

Pediatric Kidney Transplantation

A Guide for Patients and Families



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The information presented and opinions expressed herein are those of the authors and do not necessarily represent the views of the Society. This educational material is a general guide only. It does not replace the skill, knowledge, and experience of a qualified medical professional dealing with the facts, circumstances, and symptoms of a particular case.

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INTRODUCTION

This manual is designed to provide information about kidney transplantation in children for parents and family members. During this difficult time, the best way to care for your child (and yourselves) is to stay informed and to talk openly with your child's transplant team. It is also important to communicate with your child to make sure they understand what is going on and are prepared for the challenges ahead.

How to use this guide. This guide is a tool to assist you in understanding kidney transplantation and to help you talk with your child's transplant team. There is no one right or wrong way to use this guide. For some families, reviewing the entire guide from beginning to end is helpful. For other families, it is more useful to read specific sections that address questions you may have. In either case, if there is any part of this information that remains confusing or unclear, we encourage you to discuss it further with your child's transplant team. It is important to understand that this guide does not replace the important teaching and information you and your child will get from the transplant team.

WHAT DO KIDNEYS DO?

Your kidneys are an important part of your body!

The Basics

- Most people have two kidneys.
- The kidneys are located on either side of the spine, just below the rib cage.
- Each kidney is about the size of your fist.
- The kidneys are shaped like "kidney beans".
- Your kidneys are connected to your bladder by tubes called ureters.

What Your Kidneys Do

Think of your kidneys like a pasta strainer or filter. Your kidneys keep some things in your body that you need, and get rid of other things that you don't. The kidneys also do many other jobs that you need to live.

Your Kidneys:

- Make urine
- Remove wastes and extra fluid from your blood
- Control your body's chemical balance
- Help control your blood pressure
- Help keep your bones healthy
- Help you make red blood cells

WHAT IS KIDNEY (RENAL) FAILURE OR CHRONIC KIDNEY DISEASE?

For information, please go to <http://www.kidney.org/kidneydisease/>

Signs of Chronic Kidney Disease and Kidney Failure in Children

Level of kidney function is determined by the glomerular filtration rate or GFR. The GFR is expressed as mL/min/1.73 m². Normal kidney function is considered 90-120 mL/min/1.73m². We estimate kidney function in children using the

equations that include child's height as well as their serum creatinine. *Chronic kidney disease* in children is when the kidney filtration falls below 90 mL/minute/1.73m² for 3 or more months. Chronic kidney disease stage 5 or end stage kidney disease in children is when this number falls below 15 mL/min/1.73m².

Signs and symptoms of chronic kidney disease in children can vary and can be quite subtle. The first signs of decreased kidney function may be abnormal bone health and poor growth. These effects can occur with a decrease in kidney function to 60-70% of normal. Frequently children with decreased kidney function feel normal until their kidney function is very low at which time some children may have fatigue, decreased appetite, nausea, the feeling of fullness when they are eating, lack of adequate weight gain, and at times decreased school performance.

Most children with kidney function of less than 15 mL/min/1.73m² will need help to sustain life and replace the failed kidney. It is at this point that a child may need to proceed to either dialysis or transplantation. Usually your pediatric kidney doctor will begin discussions with you about your child's options early in order to prepare in plenty of time for either dialysis or transplantation.

There are two kinds of dialysis:

- Hemodialysis. Most commonly this is done with the help of a hemodialysis machine in a dialysis center, three or four times a week. With special training this type of dialysis can sometimes be done by the family in a child's home.
- Peritoneal dialysis. This is done at home by the family, mostly at night with the help of a peritoneal dialysis machine. This form of dialysis can also be done manually several times per day.

For most children kidney transplantation is considered the optimal treatment for kidney failure. Some children require a period on dialysis before proceeding with a kidney transplant. Other children, whose kidney function is slowly getting worse, will have enough time to plan for a transplant without needing to undergo dialysis. This is called a preemptive kidney transplant. Somewhere between 25% and 40% of children in the US who need a kidney transplant are able to receive a preemptive kidney transplant and avoid a period of dialysis.

HOW DOES A CHILD GET REFERRED FOR A KIDNEY TRANSPLANT?

Evaluation of a Child for Kidney Transplantation

Kidney transplant is the preferred treatment for kidney failure for most children. A kidney transplant gives a child the best opportunity to lead a normal and healthy life. However, a transplant is not a cure and comes with many new responsibilities.

Most children with kidney failure are referred by their doctor to a center with a pediatric kidney transplant program. Most children are eligible for kidney transplants. Some children are not candidates because of medical and ethical reasons.

Indications for and Contraindications to Transplantation

The causes of chronic kidney disease in childhood are varied. Children will qualify for transplants when their kidney function falls below 20 mL/min/1.73m². Generally, any child who requires dialysis is a candidate for kidney

transplantation. Examples of medical reasons that might prevent a child from being a good candidate for kidney transplantation include severe heart or lung disease, active or recent cancer (malignancy), or certain active infections and certain ethical considerations.

How is My Child Assessed for Kidney Transplantation?

Your child will have a number of medical tests, and you will be asked questions about your child's medical history by different members of the transplant team. You can also ask questions of the team. The evaluation has several purposes including establishing or confirming a diagnosis through review of medical records and biopsy material and assessing the complications of chronic kidney disease. Most patients have their assessment as an outpatient of the hospital over one or two weeks. This means they have appointments in the hospital but do not stay overnight.

The results of the tests* will give an idea of your child's overall health. The tests your child will have may depend on:

- Their age
- What is wrong with their kidneys
- How long they have been sick
- How sick they are
- Whether they have been seen at the transplant center before.

*Tests also may vary according to the health care system or country you are in.

Medical Tests

Blood Tests

These include test to identify your child's:

- Blood group (ABO typing)
- Levels of anti-human Leukocyte antigen (HLA) antibodies and how strong they are. HLA antibodies are antibodies that your child has in their body that may attack someone else's kidney. This testing helps the transplant team determine if your child has a higher risk of rejection. It also helps predict if your child might have to wait longer for a donor kidney because having these antibodies may make it harder to find a suitable matching donor.

Other Tests

These include:

- Complete blood count (CBC) with platelets
- Chemistry profile including electrolytes, blood urea nitrogen (BUN), creatinine (Cr), calcium, phosphorus, intact parathyroid hormone concentration.
- Complete liver function tests, including serum liver enzymes, bilirubin, albumin, cholesterol, and triglyceride concentration.
- Coagulation profile including an international normalized ratio (INR) and partial prothrombin time (to screen for coagulation abnormalities), homocysteine level, factor V Leiden, and prothrombin 2 tests.

- Viral serology tests, including those for hepatitis A, B, and C; cytomegalovirus (CMV); Epstein-Barr virus (EBV); varicella-zoster; measles, mumps and rubella; herpes simplex, anti treponema EIA and human immunodeficiency virus (HIV).
- Tuberculosis (TB) testing.

Tests on other parts of the body

These can include:

- Chest radiograph (x-ray).
- 12-lead electrocardiogram (EDG).
- Peritoneal fluid (cell count and differential, culture if patient is on peritoneal dialysis).
- Ultrasound of the native kidneys with Doppler (to assess blood flow to the inferior vena cava and to rule out thrombosis).
- Voiding cystourethrogram (to evaluate for urethral patency, vesicoureteral reflux, and residual urine volume).
- Pap smear if a female adolescent is or has been sexually active.

Interdisciplinary team assessments

These involve meetings and tests with different health care professionals, such as a:

- Urologist
- Pediatric nephrologist
- Pediatric transplant surgeon
- Transplant nurse coordinator
- Transplant pharmacist
- Financial representative
- Physiotherapist
- Occupational therapist
- Dietitian
- Social worker
- Child family life specialist
- Psychologist or neuropsychologist
- Pediatric dentist
- Psychologist/Psychiatrist

Again, whether your child will meet all these professionals depends on their personal situation and where they are being assessed.

Medical Consults (as needed)

Your child will also see other doctors in the hospital such as:

- An anesthesiologist (the doctor who gives your child sleep medication before an operation)
- A cardiologist (heart doctor)
- A hepatologist (liver doctor)
- A pulmonologist (lung doctor)

- A neurologist (nervous system doctor)
- A gastroenterologist (stomach doctor)

These doctors will make sure your child’s other organs are working well and that your child can safely undergo anesthesia for the transplant operation. Some centers will also have your child be seen by an infectious disease specialist

The “palliative care team” is another important team that is often included. This team helps you make decisions that are best for your child and your family.

In addition to determining your child’s medical eligibility for transplant it is also the responsibility of the transplant team to assess ability to adhere to a complex treatment regimen. This can be particularly hard for teenage transplant patients and is frequently one of the most difficult challenges after transplant. Non adherence with medications and a sometimes demanding visit and lab schedule after transplant can threaten the health and well-being of the transplant and the patient. The transplant team will likely take any concerns in this area very seriously and work with you to offer ways to increase the likelihood of success after transplant.

Standing Members of the Transplant Team:

- Transplant Nephrologist
- Transplant Surgeon
- Transplant Nurse Coordinator
- Transplant Pharmacist
- Social Worker
- Dietitian
- Financial Representative

What Happens After the Assessment?

After these consultations and tests, the whole transplant team meets to decide if your child is a suitable candidate for a kidney transplant. The team approach to care makes sure that every treatment option for your child’s case will be discussed.

If the transplant is the best option, the team will then decide how quickly your child needs it and whether your child should receive a transplant from a living donor or be placed on the kidney transplant waiting list. The team will develop a treatment plan designed to give your child the best chance of having a successful transplant.

If your child is able, it is important that they, along with you, take part in making decisions about their treatment. Receiving and living with a transplant is a big commitment, one that will stay with your child for the rest of their life.

Only if the transplant team agrees that transplant is the best option for your child **and you agree that you want your child to have a transplant**, will your child go to transplant.

Your child may not need to on dialysis before receiving a kidney transplant. For many reasons, your child’s physicians may advocate for living donor kidney transplantation. In the US about 55% of children receive a kidney from one of their parents. Each biological parent is already “half matched” for special proteins on white blood cells called HLA. The degree of matching can alter risk of rejection. Rejection is when the child’s immune system recognizes the new kidney

as foreign and “attacks” the new kidney with the intention of doing harm to it. The better the HLA matching, the less likely the body will try to reject the transplant. If children do not have a parent who is a suitable donor, they may receive a transplant from another related or unrelated living adult. If an adult is interested in donating a kidney he/she should contact the kidney transplant office to inform the transplant team of this wish. The donor will be evaluated separately for donation by the adult transplant team to make sure of the donor’s good health and eligibility to donate the “gift of life”.

How does my child get on the kidney transplant waiting list?

If your child does not have a potential living donor they may be placed on the national deceased donor waiting list through their transplant center. In the United States, organ matching is managed by UNOS – United Network for Organ Sharing, which oversees the UNET Wait List. People from all over the United States are on this list. There are similar organizations in every country in the world. In the United States, children who are listed for deceased donor kidney transplant before their 18th birthday receive priority on the national waiting list. In the United States adults and children can be listed for a deceased donor kidney at more than one transplant center and this occurs most commonly when their transplant doctors are concerned that it may be difficult to find a suitable kidney. In some situations, your child may be placed on the deceased donor waiting list “on hold” even if you child has a potential living donor. This allows your child to begin to accumulate waiting time on the list just in case their living donor becomes ineligible for any reason.

What information about my child goes on the wait list?

The wait list will include details about your child, including:

- Name, gender, race
- Date of birth
- Cause of chronic kidney disease
- Blood group
- Weight
- Height

Where do deceased donor kidneys come from?

Kidney donors can be anyone (a child or an adult) whose brain has been so damaged by injury or disease that the brain dies, even with the best medical care. When someone has reached this stage, it is called being “brain dead”. The donor might have been injured in a car accident or a fall or by drowning, for instance, or they might have had a brain tumor or other serious medical condition affecting their brain. Although the donor is no longer alive, their major organs can be saved for a short time with medications and machines so that they can be removed and transplanted into someone else.

There is also a circumstance known as a DCD donor (Donation after Circulatory Death). This term refers to a donor who has suffered devastating and irreversible brain injury and may be near death but is not considered “brain dead” by the formal medical definition of brain death. In this circumstance, the family may decide to withdraw life support. When life support is withdrawn and the heart stops beating, the organs are then recovered in the operating room.

You and your child may have a lot of questions about the donor, but please bear in mind that this information is always confidential. The members of the transplant team only know the information they need to carry out the transplant

safely. For example, they cannot tell you the kidney donor's name or where they lived. It is important to respect the privacy of the donor family's choice when they donate the kidney for your child.

Can I contact the donor family?

It is natural for some families to want to thank the donor family. Confidentiality is very important and some donor families do not want to have contact with the family of the person who receives the donated organ.

If you would like to thank the donor family, the best way is to write a letter without putting in any identifying information. You may like to ask your transplant coordinator to help you with the letter. They can then pass it on to the donor coordinator who dealt with the donor family and can find out if they want to receive the letter.

GETTING A KIDNEY TRANSPLANT

For information, please go to <http://www.unos.org/docs/WEPNTK.pdf>

How will a transplant change my child's life?

A lot depends on what your child's life was like before transplant. If they are a "normal" kid and have never taken medicine a day in their life, a transplant will make a big difference in their life. On the other hand, if they have struggled with kidney disease in the past, they may be familiar with medications, blood tests, and frequent visits to the doctor. The biggest change in your child's life is that they now have a new kidney and a chance for a full life. This gift of life is not without cost, however.

- Your child will have to take medicine every day for the rest of their life to make sure their body does not reject the new kidney.
- The medicines used to prevent rejection put your child at increased risk for other problems including infection, tumors and other possible side effects such as high blood pressure or diabetes
- They will also need to have blood and other tests for the rest of their life to make sure that their medicine is working well, look for any side effects, and look for signs of rejection and infection. They will need to develop relationships with different healthcare professionals and learn to be part of their own health care team as they get older and move from a pediatric to adult care. Good communication with your transplant team is essential to success.

HOW DO WE PREPARE FOR THE KIDNEY TRANSPLANT OPERATION?

Preparing for the hospital stay

Children coming to the hospital usually have many questions and concerns, even if they do not know how to express them. Before your child comes to the hospital, give them as much honest information about their condition as you think they can understand.

Encourage your child to trust the medical staff. It is important that children believe that we are all on the same team. If your child is very anxious you may wish to speak to a counselor. Your transplant team wants your family to be successful, so don't be afraid to ask them for help or for a referral to someone who might be able to provide extra support to your family.

Some transplant programs include checks for stress, depression, and anxiety in the overall transplant assessment and routinely have older children needing a transplant, meet a psychiatrist or doctor in adolescent medicine.

Tips for talking to your child about their transplant surgery

- Tell your child what their incision (opening for surgery) or scar will look like.
- Draw a picture of an incision on a doll or on their abdomen.
- Tell your child that they will have some pain but that they can ask for medicine to make it better. A child often is anxious about surgery because of their fear of pain.
- Tell them that the doctors and nurses are on their side and helping to make them better.
- Check that your child understands what will happen. For instance, ask them to explain in their own words what they think will happen or what could happen.

Many hospitals prepare children for surgery using age-appropriate materials such as soft cloth dolls, puppets, medical equipment, photographs, books, and other resources. They may be able to have a tour of the hospital ward prior to the surgery if they haven't stayed there before. These programs not only teach your child about hospital stays and procedures but also give them a chance to express their feelings in a non-threatening way and address any misunderstandings. When your child feels prepared, they are less afraid and feel more in control.

The transplant surgery will typically take 4 or more hours. The transplant surgeons and the anesthesiologists will meet with you and your child prior to the surgery to discuss the procedure, obtain consent, discuss the anesthesia and answer any last minute questions you may have.

Fears and concerns about surgery and recovery

It is normal to be overwhelmed by the scale of transplantation and its effect on your life, your family, and your future. Some people become very emotional for a time and you may experience many confusing or overwhelming feelings. This is normal; hang in there.

Maintaining routine during hospital stays

The hospital stay can be very upsetting for children. Their daily routine and sleep patterns change. They will also face strange and sometimes painful tests and meet many new people. It is normal for them to be irritable and bad-tempered after this experience, especially if their stay in the hospital has been a long one.

The experience can be particularly hard for younger children, who especially benefit from a regular routine. Try to keep to familiar routines as much as possible during your child's treatment. Bedtime routines are especially important for good sleep. Be sure to bring your child's favorite blanket or toy that they use to fall asleep.

When your child leaves hospital after surgery, it may take some time for things to get back to "normal". If you have questions or concerns, the members of the transplant team are there to help.

The intensive care unit (ICU) and kidney transplant ward

After surgery your child will be transferred to the intensive care unit. When your child first arrives in the intensive care unit, they will require a period of "settling in". This usually takes at least one or two hours. Your child's nurse will tell you when you can visit.

What to expect when you first see your child

Your child will be attached to many tubes and monitors, which can be overwhelming when you first see them. Remember, though, that your child's team will explain all the monitors, tubes, and IVs to you in detail.

Monitors

Your child may be on a ventilator (breathing machine) until they are ready to breathe on their own. This may take a day or two, but it can sometimes take a bit longer for babies. In addition to the ventilator, several monitors in the room will be used to check your child's heart rhythm, blood pressure, blood oxygen level, and perhaps other signs, depending on your child's specific situation.

Devices and tubes

- Your child will have a bladder catheter (a soft plastic tube, aka Foley catheter) that will continuously drain urine. This tube is inserted during surgery.
- A nasogastric tube may also be in place. This tube is inserted through a nostril and then passed down into the stomach. It is designed to drain stomach fluid.
- As your child will still be asleep or very drowsy at this time, they will get fluid, medications, and nutrition through intravenous (IV) drips. These will normally go into your child's neck or chest and arm or the back of their hand.

Your child's nurse will be able to explain all monitors and tubes to you. Feel free to ask questions.

Your child's incision

Your child will have an incision (cut) along part or the entire length of the abdomen. This will be covered with a dressing. After two or three days, the dressing will be removed and left off. Depending on their surgeon's preference, your child may have staples (wire) or a suture (thread stitches) on the incision.

Lab testing

Your child will have frequent blood tests to determine how the new kidney is working and to monitor for complications after surgery. Most often these blood tests can be drawn from one of your child's intravenous lines, avoiding the need to be poked for lab draws during this initial period.

Moving out of the ICU

As your child recovers from the surgery, the medical team will reduce their medications and begin to remove the invasive lines and monitors. The breathing machine will do less work as your child is woken up from sedation. When your child is finally disconnected from the breathing machine, they will be able to speak and, in time, have a drink.

Depending on their condition, a child can stay in the ICU for a few days or even a few weeks. When your child no longer needs intensive care, they will be moved to a regular hospital room.

Although most of the monitoring equipment will have been removed, your child may still have a bladder catheter and intravenous infusions. Over the following days, these will be gradually removed as your child's condition improves.

Working with your child's health care team

Once your child is out of the ICU and in a regular hospital room, the nurse who looks after them regularly will also have other patients to care for, unlike the ICU. Because of this you will be encouraged to play a greater role in your child's care.

At this point, too, other transplant team members, such as the physiotherapist, occupational therapist, and dietitian, become involved again in your child's care. It is important that you and your child follow their recommendations and instructions so that your child can begin to experience life with their new kidney.

This is also a time when the transplant coordinators and pharmacists will work closely with you to make sure that you are getting ready to care for your child at home.

Caring for a child with a chronic illness and going through a transplant can be stressful for everyone and can affect family dynamics. It is important to consider how other siblings might feel and to make time for spouses/partners. Many families find benefit from family-centered therapy. If this is something you feel might be helpful, your transplant team can help you identify sources of support.

LIFE AFTER KIDNEY TRANSPLANT

After the transplant, your child's care will be managed by a health-care team. It will consist of your pediatric nephrologist, your transplant surgeon, usually a nurse coordinator, a dietitian, a pharmacist and a social worker.

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

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

As you read this manual, please remember that every child is different. Also, different transplant centers have their own routines for follow-up after a kidney transplant. You are encouraged to ask your team about routine follow up schedules in your pre-transplant evaluation.

Note, too, that schedules and tests may change for many different reasons. Your kidney transplant team members will explain why they are doing a certain test or procedure in your child at a specific time. Many of the principles of renal transplant care are the same for children and adults.

Clinic Visits and Routine Testing

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

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

Clinic visits

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

Laboratory (lab) tests

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

- A patient's white blood cell count, to show any possible infection or side effects from transplant medications
- The level of waste products, such as creatinine and blood urea nitrogen in the blood, to show how well a patient's kidneys and liver are working
- "Levels", which is short for how much immunosuppressant medication stays in a patient's bloodstream and for how long (high levels could be toxic or suppress the immune system too much and low levels may cause a patient to reject the new kidney)
- Urine analysis and culture to make sure there are no signs of urinary infection and to check for protein in the urine which can be abnormal.
- The amount of glucose (sugar), or lipids (cholesterol and other fats) in the blood (some transplant medications can make them too high)
- Signs of any recent viral infections
- The level of HLA antibodies in the blood, to check if the body might start to reject the donor kidney.

Kidney tests

Renal ultrasound

Your child will have had a renal ultrasound before the transplant. This test uses sound waves to:

- Check the size, shape, and structure of the transplanted kidney
- Determine blood flow to the kidney and rule out thrombosis (blood clots) or urine leak,
- Identify if there is any fluid around the kidney (hematoma, lymphocele).

Kidney biopsy

A biopsy of the kidney may be necessary in the setting of decreased urine output, increased serum creatinine level, unexplained persistent fever or worrisome blood or protein in the urine. The biopsy can be done for many reasons including to evaluate for the possibility of rejection, recurrent kidney disease, drug toxicity or certain types of infections. Some children may have had kidney biopsies of their own kidneys before having a transplant. Those biopsies are done with the child lying face down on their abdomen. Because a transplant kidney is in a different place than the native kidney, a transplant kidney biopsy is done with a child lying on their back. The biopsy is done after consent is signed where the risks of the biopsy will be explained and after it has been decided how the patient will be kept comfortable during the biopsy. Each transplant center has different procedures with regard to sedation medications or anesthesia for the child and where in the facility the biopsy will be done but all centers will have protocols for how the child is kept comfortable and safe during and after the biopsy. The biopsy is commonly done with the assistance of the radiologists and most frequently ultrasound is used to guide the biopsy and increase safety. The biopsy typically will be done using a biopsy needle going through a very small incision made in a numbed area of overlying skin. Usually 2 to 3 pieces of

kidney tissue are obtained and sent to the pathology lab for staining and processing, a procedure that can take anywhere from one to three days to complete. The primary risk of a kidney biopsy is bleeding so certain medications that may increase the risk of bleeding may need to be stopped or held before and after the biopsy. Your transplant center will tell you if any medication changes need to be made. Following the biopsy some children are kept in the hospital overnight while others might be able to go home after a period of observation for complications. Each transplant center will have their own protocol for how this occurs. Your child will have some activity restrictions after the biopsy which your transplant center will review with you.

Other tests and procedures

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

- Glomerular filtration rate (GFR) testing, to see how well the transplanted kidney is working
- Bone mineral density, to assess bone strength
- 24-hour ambulatory blood pressure monitoring, to check blood pressure at regular intervals during your child's everyday routine.
- Developmental assessments.
- Echocardiograms
- Dilated eye exams

TRANSPLANT MEDICATIONS

The key to maintaining a successful kidney transplant is taking medications consistently and correctly for the rest of your child's life.

At first, you may feel overwhelmed with the new medications and the information about them. Your transplant team's goal is to make sure you are familiar with all of the medications your child will be taking before you leave the hospital.

Over time, it will become routine for you and your child to follow the medicine instructions. We want you to become responsible for giving the medications, and we encourage your child to become more involved in taking the medicines as they get older. However, remember that most adolescents continue to require supervision.

Types of transplant medications

In general, most transplant patients will be taking three types of medications:

- Immunosuppressants
- Anti-infectants
- Other medications.

Immunosuppressants

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

Your child will take immunosuppressants for the rest of their life, but over time they will need a lower dose.

Anti-infectants

Your child has a higher risk of developing certain infections after kidney transplantation, particularly in the first few weeks to months. While not all infections can be prevented some of them can be prevented using anti-microbial and anti-viral medications. These antibiotics and anti-viral medications work to prevent or fight infections so your child can stay as healthy as possible while they get used to their new kidney. Different transplant programs give antibiotics and anti-viral medications for different amounts of time. Some patients may only take antibiotics and anti-viral medications for the first year after transplant and other patients may take them life-long. Sometimes they may be taken after being treated for a rejection episode, as this is when your child is usually given more immunosuppressants.

Other medications

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

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

Understanding your child's medications

Because you are responsible for giving your child their medicine, it is very important that you talk with your pharmacist, doctor, or nurse to completely understand the following points.

- Name of each medicine and why your child needs it
- When to take each medicine
- How to take each medicine
- How long your child will be on each medicine
- Possible side-effects of each medicine
- What to do if a dose of medication is missed by accident
- How and when to order medications to make sure you do not miss any doses. Some of your medications may only be available at a specialized pharmacy and not at your corner drug store.

Giving medications and reporting side effects

- Always give medication at the same time every day and in the same way (with or without food), including weekends. If you give your child medicine at 9am and 9pm on Monday, you must do the same every day of the week.
- Never skip a dose! Skipping doses increases the chance that the kidney may be rejected and stop working properly. If you skip a dose, do not make up for the missed dose by doubling on the dose next time you take it. Call your transplant team if you have questions on what to do.
- Do not stop or change any dose of your child's medications unless your transplant team tells you to.
- Never give your child over-the-counter herbal (natural), or homeopathic medications or any medications prescribed by another doctor without talking to your transplant team first. This is because many medications interact with transplant medications, leading to unpleasant side effects or preventing the transplant medications from working properly.
- Call your transplant team right away if your child has side effects from any medications. They will tell you what to do.

Guidelines for taking medications

Below is a list of basic guidelines that apply to many medications. Remember, though, that each medicine that your child needs has its own rules. Please refer to the specific medication page in this manual **and** ask your pharmacist, doctor, or nurse for any other information.

Storing medications

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



Refilling prescriptions

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



Travel

- Make sure you talk to your transplant team if you are planning on traveling (especially out of the country) in case special extra precautions are needed. When traveling, always keep the transplant medications with you. You risk losing the medications if you put them in checked-in luggage and it gets lost. Medication can also be damaged from being stored at freezing temperatures in the storage area. Keep your liquid medications in their original prescription bottles. When planning a vacation there may be risks, particularly infectious disease risks that you may not be aware of. When planning a vacation it is always a good idea to discuss your plans with your transplant team.

Eating and drinking

- Never let your child eat or drink grapefruit or grapefruit juice. This includes any fruit related grapefruit, such as pomelo, and any mixed fruit juices containing grapefruit juice. Grapefruit juice can interact with some transplant medications, in particular raising the levels of immunosuppressants in the blood. Never let your child drink unpasteurized milk products or untreated water as they can have infections that may be more harmful to your child because their immune system is decreased.



Hygiene

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

Why is it important to stick to one brand of medicine

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

For example, tacrolimus (one type of immunosuppressant) is the chemical name, but Prograf® is the brand name given by Astellas, the company that makes it. But other companies also make tacrolimus and may offer it in different strengths. In addition, the body may handle medications from other manufacturers differently.

These differences can affect the amount of tacrolimus in the blood stream. If the amount is too low, the kidney could be rejected; if it is higher, your child could have more medicine side effects.

As a result, it is important to know the brand name and strength of your child's medicine and to keep choosing the same brand of drug. Make sure you tell your transplant center if the brand name or strength of the medicine changes, as your child's blood levels may need to be re-checked. Your insurance provider may require you to use one brand of medication instead of another. Please let your transplant center know if your insurance is requiring a change.

While we use the example of tacrolimus here, this rule is the same for all your transplant medications.

The following medicine pages in this section are meant as a guide and contain the most important and common information you may need. However, every child is different. Your child may need medications that are not listed here. Be assured that your child's transplant team will only choose medications that they feel will be the best for your child. If you have questions or doubts, ALWAYS call your transplant team. The medications are listed alphabetically in each section and are not listed based on which ones are used most frequently.

Immunosuppression Medications

Many different immunosuppression medications are used to prevent rejection in children receiving kidney transplants. Your transplant doctors will review these medications and tell you which ones your child will be receiving. The information that follows is general information about some common side effects for the most common immunosuppression medications being used to prevent rejection of the kidney transplant. Immunosuppression after transplant can be separated into induction, which is the initial very strong immunosuppression your child will initially receive after transplant, and maintenance, which is the immunosuppression medication that your child will receive for the rest of their life.

Induction Immunosuppression

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

Not every transplant center uses induction immunosuppression medications or uses them for every patient.

Generic name	Alemtuzumab
Brand name	Campath®
What it does	Alemtuzumab helps prevent the body from rejecting the transplanted kidney.
What it looks like	The hospital pharmacy will prepare alemtuzumab in a syringe (needle) or intravenous (IV) bag.

How it is given	Alemtuzumab is given to your child's vein over several hours.
Most common side effects	<ul style="list-style-type: none"> • Fever, chills, aches (during the infusion) • Blood pressure and heart rate (during the infusion) • Lower platelet counts • Lower white blood cell counts
Other important information	Most children will also take some medications before the alemtuzumab dose to prevent or lessen reactions during the infusion (example: acetaminophen [Tylenol®], diphenhydramine [Benadryl®]).
Generic name	Anti-thymocyte globulin (rabbit)
Brand name	Thymoglobulin®
What it does	<p>Anti-thymocyte globulin:</p> <ul style="list-style-type: none"> • Helps prevent your child's body from rejecting the transplanted kidney at the time of transplant • Treats serious rejection any time after transplant.
What it looks like	The hospital pharmacy will prepare anti-thymocyte globulin in a syringe (needle) or an intravenous (IV) bag.
How it is given	Anti-thymocyte globulin is given into your child's vein over several hours for three to 14 days.
Most common side effects	<ul style="list-style-type: none"> • Fever, chills, or aches (during the infusion) • Changes in blood pressure and heart rate (during the infusion) • Difficulty breathing (during the infusion) • Rash • Lower platelet counts [platelets help stop bleeding] • Lower white blood cell counts [white blood cells help fight infection]
Other important information	Most children will take some medications, such as acetaminophen [Tylenol®] or diphenhydramine [Benadryl®], before the anti-thymocyte globulin dose to prevent or lessen reactions during the infusion.

Generic name	Basiliximab
Brand name	Simulect®

What it does	Basiliximab helps prevent the body from rejecting the transplanted kidney.
What it looks like	The hospital pharmacy will prepare basiliximab in a syringe (needle) or an intravenous (IV) bag.).
How it is given	Basiliximab is given into your child's vein on the day of transplant and four days after the transplant.
Most common side effects	<ul style="list-style-type: none">• Fever or chills (while dose is being given)• Changes in blood pressure and heart rate (while the dose is being given)• Allergic reaction (rare)

Generic name	Methylprednisolone
Brand name	Solumedrol®
What it does	<p>Methylprednisolone is a corticosteroid. It:</p> <ul style="list-style-type: none"> • Helps prevents your child's body from rejecting the transplanted kidney at the time of transplant • Treats rejection any time after the transplant.
What it looks like	<p>Methylprednisolone is supplied in vials (small bottles). The pharmacy or your nurse will prepare your child's dose in a syringe (needle) or intravenous (IV) bag.</p> <p>Once your child is taking food by mouth, they will get it in a tablet or liquid form.</p>
How it is given	Methylprednisolone is given into your child's vein.
Most common side effects	<ul style="list-style-type: none"> • Increased blood pressure • Higher blood sugar levels • More appetite (hunger) • Weight gain • Edema (puffiness) • Higher cholesterol • Mood swings, irritability • Difficulty sleeping • More sweating (more often at night) • Mild headache • Slow wound healing
Other important information	High doses of methylprednisolone are usually given over a few days at the time of transplant or if your child has a rejection episode.

Maintenance Immunosuppression

These are medications that your child will take every day for the rest of their life to prevent rejection of the transplanted kidney.

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

Generic name	Azathioprine
Brand name	Imuran®
What it does	Azathioprine helps prevent the body from rejecting the transplanted kidney.
How it is given	<ul style="list-style-type: none">• Give azathioprine once a day, at the same time, every day.• Give azathioprine with food or without food, but give it the same way every day.• Giving azathioprine with food can lessen stomach upset (such as nausea).
Most common side effects	<ul style="list-style-type: none">• Nausea (upset stomach), vomiting (throwing up)• Reduced appetite• Low platelet counts [platelets help stop bleeding]• Low white blood cell counts [white blood cells help fight infection]• Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]• Mild headache• Dizziness• Hair loss• Rash

Generic name	Cyclosporine
Brand name	Gengraf®, Neoral®, Sandimmune®
What it does	Cyclosporine helps prevent the body from rejecting the transplanted kidney.
How it is given	<ul style="list-style-type: none">• Give cyclosporine at the same times every day, usually 12* hours apart (*8 hours apart for small children).• Give cyclosporine either with food or without food. Give it the same way every day, since changes in food intake can affect how much cyclosporine passes from your child's stomach into their bloodstream.• Neoral® and Sandimmune® are different drugs. Never swap one for the other.• Make sure that you always have the same brand of cyclosporine. Call your transplant team if you notice that the capsules or liquid cyclosporine look different from what your child normally takes.

Most common side effects	<ul style="list-style-type: none"> • Decreased magnesium in the blood • Increased potassium in the blood • Increased blood pressure • Increased blood sugar (some children develop diabetes) • Damage to the kidneys (usually if blood levels of cyclosporine are too high) • Headache • Tremors (shakiness of the hands or feet) • Upset stomach, vomiting (throwing up) or diarrhea (watery stools) • Increased body hair growth (face, arms, back, body) • Tender or swollen gums
Other important information	<ul style="list-style-type: none"> • Never give your child grapefruit juice or any juices that contain grapefruit. These products raise the cyclosporine level in your child's bloodstream. This can lead to more side effects. Read the labels of mixed fruit juices (front and back) carefully. • Never let your child eat grapefruit (even when mixed in a fruit salad) or any fruit related to grapefruit, such as pomelos or tangelos.

Generic name	Everolimus
Brand name	Zortress®
What it does	Everolimus helps prevent the body from rejecting the transplanted kidney.
How it is given	<ul style="list-style-type: none"> • Give everolimus twice a day, at the same time, every day. • Give everolimus with food or without food, but give it the same way every day. Food does not have a big effect how much everolimus passes from your child's stomach into their bloodstream.
Most common side effects	<ul style="list-style-type: none"> • Nausea (upset stomach), vomiting (throwing up) or diarrhea (watery stool) • Mild headache • High cholesterol and/or triglyceride levels • Low white blood cell counts [white blood cells help fight infection] • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body] • Low platelet counts [platelets help stop bleeding] • Delayed wound healing • Increased protein in the urine • Increase in liver function (transaminases) tests • Lung inflammation (swelling)

Other important information

- **Never** give your child grapefruit juice or any juices that contain grapefruit. These products raise the everolimus level in your child's bloodstream. This can lead to more side effects. Read the labels of mixed fruit juices (front and back!) carefully.
- **Never** let your child eat grapefruit (even when mixed in a fruit salad) or any fruit related to grapefruit, such as pomelos or tangelos.

Generic name**Mycophenolate****Brand name****Cellcept® (mycophenolate mofetil), Myfortic® (mycophenolate sodium)****Several generic products are also available**

What it does

Mycophenolate helps prevent the body from rejecting the transplanted kidney.

What it looks like

Mycophenolate mofetil and mycophenolate sodium (Myfortic®) are different drugs with different dosing instructions. Never swap one for the other.

Mycophenolate mofetil comes in:

- 250mg capsules
- 500mg tablets
- Suspension (liquid)

Mycophenolate sodium (Myfortic®) comes in:

- 180mg (light green) tablets
- 360mg (light orange) tablets

Make sure that you are always taking the same brand of mycophenolate. Call your transplant team if you notice the mycophenolate looks different from what you normally give your child.

How it is given

- Give mycophenolate at the same times every day, 12 hours apart, or as instructed by your transplant team.
- Give mycophenolate with food or without food. Give it the same way every day, since changes in food intake can affect how much mycophenolate passes from your child's stomach into their bloodstream.
- Giving mycophenolate with food may lessen stomach upset (such as cramps or diarrhea).

Most common side effects	<ul style="list-style-type: none"> • Stomach cramps, diarrhea (watery stools) • Nausea (upset stomach), heartburn or vomiting (throwing up) • Low platelet counts [platelets help stop bleeding] • Low white blood cell counts [white blood cells help fight infection] • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body] • Mild headache • Birth defects and risk of malformations in an unborn fetus (girls should change to another agent while pregnant or trying to become pregnant under close monitoring of the transplant team)
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Generic name	Prednisone / Prednisolone
Brand name	Deltasone®, Orapred®, Pediapred®
What it does	Prednisone / Prednisolone helps prevent the body from rejecting the transplanted kidney.
How it is given	By mouth
Most common side effects	<ul style="list-style-type: none"> • Increased blood pressure • Higher blood sugar levels • Upset stomach, vomiting (throwing up) or diarrhea (watery stools) • More appetite (hunger) • Weight gain • Edema (puffiness) and rounded face • Mood swings, irritability • Difficulty sleeping • More sweating (more often at night) • Mild headache • Acne (pimples) • Slow wound healing • Stretch marks <p>The following are effects of longer use of prednisone or prednisolone:</p> <ul style="list-style-type: none"> • Weaker bones • Slower growth (height) • Cataracts (a gel-like glaze over the eye(s))

Generic name	Sirolimus
Brand name	Rapamune®
What it does	Sirolimus helps prevent the body from rejecting the transplanted kidney.

How it is given	<ul style="list-style-type: none"> • Give sirolimus once a day, at the same time every day. Your child’s doctor may want your child to take it twice a day if they are on a high dose. • Give sirolimus with food or without food, but give it the same way every day. Food does not have a big effect how much sirolimus passes from your child’s stomach into their bloodstream.
Most common side effects	<ul style="list-style-type: none"> • Upset stomach, vomiting (throwing up) or diarrhea (watery stools) • Mild headache • High cholesterol and/or triglyceride levels • Low white blood cell counts [white blood cells help fight infection] • Mouth sores or ulcers • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body] • Low platelet counts [platelets help stop bleeding] • High blood pressure • Delayed wound healing • Acne (pimples) • Increased protein in the urine • Swelling • Increase in liver function (transaminases) tests • Leg cramps • Lung inflammation (swelling)
Other important information	<ul style="list-style-type: none"> • Never give your child grapefruit juice or any juices that contain grapefruit. These products raise the sirolimus level in your child’s bloodstream. This can lead to more side effects. Read the labels of mixed fruit juices (front and back!) carefully. • Never let your child eat grapefruit (even when mixed in a fruit salad) or any fruit related to grapefruit, such as pomelos or tangelos.

Generic name	Tacrolimus
Brand name	Prograf®, Hecoria®, Astagraf XL®, Sandoz
What it does	Tacrolimus helps prevent the body from rejecting the transplanted kidney.
How it is given	<ul style="list-style-type: none"> • Give tacrolimus at the same times every day, usually 12* hours apart (*8 hours apart for small children; *every 24 hours if on Astagraf XL®). • Give tacrolimus either with food or without food. Give it the same way every day, since changes in food intake can affect how much tacrolimus passes from your child’s stomach into their bloodstream. • Make sure that you always have the same brand of tacrolimus. Call your transplant team if you notice that the capsules or liquid tacrolimus look different from what your child normally takes.

Most common side effects	<ul style="list-style-type: none"> • Decreased magnesium in the blood • Increased potassium in the blood • Increased blood sugar (some children develop diabetes) • Increased blood pressure • Damage to the kidneys (usually if blood levels of tacrolimus are too high, but long term damage at “normal” doses is also possible) • Shakiness of the hands/feet (tremor) • Upset stomach, vomiting (throwing up) or diarrhea (watery stools) • Mild headache • Seizures (if blood levels of tacrolimus are too high) • Leg cramps • Hair loss
Other important information	<ul style="list-style-type: none"> • Never give your child grapefruit juice or any juices that contain grapefruit. These products raise the tacrolimus level in your child’s bloodstream. This can lead to more side effects. Read the labels of mixed fruit juices (front and back!) carefully. • Never let your child eat grapefruit (even when mixed in a fruit salad) or any fruit related to grapefruit, such as pomelos or tangelos.

Other Immunosuppressants

Generic name	Cyclophosphamide
Brand name	Cytoxan®
What it does	Cyclophosphamide is used to treat certain cases of post-transplant lymphoproliferative disease (PTLD)
How it is given	Cyclophosphamide is given into your child’s veins over several hours. Depending on the situation, your child may receive only one dose of cyclophosphamide or one dose every few weeks.
Most common side effects	<ul style="list-style-type: none"> • Changes in blood pressure and heart rate (during the infusion) • Nausea, vomiting, cramping, or diarrhea (watery stools) • Bladder problems • Lower white blood cell counts [white blood cells help fight infection] • Lower platelet counts [platelets help stop bleeding] • Rash • Hair loss
Other important information	Your child will be given extra IV fluids before, during, and after cyclophosphamide doses to protect their kidney and bladder.

Generic name	Rituximab
Brand name	Rituxan®
What it does	Rituximab is used to treat: <ul style="list-style-type: none"> • Certain types of post-transplant lymphoproliferative disease (PTLD). • A special type of rejection called antibody-mediated rejection.
How it is given	Rituximab is given into your child’s veins over several hours. Depending on the situation, your child may receive only one dose of rituximab or one dose every few weeks.
Most common side effects	<ul style="list-style-type: none"> • Fever, chills, muscle aches (during the infusion) • Changes in blood pressure and heart rate (during the infusion) • Difficulty breathing (during the infusion) • Headache, dizziness • Change in blood sugar • Rash • Lower platelet counts [platelets help stop bleeding] • Lower white blood cell counts [white blood cells help fight infection]
Other important information	Most children will also take some medications, such as acetaminophen (Tylenol®) or diphenhydramine (Benadryl®), before the rituximab dose to prevent or ease reactions during the infusion.

Other common medications prescribed after transplant

Medications to prevent and treat infections

Generic name	Acyclovir
Brand name	Zovirax®
What it does	Acyclovir is used to help prevent and treat infections caused by certain types of viruses.
How it is given	Acyclovir is given by mouth. To prevent kidney problems while taking acyclovir, your child should drink plenty of water or other fluid (unless the doctor has told them to drink less).
Most common side effects	<ul style="list-style-type: none"> • Upset stomach • Vomiting (throwing up) or diarrhea (loose stools) • Mild headache • Dizziness • Reduced kidney function (shown by higher levels of a waste product called creatinine in the blood); may also cause kidney damage.

Generic name	Atovaquone
Brand name	Mepron®
What it does	Atovaquone is used to help prevent a certain type of lung infection called <i>Pneumocystis jiroveci</i> pneumonia (PCP).
How it is given	Atovaquone is given by mouth. Atovaquone can be mixed in small amounts of orange juice or milk if your child cannot tolerate the taste or texture by itself.
Most common side effects	<ul style="list-style-type: none"> • Fever • Headache, dizziness • Inability to sleep • Nausea, vomiting, stomach cramping, diarrhea (watery stools)

Generic name	Clotrimazole
Brand name	Mycelex®
What it does	Clotrimazole is used to help prevent thrush, a type of infection caused by a yeast. Thrush can occur in the mouth and throat. If not treated, it can be spread to the esophagus (food tube) and further into the body. Thrush often looks like a white, sometimes furry coating on your child's tongue or white spots on the inside of the mouth. Your child's voice may also be hoarse.
How it is given	Clotrimazole is given by mouth.
Most common side effects	Nausea or vomiting (throwing up)

Generic name	Cytomegalovirus Immune Globulin (CMV-IVIG)
Brand name	Cytogam®
What it does	With other medications, CMV-IVIG is used to help prevent and in the treatment of CMV (cytomegalovirus) infection.
How it is given	CMV-IVIG is given into your child's vein. The infusion lasts several hours.
Most common side effects	<ul style="list-style-type: none"> • Change in heartbeat, blood pressure or breathing rate (during the infusion) • Aches • Nausea or vomiting (throwing up)

Generic name	Dapsone
Brand name	Avlosulfon®; may also be called by its short form, DDS
What it does	Dapsone is used to help prevent a certain type of lung infection called <i>Pneumocystis jiroveci</i> pneumonia (PCP).
How it is given	Dapsone is given by mouth.
Most common side effects	<ul style="list-style-type: none"> • Nausea (upset stomach) or vomiting (throwing up) • Not feeling hungry or loss of appetite • Difficulty sleeping • Headache • Hemolysis (breakdown of red blood cells), particularly in patients with G6PD (glucose-6-phosphate dehydrogenase) deficiency

Generic name	Fluconazole
Brand name	Diflucan®
What it does	Fluconazole is used to help prevent and to treat infections caused by certain types of yeast.
How it is given	Fluconazole is given by mouth.
Most common side effects	<ul style="list-style-type: none"> • Upset stomach • Vomiting (throwing up) • Diarrhea (watery stools) • Mild headache • Dizziness • Liver problems. <p>It can raise tacrolimus/cyclosporine/sirolimus levels so close monitoring of levels will be required</p>

Generic Name	Ganciclovir
Brand Name	Cytovene®
What it does	<p>Ganciclovir is used to help prevent and to treat two common viral infections in transplant patients:</p> <ul style="list-style-type: none"> • Cytomegalovirus (CMV) • Epstein Barr (EBV)
How it is given	Ganciclovir is given by mouth or into your child's vein.

Most common side effects	<ul style="list-style-type: none"> • Mild headache • Lower platelets [platelets help stop bleeding] • Lower white blood cell counts [white blood cells help fight infection] • Lower red blood cell (hemoglobin) counts [hemoglobin provides energy to the body] • Reduced kidney function (shown by higher levels of a waste product called creatinine in the blood); may also cause kidney damage • Upset stomach, vomiting (throwing up), or diarrhea (watery stools)
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Generic name	Nystatin
Brand name	Mycostatin®
What it does	<p>Nystatin is used to help prevent thrush, a type infection caused by yeast . Thrush can occur in the mouth and throat. If not treated, it can spread to the esophagus (food tube) and further into the body.</p> <p>Thrush often looks like a white, sometimes furry coating on your child’s tongue or white spots on the inside of the mouth. Your child’s voice may also be harsh.</p>
How it is given	<ul style="list-style-type: none"> • Nystatin is only available in a liquid. Your child swishes it around their mouth for a minute before swallowing it. • Your child must not eat anything for 20 minutes after taking the dose.
Most common side effects	<ul style="list-style-type: none"> • Upset stomach • Vomiting (throwing up) • Diarrhea (watery stools) • Cavities (if teeth are not brushed regularly – see below)
Other important information	<ul style="list-style-type: none"> • Nystatin contains sugar. To prevent cavities, your child should brush their teeth 20 to 20 minutes after taking it. • If your child does not like the taste of nystatin, many pharmacies can flavor it to help your child take the dose.

Generic name	Pentamidine
Brand name	NebuPent®, Pentam®
What it does	Pentamidine is used to help prevent and treat a certain type of lung infection called <i>Pneumocystis jiroveci</i> pneumonia (PCP).
How it is given	Pentamidine is inhaled through a mask or intravenously (IV)

Most common side effects	<p>When pentamidine is inhaled:</p> <ul style="list-style-type: none"> • Cough, tightness in the chest • Bitter taste in the mouth <p>Both inhaled and IV forms:</p> <ul style="list-style-type: none"> • Low white blood cell counts [white blood cells help fight infection] • Low platelets [platelets help stop bleeding] • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]
Other important information	If your child is receiving inhaled pentamidine, they may also inhale a medication called ‘albuterol’ or ‘salbutamol’ before the pentamidine to prevent coughing and chest tightness.

Generic name	Sulfamethoxazole-Trimethoprim (SMX-TMP)
Brand name	Bactrim®, Septra®, Cotrimoxazole®
What it does	<p>SMX-TMP is used to help prevent a certain type of lung infection called <i>Pneumocystis jiroveci</i> pneumonia (PCP) and certain types of urinary tract infection.</p> <p>It contains two antibiotics:</p> <ul style="list-style-type: none"> • Sulfamethoxazole • Trimethoprim <p>Your child cannot take this medication if they have an allergy to:</p> <ul style="list-style-type: none"> • Sulfonamides or “sulfa” drugs • Trimethoprim <p>Other medications to help prevent PCP will be given if your child cannot take sulfamethoxazole-trimethoprim.</p>
How it is given	SMX-TMP can be given daily, every other day or three times a week. Your transplant team will explain the schedule they use.
Most common side effects	<ul style="list-style-type: none"> • Upset stomach, vomiting (throwing up) or diarrhea (watery stools) • Mild headache • Rash • Increased sensitivity to the sun • Low white blood cell counts [white blood cells help fight infection] • Low platelets [platelets help stop bleeding] • Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body] • Increased potassium in the blood
Other important information	Because SMX-TMP makes your child’s skin more sensitive to the sun, your child will burn more easily! Make sure your child always wears sunscreen when outside.

Generic name	Valganciclovir
Brand name	Valcyte®
What it does	Valganciclovir is used to help prevent and treat viral infections in transplant patients, specifically: <ul style="list-style-type: none"> • Cytomegalovirus (CMV) • Epstein Barr virus (EBV)
How it is given	<ul style="list-style-type: none"> • Give valganciclovir once or twice a day at the same time each day. • Give it with plenty of fluids. • Give valganciclovir with food to help more to the medication pass from your child's stomach into their bloodstream.
Most common side effects	<ul style="list-style-type: none"> • Mild headache • Lower platelets [platelets help stop bleeding] • Lower white blood cell counts [white blood cells help fight infection] • Lower red blood cell (hemoglobin) counts [hemoglobin provides energy to the body] • Reduced kidney function (shown by higher levels of a waste product called creatinine in the blood); may also cause kidney damage • Upset stomach, vomiting (throwing up), or diarrhea (watery stools)

Vitamins and supplements

Generic name	Multi-vitamin
Brand name	One-A-Day®, Centrum®, AquaDEKs®, Poly-Vi-Sol®, Tri-Vi-Sol® (among many other brands)
What it does	A multi-vitamin helps to prevent low vitamin levels that can be caused by some medications or a diet low in vitamins and minerals.
Most common side effects	<ul style="list-style-type: none"> • Stomach pain • Upset stomach • Nausea and vomiting (throwing up)

Generic name	Calcium
Brand name	Oscal®, Tums® (calcium carbonate), Citracal® (calcium citrate), NeoCalGlucon® (calcium glubionate)
What it does	Calcium helps increase low calcium levels that be caused by a diet low in vitamins and minerals. It also helps to build strong bones.
Most common side effects	<ul style="list-style-type: none"> • Stomach pain • Constipation, Gas

- Nausea and vomiting (throwing up)

Generic name	Iron
Brand name	Femiron[®], Ferretts[®], Palafer[®] (ferrous fumarate), Ferate[®], Fergon[®] (ferrous gluconate), Feosol[®], Fer-In-Sol[®] (ferrous sulfate)
What it does	Iron helps increase low iron levels that can be caused by a diet low in vitamins and minerals. Iron also helps to correct blood anemia (low red blood cell (hemoglobin) counts).
Most common side effects	<ul style="list-style-type: none"> • Constipation • Dark colored stools • Stomach pain and cramping • Nausea and vomiting (throwing up)
Other important information	Iron may turn your child's stools very dark. Do not be alarmed if this happens.

Generic name	Magnesium
Brand name	Mag-Ox[®] (magnesium oxide), Magonate[®] (magnesium gluconate), Milk of Magnesia[®] (magnesium hydroxide), magnesium sulfate
What it does	Magnesium helps increase low magnesium levels that can be caused by some medications or a diet low in vitamins and minerals.
Most common side effects	<ul style="list-style-type: none"> • Stomach upset • Cramping • Diarrhea (watery stools)

Generic name	Potassium
Brand name	K-Effervescent[®], (potassium bicarbonate), Klor-Con[®] (potassium chloride), Phos-K[®] (potassium gluconate, potassium phosphate)
What it does	Potassium helps increase low potassium levels that can be caused by some medications or a diet low in vitamins and minerals.
Most common side effects	<ul style="list-style-type: none"> • Stomach pain • Diarrhea (watery stools) • Gas • Nausea and vomiting (throwing up)

Other common medications

Infection-control

Generic name	Intravenous immunoglobulin (IVIG)
Brand (and generic) names	Many brand names
What it does	IVIG: <ul style="list-style-type: none">• Gives your child immunoglobulins, which are important in fighting infection.• Along with other medications, is used to treat a special type of rejection called antibody-mediated rejection.
How it is given	IVIG is given into your child's vein over several hours.
Most common side effects	<ul style="list-style-type: none">• Fever, chills, aches (during the infusion)• Blood pressure and heart rate (during the infusion)• Difficulty breathing (during the infusion)• Rash

Diuretics

Class	Loop diuretics
Brand (and generic) names	Lasix® (furosemide), Bumex®, Burinex® (bumetadine), Demadex® (torsemide)
What they do	Diuretics (or 'water pills') help to decrease swelling by removing extra fluid from the body. They can also lower blood pressure.
Most common side effects	<ul style="list-style-type: none">• Increased amount of urine (pee)• Dizziness• Low blood pressure• Low electrolyte and mineral levels in the blood• Decreased hearing (rare)

Class	Potassium-sparing diuretics
Brand (and generic) names	Aldactone® (spironolactone), Dyrenium® (triamterene)
What they do	Potassium-sparing diuretics (or 'water pills') help to decrease swelling by removing extra fluid from the body but without decreasing potassium levels. They can also lower blood pressure.
Most common side effects	<ul style="list-style-type: none">• Increased amount of urine (pee)• Increased potassium levels in the blood• Diarrhea (watery stools)• Nausea and vomiting (throwing up)

- Low blood pressure

Class	Thiazide diuretics
Brand (and generic) names	HCTZ (hydrochlorothiazide), Diuril® (chlorothiazide)
What they do	Diuretics (or ‘water pills’) help to decrease swelling by removing extra fluid from the body. They can also lower blood pressure.
Most common side effects	<ul style="list-style-type: none"> • Increased amount of urine (pee) • Dizziness • Low blood pressure • Low electrolyte and mineral levels in the blood

Class	Thiazide-like diuretics
Brand (and generic) names	Zaroxolyn® (metolazone)
What they do	Metolazone helps to decrease swelling by removing extra fluid from the body. It can also lower blood pressure.
Most common side effects	<ul style="list-style-type: none"> • Increased amount of urine (pee) • Dizziness • Low blood pressure • Low vitamin and electrolyte and mineral levels in the blood

Anti-hypertensives (blood pressure medications)

Class	Angiotensin Converting Enzyme (ACE)-inhibitors
Brand (and generic) names	Lotensin® (benazepril), Vasotec® (enalapril), Prinivil®, Zestril® (lisinopril), Capoten® (captopril), Monopril® (fosinopril), Accupril® (quinapril), Altace® (ramipril)
What they do	ACE-inhibitors help to lower blood pressure and treat symptoms of nephrotic range proteinuria and heart failure.
Most common side effects	<ul style="list-style-type: none"> • Dizziness • Low blood pressure • Cough • Increased potassium levels in the blood • Face, tongue, or neck swelling • Elevated creatinine • Risk of malformations in an unborn fetus (teen girls should stop taking this drug while pregnant or trying to become pregnant under the close supervision of their transplant team)

Other important information	Call your doctor if your child develops: <ul style="list-style-type: none"> • Any face, tongue, or neck swelling (call immediately) • A cough that is bothersome and does not go away.
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Class	Angiotensin Receptor Blockers (ARBs)
Brand (and generic) names	Cozaar® (losartan), Atacand® (candesartan), Diovan®(valsartan), Benicar®, Olmetec® (olmesartan), Avapro® (irbesartan)
What they do	ARBs help to lower blood pressure and treat symptoms of nephrotic range proteinuria and heart failure.
Most common side effects	<ul style="list-style-type: none"> • Dizziness • Low blood pressure • Increased potassium levels in the blood • Elevated creatinine • Risk of malformations in an unborn fetus (teen girls should stop taking this drug while pregnant or trying to become pregnant under the close supervision of their transplant team).
Other important information	Avoid diets high in potassium (salts, bananas, tomatoes, potatoes, nuts and fruit juices)

Class	Dihydropyridine calcium channel blockers (CCBs)
Brand (and generic) names	Norvasc® (amlodipine), Procardia® (nifedipine), Plendil®(felodipine), Nimotop® (nimodipine), DynaCirc® (isradipine)
What they do	CCBs help to lower blood pressure.
Most common side effects	<ul style="list-style-type: none"> • Lower leg swelling (edema) • Dizziness • Tiredness • Low blood pressure • Anxiety

Class	Vasodilators
Brand (and generic) name	Apresoline® (hydralazine)

What it does	Vasodilators help to lower blood pressure quickly and can treat symptoms of heart failure.
Most common side effects	<ul style="list-style-type: none"> • Dizziness • Low blood pressure • Increased heart rate • Leg swelling • Flushing • Mood changes

Brand (and generic) name	Catapres® (clonidine)
What it does	Clonidine helps to lower blood pressure and can also help attention disorders. It comes in pills, liquid and as a skin patch that needs changing once a week.
Most common side effects	<ul style="list-style-type: none"> • Dizziness • Low blood pressure • Abnormal heart beats • Mood changes • Skin irritation where the patch is applied • Nausea and vomiting (throwing up)

Class	Beta-adrenergic blocking agent (beta-blockers)
Brand (and generic) names	Tenormin® (atenolol), Toprol®, Lopressor®, Betaloc® (metoprolol), Trandate® (labetalol), Inderal® (propranolol), Coreg® (carvedilol), Betapace® (sotalol), Corgard® (nadolol)
What it does	Beta-blockers help to lower blood pressure by making the heart beat slower. They can also control abnormal heart beats.
Most common side effects	<ul style="list-style-type: none"> • Dizziness • Low blood pressure • Slow heart beat • Lower leg swelling • Mood changes • Fatigue • Blurred vision

Statins (cholesterol and lipid-lowering medications)

Class	HMG-CoA reductase inhibitors
Brand (and generic) names	Lipitor® (atorvastatin), Zocor® (simvastatin), Lescol®(fluvastatin), Mevacor® (lovastatin), Pravachol® (pravastatin), Crestor® (rosuvastatin)
What they do	HMG-CoA reductase inhibitors (or 'statins') help to decrease the amount of bad cholesterol and lipids in the blood.
Most common side effects	<ul style="list-style-type: none">• Abdominal (belly) discomfort• Increases in liver function tests• Muscle pain and fatigue
Other important information	Call your doctor if your child develops any severe muscle pain or if your child's urine becomes dark brown. All lipid lowering drugs should be avoided in women who are or may become pregnant because it causes abnormalities in the fetus. Talk to your transplant team if you are thinking of getting pregnant or are pregnant.

Anti-ulcer medications

Class	Proton pump inhibitors (PPIs)
Brand (and generic) names	Nexium® (esomeprazole), Losec®, Prilosec®(omeprazole), Prevacid® (lansoprazole), (Pantoloc®, Protonix® (pantoprazole)
What they do	PPIs help to prevent and treat: <ul style="list-style-type: none">• Heartburn and indigestion• Stomach ulcers
Most common side effects	<ul style="list-style-type: none">• Dizziness• Diarrhea (watery stool)• Nausea and vomiting (throwing up)

Class	Histamine antagonists
Brand (and generic) names	Zantac® (ranitidine), Pepcid®, (famotidine), Axid® (nizatidine)
What they do	Histamine antagonists help to prevent and treat: <ul style="list-style-type: none">• Heartburn and indigestion• Stomach ulcers
Most common side effects	<ul style="list-style-type: none">• Dizziness• Nausea and vomiting (throwing up)• Low platelet counts• Abnormal heart beats• Mood changes

Brand (and generic) names	Carafate® (sucralfate), Mylicon®, Gas-X® (simethicone)
What they do	<ul style="list-style-type: none"> • Sucralfate helps to coat the throat and stomach to treat and prevent ulcers. • Simethicone helps to control gas.
Most common side effects	<ul style="list-style-type: none"> • Dry mouth • Stomach pain • Constipation
Other important information	<ul style="list-style-type: none"> • Carafate contains aluminum and is best avoided in patients with decreased kidney function.

Anti-platelet medications

Generic name	Acetylsalicylic acid (ASA)
Brand name	Aspirin®
What it does	Aspirin helps to thin the blood and prevent blood clots.
Most common side effects	<ul style="list-style-type: none"> • Easy bleeding • Easy bruising • Stomach upset

Generic name	Dipyridamole
Brand name	Persantine®
What it does	Dipyridamole prevents blood from clotting.
Most common side effects	<ul style="list-style-type: none"> • Easy bleeding • Easy bruising

Medications to prevent and treat blood clots

Generic name	Enoxaparin
Brand name	Lovenox®
What it does	Enoxaparin helps to prevent and treat blood clots.
How it is given	Enoxaparin is given as a subcutaneous injection (a 'needle' just below the skin) once or twice a day.

Most common side effects	<ul style="list-style-type: none"> • Easy bleeding • Easy bruising
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Generic name	Warfarin
Brand name	Coumadin®
What it does	Warfarin thins the blood to prevent and treat blood clots.
Most common side effects	<ul style="list-style-type: none"> • Easy bleeding • Easy bruising

IMMUNIZATIONS

Why does my child need immunizations?

Getting immunizations helps protect children from serious diseases. Some children with kidney disease may have missed some of their immunizations. They could have been ill at the time or on medications that weaken the immune system. Vaccines work better before transplantation and some (live vaccines) cannot be given after transplant. Your child’s kidney doctor will make every effort to make sure that your child is up-to-date on his or her immunizations before getting a kidney transplant. Please check with your child’s doctor and the transplant team on which ones your child needs before the transplant.

Do family members need immunizations?

Your child may not be able to get all immunizations such as live vaccines after transplantation and the immunizations may not work as well after your child has had a transplant. For this reason it is very important that all close contacts, particularly family members who live in the same household have all of their immunizations up to date.

When should we start immunizations after transplant?

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

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

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

Different vaccine doses or schedules

Because your child's immune system is suppressed (or weakened) by medications, your child may need different doses or schedules of some vaccines. Some school and community vaccination programs may not be able to provide a different vaccine dose. In this case, your family doctor or pediatrician will need to give these to your child instead. Talk to your transplant team about what is needed for your child.

“Live Vaccines”

In general your child should not have “live vaccines” after transplant as they may cause disease in someone taking immunosuppressive medications.

This is why whenever possible vaccinations should be updated BEFORE transplantation

On occasion some transplant centers will give live vaccines under certain conditions such as when an outbreak is occurring; however this should be done ONLY with strict observation and oversight of the transplant center

Common live vaccines are:

- Chickenpox (varicella)
- Smallpox
- Oral polio
- Rotavirus
- Measles/mumps/rubella (MMR)
- Influenza drops into the nose (influenza nasal mist, FluMist).

Other family members and your child's classmates can safely get the chickenpox, rotavirus, and MMR vaccines. On rare occasions a child will break out with a rash after the chickenpox vaccine. If this happens call the transplant team to discuss. Most often it is not contagious or it is only mildly contagious. Other household members should not get the oral polio vaccine. Only the inactive polio vaccine called IPV should be used.

What should I do if my child is in school or day care with other children who may have received live vaccine?

Talk with your school or day-care provider about your child's condition. For most situations the live vaccine in other children or adults will not cause harm to your child. If your child has had an organ transplant, talk with your doctor about possible exposure to children who have received oral polio vaccine or smallpox vaccine or other live vaccines.

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

Immunizations your child should receive (depending on age) are the following killed (non-live) vaccines:

- Injectable polio
- Hepatitis B
- Tetanus/diphtheria or Tetanus/diphtheria/acellular pertussis
- Flu shot

- Pneumococcal (both Pneumovax or Prevnar)
- Hepatitis A
- Meningococcal Vaccine
- HIB Vaccine
- HPV Vaccine
- TB skin test (which is actually not an immunization but a test to see if your child was exposed to tuberculosis [TB]before)

It is important to remember to avoid live viral vaccines and notify the transplant office when other vaccines are given. If you or your primary physician has any questions or concerns about what immunizations can or should be given to your child, please call the child's transplant office.

Flu shots

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

Vaccines and travel

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

For more details about immunization in renal disease, go to:

<http://www.kidney.org/atoz/content/vaccinationschild.cfm>

RECOMMENDED IMMUNIZATION SCHEDULE FOR KIDNEY TRANSPLANT RECIPIENTS

Ages 0-18 Years According to the *American Academy of Pediatrics, 2014*

Vaccine schedules are evaluated and updated each year in the United States by the ACIP. Similar organizations evaluate and update immunization recommendations in other countries as well. The schedule below is the USA schedule from 2014. Your doctors can tell you if updated recommendations come out each year to help protect your child and family.

This is the schedule for immunizations that need to be done before a kidney transplant. Some vaccine series can be performed faster to help protect your child before transplantation.

After transplant, live vaccines should not be given, as mentioned above. Please check with your child's kidney doctor for the shots that can be given to your child after the transplant. It is suggested that teens get shots for meningitis before they go to college. Please check with your kidney doctor about the need to give this vaccine to your teenager.

Vaccine Age Total Doses and Catch-up Vaccination (Table)

Vaccine	Age	Total Doses	Catch-up Vaccination
Hepatitis B	Birth, 1-2, 6-18 months	3	2-18 years (hepatitis series)
Rotavirus	2, 4, 6 months	RV 1 (2 dose series) RV 5 (3 dose series)	
DTaP (Diphtheria, Tetanus, acellular Pertussis)	2, 4, 6, 15-18 months, 4-6 years, DTaP not approved over age 7	5	
Tdap (Tetanus, diphtheria, acellular pertussis)	11-12 years	1 (should receive one dose of Tdap as booster to primary DTaP series)	13-18 years (a single dose of Tdap can be given if it has been at least 3 years since last Td)
<i>H. influenza B</i>	2, 4, 6, 12-15 months	4	

IPV (inactivated poliovirus)	2, 4, 6-18 months, 4-6 years	4	3 doses one month apart followed by the 4 th dose 6 months after the 3 rd dose.
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Vaccine	Age	Total Doses	Catch-up Vaccination
MMR (measles, mumps, and rubella)	12-15 months #1 4-6 years #2	2	11-18 years #2
Varicella	12-18 months #1 4-6 years #2	2	7-12 years, 2 doses 3 months apart >13 years, 2 doses 4 weeks apart
Pneumococcal vaccine (PCV 13) & (PPSV 23)	2, 4, 6, 12-15 months (PCV 13) (PPSV 23)	If 4 doses of PCV 13 and no prior PPSV 23, administer 1 dose at least 8 weeks after the most recent dose of PPV 13. Single dose PPSV 23 5 years after first dose.	2-4 years (PCV & PPSV 23) >5 years (PPSV 23)
Hepatitis A	12-23 months	2 doses separated by 6 to 18 months	
Influenza	6 months – 18 years (yearly)	Every year (need 2 doses at least one month apart for the first year receiving vaccine if <8 years. Use only inactivated vaccine post-transplant)	

Vaccine	Age	Total Doses	Catch-up Vaccination
Meningococcal	11-12 years	<p>1 (administer dose between ages 11-12 to children who have not previously been vaccinated)</p> <p>OR</p> <p>If prior dose was >3 years earlier)</p>	Booster 16-18 years
Human Papillomavirus	11-12 years	<p>3 (Second dose is given 1-2 months after first dose. Third dose is given 6 months after the first dose)</p>	

POSTTRANSPLANT COMPLICATIONS

Rejection

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

Your child's immune system will try to reject their new kidney because it recognizes that it is different from the rest of the child's body. Your child will be taking immunosuppressant medications for the rest of their life to prevent rejection.

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

Can rejection happen at any time?

Yes it can, but is most common during the first year after transplant. Most of the time, rejection is treated by giving your child extra medication by mouth. Most rejection events are mild and your child may not have any outward signs that they will feel or that you will see. As long as your child takes their immunosuppressant medications as instructed, rejection is much less likely.

How can transplant team identify rejection without any outward signs?

There are different types of rejection and some can be difficult to diagnose. The transplant team will monitor your child for signs of rejection by doing certain regular tests. These tests will depend on your child's age and risk factors for rejection. Routine lab monitoring is vital, as it may be the only sign or an early rejection episode. If rejection is caught early, it may be easier to treat. Some centers do kidney biopsies at regular times after transplant (for example at 3 and 12 months after transplant) to look for evidence of rejection in the kidney tissue. These biopsies are called surveillance or protocol biopsies.

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

What are the common signs of rejection?

Rejection is usually noticed in the results of your child's tests before your child shows any symptoms.

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

- Fever
- Fatigue
- Stomach upset
- Irritability
- Increasing high blood pressure
- Swelling or significant weight gain
- Pain or tenderness in their transplanted kidney

How can I help to prevent rejection?

- Give your child's medications exactly as directed by the kidney transplant team.
- Bring your child to all clinic appointments and follow-up tests and blood tests.
- Check with the kidney transplant team before giving your child any over-the-counter medications, including herbal (natural) medications. These medications can sometimes interfere with the immunosuppressant medications.
- Check with the kidney transplant team before giving medications prescribed by another doctor.
- Call the transplant team about any changes in your child's health that you are concerned about.

What types of test are done to diagnose rejection?

The only way to diagnose rejection for certain in your child's new kidney is by doing a kidney biopsy. Blood tests looking for donor specific antibodies (DSA, antibodies that your child is making against their new kidney) may also be suggestive of rejection.

Kidney biopsy

Kidney biopsies can find signs of rejection even though your child does not show any outward symptoms or signs. Biopsies are usually not done on a routine hospital ward but in a designated area and under sedation. Some transplant centers perform kidney biopsies on a routine schedule (protocol biopsies) to monitor for rejection. Other centers perform biopsies only if there is a concern for rejection or other kidney problem.

A pathologist looks at a small sample of kidney tissue under a microscope for signs of rejection. The results from this study are reported back as a number under a special grading scale.

Infections and Diseases

Your child will get normal childhood infections (runny noses and coughs, ear infections, sore throats, vomiting and diarrhea and so on). In general, your primary care physician can take care of these infections as if your child has not had a kidney transplant. If your child has had their transplant recently or has just received rejection treatment and develops signs of illness (fever, cough, vomiting, diarrhea) you can call your transplant team for advice as to when it is necessary for your child to be seen by either the transplant team or their family doctor or pediatrician.

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

How do I help my child avoid getting infections?

- Practice good hand washing for everyone who lives at home. Hand washing is especially important before preparing food and after diaper changes or going to the bathroom.
- Ask friends and relatives who are sick to avoid visiting until they are better.
- Have all close contacts up to date on their immunizations
- Wash hands well after contact with animal body waste (for example cleaning up after a family pet).
- ***If you have been told to do so***, tell the kidney transplant team if your child is in contact with someone who has chickenpox. We will explain how and when to do this.

Other important ways for your child to avoid infections

- Getting enough rest
- Eating healthy foods
- Drinking enough fluids
- Keeping active

What signs of infection should I watch for?

There are many signs or symptoms that your child may have an infection. Contact your pediatrician or family doctor if your child is sick with any of these signs or symptoms:

- Fever
- Runny nose and cough that is not improving after several days or is severe
- Sore throat or sore ears
- Pains in the stomach
- Vomiting
- Diarrhea that has blood or mucous or is not improving after 1-2 days
- Feeling of burning or pain when peeing
- Sores on the lips and around the mouth
- Rashes

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

Serious viral infections

Some kinds of infections may put children with kidney transplants at particularly high risk. These include:

- Chickenpox (Varicella)
- Herpes simplex virus (HSV)
- Cytomegalovirus (CMV)
- Epstein-Barr virus (EBV)
- BK virus

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

Chickenpox (Varicella)

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

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

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

chickenpox. If they are, the blood test will show up antibodies in the blood. If they are not protected your doctor may want them to have the chicken pox vaccine before transplant.

What happens if my child is at risk for chickenpox?

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

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

Although it is best to avoid chickenpox, being exposed to it is not an emergency. There are normally a few days before the virus takes hold during which your child's doctors can arrange for your child to get medication if they need it (see information below). You can contact your kidney transplant team during regular working hours to discuss the exposure.

If my child has chickenpox after transplant, will their symptoms be more severe?

In general, even in a transplant patient, chickenpox usually causes the same signs and symptoms that we see in other children: mostly the fever and the skin rash.

Rarely, chickenpox can affect other body organs in a transplant patient and potentially can make the patient very sick and on rare occasions even cause them to die.

If your child develops spots that you think may be chickenpox, please see your family doctor or pediatrician or call the kidney transplant team. Your child may need to receive anti-viral medication either by mouth or IV. If there are signs that the chickenpox rash is quite severe or if the virus appears to be affecting other organs, your child may need to be treated in hospital.

Can my child have the chickenpox vaccine after the kidney transplant?

Health experts review and update vaccine recommendations every year; in 2014, the answer is NO. The chickenpox (varicella) vaccine is a live vaccine, meaning that it could actually give your child chickenpox instead of protecting them from it.

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

Can my other children get the chickenpox vaccine?

It is safe for brothers and sisters to get the chickenpox vaccine and important for them to have the vaccine to protect them from getting wild type chicken pox and exposing the child who has a transplant. Adult family members who have not had chickenpox may also want to discuss vaccination with their family doctor.

What medications can my child get if they were with another person who had chickenpox?

If your child is exposed to someone with chickenpox or shingles, they may need medication to help prevent infection or make infection milder if it does develop.

Several types of medications may be used, including doses of varicella antibodies (by a needle) and oral or intravenous (IV) forms of the antiviral medication acyclovir.

Some of these medications need to be given as soon as possible after exposure to chickenpox to have the best chance of helping. Even if a child receives one of these preventative medications (medications to prevent the disease from developing), it is still possible that they may catch the virus. Chickenpox can develop between 10 and 28 days after being exposed to someone with the disease.

Herpes simplex virus (HSV)

Herpes simplex virus types 1 and 2 are members of the herpes virus family similar to Chicken pox, Cytomegalovirus and Epstein Bar virus described in other parts of this manual. Once infected with any member of herpes virus it stays in your body throughout life, but most times it does not cause any problem. HSV 1 and 2 are the type of viruses that can cause blisters and sores in different areas of the body.

- Herpes simplex virus type 1 (HSV-1) generally causes cold sores in the mouth or on the lips. It can be passed from one person to another through oral secretions or sores on the skin of an infected individual. Many people have had HSV1 even if they never had a blister
- Herpes simplex virus type 2 (HSV-2) is associated with genital sores. It is usually passed during sexual contact with an infected individual.

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

Can HSV be cured?

As noted above there is no cure for HSV, but many people have no symptoms from it and treatment with oral acyclovir or valacyclovir can often relieve HSV symptoms when they do occur. If children experience a lot of pain and it affects their ability to eat and drink normally, they may need to be admitted to the hospital for further treatment.

Cytomegalovirus (CMV)

Cytomegalovirus (CMV) is another member of the herpes virus family. Like HSV, and Epstein-Barr virus (see below), it is very common: between 50% and 90% of adults have been infected with CMV. Your child will be tested prior to transplant to determine if they have antibodies against CMV.

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

Most often CMV infection causes no symptoms in healthy children and adults. However, even when there are no symptoms, CMV stays in the body lifelong and on occasion can shed in secretions such as saliva, urine, semen or vaginal secretions.

CMV infection after transplant may cause no symptoms or there can be a wide range of symptoms, including fever, joint pain, reduced white blood cell counts, pneumonia, or gastritis (severe stomach upset). Because of the wide variety of

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

How is CMV diagnosed?

CMV is most commonly diagnosed through blood tests that can detect even very tiny quantities of CMV circulating in the blood. Occasionally, blood tests may be negative if the body has limited the infection to one region of the body. In these cases, tests of specific tissue (such as an intestinal biopsy) may be needed to confirm the diagnosis.

How is CMV treated?

CMV is treated differently before and after symptoms appear.

- Before symptoms appear, it is treated using preventative measures (to stop symptoms developing). These measures include anti-infective medications such as ganciclovir or valganciclovir.
- If symptoms are already present, the child usually needs higher doses of these anti-infective medications over a specific time period.

Epstein-Barr virus (EBV)

Epstein-Barr virus (EBV) is also a member of the herpes virus family. It is very common: most adults in the United States have been exposed to it by the time they turn 40. Your child may be tested prior to transplant to determine if they have antibodies against EBV.

In most people, EBV causes a viral illness that is either asymptomatic (no symptoms) or mild. Sometimes the infected person may have a sore throat, enlarged lymph nodes and flu-like symptoms which is often called mononucleosis or “mono”. This is more common when EBV infects an adolescent or young adult. Like all the other herpesviruses discussed, once a person has an EBV infection, the virus stays in the body for the rest of their life, although usually with no problems.

For transplant patients, EBV infection increases the chance of developing post-transplant lymphoproliferative disorder (PTLD). This condition can be mild or more severe and even lead to cancer and in rare instances death. PTLD can occur after a new infection or if a dormant virus (that has remained in the body after a previous infection) becomes active again.

Because of the concern for EBV causing PTLD your child may have blood work checked periodically before and after transplantation.

How is EBV treated?

Treatment of EBV depends on the results of the tests.

- No treatment is needed if neither EBV nor EBV antibodies are present in the blood.
- If there are antibodies but no EBV, a patient is usually monitored over time.
- If there is evidence of EBV in the patient’s blood, sometimes transplant doctors may lower the dose of immunosuppressants to allow the body to clear the virus on its own.
- Drugs to treat EBV are available, but often they are poorly effective or have side effects.

BK Virus

BK virus infection causes mild symptoms or is even asymptomatic in healthy hosts. Due to the effects of your child's immunosuppressants, they are at risk of developing BK disease after transplant. BK disease after transplant may lead to gross hematuria (blood in the urine that you can see) or cause your child's kidney to function poorly (BK nephropathy). Untreated BK nephropathy can lead to loss of your child's kidney transplant. Unlike CMV and EBV, there are no tests that can be performed prior to transplant to determine if your child has been exposed to BK virus.

How is BK virus diagnosed?

BK virus can be detected in the blood or urine. This testing may be performed routinely, or if the serum creatinine is elevated. BK virus can also be detected in a kidney biopsy using special staining methods.

How is BK virus treated?

BK virus is often treated with reduction of immunosuppression in order to allow the body to fight the infection on its own. Drugs to treat BK virus are available, but often they are poorly effective or have serious side effects.

Post-transplant Lymphoproliferative Disorder (PTLD)

Post-transplant lymphoproliferative disorder (PTLD) is a complication that occurs in about 6 to 10% of kidney transplant patients. PTLD is usually associated with a viral infection (EBV) after transplant. On rare occasions it occurs without a viral cause.

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

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

What type of viral infections can lead to PTLD?

The most common virus associated with PTLD is Epstein Barr virus (EBV), and other rare viruses. When a child cannot fight off a virus, they have what is called a "primary infection".

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

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

How is PTLD diagnosed?

The diagnosis of PTLD is often made in several steps. If the transplant team suspects PTLD after evaluating a patient's symptoms and doing a physical exam, they may order studies, such as x-rays, CT scans, or PET scans to look for other

evidence of it. If enlarged lymph nodes or a mass are seen in these scans or x-rays, a doctor will take a biopsy (a tiny sample) of the lymph nodes to make a diagnosis.

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

Many children who have a new PTLD diagnosis need to be assessed by an oncology (cancer) team and may have chemotherapy. Fortunately, when identified in time, PTLD can usually be treated. Children who are treated will need to be followed for the return or relapse of PTLD for the rest of their lives.

Recurrent disease after kidney transplantation

Some kidney diseases may come back in your child's kidney after transplant, leading to poor function or even loss of the kidney transplant. Talk to your child's transplant team to determine if your child is at risk of recurrent disease.

SCHOOL AFTER KIDNEY TRANSPLANTATION



When can my child go back to school?

Most children may return to school four to six weeks after transplantation. It is best to check with your child's kidney doctor, as there may be special reasons to delay your child's return to school. If family members are ill, it is always best to keep the sick person away from the child with a renal transplant. Please check with your kidney doctors about the need to isolate any sick person in the house from your transplanted child. It is important to remember that the majority of contagious illnesses are spread by hand contact so frequent hand washing (by both the child and the caregivers) is key to minimize the spread of infections to a transplanted child.

What about home schooling?

You might use a tutor for your child during extended times of missed school. If you do not feel good about sending your child to school for health or other reasons, please call and talk to your transplant team and your kidney doctor.

Can my child participate in school activities?

Once in school, children with renal transplants should take part as fully as possible in school activities. There are very few limits on physical activities. Please refer to the section on sports. Your transplant surgeon will discuss with you any activity restrictions in the first few weeks after the transplant related to the surgery itself.

Your child's behavior, emotional wellbeing, and school performance

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

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

A referral usually happens if:

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

Assessment in relation to school performance

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

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

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

Assessment for emotional support

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

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

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

In some instances, medication might be recommended for older children, who may also need to see a psychiatrist or adolescent medicine doctor for an evaluation and monitoring.

Issue	Neuropsychology role	Other services involved
Possible cognitive (thinking) difficulties	Full evaluation, consultation on results and recommended treatments	Occupational therapy – provides cognitive screening and can refer for a full evaluation if needed.
Difficulties sticking to treatment	Evaluation can inform possible underlying reasons for poor adherence	Nursing social work or psychiatry to treat any underlying emotional reasons
Emotional or behavioral concerns	Evaluation usually includes an emotional/behavioral screening	Social work or psychiatry
Attention difficulties	Can provide assessment and diagnosis of ADHD	Psychiatry involved in medication management, if needed
School liaison	Can inform and update the school about impact of the medical condition on school attendance and performance	Social work, among others

FOLLOWING A HEALTHY LIFESTYLE AFTER TRANSPLANT

Physical activity and exercise

Exercise and physical activities are part of a kidney healthy lifestyle and we encourage regular activity in all transplant patients. Regular exercise is a crucial part of keeping your child strong and healthy. It helps them develop socially, it develops their motor skills (such as hand-eye-coordination and movement), and it boosts their overall level of fitness.

We encourage you to enroll your younger child in developmental playgroups and community activities. Older children can take part in recreational and organized sports and join school or community teams. Encourage your child to try new activities – that way, they can find things that they really enjoy doing and will stick with them!

Sports and Activities

What sports can my child take part in after kidney transplantation?

Use good common sense when choosing activities for your child. The list below can be used as a guide. In general, patients are encouraged to remain active and to develop active lifestyles given the long-term health benefits of regular physical activities. Aerobic exercises are good for children with kidney transplants. Of course, no one can guarantee that any of these activities are totally safe and will not injure the new kidney. Please discuss this with your transplant team. It is a good idea to wear a kidney protector (available at some sporting goods stores or online) if there is a chance that the transplant could be injured.

Sports or activities to be avoided:

- Rugby
- American football
- Karate
- Judo
- Asian martial arts
- Ice hockey
- Trampolines
- Wrestling
- Boxing
- Dodge ball
- Gymnastics (uneven parallel bars, balance beam, tumbling)
- Snowboarding
- Downhill skiing
- Sledding
- ATV/snowmobiles (due to the increased risk of high impact crash)

Sports that are encouraged:

- Field hockey
- Running
- Jump rope
- Basketball
- Swimming
- Canoeing
- Rowing
- Weight lifting (low weight/high repetition) Weight lifting may be restricted if patient has poorly controlled high blood pressure and because of concerns for possible development of hernias.
- Volleyball
- Jazzercise
- Aerobics
- Cross-country skiing
- Skating
- Tennis
- Cycling
- Horseback riding
- Soccer
- Badminton
- Table tennis
- Golf

Smoking and second hand smoke exposure

Your child should not start to smoke after a kidney transplant. If you smoke, you should quit. If you are unable to quit, you should not smoke around your child. Talk to your transplant team for resources that may be available to help you quit.

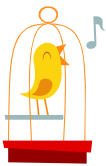


Pet Safety

Patients who have received organ transplants are more likely than most people to get diseases from animals. However, simple tips can be followed to reduce their risk of getting sick after contact with animals. These recommendations were originally made for bone marrow transplant patients, but they also may be useful for other organ transplant patients. Although this section focuses on how to protect organ transplant patients from pet related diseases, many groups support the health benefits of pets.

First and foremost **keeping clean** is essential to minimize the risk of spread of disease from your pet to a child with a transplant. Thorough hand washing with water and soap after handling animals and their feces (stool) is essential. It is recommended that the transplant patient avoid direct contact with animal feces. Adults should supervise the hand washing of children after they have contact with animals.

Caring for your pet to minimize transmission of illness to your child includes seeking veterinary care for an ill pet as soon as possible. You should consider having any **cat or dog that has diarrhea** checked by a veterinarian for infection with *Cryptosporidium*, *Giardia*, *Salmonella*, and *Campylobacter*.



Birdcage linings should be cleaned daily and gloves should be worn whenever handled items contaminated with bird droppings. Children who are transplant patients should NOT be exposed to bird droppings. Routine screening of healthy birds for zoonotic diseases is not recommended.

It is recommended that children with transplants avoid cleaning **fish tanks**.



It is recommended that children with transplants NOT **clean a cat's litter box**. If done, use careful hand washing afterwards. You should consider NOT placing the litter box in kitchens, dining rooms or other areas where food is prepared or eaten. Pet cats do not need to be tested for toxoplasmosis.

Just like people, pets can get diseases from eating contaminated food. By protecting your pet from **food borne diseases**, you can protect you own health as well. Pets should be fed only high-quality commercial pet foods. If eggs, poultry, or meat products are given to your pet as supplements, they should be well cooked. Any dairy products given to your pets

should be pasteurized. Additionally, pets should be prevented from drinking toilet bowl water and from having access to garbage. Do not let your pet scavenge for food, hunt, or eat other animal's feces.

When getting a new pet, avoid animals that are ill, stray, or young (cats or dogs less than 6 months old). These animals are more likely to carry diseases.

Potential animals to avoid for they are considered high-risk animals for immunocompromised people (including organ transplant patients)

- Reptiles, including lizards, snakes and turtles
- Baby chicks and ducklings
- Exotic pets, including monkeys- **NOTE:** all persons should avoid direct contact with wild animals. Do not adopt wild animals as pets or bring them into your home. Contact with these animals and their environments should be avoided by people with compromised immune systems. If you do touch these animals or their environment (their food or cage, for example), wash your hands thoroughly with running water and soap. Additionally organ transplant patients should be extra cautious when visiting farms and when in contact with farm animals, including animals at petting zoos and fairs.

These pet safety guidelines can be found at: <http://www.cdc.gov/healthypets/specific-groups/organ-transplant-patients.html>



Dental Care

Why does my child need dental care before and after kidney transplant?

The mouth has a large number of bacteria in it. The use of transplant medications after transplantation makes it harder for the body to fight infection. A bad dental cavity may turn into a tooth abscess if the immune system is low. Some of the drugs used after transplant, such as Neoral® (cyclosporine) and some of the antihypertensive medications (amlodipine, isradipine, nifedipine, verapamil), may cause gum swelling and overgrowth. This, in turn can lead to gum disease. It is important for your child to be seen by a dentist before transplant. Have your child's teeth cleaned and all cavities filled. Following transplant, twice-yearly dental visits with cleanings are recommended. It is generally recommended to wait until 3 months after transplant to begin seeing the dentist again. Your child's transplant team may require your child to receive antibiotics prior to dental visits. Ask them for more details.



Ophthalmologic (Eye) Care

Many children are prescribed prednisone after transplant as part of their immunosuppression regimen. Because of the risk of side effects affecting the eyes, we recommend monitoring eye health for cataracts and glaucoma by a professional. It is recommended that all children should have dilated eye examinations once a year while they are on prednisone to monitor for the development of cataracts and/or glaucoma. If your child complains of blurry vision, eye pain or tearing he should be evaluated by a physician sooner.

Skin Care

Transplant patients have a higher risk of developing skin cancer. The transplant immunosuppression medications that allow your child's kidney to work and survive also increase the risk of skin cancer. It is very important that children with kidney transplants and their families know about how to protect themselves from the sun. This should be done both before and after the transplant. Children with moles or unusual moles should be checked by a dermatologist before transplant and followed closely after transplant.

Prevention of skin cancer means daily use of a sunscreen with a sun protection factor (SPF) of 30 or more. Clothing with long sleeves and a tight fabric weave should be worn outdoors, as well as a broad-brimmed hat. Stay out of the direct sun between 10 a.m. and 2 p.m. as much as possible. Tanning beds should not be used.

Transplant patients could have problems with warts. Warts are caused by a virus (HPV). They may have more and larger warts that last longer and are harder to treat. Transplant medications may make it harder for your child to fight off the virus that causes warts. If your child has too many large or painful warts before transplant, he or she should be checked by a dermatologist who has experience dealing with warts in children. We do not have medicine to prevent warts but there is a vaccine to prevent genital warts. Genital warts can cause cancer in both men and women and transplant patients have a higher risk of cancer than people who have never had a transplant.. This vaccine is available and recommended for both boys and girls; since it works best before people become sexually active it can be given starting as young as 9 years of age.

Commonly children after transplant will be prescribed a sulfa drug (typically trimethoprim-sulfamethoxazole, Bactrim® or Septra®). On rare occasions they are prescribed an antifungal medicine called voriconazole. These medications will increase sun sensitivity.

More information about skin care and skin cancer prevention can be found at:

<https://www.kidney.org/news/ekidney/august11/SunProtection>



Nutrition and Diet after Kidney Transplant

Diet plays a very important role in promoting good health and wellbeing after a kidney transplant. This is done by eating a well-balanced, varied, and heart-healthy diet. Following transplant, children should follow heart-healthy food guidelines. These include:

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

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

General Recommendations

Bone Health

Long-term use of prednisone may place your child at increased risk for osteoporosis (weakening of bones) and bone fractures. It is therefore very important to get enough vitamin D and calcium from food. Some good sources of calcium are:

- Milk
- Cheese
- Yogurt
- Canned salmon or sardines with bones
- Calcium-fortified orange juice

When possible, choose lower-fat milk products. This will help control weight gain and promote a heart-healthy diet.

Vitamin D deficiency is very common in children, particularly those in the northern part of the continent. Your transplant doctors will likely test for Vitamin D deficiency and possibly prescribe vitamin D supplements with or without a calcium supplement in order to keep your child's bones healthy.

You may need to increase the phosphorus in your child's diet particularly if your child was on a dietary phosphorous restriction before the transplant. The best sources are:

- Dairy products
- Nuts and nut butters
- Dried beans, lentils and peas
- Seeds

Potassium Intake

Typically children after transplant will be able to have normal amounts of potassium-containing foods (potatoes, orange juice, bananas). Ask your doctor if your child has any restrictions on how much potassium they can have in their diet after the transplant.

Sodium

In general, it is a good idea after transplant for your child to limit salt in their diet. Some of the medications (prednisone, cyclosporine, and tacrolimus) increase the chance of having hypertension after transplant and also make it harder for your child to handle salt loads.

Some common foods that are HIGH in sodium are:

- Salt
- Cured meats (bacon, ham)
- Luncheon meats
- Canned or dried soups
- Ethnic foods: Chinese, Japanese, Mexican and Italian
- Sauces and condiments: Worcestershire, chili and soy
- Prepared casseroles

- Macaroni and cheese mixes

Ask your doctor if you need to restrict the salt in your child's diet. The dietitian will meet with you if this is needed. For some babies with kidney transplants, extra salt may actually be needed.

Heart-Healthy Diet

Some transplant medications will raise your child's cholesterol levels. This, in turn, is known to increase the risk of getting heart disease.

To help lower cholesterol levels:

- Limit the total amount of fat in the diet as well as the saturated fat (fat from animals). Choose low-fat dairy products (skim or 1% milk, low-fat cheese, yogurt, ice milk) and lean meats.
- Avoid fat listed as animal or vegetable shortening, lard, palm, and coconut oil.
- Choose olive and canola oil, and non-hydrogenated margarines.
- Increase high-fiber foods as fiber helps keep cholesterol from being absorbed. Fresh fruits, vegetables, and whole-grain products are high-fiber foods.

Food Safety

Transplant medications place your child at a higher risk for infections, so it is very important to prevent illness that comes from food.

Safe food handling is a must!

- **Wash hands often. Always wash before handling food**
- **Wash fruits and vegetables under running water**
- **Separate foods to be eaten raw from raw meats – Use separate cutting boards**
- **Sanitize sinks and chopping boards with ½ teaspoon bleach in two cups of water**
- **Use a fast-check thermometer to check the temperature of cooked meats**
- **Hot dogs, hamburger, and sausage must be well cooked (160 degrees) even if they are irradiated**

Do NOT share utensils or food.

Do NOT eat these foods RAW: eggs, milk (unpasteurized), seafood, red meat and poultry.

Common Questions about Diet after Kidney Transplant

-My child is gaining a lot of weight after transplantation. Is this healthy?

A common problem with transplant patients is gaining too much weight. Babies, children, and teens are expected to gain weight as they get older. It is needed for growth. But too much weight can easily happen:

- Your child can eat his or her favorite foods again
- Your child has much better appetite
- Prednisone can increase his or her appetite
- Food tastes better!

Eating too much and lack of exercise lead to obesity. This leads to high blood pressure and diabetes, and may lead to heart attack and stroke. Even at normal weights, transplant patients are at higher risk for diabetes, high cholesterol, and heart disease for many reasons. Obesity adds to his or her risk. It can also hurt your child's self-image, especially in teenage years. A healthy lifestyle is the key to controlling your child's weight gain and reducing their risk for heart disease. It includes regular exercise and a healthy, well-balanced, low-fat diet.

-What shall I do to prevent excessive weight gain?

Excessive weight gain can be prevented. Try these strategies to help your child keep from gaining too much weight.

- Limit high-fat foods: fast food, fried foods, chips and other high-fat snacks, cakes, donuts, pastries
- Avoid "simple" sugars: sugar, sweets, soda pop, and drinking too much juice. Drink mostly water. This will become even more important if your child gets high blood sugar, a possible side effect of prednisone and other transplant medications.
- Let your child eat three meals a day with average helpings. Serve many different kinds of food. Avoid too much snacking.
- Have many kinds of healthy low-fat snacks on hand for when your child cannot control the "munchies". Some of these are raw vegetables, fruits, and unsalted, unbuttered popcorn.
- BE ACTIVE EVERYDAY. Regular exercise is a very important part of keeping a healthy body weight. Any exercise should be discussed with your transplant nurse and doctor. In general, it is suggested that children participate in some form of physical activity approximately 6 times per week for at least 30-60 minutes. In addition to activity it is important to limit sedentary activities- watching TV, playing computer games or video games to less than 1 hour per day.

-My doctor tells me my child's transplant kidney is still slow to start. What diet is good for my child?

If your child's new kidney is slow to start, your child may need to remain on his or her kidney diet. This means limits on sodium, potassium, phosphorus, and fluid. But, as the kidney begins to work, your child will be able to have many more kinds of food. Your dietician will provide advice regarding the diet your child should follow after transplant.

-My child was on fluid restriction before transplantation. Should my child drink MORE fluids now that the kidney is working well?

This is very, very important. Once your child has normal kidney function, your child will need to drink more fluid, preferably water, each day. The amount of fluid will depend on his or her weight. The more he or she weighs, the more he or she will need to drink: possibly up to 8 glasses of fluid a day. Your transplant doctors will advise you on how much fluid is ideal for your child to drink every day. The majority of fluid intake should come from water, fat-free or low-fat milk and sugar-free drinks.

-My child had been on tube feeding for a long time. Should I stop the tube feeding after transplantation?

Some children, mostly those under the age of 5 years, have been on tube feedings before their transplants. Those children may have not eaten solid foods at all. Or they may have only nibbled food now and then in the months or years before their transplants. The good news is that most children who have been on tube feedings are able to stop the tube feedings and go on to eat a normal diet after transplantation but this transition may be slow.

Some children can begin to eat right away. But most children will take a few weeks or months to slowly decrease their tube feeding and slowly increase eating. The formula used for tube feeding will most likely change right after transplantation. The new formula will have normal amounts of potassium and phosphorus. It will have higher amounts of protein as well. Some children may need to work with a feeding specialist to help them eat normally again. At times after transplant, the feeding tube is used at night to give more fluids.

-Can my child go out in the sun as usual?

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

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



GROWTH AFTER KIDNEY TRANSPLANT

Children with chronic kidney disease have problems with growth and are shorter than their peers. One of the main causes of poor growth in kidney failure is that the body does not respond optimally to its own growth hormone. Children with kidney disease can grow if they are given growth hormone.

-Will my child grow normally after kidney transplant with good kidney function?

Children can grow well after kidney transplant. Many transplant programs now use minimal or no corticosteroids after transplant, which permits better growth in children. Steroids are the main medications that can slow growth in children after kidney transplant. Younger children tend to have the best growth rates after transplantation. If your child is not growing well after transplant, discuss the problem with your doctor to assess if your child is taking in enough calories for growth or if the dose of prednisone he or she is on should be lowered. Your doctor may even want to start treatment with growth hormone although growth hormone is not typically used in the first 6 to 12 months after transplant and also not in children who are having difficulty with rejection of their transplanted kidney.

-My child was on growth-hormone treatment before kidney transplant. Can he or she continue on it?

Some children grow very well after transplantation, especially if the kidney works well. Your child may or may not need growth hormone after transplantation. If your child is not growing enough, please talk with your transplant doctor about the growth hormone. Your child should have stable kidney function with no rejection under way before going back on the growth hormone and typically it is not used in the first 6 to 12 months after transplant.

It is best to give growth hormone to children before they go through puberty. Bone x-rays are done before starting growth hormone treatment to see how much the child might be able to grow.

-What are the side effects of growth-hormone therapy in children after transplantation?

Growth hormone can do the following:

- Possibly stimulate the immune system. This means your child's kidney function must be closely checked while on the growth hormone.
- Increase in serum creatinine suddenly for no reason. This is a blood test used to measure kidney function
- Increase in acute rejection in children who had more than one rejection in the past (found in some studies). This does not seem to happen in stable patients.
- Make kidney function worse. It could do this by increasing the body's attempts to reject the kidney.
- Require changes of some medications (such as prednisone).
- Cause high blood sugar, diabetes, and headache after transplant.
- Spur cancer growth (has been reported in patients receiving growth-hormone treatment).
- Cause high blood pressure.

IMPORTANCE OF ADHERENCE WITH MEDICAL CARE

Kidney transplant is a major procedure. It can be very challenging at times and hard to manage. It means your child has to take a number of medications. Your child will have to change their lifestyle as well. It can be overwhelming at times, especially for a teenager. It is very important to keep working closely with the transplant team to keep your kidney healthy. The team is there to help you during the hard times.

Non-adherence means failure to follow-up or to adhere to a treatment plan suggested by your transplant team. It happens most often in children and teens between 11 and 20 years of age and even in young adults up to 24 years of age. It can cause loss of the kidney transplant. The teen years are times when feelings about independence, body image, and acceptance by peers are very strong. Some of the transplant drugs cause changes in how a person looks and can create a problem with body image. Taking medicine throughout the day may become socially awkward as well. It can all be very frustrating for a teen.

Non-adherence can happen in different ways:

- Not taking medicine on time or as instructed
- Not keeping up with medical appointments
- Not getting needed blood tests
- Not taking medical advice about diet, activity, or other issues

TIPS AND FACTS TO HELP KEEP YOUR KIDNEY HEALTHY AS LONG AS POSSIBLE:

Keeping a kidney transplant healthy means a change in lifestyle. It will take some discipline. Keeping a kidney healthy can sometimes be very stressful. Please talk to your transplant team about your concerns.

- If you have a crisis in your life, please contact your transplant team at once for help. They are there to help and support you.
- Taking your medications regularly every day and on time is very important. It is the only way to keep your body from rejecting your kidney. This can happen even after many years of having a stable transplant if you stop taking your transplant drugs suddenly or if you do not take them as instructed.
- If the medications get in the way of your daily activity, or you are having bad side effects, please talk to the transplant team. There may be changes in your medications that can be made to help you. Do not stop or change medication on your own.
- If your insurance coverage is running out, please talk to your transplant team. They will help you find a way to get the medications you need without a break in your treatment. Many children can stay on their parents insurance until they are 26 years of age.
- Keep your regular doctor appointments
- If you are close to 18 years of age and worry about being switched to adult nephrology care, please discuss your concerns with your regular transplant doctor. Sometimes this transfer can be delayed or done slowly until you get to know your new adult nephrologist.
- Always remember that if you lose your kidney because of non-adherence you will go back on dialysis. You may be on it for a long period of time before you can get another kidney because your body may have developed antibodies during the rejection that makes it harder to accept easily another kidney. Dialysis is not a good alternative to transplant. You will still need to take a lot of medications for your kidney failure.

LIFE OF THE KIDNEY AND THE NEED FOR FUTURE TRANSPLANTS

The use of new transplant drugs to keep the body from rejecting the kidney has made it possible to keep a new kidney for a long time. A key point in keeping the kidney working well is staying on a strict medication schedule and following medical advice. Some kidneys can work for many years. The average life of a kidney transplant is about 10-15 years but they can last as long as 30 years. Some can keep working for a longer time. Children may need a second or even a third kidney transplant if the first one fails. Remember that many new advances and new medications are being introduced every day. We expect transplanted kidneys to keep working longer in the future. These days, children with kidney transplants can live normal lives. They can look to a bright future like all other children.

ADOLESCENCE ISSUES

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

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

The kidney transplant team is very aware of these challenges. Visits to the team include evaluation, ongoing support, and guidance to foster healthy teenage development, coping skills, and the ability to follow the treatment plan.

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

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

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

Sexuality and Reproductive Health for Teenagers and Young Adults with Kidney Transplants

In this section of the brochure, we discuss the following:

- Common questions about sexuality and the transplant recipient (including safe sex, birth control, sexually transmitted diseases (STDs), and pregnancy)
- Some myths and facts
- Regular sexual health checkups

Questions that often arise with teenagers who have had kidney transplants include the following:

- What if I don't want to have sex and my partner is pushing me? How can I say NO?
- What is safe sex?
- Can I get pregnant?
- Can I father a child?
- Will the medications I take affect my baby?
- Will the disease that affected my kidney be passed on to my children?
- Will I lose my transplanted kidney if I get pregnant?
- What about sexually transmitted diseases (STDs)? Do they mean the same for me as for others?
- I know safe sex is important, but my partner doesn't agree. What should I do?

The question regarding medications affecting the baby is a very important question since some medications will possibly harm a fetus or cause birth defects. More information about the risks to a fetus of medications prescribed to transplant patients is found in this guide in the medication section under the individual medications. For example, mycophenolate mofetil (Cellcept) or anti-hypertensive medications (ACE inhibitors, Lisinopril, enalapril) are commonly prescribed medications for patients with transplants and are potentially harmful during pregnancy. It is always a good idea to talk to your transplant team specifically about this concern.

Deciding to Have Sex

Sex is a loving experience between two people, something to cherish. The first time should be particularly special. Decide ahead of time when and what is right for you.

There's plenty of pressure on your people to have sex. TV and movies might make you think there's a lot you're missing. Remember, most TV shows and movies exaggerate. Don't feel pressured. Your sex life is your own business. When, with whom, and how you make love are your choices. You have the right to say no any time you want. If you want to put it off until later, it's up to you to say what you want.

If the decisions are troubling you, take time to talk to an adult you trust: your parents, a friend, your nurse, your doctor, a school counselor, a religious leader. These things can usually be discussed privately. You have the right to ask in advance if your conversation will stay private. All health professionals must keep talks with patients confidential. They can't tell your parents what you've been talking about unless you give them permission.

Even if you're not yet ready to start having sex, it's important to know about safe sex. That way you'll be prepared to make good choices when the time is right.

Safe Sex

Important things to think about before deciding to have sex are the possibilities of pregnancy and STDs. Hugging, kissing, caressing, and massaging:

They're all part of safer sex. If you decide to do more, you and your partner need protection. This and more are discussed following.

Myths

- I can't get pregnant now that I've had a transplant. **THIS IS NOT TRUE.**
- I look younger than my friends, so I can't get pregnant. **THIS IS NOT TRUE.**
- The disease I had before transplant affected my fertility. I don't need to worry. **THIS IS NOT TRUE.**
- I'm tired of being treated like a child because I'm small. If I have a baby or have sex, people will start to treat me like an adult. **THIS IS NOT TRUE.**
- I want to be accepted by my friends, and the only way is to have sex. **THIS IS NOT TRUE.**
- STDs affect others, not people like me. **THIS IS NOT TRUE,**

Facts

- Almost any young woman can get pregnant. **Never assume you can't!**
- Almost any young man can make a girl pregnant. **Never assume you can't!**
- Fertility isn't an "all or none" thing. Some medical conditions may reduce fertility, but all that is needed for pregnancy to occur is **one egg and one sperm.**
- Having a baby before you're ready can make your life very difficult. **Think about it carefully.**
- Real friends don't pressure you to do things you don't feel right about.
- Even if someone looks great, you can't be sure they don't have an STD or even HIV. Anyone can get an STD if they don't protect themselves, whether they're gay or straight, fertile or infertile.

Prevention of Pregnancy

If you're thinking about having sex, you probably want to know about preventing an unplanned pregnancy. Here we discuss the types of birth control teenager's use most often. Even if most methods depend on the girl to do or take something, it's really important for guys to understand and support their girlfriends. Don't forget-only a condom can prevent STDs.

No method of birth control works perfectly! There is always some risk of pregnancy. However, the risk can be quite small with correct use of the birth control methods described. Remember, though, that many sexual activities such as holding hands, hugging, touching, and kissing are almost always safe without any special precautions.

Birth Control Methods Used Most Often by Young People

Hormonal Methods

These include birth control pills and Depo-Provera® shots. The hormones stop the egg from leaving the ovary. They also make the mucus in the vagina too thick for sperm to move in. They prevent pregnancy between 90% and 99% of the time when taken as directed. Hormonal oral contraceptives can increase blood pressure and increase the risk of blood clots so careful consideration of this form of birth control and monitoring of blood pressure is essential.

Implanted devices such as IUD or Nuva Ring® can have increased risks of infection in transplant patients who are on immunosuppression medications and at times the effectiveness of these devices can be decreased in transplant patients. IUDs are not absolutely contraindicated in transplant and therefore you should have a conversation with your transplant doctors if you are considering this method of birth control.

All medicines have side effects. You need to speak to your health provider doctor to find out which pill is best for you. A specialist in gynecology or adolescent (teen) medicine can be very helpful.

Important things to tell your doctor:

- The medications you take for transplant
- If you have migraines, in particular, the kind with flashing lights or that make parts of your body numb or weak.
- If you have had problems with blood clots. These can be clots in your dialysis fistula or catheter, in your legs or lungs, after surgery, or at any other time. If anyone in your family has had clots and became very sick or died from them (especially if they were young when it happened).

Barrier Methods

These include the condom and diaphragm. The condom is a popular method. It blocks the sperm from getting to the egg. Used the right way, condoms prevent pregnancy 60% to 85% of the time. Condoms are the only good protection against STDs.

Along with using a condom each time, many young women and their male partners want more protection from pregnancy. The condom is very good at preventing STDs. The hormonal methods are better for preventing pregnancy. The best protection is to use both together.

Birth Control Methods That Don't Work Well

- The "Withdrawal" Method
- The "Rhythm" Method

Emergency Contraception (“Morning-After Pill”)

This may be used in an emergency. It can't prevent all pregnancies, but it does prevent most. The morning-after pill must be started within 72 hours (less than three days) after having sex, and the sooner the better. If you can't reach your own health care provider, call your local emergency clinic. Remember to tell the doctor about the medications you take for your transplant. You may find it helpful to tell an adult you trust that you're worried about being pregnant and what happened. Then you need to decide what birth control method will work best for you in the future.

Call your doctor if:

- You have questions about sex.
- Your period is more than a week late and you had sex with someone.
- You know the condom broke, or you didn't use one, and no other method of birth control is being used.
- You think you might need emergency contraception (the morning-after pill)

Useful Website:

www.plannedparenthood.org

Sexually Transmitted Diseases

About STDs

It is especially important for transplant patients to keep from getting STDs. The transplant drugs they take make the risk of infection and of serious problems higher. There are a lot of different STDs, but they all have one thing in common: they are spread from one person to another during some type of sexual activity.

Well known STDs include chlamydia, gonorrhea, herpes, crab lice, syphilis, condylomata (genital warts), trichomoniasis, herpes simplex virus (HSV), HIV (the virus that causes AIDS), and hepatitis B and hepatitis C (two different viruses that cause liver disease). Some STDs are much more dangerous than others and can make you very sick. Some can be deadly.

There are treatments for some STDs, but not for all of them. Prevention is very important. Often a person can have an STD and not know it because they have no symptoms and don't feel sick. (This is especially true for chlamydia.) They can spread the disease to their sexual partners if they are not careful.

Prevention of STDs

Safer Sex

Many activities are almost always safe without any need for precautions. These include holding hands, hugging, kissing, and touching.

If you choose to have intercourse, you can protect yourself against almost all of the STDs. You do this by using condoms each and every time.

Other STD Facts:

- You're more likely to get an STD if you have more than one sexual partner or if your partner has had other partners before you.
- You can get the same STD more than once, even if you've been treated.
- You can get an STD even if you have sex just one time.
- The "withdrawal" method does not prevent STDs.
- If you think you may have an STD, you must get treated as soon as possible.

Call your doctor if you have any symptoms you think might be from an STD. Don't wait! You can also go to an STD clinic or community health center.

Examples of STD symptoms:

- Burning or pain when urinating
- Strange or weird-smelling discharge from the vagina or penis
- Itching, burning, or pain around the vagina, penis or anus (bottom)
- Rashes, sores, blisters, or growths around the vagina, penis, or anus
- You think you might have had sex with someone who had an STD.

So, you don't feel like using a condom anymore?

If you're in a stable relationship, and both have only one partner, or if you're married or living together, maybe you're thinking of not using condoms. Before you make that decision, both you and your partner should be tested for HIV and other STDs. The same goes if you're trying to get pregnant. If the results of the tests are negative, you can stop using condoms for as long as you both stay faithful to each other.

Pelvic Inflammatory Disease

What is it?

Pelvic inflammatory disease (PID) is an infection that starts in the uterus and moves into one or both fallopian tubes. (These are the tubes that connect the uterus to the ovaries.) From there it can move to the ovaries and can spread into the abdomen as well. The organisms that cause STD's can cause PID. (Gonorrhea and chlamydia are common causes of PID.) Symptoms may include the following:

- Lower stomach pain
- Thick, creamy, yellow, or clear vaginal discharge
- Bleeding or spotting between periods
- Fever or chills
- Pain during sex
- Pain or burning when you go to the bathroom

A doctor must always check you to see if you have PID.

PID is a very serious infection. It increases your risk of developing a pregnancy outside the uterus (ectopic pregnancy) and of not being able to have children. The outcome depends on the following:

- How long you have been infected and how much the PID has spread
- Proper and early treatment
- The number of PID infections you have had

How do you treat PID?

Antibiotics. It is very important to take all the medicine prescribed. Don't forget to tell your doctor about your other transplant drugs. Some antibiotics can change your drug levels and affect your kidney function.

Contacts. Everyone you have had sex within the last three months must also be treated, even if they have no symptoms. Don't have sex until both you and your partner have finished all the medicine.

Follow-up. See your doctor again two or three days after you start your treatment to make sure the infection is under control. See the doctor again one week after you finish all the medicine. You need to make sure that it is gone.

Prevention. See the section on STD prevention. STDs can cause PID.

Call your doctor immediately if:

- Your pain gets worse
- You vomit and cannot keep your medication down
- You have a fever higher than 101°F (38.4°C)
- You feel you are getting sicker

Other Health Issues Related to Sexual Activity

Urinary Tract Infections

Many women get urinary tract infections (UTIs) after sex, even if they've never had them before. Some women with kidney transplants may have had problems with UTIs before. These may get worse or more frequent after sex.

These UTIs happen because the tube that drains the bladder is right in front of the vagina. This tube is called the urethra. During sex, the movement of the penis in the vagina rubs the wall of the urethra next to it. This can push bacteria from the urethra up into the bladder.

For women with kidney transplant, UTIs may be quite serious because of the transplant drugs they take. Sometimes the infection can invade the bloodstream. This can make you very, very sick. Another concern with UTIs for transplant patients is that they can lead to damage of the kidney transplant.

Symptoms of a UTI may include the following:

- Pain or burning during urination
- Pain in the lower abdomen
- Fever or chills
- Foul-smelling urine

If you think you have an UTI, call your transplant team or regular doctor at once. It is important to get your urine tested as soon as you have symptoms. You need to have both a urinalysis (rapid test) and a urine culture. Remember that the urinalysis may not always show an infection in a transplant patient. This is due to the transplant drugs. If you have UTI symptoms, ask your doctor if you can start treatment while you wait for the results of the urine culture, even if the urinalysis is normal. Medicine can be changed if needed when the culture results come in.

Don't forget that some antibiotics may react with your transplant drugs. Always discuss this with the doctor.

If you get a lot of UTIs after having sex, talk with your doctor about ways to prevent them. Some women need to take an antibiotic, either after sex or every night. Your doctor and transplant nurse can help you find the method that works best for you.

Yeast Infections (Thrush)

Many women have problems with yeast infections. These are most often caused by an organism called *Candida*. Yeast normally live in the bowel. They can grow out of control when antibiotics upset the balance between the "good" bowel bacteria and the yeast. Yeast infections may be more of a problem after puberty. They are also a problem for people who take a lot of antibiotics or who are on transplant drugs. Men may get yeast infections as well, but they tend to be less frequent.

Yeast (thrush) shows up most often in the mouth and vagina. In the mouth, there may be redness with white spots. In a vaginal yeast infection, women may have itching, burning, and a white "cheesy" discharge. Thrush is easy to treat with antifungal creams or oral medicines. It is important to see your health-care provider to be sure it is a yeast infection before starting treatment.

Once in a while, yeast infections can be more serious. This happens when they invade the bloodstream or the kidney. That's why it is important to find and treat them early.

People sometimes use natural remedies to treat thrush. Always discuss with your transplant doctor or nurse first. Some of these remedies may interact with your transplant drugs. This can cause serious side effects. Other can sometimes be harmful to kidneys.

Above all, don't stop your transplant drugs!

Deciding to Have a Baby



This is a very big decision for anyone. As a patient with a kidney transplant, you have extra things to think about, such as the impact on your own health.

If you decide it's the right time for you to have a baby, there are many things to think about. You need to talk to your transplant doctor and nurse before you start trying to become pregnant. You should also see an obstetrician (specialist in pregnancy) who has taken care of other transplant patients.

For women, it's best to wait at least one to two years after transplant to become pregnant. By that time, you are taking a lower dose of your transplant medicine, and your graft function is stable.

Pregnancy is generally safe if you have the following

- Good kidney function
- No protein in the urine
- Normal blood pressure
- No ongoing rejection
- A normal ultrasound of your kidney graft

Pregnancy after a transplant is seen as a high-risk pregnancy and should be watched closely by both your transplant doctor and obstetrician. You will have a higher risk of the following:

- Kidney infection
- High blood pressure
- Anemia (low blood count)
- Protein in the urine
- Premature birth
- Perhaps an increased chance of a rejection event

Can your baby get the same disease that affected your native kidneys?

This is a very important question. It is something you need to discuss with your transplant specialist. Some diseases that lead to kidney failure in children may be inherited, but not all are. Your doctor will be able to help you sort this out. If there is a chance that your condition was inherited, you can ask to talk to a genetic counselor. The best time to do this is before you get pregnant. Genetic testing may be possible. This can be done before you decide to have a baby or early in your pregnancy. You need to discuss these issues, as early as possible, with your transplant doctor and obstetrician.

If you have had CMV infection your doctor should watch and test your baby when it is born to see if has been infected. Most (75-80%) of babies that get CMV during pregnancy have no symptoms but some can have problems with growth of the body or the brain. In addition, it can sometimes cause problems with development or hearing loss over time.

The following drugs for transplant patient must be changed to something else if you are pregnant:

- Mycophenolate mofetil (Myfortic® or Cellcept®)
- Sirolimus (Rapamune®)
- Angiotensin converting enzyme inhibitor BP medications (Lisinopril or enalapril)
- Angiotensin II receptor blockers (losartan, Cozaar or Cosaar®)

These drugs are thought to be low risk during pregnancy:

- Cyclosporine
- Tacrolimus
- Azathioprine

- Prednisone

Sexual Health Checkups

Even if you're not having sex, you should have regular checks of your sexual and reproductive health. This is definitely the case once you become sexually active.

For women, this means regular checkups. After the age of 21, pap smears are recommended. Screening for STDs should happen after you have become sexually active. Pap smears are done to look for cancer of the cervix. If it is found early, cancer of the cervix is easy to treat. If it is found late, it can be very serious. You can also discuss your periods and whether you have problems with a large amount of blood loss or menstrual cramps. There are ways to help these problems.

For men, regular testicular exams are important. Cancer of the testis is the most common cancer found in teens and your men.

 ***You're in control. You need to schedule your regular checkups.***

Cervical Cancer

-What is it and how does it occur?

The cervix is where the uterus joins the vagina. Cervical cancer is one of the most common cancers found in women. It affects women with transplants more than three times as often. The most common type, squamous cervical cancer, may be caused by an STD, the human papillomavirus (HPV). This virus causes genital warts as well. A vaccine against HPV is available and recommended for all kidney transplant recipients, both male and female.

You are at greatest risk for cervical cancer under the following circumstances:

- You have had an organ transplant
- You have an abnormal Pap smear
- You or your sexual partner has or had genital warts
- You have many sexual partners
- Your partner has had many partners in the past
- You don't use condoms
- Your sexual partner's previous partner had cervical cancer or abnormal cells on the cervix
- Your sexual partner has or had cancer of the penis
- You smoke cigarettes
- Your mother took the hormone DES while pregnant with you.

-What are the symptoms of cervical cancer?

Early on, there are no symptoms. It is usually found by a Pap smear and pelvic exam. Young women should start having Pap smears and pelvic exams after the age of 21.

Later, symptoms may include the following:

- Abnormal vaginal bleeding
- A bloodstained discharge at unexpected times, such as between menstrual periods or after sex
- An abnormal vaginal discharge: cloudy or bloody, or mucus with bad odor

-How is cervical cancer diagnosed?

Your doctor will take a Pap smear. During this test, a small spatula (like a Popsicle stick) and tiny brush are used to obtain cells from the cervix.

-What can you do to help prevent cervical cancer?

- Avoid having a lot of different sexual partners
- To reduce your risk, your partner should also have as few partners as possible
- Use latex condoms every time you have sex, especially if you or your partner have had many partners in the past
- Have regular gynecology checkups, with a Pap smear, after the age of 21. Once you begin to have sex.
- Women with a transplant should have a Pap smear every year
- If you have abnormal vaginal discharge, bleeding between periods or with sex, or painful intercourse, see your doctor as soon as possible
- Don't smoke
- Get the HPV vaccine prior to the onset of sexual activity

Some information regarding...Testicular Cancer

Signs and symptoms of testicular cancer include:

- A lump or enlargement in either testicle
- A feeling of heaviness in the scrotum
- A dull ache in the abdomen or groin
- A sudden collection of fluid in the scrotum
- Pain or discomfort in a testicle or the scrotum
- Enlargement or tenderness of the breasts

Cancer usually affects only one testicle.

When to see a doctor. See your doctor if you detect any pain, swelling or lumps in your testicles or groin area, especially if these signs and symptoms last longer than two weeks.

TRANSITION FROM PEDIATRIC TO ADULT CARE

Adolescence can be a challenging time for patients as they grow and have more independence and self-awareness. As you and your child go through this period, we will work to ensure that the family benefits from a smooth process for eventually transitioning (moving) your child and their care to an adult transplant team.

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

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

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

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

Early transition preparation (10-13 years)

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

Middle transition preparation (15-17 years)

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

Late transition (18-23 years)

- Healthcare providers continue to see the patient alone for part of the visit.
- Patients can verbalize their health history, current conditions, and importance of short-and long-term problems.
- Patients know their medications and are responsible for taking and ordering medications.
- Patients are responsible for making their appointments and can verbalize their follow up care plan.

- Patients understand their medical history and any chronic problems (for example hypertension, acne, kidney dysfunction).
- Patients know the contact information for their primary care provider, transplant team, social worker, insurance provider, and pharmacy.
- Caregivers prepare to be consulted by the child about health decisions.
- Patients designate a health care proxy, complete advanced directives, and provide consent to transfer their information to the adult transplant program.
- The pediatric program schedules a transition visit about six months before the transfer of care to the adult program. The visit includes meeting the new team of providers and touring the facilities.
- If possible, the patient is connected with another individual who has already completed the transition process.

RESEARCH

-Why do research in children?

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

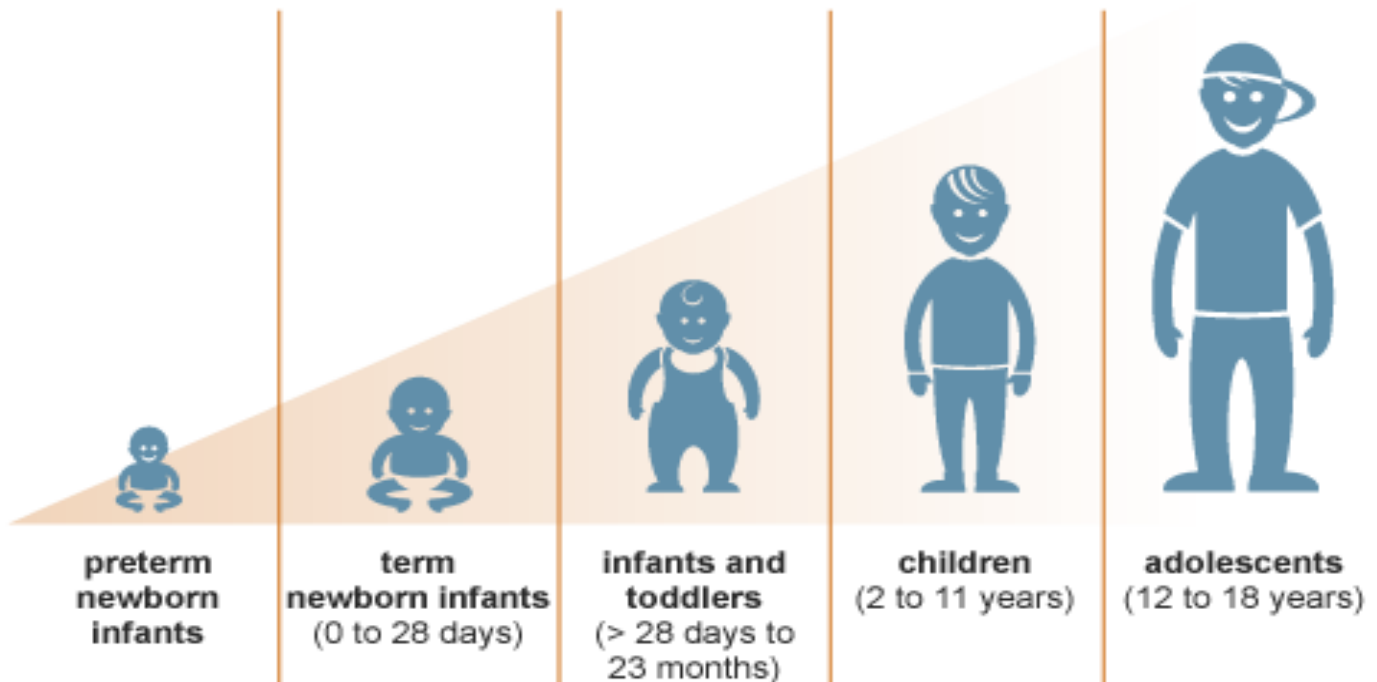
Most of the medications and treatments that we will use in your child are not officially approved by the Food and Drug Administration (FDA) in the United States for use in children with kidney transplants. However, they are used all over the world every day.

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

-Why are children different than adults?

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

Stages of growth



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

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

-Why are clinical research studies important?

The can help us:

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

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

How can my family help?

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

Whether your child will participate will always be your decision. If you choose not to participate, your child will not be treated differently or receive different treatment than if you were to participate. If you choose to participate in any of the studies, you have the right to withdraw at any point if you change your mind.

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

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

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