplant team to find out what they recommend for their own patients.

Programs that are open to tattoos and piercings have the following recommendations:

Piercings

- Make sure that the site being pierced is cleaned very well and that only a new, sterile, stud (or other piercing ring) is used.
- Follow the cleaning instructions given by the piercer for the first four to six weeks.
- If the site turns red, is painful, or has any discharge, your child should see their doctor as soon as possible to check for any infection.

Tattoos

- Make sure that a new, sterile, needle is used.
- If possible, ask for new bottles of ink that have not yet been opened.
- Follow the instructions given by the tattoo artist for keeping the site clean.
- If the site turns red, is painful or has any discharge, your child should see their doctor as soon as possible to check for any infection.

Can My Child Have a Pet?

You can safely have a pet in your home if your family follows a few simple guidelines.

- Have your child wash their hands well after handling pets, cleaning cages or litter boxes, or picking up feces (also known as stool or "poo").
- Make sure your pet is regularly seen by a vet and is up-to-date with all vaccinations.
- Most animals are safe from a transplant perspective. If you have any questions about a specific species, please talk with your transplant team.

Can My Child Travel?

Your child can travel after transplant if they have been well, without medical complications. Please talk with your transplant team before you make any travel plans, especially if traveling abroad.

Tips for Safe Travel

- Always carry your child's medications with you—never pack them in your checked-in or stowed luggage in case it gets lost.
- Keep medications in their original containers (bottles or pill packages) with the pharmacy labels on them.
- Consider buying travel health insurance if you are planning international travel. Check if it covers pre-existing conditions.
- Well before your trip, talk with your transplant team and a travel clinic about any vaccines your child needs for traveling abroad.
- Ask your transplant center for a letter about your child's condition and how to contact the transplant team in case your child needs medical attention while away.
- Know the location of the nearest hospital at your destination and ask your transplant team if they can recommend doctors in the area.

My Child Still Has Trouble Sleeping. Is This Normal?

Many children who have a heart operation have difficulty sleeping and concentrating afterwards and may show signs of hyperactivity. This is also true of transplant children, who have been found to have more schooling and behavioral issues compared to healthy children. Help is available through psychological counseling and/or medication.

My Child Has Started Wetting the Bed at Night. Why Is This?

Bed-wetting is common after transplant surgery. It may be due to the trauma of being in hospital, but it can also be caused by urinary infections. Another reason is the heart beats quickly even during sleep. This means, even at night, the kidneys get a lot of blood and so produce more urine. The usual treatments for bedwetting can often be helpful and may include behavioral techniques and/or medications. Your transplant team may ask your family doctor or pediatrician to manage this issue.

Adolescence

Adolescence or "the teenage years" are challenging even for children without health problems. Children with a chronic illness can have even greater difficulties when they become teenagers. In addition, behaviors that are a "normal" or "expected" part of the teenage years can put heart transplant patients at risk for rejection or other medical problems.

The teen years are a struggle for most of us, but it can be even more difficult if transplant occurs at this time in a person's life. Some of the normal teen milestones might be delayed, such as driving, exploring sexuality and experimenting with moral guidelines (or what some might call "rebelling"). Separation from their peers, isolation and loss are all part of the teen transplant experience.

The heart transplant team is very aware of these challenges. When your child visits the team, they will assess your child and provide support and guidance to foster healthy teenage development, coping skills and discipline to follow the treatment plan.

When your teen meets the transplant team, they will have a chance to discuss issues such as:

- Capacity to consent or assent to treatment.
- Their home situation.
- Education.
- Their body image.
- Any substance use.
- Their history of following the treatment plan.
- How puberty is going.
- Their sexual history.
- Their mood, including any suicidal thoughts.
- Coping skills.
- Death and dying.

Not following medical treatment and recommendations is the leading cause of death in the teenage years. It is very important to maintain communication with your teen and get them preventative support if they need it.

Transition From Pediatric to Adult Care

Adolescence can be a challenging time for patients as they mature and have more independence and self-awareness. As you and your child go through this period, your transplant team will work with you and your child to ensure a smooth transition, or move, to an adult transplant team for future care.

Transition is the gradual, planned movement of teenagers and young adults with chronic physical and medical conditions from a child-centered to an adult-centered healthcare system. While transition varies between transplant programs, it often begins between age 10 and 14, and it is completed by age 18 to 24.

Planning for transition begins at an early age and is focused on helping patients to develop into independent and confident young adults capable of caring for their chronic condition. Support is provided to caregivers, as their roles also change with their child's evolving needs.

This planning involves good communication between the patient and family and the pediatric and adult transplant providers. The goal is to help patients develop the knowledge and skills they need to manage their own care and make good personal and medical decisions. This includes taking their medications as prescribed or following up with clinic and test appointments as recommended. During this time, the doctors and nurses will talk about different topics, from signs and symptoms of infection and rejection to insurance and pharmacy issues.

Successful transition planning helps to ensure co-ordinated care that is culturally sensitive, appropriate for your child's age and development and family focused.

Early Transition (10-13 Years)

- The concept of transition is raised with the family.
- Healthcare providers may begin to see the patient alone for part of the visit.
- Healthcare providers discuss medical health with patients and caregivers.
- Caregivers manage medical appointments, medication refills and oversee patients' taking of medications.

Middle Transition (15-17 Years)

- Healthcare providers continue to see the patient alone for part of the visit.
- Patients are provided with a binder of information designed to teach them about their condition and prepare them for eventual transfer to an adult transplant program.
- Patients learn the names of their medications, doses and schedule.
- Caregivers help patients manage their healthcare (for example by supporting them with reminders for taking their medications).
- Patients and caregivers develop a calendar for appointments together.
- Patients and caregivers discuss their concerns, goals and questions with the pediatric transplant team.

Late Transition (18-23 Years)

- Healthcare providers continue to see the patient alone for part of the visit.
- Patients can explain their health history, current conditions and importance of short- and long-term problems.
- Patients know their medications and are responsible for taking and ordering them.
- Patients are responsible for making their appointments and can explain their follow-up care plan.
- Patients understand their medical history and any chronic problems (for example hypertension, acne, lack of kidney function).
- Patients know the contact information for their primary care provider, transplant team, social worker, insurance provider and pharmacy.
- Caregivers prepare to be consulted by the child about health decisions.
- Patients designate a health care proxy, complete advance directives and provide consent to transfer their information to the adult transplant program.
- The pediatric program schedules a transition visit about six months before the transfer of care to the adult program. The visit includes meeting the new team of providers and touring the facilities.
- If possible, the patient is connected with another individual who has already transitioned.

Research

Why Do Research in Children?

Many studies have been done to evaluate treatment in adult heart transplant patients, but more needs to be done in pediatric heart transplant patients. In addition, medications, devices and treatments are often not as well tested in children, especially children with heart transplants.

Most of the medications and treatments we will use in your child are not officially approved by Health Canada or the Food and Drug Administration (FDA) in the United States for use in children with heart transplants. However, they are used all over the world every day.

In sum, children are not little adults. We need to think about how a child's brain and body are developing, as well as the way medications and other treatments are handled in a child's body over time.

Why Are Children Different Than Adults?

Children are growing; they are changing and maturing all the time. For instance, when thinking about the right dose for a child, we look at their stage of growth.

An eight-month-old is completely different than an eight-year-old who, in turn, is completely different than an 18-year-old. So even among children, everyone is different. And at each of these stages of growth, they may need different doses of medicine, different sizes of devices or different types of therapy.

Many medications are filtered out of the body and handled differently by a child's developing liver or kidneys. Because research has been so limited, we don't know how the medications will affect these organs in the long-term. We need to study them to find out.

Why Are Clinical Studies Important?

They can help us:

- Understand differences in children as they grow and develop.
- Identify the best dose of medications to prevent rejection but reduce other long-term side effects.
- Produce chewables, liquids or tablets that are easier for children to take.
- Find treatments for problems occurring only in children with heart transplants.
- Find treatments for new or existing diseases to improve the health of children in the future.

Past studies in heart transplant patients have helped us provide the current treatments given to your children.

How Can My Family Help?

Your family may be approached by the transplant team doctor, clinical research nurse or another member of the heart transplant team to take part in one or more research projects. The team member will explain the project and answer any questions you may have about the study.

All medical information collected in a research study remains confidential, and all information identifying your child, such as name or birth date, will be removed. There are very strict rules about research in children, and all studies, no matter how big or small, are approved by a research ethics board.

While your child may not directly benefit from the results of a research study, we believe the heart transplant research we are doing today will greatly benefit our patients of tomorrow.

Whether your child will take part will always be your decision. If you choose not to participate, your child will not receive different treatment. If you choose to participate in any of the studies, you have the right to withdraw at any point if you change your mind. This will not affect your child’s treatment.