Pediatric Kidney Transplantation:

What You Need to Know

Intermountain
Primary Children's Hospital
The Child First and Always®

Welcome

Welcome to Primary Children's Hospital (PCH) where our caregivers work tirelessly to accomplish our organization's mission of "The Child First and Always." Everything we do, each decision we make, is about what's best for the child — now, and forever.

Kidney Transplant Program

81 North Mario Capecchi Drive,
Salt Lake City, UT 84113

Phone: 801-662-6800
Fax: 801-662-6810

© 2022 Intermountain Healthcare. All rights reserved.

© 2022 Intermountain Healthcare. All rights reserved.

© 2022 Intermountain Healthcare. All rights reserved.

What's Inside…

© 2022 Intermountain Healthcare. All rights reserved.

Before You Start

Take some time to learn about symptoms or important situations your child may be experiencing so that you know what to do, who to call, and when to call. Memorize the phone numbers or put them in a place where you and your child's caregivers can easily find them.

When should I call after business hours?

Call if your child is having one or more of these symptoms:

- **Fever** with a temperature **above 101 degrees** Fahrenheit (F) or 38.5 degrees Celsius (C).
- **Two blood pressure readings** that are **NOT normal** for your child. Check often so that you know your child's normal range!
- Vomiting
- Diarrhea
- Not urinating (peeing) regularly
- Not drinking enough over 24 hours

© 2022 Intermountain Healthcare. All rights reserved.

© 2022 Intermountain Healthcare. All rights reserved.

When to Call and What to Do

Situation	**Symptoms** (Examples, not all-inclusive)	**What to do**
Life-threatening situations	Shortness of breath, chest pain, uncontrollable bleeding	**Call 911 right away!** DO NOT call the transplant office or the nephrologist on-call.
Condition needing immediate medical attention, but not necessarily life-threatening	Broken bones, brief loss of consciousness, falls	**Go to the nearest ER.** Tell them that your child had a kidney transplant and they will contact the on-call nephrologist if necessary.
Urgent medical problems, but not life-threatening	See symptoms listed below	**Call the kidney transplant office at 801-662-6800 during business hours.** After hours, have the on-call nephrologist paged through the Primary Children's Hospital operator at 801-662-1000.
• Medication prescription refills • Medication questions • Scheduling appointments • Lab results • Paperwork • Clinic follow-up	Symptom free	**Call the kidney transplant office at 801-662-6800 during business hours.** The on-call nephrologist should not be called for issues that can be taken care of by the transplant office during business hours.

When to call your transplant doctor or other care team members

To best manage possible rejection, call the transplant center right away if your child:

- ☐ Has a drop in the amount of urine (pee) or has blood in their urine
- ☐ Has a fever above 100°F (38°C)
- ☐ Has tenderness in the area of the new kidney
- ☐ Feels like they have the flu
- ☐ Gains more than 3 pounds in 2 days
- ☐ Has symptoms of a respiratory infection (fever, cough, nasal congestion, runny nose, a sore or scratchy throat) or a cough or cold that will not go away
- ☐ Forgets to take any dose of anti-rejection medication or takes it later than it should be

To best manage infections, call your doctor as soon as possible if you have:

- ☐ A fever above 100°F (38°C)
- ☐ Sores, wounds, or injuries (especially if they fail to heal)
- ☐ Drainage from a surgical scar
- ☐ Symptoms of a bladder or kidney infection (needing to pee more often, having pain or burning when peeing, having urine that is cloudy or reddish in color or smells bad)
- ☐ Symptoms of a respiratory infection (fever, cough, nasal congestion, runny nose, a sore or scratchy throat) or a cough or cold that will not go away

© 2022 Intermountain Healthcare. All rights reserved.

The Kidney Transplant Team

The Kidney Transplant Team is made up of medical professionals whose focus is to work **with** you to ensure the health and success of your child's kidney transplant.

Nephrologist [nef-RAWL-o-jist]**.** Pediatric nephrologists are doctors who specialize in treating kids with kidney disease and kidney failure. Our nephrologists will lead your child's healthcare team in developing a treatment plan that is right for your child.

Transplant surgeons. Transplant surgeons are physicians who specializes in surgery and perform the kidney transplant surgery. They are responsible for transplanting the new kidney into your child. They also supervise your child's surgical care before, during, and after the transplant surgery.

Transplant coordinator. The transplant coordinator is a nurse who has special training in the management of transplant patients. They are your key contact person for questions at any point before, during, and after transplant. The coordinator will:

- Help keep track of your child's condition while they are waiting for transplant.
- Provide family education before, during and after transplant.
- Coordinate the actual transplantation. This includes letting you know when a donor organ becomes available.
- Communicate any questions and concerns to the appropriate team members before and after your child's transplant.

After your child's transplant, you will see the nurse coordinator in clinic. You will be communicating with them frequently, regarding your child's progress, labs, questions and concerns.

Financial coordinator. This is someone who will help you with the financial aspects of your child's transplant and aftercare. They will help you understand how your insurance plan will cover the costs of transplantation evaluation, surgery, and follow-up care. The financial coordinator, along with your transplant coordinator, will contact your child's insurance company to determine transplant benefits and help with pre-approval of the transplant surgery and the hospital stay. They will also help you determine if you can get help from any federal insurance plans, such as Medicare.

Social Worker. Social workers are trained to help people during difficult times in life. Our social workers help you and your child with challenges that may come from living with kidney disease and maintaining dialysis treatments. Your child's social worker can connect you to helpful resources.

Child Life Specialist. Child life specialists are experts in child development. They work to ensure life remains as normal as possible for children in the dialysis center and after a kidney transplant. Our child life specialists will work with your child and family to decrease stress and anxiety.

Dietitian [die-uh-TISH-un]**.** The transplant dietitian is an expert on the nutritional needs of children with kidney disease and those who have received a transplant. The dietitian will evaluate your child's nutritional status and will work with the other team members and your family to maximize your child's nutrition, before and after transplant.

© 2022 Intermountain Healthcare. All rights reserved.

Pharmacist. The transplant pharmacist monitors your child's transplant medications and provides education about them. The pharmacist teaches family and caretakers how to give medications and about the side effects.

Psychologist [sie-CAWL-o-jist]**.** A psychologist is someone with advanced training who specializes in counseling. They help provide support for the mental, emotional, and behavioral needs or your child and you. They can teach coping skills and help with the stresses of having a chronic disease. While there is not a specific psychologist or behavioral health specialist assigned to our kidney transplant patients, one can be recommended.

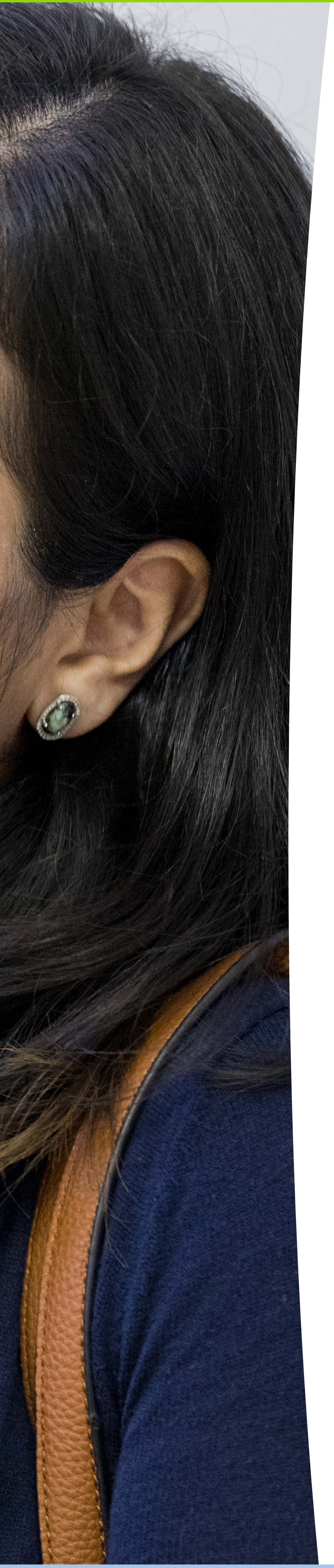
Administrative assistant. The administrative assistant, also called a clinic coordinator, will be the first person you speak with when you call the transplant office. The clinic coordinator will direct your call to the appropriate team member, take messages if the person is unavailable, and help make arrangements for the transplant evaluation visit and any follow-up testing. They can help you make appointments for pre- or post-transplant clinics, get lab results, pass on information from the transplant team, and answer any general questions.

You and your child are a key part of the team

Together, you will work with members of the transplant team to ensure that your child's new kidney remains healthy. It's important to give the office 24-hour notice of any needed prescription refills. You will also need to find a primary care physician for your child. They will help you manage medical problems not related to your child's kidney transplant (such as ear infections, flu, and respiratory infections).

© 2022 Intermountain Healthcare. All rights reserved.

© 2022 Intermountain Healthcare. All rights reserved.



Caring for Your Child after Kidney Transplant

After a kidney transplant, your child's body will begin to respond as if they had their own healthy kidneys. However, it is important to know that a transplant is not a cure for chronic kidney disease (CKD). Your child will continue to need follow-up care. Most patients will have multiple transplants during their lifetime. A transplant can extend your child's life. Knowing what's involved in managing your child's care after transplant will improve their chances of a healthy life.

You and your child will need to:

- Keep all appointments with your transplant team and follow their advice on when to have lab tests and how often to see your child's doctor.
- Make sure your child takes all medications exactly as prescribed by their doctor. This will help keep their body from rejecting the new kidney. Your child will need to take these every day without missing a dose.
- Live healthy. Have your child eat healthy foods. Do not allow them to smoke or be around second hand smoke. Make sure they get regular physical activity. Help them reach and stay at an appropriate weight. This will reduce their risk of developing diabetes, heart disease, stroke, high blood pressure, and other conditions.

© 2022 Intermountain Healthcare. All rights reserved.

Tests to Be Done at Home

It is important for the kidney transplant team to be able to track trends in your child's health. This will help them decide on the plan of care that is best for your child and the health of their kidney. This means you and your child will be required to keep a daily record of your child's blood pressure, temperature, and weight. **Bring this record to clinic with you every time you come.**

You will need a:

- Blood pressure cuff (The first one will be provided by the kidney transplant program.)
- Reliable thermometer
- Scale
- Notebook to record all test results

Temperature	You will need to check your temperature at least once a day for the first 2 months after transplant, more frequently if your child is not feeling well. After the first 2 months, take temperatures as directed by the kidney transplant team. The temperature can be taken by mouth or under the arm. Fever in a kidney transplant patient may be serious. It may be a sign of rejection or infection. A temperature 101° F (37.7° C) or higher is considered a fever. Call the kidney transplant office if your child's temperature is **101°** or higher. After business hours, call the on-call nephrologist.
Weight	**You will need to check your weight every day after transplant.** Consistency is key! You should be using the same scale, at the same time of the day, and wearing approximately the same clothes. If you check your weight in the morning, be sure to weigh after emptying your bladder. Weight should be recorded every day in your record book. **Call the kidney transplant office if you gain more than 2 pounds in one day.** A sudden increase or decrease in weight can signal a problem.
Urine output	"Urine output" is the clinical name to describe how much your child is peeing. You will need to record your child's urine output for the first 2 weeks after they go home from the hospital. This does not need to be an exact measurement of urine, just how many times they are urinating in a 24-hour period. Urine output is an important indication of kidney health. Going less often may be a sign of serious problems. Plus, it is good for your child to get in the habit of paying attention to how many times a day they normally urinate. Call the kidney transplant office or the on-call nephrologist if your child has a decrease in urine output, pain with urination, blood in their urine, or has cloudy urine.
Blood pressure (BP)	After transplant, you will be asked to record your child's blood pressure twice a day—once in the morning when they get up and again at bedtime. If your child is on blood pressure medications, take their blood pressure before your morning or evening doses. This helps to ensure their blood pressure isn't too low before taking their medications. Your discharge instructions will have guidelines to follow for managing your child's blood pressure. These will help you know when to call your care team with any concerns.

© 2022 Intermountain Healthcare. All rights reserved.

Taking your child's blood pressure

Accuracy is critical. Here are some important points to remember:

1. **The blood pressure cuff needs to be the correct size.** A properly sized cuff is one in which the inflatable part of the cuff completely encircles the upper arm.
2. **Rest for at least 5 minutes** before checking your blood pressure.
3. **Sit in a comfortable position with both feet flat on the ground and your back supported.** It is best to have your arm raised to the level of your heart on a desk or table. Remember to sit still and avoid talking during the reading.
4. Remember, **do not take a blood pressure reading in an arm that has dialysis access or fistula**.

Before you leave the hospital, you will be given high and low blood pressure guidelines. **Please call the kidney transplant office if you get 2 readings in a row that are outside of those guidelines.**

Key points to remember about home vital signs

Consistency is key! Use the same scale, thermometer, and blood pressure machine every time. Have your child wear the same clothes (or no clothes) when being weighed. Vital signs will be affected by the activities that your child was doing right before the test.

Always check your child's blood pressure if they feel **sick** or have a **headache**. The transplant coordinator or the on-call nephrologist will ask for this information when you call. It helps the doctor figure out what is going on with your child's new kidney.

If any changes are noted from day-to-day, such as a change in blood pressure, temperature, or weight, **please call the kidney transplant office** to see if these changes are significant. Waiting to see if problems will go away on their own often leads to spending time in the hospital and may damage the new kidney.

As you get further out from transplant, the need to record daily vital signs will decrease. However, it is important that you check vitals on a regular basis. Keep in mind, **the time that it takes to test your home vital signs daily is much less time than a hospitalization for a rejection episode.** These vital signs can help you and your care team detect problems with your kidney before any damage occurs.

© 2022 Intermountain Healthcare. All rights reserved.

Transplant Clinic Visits and Labs

A typical schedule for follow-up care with the transplant team will include the following blood tests and clinic visits. Please be aware that this schedule will vary according to how well your child is doing. A typical clinic schedule is shown below.

Month	Clinic Visits	Blood Work
1st Month	Every Tuesday and Friday	Every Tuesday and Friday
2nd Month	Every Tuesday	Every Tuesday and Friday
3rd Month	Every other Tuesday	Every Tuesday
4th to 6th Months	Every other Tuesday	Every other week
7th to 12th Months	Every 4 weeks	Every 4 weeks
After 12 Months	Gradually increase to once every 3 to 4 months, maximum	Every 4 weeks

If you do not live locally, you may need to stay in the local area for the first month after being discharged from the hospital. Your social worker can help you explore available housing options

Why are labs and clinic visits so frequent the first year?

- The first 3 months after a transplant is when there is the greatest risk for infection. This is due to the higher immunosuppressant medications given right after transplant.
- The team needs to regularly check the levels of tacrolimus in your child's blood to make sure they stay within target range. Many changes are made in the first 3 months.
- Frequent visits allow your child's care team to watch for an acute rejection.

© 2022 Intermountain Healthcare. All rights reserved.

What to expect on a transplant clinic day?

1. It is best to have your child's labs drawn before the clinic visit. This gives the team the most current information in case they need to make changes to your care plan while you are at the clinic. (Register for your lab draw at the Primary Children's Outpatient lab on the 1st floor of the Eccles Outpatient Services building.)
2. **Bring your home vital sign record to each clinic visit for review, as well as your medication bottles and pill organizer to check for accuracy.**
3. Check in at Station 5 on the 3rd floor of the Eccles Outpatient Services building. At each visit, you will need to fill out a "Pediatric Kidney Transplant Clinic Intake Form" while you are in the waiting room. You will need to have a list of medications your child is currently taking. Please fill out the form completely and accurately at each visit.
4. In the exam room, your child will be asked to give a fresh, clean-catch urine sample for routine urinalysis. **Do not let your child go to the bathroom right before coming to the clinic.**
5. Your child will be weighed and measured, have their blood pressure checked, and temperature taken.
6. You and your child will meet with the transplant pharmacist and pharmacy technician, dietitian, nephrologist, social worker, child life specialist and transplant coordinator.
7. At the end of each appointment, the transplant coordinator will review your printed clinic "Visit Summary" to make sure your questions have been answered regarding the plan of care. At that time, you will be given an appointment for your next clinic visit.

© 2022 Intermountain Healthcare. All rights reserved.

What do I need to know about lab work?

Lab work needs to be done on a regular basis. This allows the transplant team to closely follow your child's kidney function, infection markers, and drug levels. Sometimes blood work is the only way for the nephrologist to detect a possible rejection. It is one of the most important things you can do after transplant to keep your child's kidney healthy and happy.

Important points with lab work:

After the transplant, your child will likely be able to go back to their normal activities. **Parents should talk with their doctor about any concerns they have related to their child's future sexual activity, fertility, or pregnancy.**

1. **Appropriate timing of your child's lab draw is extremely important!** It needs to be drawn as close to 12 hours after the last dose of tacrolimus as possible. If your child takes extended-release tacrolimus, the timing of the lab draw should be 24 hours from your child's last dose. This will be about 30 minutes before the time of their next dose. The transplant team understands that the lab can delay your child's draw time, even if you are there on time. **We advise you to arrive at the lab 30 minutes or more (depending on your lab) before the desired time** in order to ensure that your labs are drawn right before the next dose of tacrolimus. **If blood is drawn more than 1 hour late or early, the result will not be accurate. Inaccurate timing of labs wastes both your time and money.**
2. **Do not give your child their dose of tacrolimus until after the blood is drawn.** Taking the dose before the blood draw causes the tacrolimus level to be incorrect. Bring your child's tacrolimus dose with you so they can take it immediately after the blood draw is finished. They can take all other medications as usual.
3. **It is your responsibility to make sure the lab faxes your child's results to the kidney transplant office.** The fax number is **(801) 662-6810**. The fax number is also located at the top of every lab order form, including your child's standing order.
4. Call the kidney transplant coordinators at **(801) 662-6809 (lab line)** to let them know **when** and **where** the labs were drawn. The line goes directly to a voicemail. This system ensures the labs are received and reviewed and not missed because the lab did not fax them to the office.
5. The transplant coordinator will call with the lab results.

If your child is getting lab work done at Primary Children's Eccles Outpatient Services, the lab hours are:

7:00 am to 6:00 pm
Monday through Friday

If it is after 6:00 pm, on the weekend or a holiday, you can still have your labs drawn at the inpatient lab at Primary Children's Hospital, located on the 1st floor of the main hospital.

© 2022 Intermountain Healthcare. All rights reserved.

Are there doctors I need to see on a regular basis?

Yes! There are doctors that you need to see after transplant. They include:

- **Primary care doctor:** A primary care doctor is a key member of your child's healthcare team. They will to help you manage medical problems not related to the kidney transplant. This could include ear infections, influenza, respiratory infections, and other common childhood illnesses. These healthcare providers also provide preventive care exams and immunizations. If your child does not have a primary care doctor, we can help you find one. **Remember that nephrologists are not primary care doctors!**
- **Dentist:** We recommend a routine dental appointment every 6 months to have your child's teeth cleaned and examined.

  During the first 6 to 12 months after transplant, your child should have a dose of antibiotics at least 1 hour before the appointment if they are having their teeth cleaned or filled, or having dental surgery. You can ask your child's dentist to order these. If there are any questions about this recommendation, please call us.

- **Other specialists (as needed):** Your child may also need to see other specialists, such as a urologist (for problems with their urinary tract), a dermatologist (for problems with their skin), or a cardiologist (for problems with their cardiovascular system).

Be sure to let any doctor or dentist caring for your child know that your child has had a kidney transplant. Give them a list of the medications your child is currently taking.

© 2022 Intermountain Healthcare. All rights reserved.

Watching for Complications

Possible complications with a kidney transplant are listed below:

High blood pressure (hypertension)

Many patients have frequent high blood pressure readings. This is called hypertension. It happens because the medications that help prevent rejection of the transplanted kidney may also cause high blood pressure. It is also common for patients who had high blood pressure before transplant to see an increase in their blood pressure after the transplant. Untreated high blood pressure can damage the kidney and other organs. That is why it is so important that blood pressure readings are done regularly at home.

Infection

Infection may occur because your child's immune system has allowed other "invaders" (besides the transplanted kidney) to remain and live inside your child's body. The same medications that are so helpful in preventing rejection may also make it harder for your child to fight infection. This means that infection can occur and spread much more quickly. Infection is more likely to occur during the first few months after transplant when doses of immunosuppressive medications are highest. In general, patients are most likely to develop infections in the urinary tract and lungs. Remember to always call the transplant office or on-call nephrologist if symptoms appear. You will probably be asked to get lab tests.

Most common infections and symptoms

Urinary tract infection

- Fever
- Having to urinate more often
- Sense of urgency to urinate
- Burning pain when urinating
- Cloudy urine

Lung infection

- Yellow, green, or bloody sputum [SPYOO-tum]
- Chest pain
- Fever

Wound infection

- Swelling, pain, or redness around a wound
- Increased or new drainage from a wound

What can I do to prevent infections?

- Wash hands often, especially before or after eating and handling food.
- Avoid people who are sick. Have your child wear a mask when in public to reduce exposure.
- Avoid large crowds for the first 2 to 3 months after transplant.
- Teach your child good hygiene (cleanliness).
- Teeth should be brushed twice and flossed daily. Have them take antibiotics before dental procedures as recommended.
- Watch for signs and symptoms of infection and report any to the transplant team.
- Keep your child up-to-date with their shots, including COVID-19 and flu vaccines.
- Give your child a well-balanced diet.
- Do not allow your child to share eating utensils.
- Do not allow them to clean up animal waste.

© 2022 Intermountain Healthcare. All rights reserved.

Special infection risks after transplant

Cytomegalovirus [si-tow-MEHG-uh-low-vi-rus] (CMV)

CMV is the mostly commonly seen viral infection in transplant patients. CMV is a common virus that infects people of all ages. CMV is not a serious illness for most people who are healthy. Most healthy people with CMV do not have any signs or symptoms because their normal immune system keeps the infection "silent." A CMV infection can be more serious for patients with a suppressed (or weakened) immune system. Signs and symptoms may include:

- Sore throat
- Swollen lymph nodes
- Fever
- Headache
- Fatigue
- Weakness
- Muscle aches
- Loss of appetite
- Nausea, vomiting
- Decreased white blood cell count

Epstein-Barr virus (EBV)

EBV is another common virus that most people have been exposed to by the time they are adults. EBV is an infection that can cause "mono" (mononucleosis). In a healthy person, symptoms are usually mild, and the disease is self-limiting. However, in a transplant patient with a decreased immune system, this virus can lead to a serious condition, known as PTLD (post-transplant lymphoproliferative disease). PTLD is a cancer-like condition that occurs in a small percentage of transplant recipients. Your child will be monitored frequently during the first year of transplant then every 6 months for this virus. The virus is diagnosed through blood tests and physical examination. It is treated with antiviral therapy and reduction of immunosuppression.

Signs and symptoms may include:

- Fever
- Sore throat
- Fatigue
- Abdominal pain
- Swelling of lymph nodes in the neck

Post-transplant lymphoproliferative [lim-fo-pruh-LIFF-er-uh-tiv] disorder (PTLD)

This disorder is almost always related to EBV but some patients can develop PTLD without being EBV positive. It is specific to patients who are on long-term immunosuppression. One or 2 out of 100 patients who have an organ transplant will get it. Treatment may include decreased immunosuppressant therapy, biologic, or chemotherapy. If PTLD is discovered, your kidney transplant team will work together with the oncology (cancer treatment) team to determine the best treatment.

BK virus

This is another virus that affects many people, and is usually dormant (silent) in people with normal, healthy immune systems. However, this virus can cause damage to a transplanted kidney in patients who have a decreased immune system. BK virus can be detected in the urine and the blood. Kidney transplant patients are regularly checked for BK virus every 3 months for 2 years.

Treatment includes reducing the anti-rejection medication to allow the immune system to fight the virus, and sometimes medications.

© 2022 Intermountain Healthcare. All rights reserved.

Watching for Complications (Continued)

Pneumocystis carinii [new-mow-SIS-tis-care-in-ee] pneumonia (PCP)

Also known as pneumocystis jiroveci [new-MOW-sis-tis-jee-ruh-VEH-chee] pneumonia (PJP)

This is a type of pneumonia that can be very serious in patients with a decreased immune system. Symptoms may include fever, dry cough, shortness of breath, chest discomfort, and fatigue. Because this condition can progress quickly, it is important that you notify your transplant physician or transplant coordinator, as soon as possible, if your child experiences these symptoms.

Bactrim is the brand name of an antibiotic that is a combination of other 2 antibiotics—trimethoprim and sulfamethoxazole. It is given to kidney transplant patients as way to prevent this type of pneumonia. This is why PCP rarely occurs today. If any other doctor recommends stopping this medication, please contact your transplant coordinator or transplant physician before you make any changes to your medications.

Treatment for PCP usually includes admission to the hospital and the use of IV antibiotics.

Non-melanoma skin cancer

Because transplant patients take medication to suppress their immune system, they have an increased risk of developing skin cancer. In some cases, the risk is 65 times greater, compared to people who have not had a transplant.

Additional risk factors for developing skin cancer also include:

- Fair skin
- Lots of freckles
- Red or blonde hair
- Blue, green, or hazel eyes
- Extensive sun exposure
- Family history of skin cancer
- Previous history of skin cancer

Almost all skin cancers can be cured if detected early. It is very important to check your child's skin frequently, looking for any new or changing growths (such as changes in moles, bleeding spots, pink patches, or spots). It is also important to have your child checked regularly by a dermatologist.

Tips for skin protection strategies:

- Use sunscreen with at least sun protection factor (SPF) of 30 or greater
- Re-apply sunscreen every 2 hours while outdoors, or if your child is swimming or sweating
- Have your child wear sunglasses, protective clothing, and a broad-brimmed hat
- Limits outdoor activities between 10:00 am and 4:00 pm. This is when the sun's rays are the strongest
- Avoid tanning booths

© 2022 Intermountain Healthcare. All rights reserved.

Kidney Transplant Rejection

Kidney rejection is when your child's immune system attacks the donated organ. Rejection is common in transplant patients and happens because the body recognizes the organ as a foreign object. A rejection episode can happen despite everyone's best efforts to prevent it. Early detection can improve your child's chances of keeping the transplanted kidney. Report any signs or symptoms of possible rejection to your child's transplant coordinator or transplant physician as soon as possible.

How does rejection happen?

Your child's body has a wonderful natural defense called the immune system. This is the system that fights diseases and infections caused by "invaders." These "invaders" may include bacteria, viruses, and a kidney transplanted from someone else. Even a common cold or flu wakes up your child's entire immune system.

The immune system has a complex army of protective chemicals and cells that are called into action to fight invaders. They include white blood cells (lymphocytes), T-cells, B-cells, and antibodies. The problem is that your child's immune system cannot tell the difference between a common cold and a helpful transplanted kidney. The immune system wants to defend the body. When it does, it is possible to have a kidney rejection episode.

What are the main signs and symptoms of rejection?

Creatinine and blood urea nitrogen (BUN) levels are considered "renal function tests." They are blood tests that measure the status of the kidney. Other signs include:

- Abdominal (belly) or kidney transplant tenderness or pain
- Swelling of ankles, hands, and face that cause weight gain
- Flu-like symptoms
- Feeling tired
- Not urinating very often
- Rising blood pressure
- Not hungry
- Feeling sick or not as healthy as normal
- Fever

Some patients do not have any physical signs or symptoms, other than increased creatinine levels. This is why is so important to have lab tests done on a regular basis and as directed by the kidney transplant team. Elevated renal function tests are the earliest sign of rejection. Steps to prevent rejection include:

- Taking all medications exactly as instructed by your transplant team. Never run out of your immunosuppressive medications.
- Attending all transplant clinic visits and getting your lab work done as directed.
- Monitoring your home vital signs.
- Seeing a doctor when you get sick! Be sure to call the transplant office and let us know what your doctor told you to do, especially if you are prescribed new medications.
- Calling the clinic right away if you have any of the listed signs and symptoms.

About rejection

- Rejection does not mean you will lose your transplanted kidney.
- Rejection treatments may require hospitalization. A kidney biopsy is often necessary for diagnosis.
- Patients may have one or more episodes of rejection.
- Chances of rejection decrease over time, but can happen at any time.
- Rejection can happen suddenly, or may occur over a long period of time.
- Early detection of rejection improves chances of keeping your transplanted kidney.

© 2022 Intermountain Healthcare. All rights reserved.

Medications After Transplant

When your child gets a new kidney, their body may see it as an "invader" and respond by trying to attack it. This is how rejection episodes can occur. To help keep their body from attacking or fighting the new kidney, medications must be taken for as long as they have their transplanted kidney.

Your child's medications prevent rejection. Sometimes, missing even one dose is enough to cause rejection. Your most important responsibility after transplant is to make sure your child takes their medications exactly as directed by their doctor. Not doing so is one of the leading causes of transplant failure in pediatric and adolescent transplant patients.

The transplant pharmacist will provide education about medications before and after transplant, including during follow up clinic visits. Children should also learn about their medications by helping to prepare their daily doses, with the goal of eventually calling the pharmacy to order their own refills. Teach these skills to your child as soon as possible.

Medications and dosages differ from patient to patient. Some things that affect how medications are given include:

- Age
- Weight
- Height
- Absorption of the drugs
- Transplant issues

Some medications do not mix well with others. It is important to let the transplant team know ALL the medications you are taking, including over-the-counter and herbal medications or essential oils.

Please bring your medications with you to clinic so you can let the transplant coordinator, pharmacist, or pharmacy technician know if you need any medication prescription refills.

It is your responsibility to make sure your child does not run out of refills and always has enough medications on hand. Allow at least 48 business hours for the transplant office to refill any prescriptions.

Helpful medication hints

- Give your child their medications at the same time every day (generally, 8:00 am and 8:00 pm) without missing any doses, even if they feel fine. **Remember, missing even one dose can lead to rejection.**
- If your child misses a dose, have them take it as soon as you remember **and** if it is within 6 hours of the normally-scheduled dose. If it has been more than 6 hours from the time they usually take a dose, skip the dose and get back on their normal schedule. If you do miss a dose, tell your transplant coordinator.
- **Do not stop or change any medications for any reason** (such as the cost of the medication, adverse effects, and so on). Talk with the transplant team first. The social worker, transplant coordinator, or financial advisor can help with finding funds for the medications, if needed. If your child is having side effects, the dosage of the medication may be changed, or a new medication may be prescribed.
- Keeping a record, like a chart or calendar, will help you keep track of their medications. You can also keep track by using the printed Medication Action Plan (updated copies provided in clinic), the MyMedSchedule Plus app, alarms on your phone, or a pill box.
- **If your child vomits within 30 minutes of taking their medications, they should take another dose.** If it is been longer than 30 minutes, wait until the next dose is due.
- Never run out of medications. Keep at least a 1-week supply available.
- Only give the medications prescribed for your child. Check with the transplant coordinator or pharmacist before giving any new medication or herbal product, including over-the-counter cough, cold, and allergy medications, antacids, and essential oils.

© 2022 Intermountain Healthcare. All rights reserved.

When should I call the transplant team about my child's medications?

You should call if you have any confusion about the correct medication dose, or your child:

- Is unable to take their medication because they are nauseated, feeling sick, or vomiting.
- Has diarrhea and you are worried if they are absorbing the medications.
- Has forgotten to take their medication or missed any doses.
- Is having an unusual reaction or adverse effects from the medications.
- Would like to take any over-the-counter cold remedy, cough suppressant, herbal medication, or medication you have not previously discussed with the transplant team.
- Is prescribed new medications by a provider that is not your transplant physician.

What do I need to know about my child's medications

Here are some questions that you should ask yourself:

Are the medications brand or generic?

This is particularly important with the immunosuppressant medications tacrolimus (Prograf / Envarsus XR) and mycophenolate (CellCept / Myfortic). Knowing both the generic and brand names can help you identify the medications your child takes. It is also helpful to know which manufacturer made the pills, as levels can vary from brand-to-brand.

What is the purpose or reason for taking the medication?

See the medication descriptions on pages 24 to 28.

How should my child take their medications?

Follow the instructions about what time of day, whether they should take it with food, and if they cannot be crushed, etc.

What are the most common side effects of the medications?

See side effects listed on the following pages. If your child is having side effects, contact the transplant coordinator to see if anything can be done to resolve them.

What do my medications look like?

Knowing what your medications look like can help you recognize if you are taking the correct medication.

Make healthy choices

Possible side effects of post-transplant medications are weight gain and developing diabetes or heart disease. However, you can help reduce these risks if your child:

- **Maintains a healthy weight.** Follow a healthy diet with the help of their dietitian.
- **Controls high blood pressure and cholesterol.** Provide a low-salt, heart-healthy diet (such as the DASH diet), give prescribed medications for these conditions, and check their blood pressure every day.
- **Remains physically active** (as directed by their doctor).
- **Avoids exposure to second-hand smoke, or smoking.**
- **Controls their diabetes**. Follow their care plan for medications, diet, and glucose monitoring.

© 2022 Intermountain Healthcare. All rights reserved.

Anti-rejection medications

Tacrolimus (Prograf / Envarsus XR)

Purpose

Suppresses the immune system to prevent and treat rejection after transplant.

How supplied

- Capsules – 0.5 mg, 1 mg, 5 mg
- Compounded Liquid – 1 mg / mL
- Extended release tablets – 0.75 mg, 1 mg, 4 mg

Information

- Take it at the same time each day, 12 hours apart (preferably at 8:00 am and 8:00 pm) for immediate release tacrolimus (Prograf). If you normally take your tacrolimus with food, always take it with food. If you normally take your tacrolimus on an empty stomach, always take it on an empty stomach. Be consistent with how you take your tacrolimus.
- If you take Envarus XR it should be taken at the same time each day, 24 hours apart, preferably in the morning. It is best to take on an empty stomach but talk with your transplant pharmacist if this doesn't work for you.
- Do not cut, open, or break tacrolimus capsules and tablets.
- Store tacrolimus compounded liquid at room temperature.
- Do not eat grapefruit or pomegranate or drink grapefruit juice or pomegranate juice while taking tacrolimus. This can make your tacrolimus level go too high.
- Many medications can interact with tacrolimus, which could increase or decrease the tacrolimus levels.

Levels are monitored by blood draws taken just before the morning dose (about 12 hours after last dose for immediate-release tacrolimus / Prograf or 24 hours after last dose of extended-release tacrolimus / Envarsus XR). Accuracy in blood draw timing will provide the most accurate results to prevent overdosing or repeat lab draws.

Abbreviations:

mg: milligrams

mL: milliliters

Most common adverse effects

(More common with higher blood levels)

- **Nervous system.** Headache, trouble sleeping, hand tremors
- **Kidney.** Can decrease blood flow into the kidney. If this happens you can have high blood pressure or abnormal kidney function tests.
- **Infection.** Lowers your body's ability to fight infection, putting you at higher risk to develop an infection
- **Other.** Nausea, diarrhea, high blood sugar and risk of diabetes, hair thinning, low magnesium and phosphorous levels, and high potassium levels

There is a higher risk of cancer for people taking tacrolimus long-term. Skin cancer is the most common, so remember to protect your skin with sunscreen with an SPF of 30 or more.

Mycophenolate (CellCept / MyFortic)

Purpose

Suppresses the immune system to prevent and treat rejection after transplant.

How supplied

Mycophenolate mofetil (CellCept):

- Tablet / Capsule – 250 mg, 500 mg
- Oral suspension 200 mg / mL

Mycophenolate sodium, delayed release (Myfortic):

- Tablet – 180 mg, 360 mg

Information

- Take twice a day, with or without food. Taking with food may help with stomach upset.
- Only take the dosage ordered by your doctor.
- Do not cut, open, crush, or break mycophenolate capsules or tablets
- If you miss a dose or are unsure if you took one of your daily doses, **do not take a double dose.** Call the transplant office to let them know.

© 2022 Intermountain Healthcare. All rights reserved.

- Oral liquid mycophenolate is good for 60 days after you get it from the pharmacy. Store at room temperature. Discard any remaining medication after 60 days and get a refill.
- Females of childbearing age should use 2 forms of contraception (protection) while taking mycophenolate and for 6 weeks after stopping this medication because it harms the unborn child (birth defects). **Females who want to become pregnant, are pregnant, or are breast feeding should wear gloves and practice good hand hygiene when handling mycophenolate.**

Most common adverse effects

May lower the number of white blood cells (infection fighting cells)

- Nausea, upset stomach, vomiting
- Diarrhea

Prednisone / prednisolone (steroids)

Purpose

- Prevents and treats transplant rejection. It stops white blood cells from attacking the new kidney.

How supplied

- Liquid, tablets, intravenous

Information

- Take with food to decrease stomach upset.
- Check the strength of your prednisone to make sure you are taking the correct dose.
- **Never suddenly stop taking prednisone!** Steroid doses must be lowered slowly because the body can become sick if it is stopped suddenly.

Most common adverse effects

Steroid adverse effects are dose related. The higher the dose, the greater the risk of adverse effects.

Short-term adverse effects

- Upset stomach and stomach ulcers. Always take this medication with food.
- Changes in physical appearance, such as round cheeks, increased growth of facial and body hair, and acne.
- Increase in appetite. Your child can gain a lot of weight unless they are careful about their diet. Providing a healthy diet and exercising regularly can help your child prevent weight gain.
- Increased risk of infection, especially while on high doses. **Avoid people with obvious infections** and practice good hand washing.
- Decreased ability for the body to heal. It may take longer for wounds to heal.
- High blood glucose, which sometimes requires control by diet and insulin. This condition usually gets better or resolves when your dosage is lowered.
- Emotional changes or difficulty sleeping. Normal "moods" or emotions be exaggerated. This is often unexpected and can be seen by other family members as irritability. By educating those closest to your child, the effects of these mood changes can be minimized.

Long-term adverse effects

- Changes in physical appearance such as enlarged stomach and fat deposits over upper back. Weight control and high protein or low-fat diet may make these changes less noticeable.
- Fragile skin, pigment changes, and increased risk of cancer, usually in the form of skin cancer.
- Delayed growth and fragile bones. High doses of steroids delay growth in children. The dietitian will check height and weight during clinic visits. Extra calcium and vitamin D might be needed to help build strong bones.
- Eye problems, such as blurred vision, cataracts and glaucoma. Regular eye exams by an ophthalmologist, not an optometrist, are needed.

© 2022 Intermountain Healthcare. All rights reserved.

Anti-infection medications

Taking medications that lower the immune system and prevent rejection of your transplanted kidney can increase the risk of getting certain infections. Here are some medications that help prevent infections:

Trimethoprim / sulfamethoxazole (Bactrim, Septra)

Purpose

Prevent urinary tract infections (UTIs) and PCP pneumonia.

Adverse effects

- Can make it easier to get a sun burn. Protect your skin!
- Nausea, vomiting, diarrhea
- Rash

This medication is usually taken for 2 months after transplant or longer if needed for UTI prevention. Will restart this medication if strong medications are needed to treat rejection.

Fluconazole (Diflucan)

Purpose

Prevents a type of fungal infection in the mouth and throat called thrush.

Adverse effects

- Nausea, vomiting, diarrhea
- Interacts with tacrolimus, so the tacrolimus dose may need to be changed if starting or stopping this medication.
- Usually taken for 1 month after transplant and restarted if strong medications are needed to treat rejection.

Valganciclovir (Valcyte) / **Valacyclovir** (Valtrex) / **Acyclovir** (Zovirax)

Purpose

Prevents or treats certain viruses, such as CMV or herpes simplex virus (HSV) that are more common in patients with suppressed immune systems.

Adverse effects

- Low white blood cell count and platelet count
- Nausea, vomiting
- Headache

The specific medication your child receives depends on their viral risk level.

This medication is usually taken for 3 months after transplant and restarted if if strong medications are needed to treat rejection or your child has a viral infection.

Medications to avoid

The following medications contain ibuprofen or naproxen and should be avoided. Please be aware that this list in not inclusive and you should always read labels.

- Advil
- Aleve
- Motrin
- Nuprin
- Midol
- Pamprin-IB

e

Avoid products that contain salicylate, the active ingredient in aspirin (for example, Pepto Bismol). These medications can damage your child's kidney if they are taking immunosuppressants.

Do not give your child any new medications without first checking with the Transplant Coordinator to verify they are safe to take. Do this anytime a new medication is prescribed by anyone other than your child's Transplant Nephrologist (including those prescribed by your child's primary care doctor).

© 2022 Intermountain Healthcare. All rights reserved.

Stomach medications

These medications are used to protect your stomach against ulcers by reducing stomach acid. they are most frequently needed while taking steroids or aspirin. Two common medications used include:

- **Famotidine (Pepcid)**
- **Omeprazole (Prilosec)**

Supplements

It is not uncommon to need supplements to make up for deficiencies in your blood levels after transplant.

Iron (ferrous sulfate)

Anemia is common after transplant and may be treated in several ways. The easiest is an oral iron supplement. Take with meals or milk. Watch for signs of constipation. If anemia continues, your child may need a medication like epoetin alfa (Epogen / Retacrit / Procrit) or darbepoetin alfa (Aranesp) which are administered as injections.

Filgrastim (Neupogen / Granix / Nivestym / Zarxio)

- May be necessary if the white blood cell count falls too low
- Administered as injections

Magnesium, phosphorous, vitamin D (cholecalciferol), **and calcium**

May be necessary to replace low blood levels and help with bone strength

Sodium bicarbonate or sodium citrate / citric acid (Bicitra / Cytra-2)

May be necessary to increase bicarbonate levels / lower acid in the blood.

Over-the-counter remedies

Call the transplant office if you have any questions about your child's symptoms or over the counter remedies.

Treating coughs and colds

All children under the age of 4 should avoid cough and cold medications. Transplant patients should also avoid over the counter cough and cold medications that contain pseudoephedrine or phenylephrine, as these products can increase blood pressure.

Treating allergies

- Most over-the-counter allergy medications such as diphenhydramine (Benadryl), cetirizine (Zyrtec), and loratadine (Claritin) are okay to relieve allergy symptoms
- Avoid products such as Zyrtec-D or Claritin-D as these contain pseudoephedrine which can increase blood pressure

Treating pain and fever

- Acetaminophen (Tylenol) is safe to use for pain or fever. Make sure to not take more than the recommended daily dose.

  Many over-the-counter products contain acetaminophen. It is important to look at the ingredient labels before taking anything else with acetaminophen. Taking too much acetaminophen can make your child overdose.

© 2022 Intermountain Healthcare. All rights reserved.

Overview of common medications after transplant

Generic	Brand	Use
Tacrolimus	Prograf/Envarsus XR	Immunosuppressant, prevents rejection
Mycophenolate	CellCept/MyFortic	Immunosuppressant, prevents rejection
Prednisone/prednisolone	N/A	Prevents and treats transplant rejection
Trimethoprim/ sulfamethoxazole	Bactrim, Septra	Prevents certain bacterial and fungal infections
Fluconazole	Diflucan	Prevents certain fungal infections
Valganciclovir	Valcyte	Prevents certain viral infections
Valacyclovir, Acyclovir	Valtrex, Zovirax	Prevents certain viral infections
Amlodipine	Norvasc	Lowers blood pressure
Nifedipine	Procardia	Lowers blood pressure
Labetalol	Trandate	Lowers blood pressure
Lisinopril	Zestril	Lowers blood pressure
Famotidine	Pepcid	Prevents stomach ulcers, reduces stomach acid
Omeprazole	Prilosec	Prevents stomach ulcers, reduces stomach acid
Filgrastim	Neupogen, Granix, Nivestym, Zarxio	Treats low white blood cell count
Acetaminophen	Tylenol	Pain medication, reduces fever
Amoxicillin	Amoxil	Antibiotic
Amoxicillin/clavulanate	Augmentin	Antibiotic
Ciprofloxacin	Cipro	Antibiotic
Diphenhydramine	Benadryl	Antihistamine
Losartan	Cozaar	Lowers blood pressure
Ferrous sulfate	Ferosol	Iron supplement
Nitrofurantoin	Macrodantin	Antibiotic
Penicillin	Pen VK	Antibiotic
Sodium bicarbonate	N/A	Increases bicarbonate levels Lowers acid in the blood
Sodium citrate/citric acid	Cytra-2 Bicitra	Increases bicarbonate levels Lowers acid in the blood
Sodium/potassium phosphate	Phos NaK KPhos Neutral	Increases phosphorus levels

© 2022 Intermountain Healthcare. All rights reserved.

Nutrition and Transplant

Kidney transplant patients have few dietary restrictions if their kidney is working well. However, some of the immunosuppressive/anti-rejection medications and other medications you are on may cause changes in your body. Making healthful food choices can help lessen these side effects and help you achieve and maintain good overall health. It is important that you are familiar with some of the changes that may occur in your body related to your medications.

Nutrition problems from medications

Possible Problems	What can I do?
Unwanted weight gain	• Choose food wisely • Try low-fat cooking • Exercise regularly • Keep busy!
Low blood phosphorous	• Eat low-fat, high phosphorous foods (skim or low-fat milk, yogurt, low-fat cheese, extra-lean meats, chicken, dried beans)
High cholesterol and triglycerides	• Choose low-fat foods regularly • Exercise! • Lose weight, if needed • Increase soluble fiber
High blood glucose	• Space out meals • Limit intake of carbohydrates (sugar, starches) • Exercise regularly • Lose weight, if needed
High blood pressure	• Lose weight, if needed • Limit salt intake
Stomach irritation	• Space meals and snacks throughout day • Limit caffeine intake • Take prednisone with food
Bone changes and pain	• Take in enough calcium, either through diet and/or with supplements • Exercise regularly
High blood potassium (usually temporary)	• Limit high potassium foods and drinks until resolved

© 2022 Intermountain Healthcare. All rights reserved.

Diet Recommendations After Transplant

After surgery, the kinds of foods your child gets to eat will depend on how well the “new” kidney is working. If the kidney is not working well at first, they may need to remain on the pre-transplant diet for a while. This may include restrictions on protein, phosphorous, sodium, potassium and fluids.

Their diet will change once the kidney is working normally. However, because of the medications needed to prevent rejection, **they may still not be able to eat everything they want**.

Exercise and activity

Check with the doctor or transplant coordinator to make sure that their activities and exercises are medically appropriate.

Low salt

Less than 2000 mg per day

Calcium

1200 mg to 1500 mg per day

Calories

The right amount to reach and maintain ideal body weight

Protein

Enough to build and repair muscles and tissue

Low-fat and cholesterol

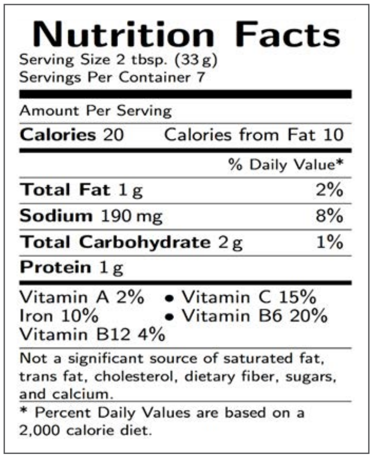
- One third of total calories from fat
- 250 mg to 300 mg cholesterol per day

© 2022 Intermountain Healthcare. All rights reserved.

Sodium

Reading food labels is helpful when trying to limit sodium intake. Ask your dietitian for help if you are having trouble or if you need ideas on healthful food choices. Look for "sodium mg" and pay attention to serving size.

Use herbs and other low sodium seasoning in place of salt. For example, basil, oregano, parsley, onion and garlic powders provide great flavor. Mrs. Dash® seasoning mix is a good commercially prepared no salt seasoning that comes in a variety of herbal combinations.



Nutrition Facts
Serving Size 2 tbsp. (33 g)
Servings Per Container 7

Amount Per Serving
Calories 20 Calories from Fat 10

% Daily Value*

Total Fat 1 g	2%
Sodium 190 mg	8%
Total Carbohydrate 2 g	1%
Protein 1 g	

Vitamin A 2% • Vitamin C 15%
Iron 10% • Vitamin B6 20%
Vitamin B12 4%

Not a significant source of saturated fat, trans fat, cholesterol, dietary fiber, sugars, and calcium.

* Percent Daily Values are based on a 2,000 calorie diet.

Calories

Because you child now has a healthy kidney, you may notice that their appetite is much bigger than in the past. Although many patients may need to gain weight at first, your child should do this slowly and stop when they reach the appropriate weight for their height and age. When gaining weight, it is best to **gain about 1 pound (.5 kg) per week** to rebuild muscles they may have lost because of kidney failure. If your child is at an okay weight at the time of transplant, they will need to be **very careful** with their diet to control weight over the next several months. It is not uncommon for new transplant patients to gain **20 to 30 pounds in the first 3 months** after a transplant if they do not make wise food choices.

Important points to remember when working to control weight:

Eat less sugar and concentrated sweets

Instead of:

- Cookies
- Candy
- Cake
- Sugary drinks (sodas, fruit punch, Kool-Aid)
- Juices (Although juices have "natural" sugar, they still have a lot of calories.)

Choose:

- Fresh fruit
- Canned fruit packed in water
- Lower calorie snacks

Limit fat intake

Choose nonfat and low-fat dairy and meat:

skim milk, nonfat yogurt, mozzarella cheese, extra lean meats, chicken and turkey breasts without the skin

Use low-fat cooking methods:

baking, broiling, grilling, non-stick pan with cooking spray

Keep a supply of low-calorie snack foods and drinks for nibbling between meals:

raw fruits and vegetables, low-calorie lemonade and iced tea (made with lemon juice and sugar substitute), low calorie and low sodium soups

Be active and exercise

Activity and exercise can help burn calories and avoid gaining too much weight. It also provides an improved sense of well-being,keep the heart strong and healthy, and increase muscle mass.

There are many low-fat and nonfat foods available now which can help with weight control. Remember to limit portion sizes and watch for sodium content.

Protein

It is important to get enough protein in your diet for building muscles and keeping your child strong and healthy. If they are eating well it is usually not hard to get the protein they need. Be sure to include high quality protein at meals and snacks. The usual portion is 3 to 4 ounces per serving, which is about the size of a deck of cards. High quality protein comes from animal sources such as eggs (limit to 3 per week if you have high cholesterol), lean beef and pork, fish, poultry, low-fat or skim milk, and other low-fat or nonfat dairy foods such as mozzarella cheese and low-fat or nonfat yogurt. You can also get protein from dried beans and peas. **Never give your child high protein sports drinks or powders unless specifically recommended by your transplant dietitian.**

Fat and cholesterol

Transplant medications and too much weight gain after transplant may cause your child's cholesterol and triglycerides to go up. This creates a higher risk for heart disease. Fat should be limited to 30 percent (one third) of total calories. Cholesterol should be limited to 300 mg per day or less. Remember that **all fats and oils are very high in calories**, even the "good" ones such as olive oil and canola oil, and should be used sparingly. It is better if fats and oils are made from polyunsaturated or monounsaturated vegetable oils. Examples are safflower, corn, soybean, canola, or olive oils. Read labels. The first ingredient should be liquid oil.

Calcium

Kidney transplant patients have a higher risk of bone disease due to kidney failure and long-term use of transplant medications. The medical term for bone disease is osteoporosis [oss-tee-oh-poor-OH-sis]. To prevent osteoporosis, **most transplant patients need between 1200 mg to 1500 mg of calcium per day.** To help replace lost calcium in the bones and increase bone strength, plan meals to include 3 to 4 servings of low-fat or nonfat, high calcium dairy foods each day. If your child does not like milk, try nonfat or low-fat yogurt and low-fat cheeses instead. If your child does not eat dairy, try foods like salmon, soybeans, tofu, spinach, and egg whites. Calcium-fortified foods such as juices, cereals, and breakfast bars can also help you meet your calcium needs. Be sure to ask your child's dietitian for recommendations.

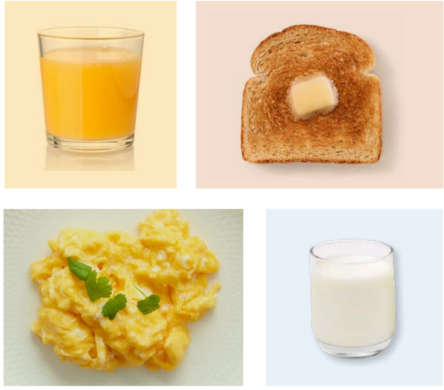
© 2022 Intermountain Healthcare. All rights reserved.

Recommended daily dietary allowances

Food Group	Foods to Use	Foods to Avoid
DAIRY 3 to 4 servings	• Skim, 1%, dry, or evaporated milk • Nonfat and low-fat cheeses (Healthy Choice, mozzarella) and nonfat or low-fat yogurt • Nonfat or low-fat sherbet, sorbet, • Ice milk, frozen yogurt	• Whole or condensed milk, buttermilk • Cheese (cheddar, Colby, American, processed), cheese spreads, cottage cheese, ice cream, creamer, whipped cream
MEAT / PROTEIN 3 ounces per serving 2 servings per day	• Beef, pork, lamb (lean, trimmed of fat) • Low-fat luncheon meets • Poultry without skin • Fresh, frozen, or water-packed fish • Egg whites or egg substitutes • Dried beans or peas • Old fashioned peanut putter	• Marbled, fatty, cured ham, bacon, sausage, hot dogs, luncheon meats • Goose, duck, capons • Fried or breaded chicken or turkey, organ meat (liver / kidney) • Breaded or fried fish • Egg yolks • Canned beans, pork and beans, peas • Peanut butter that is salted and hydrogenated (in small amounts: 1 tablespoon)
FRUITS and VEGETABLES 4 to 5 servings	• All fresh, frozen, and canned fruits and vegetables (without added salt)	• Coconut, avocado, olives • Deep fat-fried, or with cream or butter sauces • Vegetable juice cocktail
GRAINS 6 to 11 servings (depends on calorie needs)	• Hot and cold cereals • Homemade pancakes, waffles, or muffins prepared without egg yolks or oils • Rice, macaroni, spaghetti	• Granola type cereals • Packaged Items high in fat or eggs • Pasta made with egg yolks
FATS and OILS 5 to 8 servings (1 teaspoon = 1 serving)	• Soft margarine or oils, such as corn, safflower, sunflower, soybean, canola, olive, liquid margarine • Nonfat salad dressing and mayonnaise, nonfat dairy creamers • Unsalted nuts (small portions)	• Coconut or palm oil, butter, lard, animal fat, hydrogenated vegetable shortening • Full fat salad dressings, mayonnaise • Salted nuts • Cocoa butter, chocolate, non-dairy creamers
DESSERTS (on occasion)	• Angel food cake, flavored gelatins, Fig Newton cookies, animal crackers, graham crackers, ginger snaps • Plain hard candy, mints, soft jelly candy	• Commercially prepared cakes, cookies, custards, or puddings • Desserts made with whole milk or cream, egg yolks, coconut or palm oil, or animal fat
SOUPS	• Broth-based low sodium soups and bouillon • Fat-free gravies and sauces	• Canned soups (except low salt)
OTHER	• Herbs, spices, aromatic seeds, lemon juice, vinegar	• Salt, soy sauce, MSG, condiments (in very small amounts), any seasoning listing sodium in the first 3 ingredients

© 2022 Intermountain Healthcare. All rights reserved.

Recommended daily dietary allowances: *Meal Plan*



Breakfast

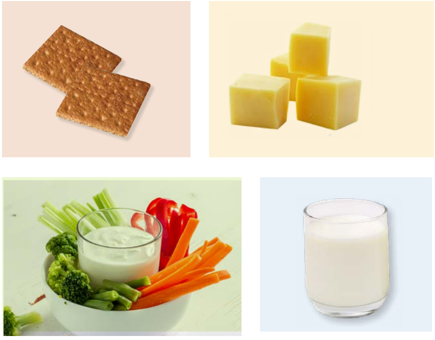
- Unsweetened fruit or ½ cup juice
- Once slice whole grain toast or ¾ cup dry cereal
- 2 egg substitutes or egg whites, scrambled
- One cup nonfat milk
- One teaspoon margarine, jelly, or honey

Lunch

- 2 ounces of lean meat, fish, chicken, or ½ cup low-fat cottage cheese
- 2 slices bread, 1 hamburger bun, or 2 small rolls
- 1 teaspoon margarine or mayonnaise
- Green salad with 2 teaspoons oil and vinegar dressing
- 1 medium apple, sliced
- 1 “100 calorie” snack pack
- 1 cup nonfat milk

Dinner

- 4 ounces of lean meat, fish, chicken, or turkey
- ½ cup of potato, rice, spaghetti, cooked dried beans
- ½ cup cooked or raw vegetables
- 1 small roll, 1 slice of whole grain bread, or 1 whole-grain tortilla
- Green salad with 2 teaspoons low-fat mayonnaise, oil, or salad dressing
- Fresh or canned fruit (½ to 1 cup, or 2 canned unsweetened peach halves)
- Margarine, 2 teaspoons



Evening snack ideas

- 4 low salt, low-fat crackers with 1 ounce of low-fat mozzarella cheese
- Carrot sticks, celery, cucumbers, broccoli with low-fat ranch dressing (1 tablespoon)
- 1 cup nonfat milk with 4 vanilla wafers
- Cereal with nonfat milk
- Low-fat or nonfat yogurt
- Low-fat cottage cheese and fruit

© 2022 Intermountain Healthcare. All rights reserved.

Fluids

After kidney transplant, it is very important that your child drink enough fluids to stay well-hydrated and limit stress on the kidney from medications. Your physician will tell you how much fluid is necessary per day.

What can I do to make sure my child is drinking enough?

Find a reusable water bottle they like and see how many ounces of water it holds. Then figure out how many times they need to fill it to meet their transplant fluid goals. If you do not have a water bottle we will give you one. You and your child can also use a phone “app” to help track how much they are drinking. Some good ones include: H2Overload (NKF), Drink Water Reminder, Waterly, Drink Water Tracker, My Water, Drink Water Aquarium, and Plant Nanny. It is best to drink fluids throughout the day rather than drinking a large amount just before bedtime (to make up for what you didn’t drink during the day).

Anything that is liquid at room temperature can be counted as part of the total fluid intake. The best thing to drink is water. If it will help your child to drink more, you can use flavor packets, such as Crystal Light or something similar. Just make sure they do not contain any added vitamins, herbs, energy boosters, or caffeine. Milk, chocolate milk, and juices diluted with water are also good choices. Soda and other sugary drinks should be limited to no more than 12 ounces per day. Less is better.

Always check with your Transplant Care Team (Nurse Coordinator, Transplant Nephrologist, OR Transplant Dietitian) before allowing your child to have sports drinks. Energy drinks frequently contain caffeine or other stimulants and will not help them stay well-hydrated. They are generally not healthy for your child or their kidneys. They can also increase blood pressure, which can be harmful to the new organ.

© 2022 Intermountain Healthcare. All rights reserved.

Dehydration

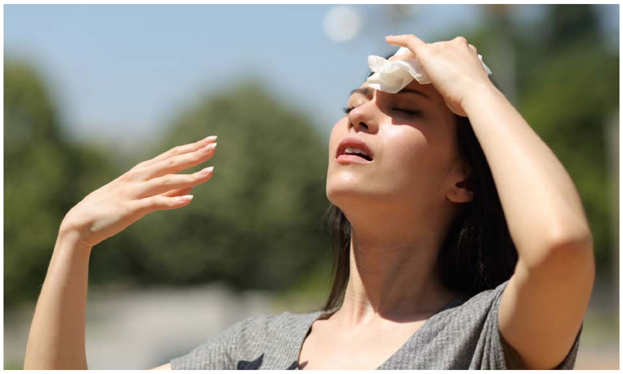
Dehydration is when the body doesn't have enough fluids to work property. Children who have had a kidney transplant can easily become dehydrated. It is especially worrisome in a child with a transplant because:

- The level of tacrolimus (Prograf) in your child's blood will increase, leading to kidney injury.
- Your child's blood will thicken, increasing the risk that the blood vessels of the kidney may become clotted.

The most common reasons for dehydration are excessive vomiting, diarrhea, and not drinking enough while exercising. Diarrhea due to infections can happen quickly in immunocompromised children and can cause dehydration.

To prevent dehydration, it is important to know these signs and symptoms:

- No urination for 12 hours. (If your child is less than 6 months old, they may continue to urinate even though they are dehydrated.)
- Dark circles under the eyes
- Sunken eyes
- Tired, weak, and lethargic
- Looks suddenly "skinny"
- Sticky mouth
- Increased thirst or hunger
- Sunken fontanel in infants
- Decreased weight
- Loose skin or tenting of the skin



If your child cannot keep fluids down or has signs of dehydration, contact the transplant team right away. Severe dehydration can be life-threatening.

© 2022 Intermountain Healthcare. All rights reserved.

Food safety

Because your child will have a weakened immune system, they have a higher risk of getting food borne illness (food poisoning). This is especially true right after transplant when medication doses are high. To protect your child, they should **avoid** the following foods:

- **Raw or cooked shellfish** including oysters, clams, mussels, and scallops
- **Raw or unpasteurized milk or cheeses** and soft cheeses, such as feta, brie, camembert, blue-veined and Mexican-style cheese. It is **okay** for your child to eat hard cheese (like Parmesan or Cheddar), processed cheese, cream cheese, cottage cheese, and yogurt.
- **Raw or undercooked eggs**, foods containing raw or lightly cooked eggs (including certain salad dressings), cookie and cake batter, sauces, and beverages such as unpasteurized egg nog. Foods made from commercially pasteurized eggs are safe to eat.
- **Raw or undercooked meat or poultry**
- **Raw sprouts** (alfalfa, clover, and radish)
- **Unpasteurized milk, fruit, or vegetable juices** These drinks will carry a warning label.
- **Buffets**
  Foods in a buffet are often not kept at a safe temperature.

Remember:

- Sanitize cutting boards after use. Use a separate cutting board for meats to avoid cross contamination.
- Carefully wash and peel all fruits and vegetables.
- Keep hot foods hot and cold foods cold.

Ask your child's dietitian if you have any questions about food safety.

© 2022 Intermountain Healthcare. All rights reserved.

© 2022 Intermountain Healthcare. All rights reserved.

Managing Life after a Kidney Transplant

Having a kidney transplant is the treatment option that allows your child the most similar lifestyle to what they had when their own kidneys were healthy. Once they recover from surgery, they will be able to continue to work, attend school, travel, and enjoy most of the same activities and hobbies.

They will, however, need to modify some activities to protect their new kidney and take extra precautions to avoid infections. Use the information on the next pages as a general guide. Follow your transplant team’s directions for the level and type of activity that will keep your child healthy.

© 2022 Intermountain Healthcare. All rights reserved.

Going Back to School

Most transplant patients require 6 to 8 weeks off from school, depending on what your child's doctor thinks is best. Once your child is cleared to return to school, the social work and medical teams will talk with you and your child about what they need to do. We can give you letter to share with the school that says that you have medical clearance.

Getting support at school

Children who have a transplant have a greater risk for learning and attention (cognitive) problems. These are a result of their underlying disease, the transplant, treatment, and hospitalization. When your child goes back to school, it will be helpful to have support in place to help foster their success. The educational system can be difficult to navigate, and getting help is not always easy. Here are some helpful tips:

- As your child prepares to go back to school, **write a letter asking your child's school evaluate your child.** This will help you know what support they may need. The evaluation will also help you create or change your child's IEP or 504 plan.

  What's an IEP or 504 Plan? IEPs and 504 plans are written educational documents that provide accommodations to students in the school setting. An IEP, or Individualized Education Program, is a set of services delivered to a child that includes special education services. A 504 Plan provides accommodations and supports to children with physical or mental disabilities within the general education setting. Each requires that the needs of students with disabilities be met with reasonable accommodations. Children who have had a transplant can qualify for a 504 Plan based on their medical condition. In some circumstances, such as when there are concerns about learning or thought function, they may qualify for an IEP.

- **The school will complete an evaluation.** This may include measures of thought or academic functioning, and behavior.
- **The evaluation team will schedule a meeting with you**, your child's teacher, and other school personnel involved in the evaluation. The team will:
  - Review the results of the evaluation
  - Decide if your child qualifies for services
  - Decide which services are most appropriate to help your child learn. These may include special education services, behavioral supports, or modifications to test taking or other educational activities

Children who have had a transplant often have difficulties with attention, focus, memory, and processing speed. This can be because of their medical condition or the medications they take. In addition to the recommendations from the school, these are common accommodations for children with transplants:

- Extra time on tests or tests that are untimed
- Extended deadlines on long-term projects or modifications to the required workload
- Various medical provisions, such as:
  - Being allowed to go to the nurse or use the bathroom when needed
  - Access to a water bottle throughout the day or a special diet
  - Modified physical education to comply with activity restrictions
  - A plan for emergency care (such as staff being trained to use cardiac equipment)
  - Excused absences for medical appointments

Your child's physician, transplant coordinator, or transplant psychologist can help you request these accommodations, and can provide written documentation of medical necessity as needed.

© 2022 Intermountain Healthcare. All rights reserved.

Exercise

Exercise will begin the day after your child's transplant surgery. They will start by walking the hall several times each day. This will continue until discharge.

After surgery, your child's muscles may feel weak. This may be due to inactivity or as a side effect of the prednisone. Your child will be able to regain and increase muscle strength with regular exercise. **Have your child continue walking every day after they go home.** After 6 weeks, your child can increase activity and include things such as bicycling, sports, and exercise classes.

For the first 3 months, your child should avoid pulling or straining the abdominal muscles. For example, no heavy lifting or sit-ups. Avoid all contact sports as well as any activities which are jarring, like horseback riding or snowmobiling.

After three months, your child should be able to participate in most activities. However, you should check with your child's transplant coordinator or transplant doctor before they do any of these activities.

Weight control cannot be successful without exercise. **A good exercise program should be part of your child's daily routine.** Choose an activity that they like to do. Your child will more likely continue the activity if it is fun. Consider including a routine daily activity such as a brisk walk or hike, combined with active sports such as swimming and biking.

If your child feels bone or joint pain, report it to your doctor or transplant coordinator. This may be a medication side effect and may indicate the need for further investigation.

Safely return to school, sports, work

After your child recovers from surgery, they can likely return to most of their previous activities. However, their doctor might make some suggestions.

Your child will likely be able to return to school (or work) within 2 months. If their activity previously required heavy lifting or some exposure to germs, they might need to talk with the transplant social worker or others on their transplant team about other job options. Remember, your child will need to protect their new kidney from injury and avoid the risk of infection.

Your child should talk with their physician before driving. It will likely be a few weeks after surgery before they can safely drive. The medications they will be taking can make them dizzy or have blurred vision, making driving dangerous.

Once the doctor says it is okay, walking, biking, hiking, and swimming are all good ways to stay healthy and build muscle and bone strength. Work with your child's transplant team to develop an exercise plan for their needs. **Avoid physical exercise or weightlifting until the doctor says it is okay, and do not allow your child to participate in contact sports** (football, soccer, basketball, rugby).

© 2022 Intermountain Healthcare. All rights reserved.

Developmental Milestones

Children respond to their world in different ways as they learn and grow. This increase in knowledge is called development. Illness and hospitalization can directly affect a child's development. Their experiences may change the way they respond to the healthcare environment. To help them grow, it is important for you and the healthcare team to support your child's development after their transplant. This will help both you and your child better manage all the changes. Below, you will find common responses to hospital experiences according to age group, plus ideas to help support your child's development.

Developmental Stage	It is Important to:
Infant Birth to 2 years old During this time, infants form bonds with their family members. It is important for infants to build a sense of trust and safety in the world around them. Your infant relies on you to provide that sense of security while meeting daily health care needs. Your child may have more temper tantrums and stop using newly learned skills.	• Create a dependable schedule. • Allow time for your child to adapt to and explore new situations. • Create a quiet and soothing environment. • Provide opportunities for skin-to-skin holding. • Engage your child in peek-a-boo and other games that introduce the idea of separation. • Introduce opportunities for your child to explore safe medical equipment (for example, Fisher Price® medical equipment).
Preschool 2 to 6 years old Children at this age do not have the words to tell you how they feel or understand what is happening. They may have a hard time understanding the health care experience. Some children will create fantasy reasons for why they were in the hospital or needed a new kidney. Some responses you might see are temper tantrums or regression (acting younger than they are). They may lose newly learned skills, cry and respond strongly from being away from family members.	• Create a dependable schedule. • Provide choices in age-appropriate activities. • Provide opportunities to explore safe medical equipment and rehearse hospital experiences. • Listen to your child's memories of the hospital and transplant experience. • Help your child use words to describe emotions. • Continue to read stories or play games with your child that relate to separation. • Be consistent with rules. • Encourage and teach your child to make healthy choices.

(Continued on next page)

© 2022 Intermountain Healthcare. All rights reserved.

Developmental Stage	It is Important to:
School age 6 to 12 years old School-age children can talk about their transplant experience in detail. They have a better understanding why they needed a transplant and how to keep their new kidney healthy. Children at this age value independence. Your child will develop skills to promote a sense of confidence, competence and social connectedness with family and friends. This will be important for helping them cope after a transplant.	• Continue to keep a dependable schedule or a routine like before their transplant. • Start helping them know the names and purpose for each medication they are taking. • Help them learn to talk with staff during clinic appointments about what is happening to their body. • Help them talk with staff about the food they eat and understand healthy food choices. • Encourage your child to talk about their feelings and how they are coping with their medical experiences. • Promote attending school on a regular basis. • Encourage opportunities to hang out with friends and family. • Meet other children who have had similar medical experiences.
Adolescents (Teenagers) 13 to 18 years old Teenagers will be able to talk about their transplant experience. It is important to make sure your teen feels safe, and they have some control over their situation. Your teen may choose not to describe their experience well because they may feel awkward about their body or fear losing control of the situation. Your teen will begin taking responsibility for their behavior and emotions. It is important to respect their privacy.	• Know the names, purpose, and side effects of each medication. • Communicate honestly with your teen. • Respect their privacy. • Involve them in health care education and decision making. • Listen to their concerns and answer their questions. • Let them talk about their fears and concerns about medical care. • Encourage opportunities to hang out with friends and family.
Young adult 18 to 21 years old Young adulthood is a time of transition. Young adults are actively moving toward the adult renal (kidney) program and becoming independent of their parents. After high school, the health care team will help them make this transition as smooth as possible.	• Know the names, dosages and understand the purpose and side effects of each medication they are taking. • Communicate with the doctor and pharmacist to get prescription refills in a timely manner. • Understand and follow healthy food choices. • Follow through with making and keeping clinic appointments. • Independently ask questions and seek accurate information related to their medical experience. • Speak for themselves and make appropriate decisions about their medical care.

© 2022 Intermountain Healthcare. All rights reserved.

Social Issues and Community Resources

Transplantation can bring up many different emotions. You and your child may feel excitement and hope, expectation and uncertainty. For some families, it is a long-awaited-event. For others it may feel sudden and unexpected. Whether you have had years to prepare, or only a short time, all families experience a full range of emotions and challenges.

Managing expectations

A transplant gives you and your child the opportunity to adopt a healthier lifestyle. You may be excited for your child to have more energy. You may look forward to spending less time in the hospital. They may be ready to get back to their favorite activities and to feel better overall.

Although a new transplant can be exciting, the early adjustment period can also be difficult. Some patients have described this stage as a "roller coaster ride." Ever-changing lab values, medication adjustments, and rehospitalizations can be difficult. You and your child may experience disappointment and feel unprepared.

During this time, the team will be there to support you. They will watch your child closely and adjust medications as needed. The transplant coordinator will be available to answer your questions and concerns. Your social worker will provide ongoing assessments and be available for supportive counseling. They can also connect you to others who have had similar experiences, as well as school services, community resources, and referrals for long-term therapy. Hopefully, having this team of experts working with you will bring you peace of mind during this journey.

Staying true to the program

Adherence [ad-HERE-enss] is the act of staying true to something. In this case, it is about staying true to your child's transplant recovery and maintenance plan. You might find that once you and your child have gotten used to the new routine, it is easy to "forget" to follow the care plan. This is normal. Patients and parents will miss a medication now and then, but missing medications regularly can cause problems. In fact, one of the leading causes of transplant failure in teenagers is from missing medications. The transplant team will continue to support you and your child by reinforcing the importance of routine transplant follow-up and taking medications as required.

Balancing family needs with transplantation

Transplantation is complex and impacts the entire family. Each family member has unique needs, and everyone is impacted in a different way.

Return to normal family life

After the transplant, you will likely be able to resume normal activities. **Talk with your doctor about any concerns you have related to your child's future sexual activity, fertility, or pregnancy.**

© 2022 Intermountain Healthcare. All rights reserved.

Siblings

Since your child will need a lot of care and attention during the transplant process, their brothers and sisters may feel left out, resentful, frightened, or confused. It is important to encourage them to express their feelings, both good and bad. They should be allowed to visit their sibling in the hospital. They also need opportunities for one-on-one time with parents whenever possible. Your social worker and Child Life Specialist are available to provide support as needed.

Work, home, and family responsibilities

Transplant and hospitalization will require you to take time off work. You will need to watch your child closely and take them to frequent lab and clinic appointments after they go home. This may require additional time away from work and other responsibilities. If needed, your social worker can help you with any documentation or Family Medical Leave Act (FMLA) paperwork.

Many families live a long distance from the hospital. You may need to move close to the treatment center temporarily while your child heals after surgery. After, you can return home and travel back and forth for follow-up appointments. Your social worker will check in with you regularly and can provide resources for places to stay, mileage assistance, and other supportive resources that you and your family may need after transplant. This is also a great time to use your personal support system.

Travel smart. Your child may be asked to limit or avoid travel for a period of time after surgery. Talk with the transplant team about any travel plans your child has while recovering and adjusting to life with a kidney transplant.

Community resources

DonorConnect

If your child received a transplant from a deceased donor, your social worker will talk with you about the process for writing to your donor family, if you choose to do so.

Youth transplant camp

The National Kidney Foundation hosts a week-long camp for children who are 8 to 17 years of age and received a kidney, liver, or heart transplant. The camp is located in Emigration Canyon. It provides kids with the opportunity to bond through shared experiences. Your social worker can provide more details and registration information.

Family camp

The National Kidney Foundation hosts a camp for kidney transplant and dialysis families at Aspen Grove in Provo Canyon. This event is usually held in September for 3 days. Families are able to spend time together, share experiences, and make connections. Your social worker can provide more details and registration information.

Transplant games

The United States Transplant Games are held every other year. Transplant recipients from around the world and their families compete in Olympic-style events. Donor families are also allowed to join. Families who take part say it is a valuable and enriching experience. Your social worker can provide more details.

Family-to-family contacts and peer support

Many families who have lived with transplant for several years volunteer to meet with other children and families who are new to the transplant process. Talk to your social worker if you would like to meet with another child and family. They can support and prepare you for what's ahead. Although everyone's journey is unique, it can be helpful to connect with someone who has had a similar experience. Your social worker can also help you find reliable community support networks and events related to kidney disease and transplant.

© 2022 Intermountain Healthcare. All rights reserved.

Insurance

The following information should help you better understand your health care benefits and how they work with the end stage renal disease Medicare program. Together, these two programs will help you manage the medical expenses of dialysis and transplant.

Why is my child entitled to Medicare?

Medicare is taxpayer-supported health insurance managed by the government. It is for people over 65 years of age. However, children who are legal citizens of the United States and need dialysis and transplant are eligible for Medicare coverage under the End Stage Renal Disease (ESRD) program. **Kidney failure is the only medical condition covered by Medicare.** How much assistance you get is dependent on the number of work credits you have paid into the Social Security system. Since children have not worked, they are entitled through their parents work records.

How do I apply for the Medicare ESRD program?

You and your social worker will fill out the appropriate Medicare applications when your child starts dialysis or receives a transplant. A few weeks later, the local social security office will ask you to send in a copy of your child's birth certificate. Then, within 2 to 3 months you will receive a letter and a card in the mail verifying your child's eligibility.

When does Medicare coverage start?

Medicare coverage starts the first day of the month in which you receive a kidney transplant or start peritoneal dialysis. If you are on hemodialysis, Medicare has a waiting period before starting benefits. Coverage will begin on the 1st day of the 4th month of your hemodialysis treatment.

What does Medicare cover?

Medicare coverage has 3 parts:

- **Medicare Hospital Insurance** (Part A): Helps cover inpatient hospital care, nursing home, and home health care.
- **Medicare Medical Insurance** (Part B): Helps cover physician fees, outpatient services, medical supplies, and the first year of immunosuppressive medications.
- **Medicare Prescription Coverage** (Part D): will help cover most medications after transplant.

How does Medicare work with group health Insurance?

If your child is covered by your employer's group health insurance, your group insurance will be the primary, or first, payer, for the first 30 months. Medicare will pay second, or be secondary. After 30 months, Medicare becomes the primary payer for as long as your child is on dialysis or for the first 30 months after the transplant. Patients receive 36 months of Medicare coverage for a kidney transplant. If your child receives another transplant, the eligibility timeline starts again.

If you do not have group health insurance, Medicare will be the primary payer from the beginning. Your social worker will help you identify other resources for secondary coverage. If you have Medicaid from your home state, Medicare is the primary payer from the start of your eligibility.

© 2022 Intermountain Healthcare. All rights reserved.

Can I get a Marketplace plan in addition to Medicare?

No, you cannot have both. Like Medicare, Marketplace (Obamacare) plans are supported by the government. If you currently have a Marketplace plan, you will need to drop your Marketplace plan the day before your Medicare coverage starts. This avoids overlap in coverage. You will not qualify for help from the Marketplace to pay your Marketplace premiums or other medical costs (often referred to as subsidies). If you keep getting help to pay for your Marketplace plan premiums after going on Medicare Part A, you may have to pay back all or part of the help you got when you file your federal income taxes.

Hospital Insurance (Part A)

Medicare hospital insurance helps pay for services while your child is hospitalized. Medicare hospital insurance has a "deductible." This is a percentage of the cost of services that you must pay each "benefit period." Your first benefit period starts the first time your child enters a hospital after your Medicare begins. A "benefit period" ends when your child has been out of the hospital for 60 days in a row. There is a limit on how many days of hospital care Medicare can pay for in each benefit period. Medicare pays all covered services (after the deductible) for the first 60 days. From day 61 to 90, Medicare pays half of covered services. If your child is hospitalized for over 90 days, you can use your "Lifetime Reserve Days." Each person has 60 "Reserve days" during which Medicare will pay all but a certain portion for covered hospital expenses. "Reserve days" are not renewable. Most families do not pay deductibles because the secondary payer (private insurance or Medicaid) will cover that cost.

Medical Insurance (Part B)

Medicare medical insurance helps pay for your physician fees, medical equipment and supplies, outpatient services (including dialysis, labs, x-rays), and the first 36 months (3 years) of immunosuppressive medications after a transplant. Medicare insurance has an annual deductible and monthly premiums (cost to purchase the insurance). Medicare will generally pay 80 percent of approved charges. You or your secondary payer must pay the remaining 20 percent. It is important that you pay your monthly premium right away. If you are late with your payment, your Medicare Part B insurance may be cancelled. It is very difficult to get it back again.

Note: This is only a brief summary. For a complete explanation of Medicare benefits, please refer to the Medicare handbook. You may also get specific information by referring to the *"Medicare Coverage of Kidney Dialysis and Kidney Transplant Service"* booklet, CMS product 10128.

Important things to remember

It is extremely important that you maintain adequate insurance coverage lifelong. You will have on-going medical expenses to maintain your new kidney. Transplant medications are expensive. Maintenance drugs may cost as much as $2500 a month.

© 2022 Intermountain Healthcare. All rights reserved.

What if I do not want to use my Medicare?

Some may feel their group health insurance is good enough without Medicare and do not want to pay the additional Part B premiums. However, refusing Medicare insurance for a transplant or not paying premiums can be a serious financial risk. **We recommend that you do not discontinue Medicare.** Your group insurance can drop you if you do not use Medicare insurance. Then, you would have to wait until open enrollment to reinstate your Medicare. This can leave you without health care benefits for a period of time. Please check with your transplant financial coordinator before refusing Medicare.

How does the hospital do the billing?

When you are admitted for a kidney transplant, the admitting clerk will check your coverage. Most insurance companies require that you pre-authorize the transplant surgery. The social worker will help you with this process. Medicare does not require pre-authorization. If you have not applied for Medicare, let the admitting office know that you will be applying for Medicare. It will be effective the first day of the month of your child's transplant. With correct information, the billing office can then bill both your insurance and Medicare appropriately.

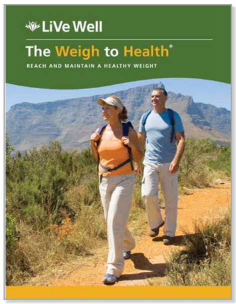
© 2022 Intermountain Healthcare. All rights reserved.

Final Thoughts

Thanks to modern medications and transplant treatment advancements, many patients never have a single rejection episode.

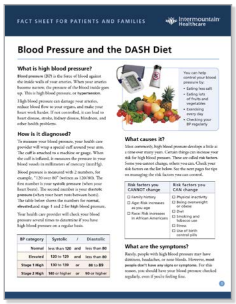
By following your transplant team's instructions and leading a healthy lifestyle, the chances are excellent that your child's kidney will give the gift of a new life for many years. So go out there and enjoy life to the fullest!

Intermountain resources for a healthy lifestyle

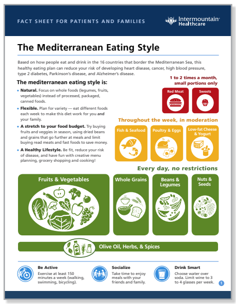


LiVe Well
The Weigh to Health®
REACH AND MAINTAIN A HEALTHY WEIGHT

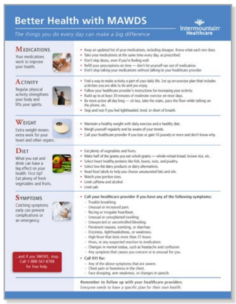
LiVe Well
8 to LiVe By
HABIT BUILDER FOR KIDS, TEENS, AND FAMILIES



FACT SHEET FOR PATIENTS AND FAMILIES
Blood Pressure and the DASH Diet



FACT SHEET FOR PATIENTS AND FAMILIES
The Mediterranean Eating Style



Better Health with MAWDS
The things you do every day can make a big difference

Where can I find more information?

For more general information about transplants, visit:
UNOS.org — "What Every Patient Needs to Know"

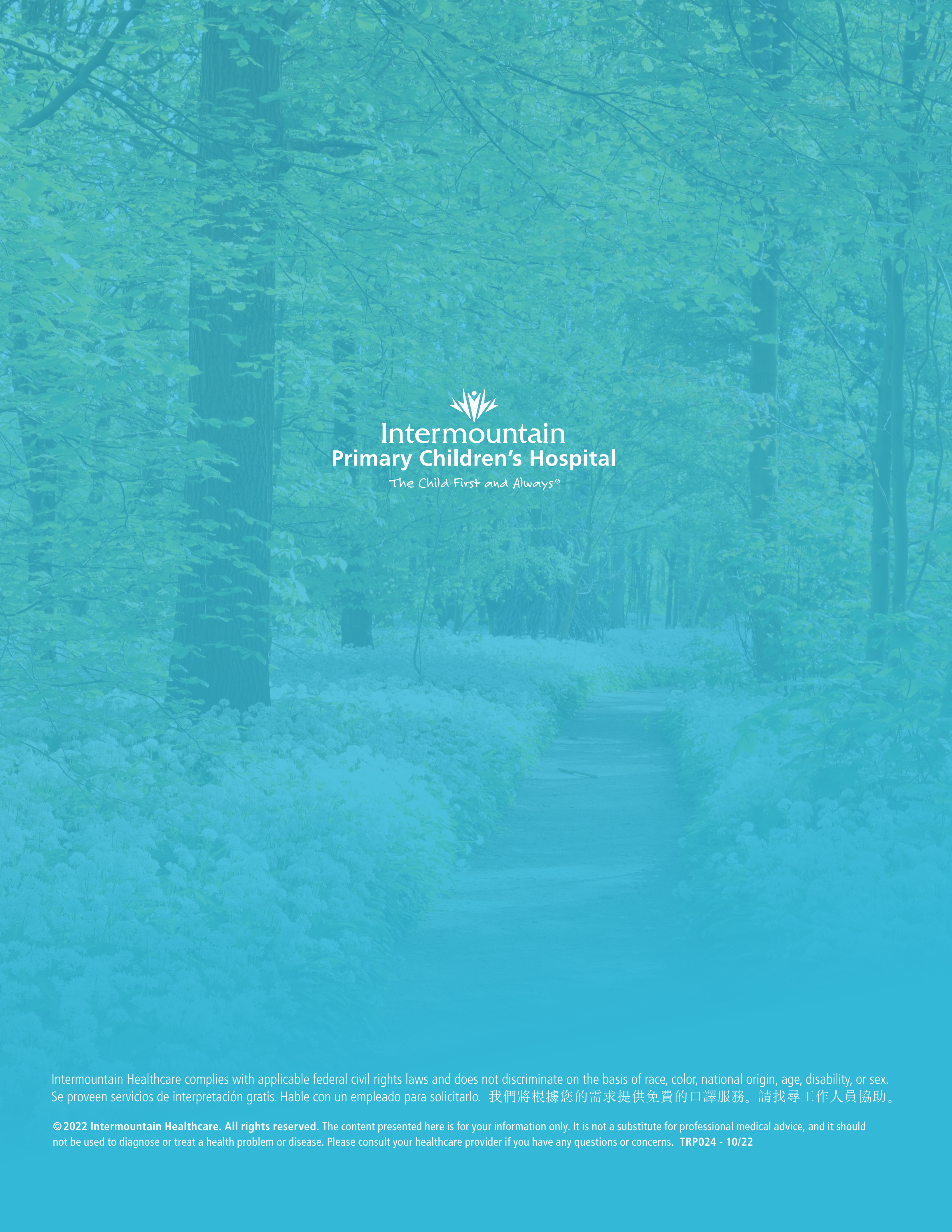
© 2022 Intermountain Healthcare. All rights reserved.

Notes

© 2022 Intermountain Healthcare. All rights reserved.

Notes

© 2022 Intermountain Healthcare. All rights reserved.



Intermountain
Primary Children's Hospital
The Child First and Always®

Intermountain Healthcare complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. Se proveen servicios de interpretación gratis. Hable con un empleado para solicitarlo. 我們將根據您的需求提供免費的口譯服務。請找尋工作人員協助。

© 2022 Intermountain Healthcare. All rights reserved. The content presented here is for your information only. It is not a substitute for professional medical advice, and it should not be used to diagnose or treat a health problem or disease. Please consult your healthcare provider if you have any questions or concerns. **TRP024 - 10/22**