



PennState Health

Milton S. Hershey
Medical Center

PATIENT GUIDE

PEDIATRIC KIDNEY TRANSPLANT



PENN STATE HEALTH MILTON S. HERSHEY MEDICAL CENTER | TRANSPLANT PROGRAM
717-531-6092 or 1-800-525-5395

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:: **How To Contact the Transplant Office**

Location: Penn State Health Milton S. Hershey Medical Center
Penn State College of Medicine

Telephone: 717-531-6092 or 1-800-525-5395

Fax: 717-531-3717 or 717-531-0124

Address: Penn State Health Milton S. Hershey Medical Center
Division of Transplantation
Mail Code 520, ASB 4301
90 Hope Drive
Hershey, PA 17033-0850

Office Hours: Monday-Friday, 8 a.m.–5 p.m.

After Hours: **While waiting for transplant:**
Contact your referring doctor, who will continue to manage your care until you receive a transplant.

After transplant:
Holidays, evenings and weekends,
call 717-531-8521 and ask for the
kidney transplant coordinator on call.

You can find us online at pennstatehealth.org/services-treatments/transplant-surgery

:: Introduction

Welcome to the Penn State Health Milton S. Hershey Medical Center Transplant Program. Like many children and parents beginning the evaluation process for a kidney transplant, you probably have questions and concerns. This guide is a resource that you can refer to every step of the way. We encourage you to read the entire guide and ask your doctors, nurses and other staff about anything you do not understand. As your transplant team, we know that you have likely experienced a great deal of stress and encountered many hurdles related to living with serious health issues. Whether you are facing physical, emotional or financial challenges, we are here to support you as you gather information and make decisions.

Please keep this guide nearby and place correspondence regarding the transplant process inside. You also will need to bring the guide with you when you are called in for the transplant surgery because we will need to review the post-transplant care with you at that time.

In the pages that follow, you'll find a brief discussion of how a healthy kidney works and what happens when that kidney is damaged, as well as specific information about the transplant program at the Milton S. Hershey Medical Center. This guide also describes the evaluation and selection process for kidney transplant, the wait for a donor kidney, the operation, and the immediate postoperative period. The information about post-transplant care is very important. There's a glossary at the end of the guide so you can easily look up definitions of important terms.

It is especially important to learn about your child's medications and how to maintain good health with a newly transplanted kidney. Being well-informed about care before and after the transplant is a vital part of the recovery process. Remember, if you have any questions, call your transplant coordinator, who is available Monday through Friday from 8 a.m. to 5 p.m.

The United Network for Organ Sharing (UNOS) provides a toll-free patient services line to help transplant candidates, recipients and family members understand organ allocation practices and transplantation data. Please call

888-894-6361 to discuss any problems with your transplant center or the transplantation system in general.

Thank you for choosing Penn State Health Milton S. Hershey Medical Center to learn more about organ transplantation.

:: **Your Transplant Team**

Transplant Surgeon

Our transplant surgeons have advanced training in kidney transplant surgery. The surgeon will meet with you and your child before the transplant surgery to determine, with the help of other members of the medical team, whether transplant is the best option. He or she will discuss the risks and benefits of the surgery and answer any questions you may have about the surgery or follow-up care. The surgeon will perform the transplant surgery and oversee all aspects of your child's care during the hospital stay and the first six weeks after transplant.

Pediatric Nephrologist

Pediatric nephrologists specialize in the medical treatment of kidney disorders in children and work with the transplant team to ensure optimal functioning of the new kidney. They monitor all nonsurgical aspects of your child's care. In cooperation with the transplant surgeon, the pediatric nephrologist will adjust your child's medications after transplant and monitor kidney function to identify any problems.

Transplant Coordinator

Your child's transplant coordinator is your main source of contact with the transplant team. The coordinator is a highly trained registered nurse who is an integral part of the transplant process, both before and after surgery.

Before transplant, the coordinator will guide you through the education and work-up process and is your contact person for any questions or concerns you have while awaiting transplant. After transplant, your child's care will be transferred to a post-transplant coordinator, who will teach you post-transplant care and how to give medications properly. The coordinator also will review your child's lab work with our physicians and answer any questions you have.

Transplant Social Worker

Transplant social workers provide support, education, counseling and assistance throughout the evaluation and transplant process. They assist patients and families as they adjust to life with a chronic illness, living with a transplant and

resuming life after a transplant. Social work services are available for all pre- and post-transplant patients and their families, as well as for living organ donors.

Transplant Financial Counselor

The transplant financial counselor reviews your insurance coverage and explains what coverage you have for surgery and medications. The counselor also makes recommendations for additional coverage to minimize your out-of-pocket expense after transplant.

Transplant Dietitian

Our transplant dietitian provides nutrition counseling for patients awaiting transplant, post-transplant patients and living donors. Nutrition support is tailored to meet the needs of each patient.

Transplant Pharmacist

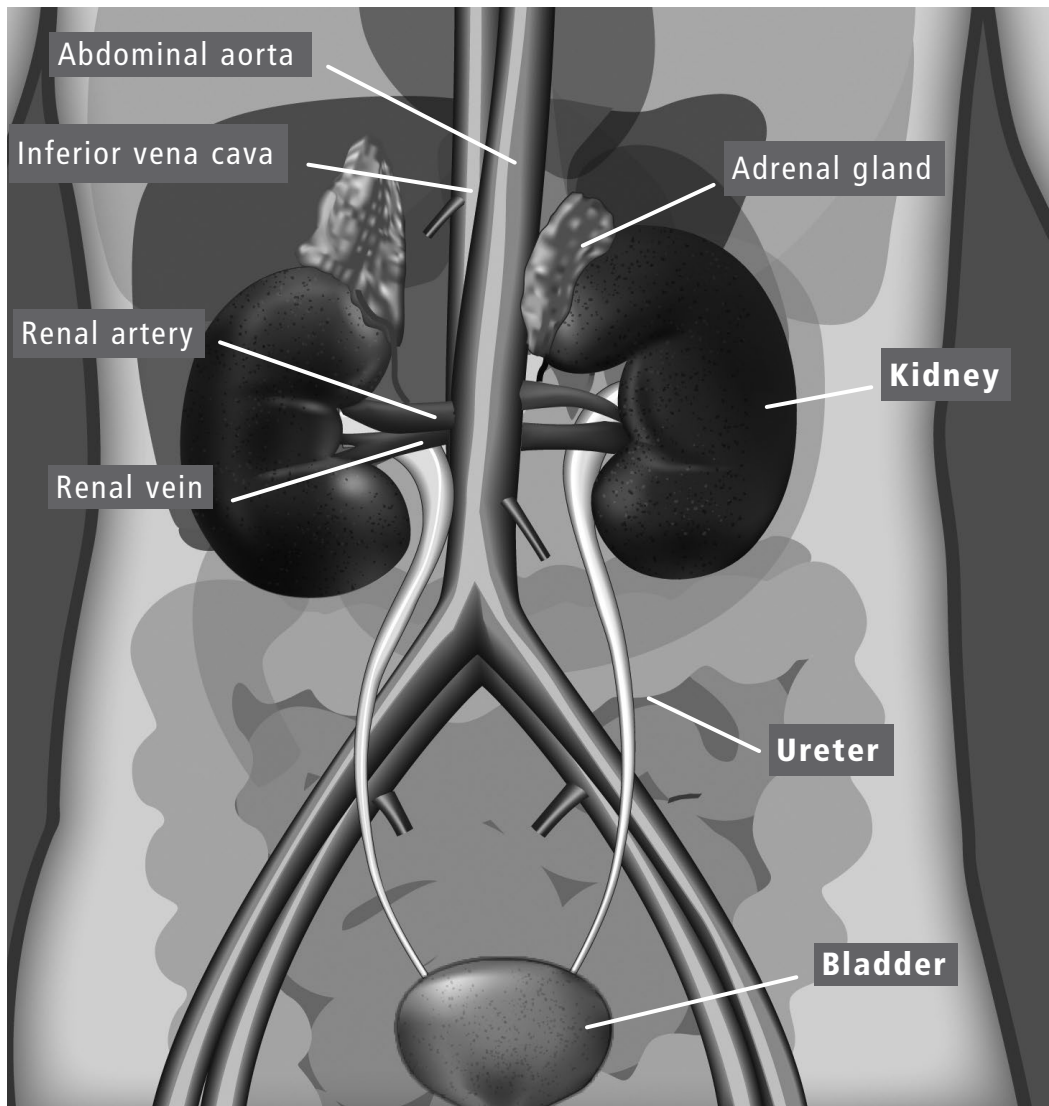
Transplant pharmacists have in-depth knowledge of transplant-related medications. They educate patients and their families about immunosuppressive medications, side effects of medications and proper dosing.

Transplant Office Assistants

Transplant office assistants work closely with our transplant coordinators to provide administrative support, such as answering phone calls, scheduling and entering test results and patient information.

:: Pre-Treatment: How Do Kidneys Work?

The kidneys are two bean-shaped organs located behind the stomach on either side of the spine, just below the ribs. Each kidney is about the size of your fist.



The kidneys function to:

- Filter blood by removing toxins and waste products, which are produced by normal body activities, such as breathing, eating and exercise
- Produce hormones that help regulate blood pressure and red blood cell production
- Manage fluids and electrolytes by helping to get rid of extra fluid or keep fluid in the body if it is needed, as well as to maintain proper salt and acid levels

The kidneys may stop functioning due to a problem that happens immediately, acute kidney failure, or a condition that happens over time, which is called chronic kidney disease. Kidney failure can be related to a chronic disease or from a problem your child had from birth. Generally, chronic kidney disease affects both kidneys, and there are often no symptoms.

When the kidneys have not been working correctly, the waste products and fluids they normally remove start to build up in the body. This results in the signs and symptoms of kidney disease, which can include:

- Fluid retention – puffiness in the face; swelling in the hands and feet
- A change in urination (more or less frequent painful, or difficult)
- Shortness of breath
- Mental confusion
- Tiredness or excessive fatigue
- Abnormal blood or urine test results

:: **Treatment Options**

If kidney disease progresses to kidney failure, called end-stage renal disease, the options include dialysis or transplant.

Dialysis

There are two different types of dialysis: hemodialysis and peritoneal dialysis. Both have advantages and disadvantages. Your child's pediatric nephrologist will explain both types, and help you choose the best option if dialysis is needed. Keep in mind that your child does not have to start dialysis to be able to receive a kidney transplant.

Transplant

Since children need good kidney function to grow and develop, transplant is preferred. We will discuss your transplant options in this guide and during your initial appointment with the transplant team.

When you decide that transplant is the best treatment for your child, you are agreeing to abide by the following guidelines:

- Give your child the medications as prescribed.
- Come to clinic as scheduled.
- Get your child's bloodwork as requested.
- Come to the hospital for biopsies and procedures, as needed, after transplant.

Deceased Donors Versus Living Donors

Kidneys may come from either deceased or living donors.

Deceased donors

Deceased donors are people whose families have decided to allow their organs to be used to help save the lives of others.

Deceased donor kidneys are distributed based on a point system. Potential recipients on the transplant list are given points based on the following criteria:

- Time on the transplant list.
- Antigen or tissue matching.
- Percentage of reactive antibody levels. Patients who have developed high levels of antibodies from prior transplants, prior transfusions or other sensitizing events receive priority because they are difficult to match.
- Age (those younger than 18 receive priority).
- Prior living donors also receive priority.

Every time there is a deceased donor, a new list of potential transplant patients is generated. Where your child appears on that list will depend on how well your child matches with that particular donor and the other factors listed above. You can find additional information about how kidneys are distributed in the UNOS publication “Questions and Answers for Transplant Candidates about Kidney Allocation.”

Living donors

A living donor is a person who volunteers to be a donor for a person who needs a kidney transplant. That person may be a family member, friend, or anonymous donor (someone the recipient does not know). The donor chooses to give one kidney to the person who has kidney failure. The first step for the living donor kidney transplant option is determining if a donor and recipient have compatible blood types, which are shown on the following table:

| Recipient's blood type | Compatible donor's blood type |
|-------------------------------|--------------------------------------|
| A | A or O |
| B | B or O |
| O | O |
| AB | A, B, AB or O |

Rh factors (positive and negative) do not need to match.

Paired Kidney Donation

If a prospective living donor is not a compatible blood or tissue type, paired kidney donor exchange may be an option. Pairs of incompatible donors and recipients may be entered into this program to “swap” kidneys. Your transplant coordinator will explain this option in more detail, if appropriate.

Advantages of Living Donor Kidney Transplants

There are advantages to receiving a kidney from a living donor:

- **Shorter wait time.** Your child may not have to wait on the list for several years before getting a transplant. Living donor transplants can often be scheduled in as little as a few months.
- **Scheduled surgery.** Because living donor transplants are scheduled, both donor and recipient families can plan for child care, absence from work and other concerns.
- **Shorter time without blood flow to the kidney.** A living donor kidney usually begins to work immediately because it generally goes without blood flow for a shorter time than a deceased donor transplant.
- **Slightly decreased risk of rejection.** For many reasons, living donor transplants have a lower risk of rejection.
- **More available donors for those on the list.** Using a living donor for your child increases the number of deceased donors for those who have no living donors.

Living Donor Surgery

There are two options for living donor surgery:

1. **Laparoscopic.** The surgical removal of a kidney is called nephrectomy. With laparoscopic surgery, the surgeon uses small cameras and instruments (through very small incisions on the abdomen) to free the kidney, which is then removed through a small incision that is a few inches below the donor's belly button. A kidney removed using this approach results in less pain and discomfort for the donor, a very short hospital stay (one to two days) and a faster recovery. Most donors are ready to return to work and normal activity within four to eight weeks after surgery.
2. **Open.** This approach is only used in the event the surgeon finds the kidney might be damaged using the laparoscopic approach or if the donor's life becomes jeopardized in some way. The surgeon makes an incision that runs along the lower edge of the rib cage, from the middle of the abdomen to the back, on the side where the kidney is to be removed. It can be a painful incision after the donor wakes up from surgery, and the donor will often have a five- to seven-day hospital stay, with an eight- to 12-week recovery period.

What is the Process for Potential Living Donors?

Potential donors MUST call our office to begin the donor evaluation process. We cannot call them to start this process – they need to establish their own willingness to donate. **Please have interested donors complete the donor questionnaire online at livingdonationpa.org. If this is not possible, they may call our office at 800-525-5395.** Potential donors should:

- Generally be between the ages of 18 and 70
- Not have a history of diabetes, uncontrolled high blood pressure, any cancer or kidney disease.

A dedicated donor advocate team will work with the donor to ensure that all of the donor's rights are respected.

Living donors undergo a very thorough work-up to make sure they are safe to function with just one kidney. Donors may also need to have a psychological evaluation to be sure they completely understand the risks associated with the surgery. Please remember: If we find that a potential donor is at a health risk, either now or at any time in the future, by donating a kidney, we will NOT be able to proceed with that person as a living donor. After the surgery, donors require a recovery period, but are able to return fully to their normal activities.

:: **Transplant Evaluation**

Evaluation Process

We will not be able to place your child on the transplant list until you have completed all four steps listed below. You will be notified by our office when a decision has been made about your child's listing status.

Step 1: Evaluation visit. This four- to five-hour appointment includes transplant education, a medical history review, physical exam, psychosocial evaluation, blood draw for tissue typing and viral screens and reviews of nutrition, medication and financial/insurance coverage.

Step 2: Completion of required tests/procedures. During the Step 1 appointment, the transplant coordinator will review what tests and procedures are needed to determine if your child is a candidate for a transplant.

These tests may be done close to where you live or at Hershey Medical Center, depending on your preference or insurance requirements.

The tests need to be completed, and the results sent to the Transplant Office for review by your child's transplant coordinator, before your child can be listed for transplant. The sooner they are completed, the more quickly we can decide if your child will be able to receive a transplant.

Notify your child's coordinator when the studies are completed.

Step 3: Coordinator's review of test results. Your child's coordinator reviews all test results. If there is any question about the results, the coordinator will meet with one of the pediatric transplant nephrologists and let you know if additional testing is needed. **If your child has completed all of the testing and you have not heard from the coordinator, please contact our office.**

Step 4: Selection committee's decision for listing. Once the coordinator has determined that all of the requested testing is completed, our selection committee will review your child's case to see if there are any medical or psychosocial concerns. The entire transplant team decides whether your child is able to be placed on the transplant waiting list. After the decision is made, we will notify you and your child's nephrologist and, if approved, your child will be added to the waiting list. If there are any concerns raised during the meeting, either additional testing will be ordered and your child's case presented again at a later meeting, or we will explain why your child cannot be listed for transplant.

You will receive a letter from our office after your child has been placed on the transplant waiting list with the date your child was listed. Please keep this letter with your transplant patient guide.

Testing

The following is a list of basic tests that may be required for transplant listing. The actual list of tests may vary depending on your child's medical history and physical findings.

- **Chest X-ray.** A picture that identifies any abnormalities of the lungs and lower respiratory tract
- **Abdominal ultrasound.** A radiology study that evaluates the liver, gallbladder and native (existing) kidneys for abnormalities
- **Computed tomography scan (without contrast).** A type of X-ray to further study the abdominal organs and blood vessels
- **Electrocardiogram (EKG).** A tracing of the heart's electrical activity and that can reveal any abnormal rhythm or activity
- **Echocardiogram.** Checks the heart structures and valves
- **Lab work.** Includes urinalysis and blood tests for blood counts, blood and tissue typing, and kidney and liver function, as well as viral, tuberculosis, HIV and hepatitis testing.

- **Vaccines.** Testing is done to review immunity and determine if any additional vaccines are necessary. Required vaccines may include chickenpox; measles, mumps and rubella (MMR); pneumococcal; and hepatitis.
- **Gynecologic exam.** For females who are 18 years and older or sexually active

:: **Waiting for a Transplant**

How To Prepare

Waiting for that phone call can be the one of the most difficult times for patients waiting for transplant surgery. The wait time for deceased donor pediatric transplants in this region varies from months to years. We are unable to tell you exactly how long your child may wait for a deceased donor kidney transplant.

This time can be very frustrating, and it's important to have a good system of support and encouragement. You may want to speak to your child's pediatric nephrologist, dialysis social worker, transplant coordinator or transplant social worker.

Several things are **extremely important** to remember once your child is approved for transplant:

1. **Be available.** It is extremely important that we are able to contact you when a kidney becomes available. We usually have only up to one hour to reach you when we receive a kidney offer. Please make sure we have all phone numbers where you can be reached. If you don't have access to a reliable phone, please let us know so that we can make other arrangements to contact you.
2. **Get bloodwork done regularly.** While your child is on the transplant waiting list, you must provide a sample of your child's blood every two or four weeks (one tube). This sample is used for panel reactive antibody (PRA) screening, as well as to crossmatch your child's blood with blood from potential donor organs. Without a current sample, your child's transplant may be postponed or delayed. You'll find a prescription for this bloodwork enclosed with the letter you receive from our office when your child is placed on the transplant waiting list.

Be sure your child's dialysis unit has a copy of this prescription.

3. **Keep your child as healthy as possible.** The healthier your child is going into transplant surgery, the better and more quickly your child will recover and return to a more normal lifestyle. We strongly recommend the following for a successful transplant:
 - Have your child see a primary care doctor or pediatrician on a regular basis.
 - Keep your child's routine health screens and vaccinations up to date.
 - Follow any diet prescribed for your child.
 - Return to see us on a yearly basis while waiting. We will schedule follow-up visits and additional testing as necessary.

4. **Keep us informed.** It is very important that you call us when any of the following occurs:
 - Change of name, address or phone numbers
 - Change of insurance carrier or loss of insurance
 - Change of doctor or dialysis unit
 - Change of type of dialysis
 - Any hospital admissions
 - Any infections that are treated with antibiotics
 - Any surgical procedures

Every six months, we will send you a patient information update so you can provide any new information you may have forgotten to tell us. Please review this form, make any changes or corrections and mail it back to us as soon as possible.

Making these changes as soon as they occur will help us to contact you when a donor kidney becomes available for your child.

Note: If we are unable to reach you, or if your child is in the hospital for surgery or has an infection, we may have to change your child's listing status to "inactive" or "status 7." This does not remove your child from the transplant list. However, your child will not be considered for any kidney offers until we make your child's status "active" again. If you are told that your child's listing is status 7, please be sure you understand the reason(s) for the listing change and work on resolving the issues so we can change your child's status back to active.

:: Transplant Procedure and Recovery

Receiving the Call and Having a Plan

Be prepared. You never know when you will get a call that a kidney is available for your child. Be sure you have worked out details such as:

- Who will drive you and your child to the hospital?
- Who will watch or care for your other children, parents, pets or anyone else you normally provide care for.
- Who will watch your house/get your mail while you are with your child receiving the transplant?

When you are called with an available kidney offer, the coordinator will:

- Conduct a medical/physical review. This ensures it is safe to proceed with transplant at that time.
- Review instructions. The coordinator will give you specific instructions about coming to the hospital.
- Let you know if and when your child may eat or drink anything. Your child's stomach must be empty to be able to have surgery.

You will need to bring all current medications and your insurance cards with you to the hospital. It is possible you may receive a call that your child is a backup for a kidney. This means there are other people in line ahead of you, and your child may not receive this kidney. You will receive a follow-up call letting you know whether your child will receive the kidney.

To avoid wasting available organs, there are always several patients being crossmatched for each kidney. Crossmatching is the final step before getting a transplant. This means your child's blood and the potential donor's blood are studied to see if your child's blood will react to the donor blood. The crossmatch

must be compatible (no reaction between your child's cells and the donor's cells) before your child can receive the transplant. This procedure takes approximately five to eight hours to complete. There may be times you will be asked to bring your child to the hospital but may not receive a transplant because the crossmatch is not compatible or there is someone ahead of your child who is a better match for the transplant. While this process is frustrating, it is necessary to be sure that every kidney has at least one patient who will be ready to receive the transplant.

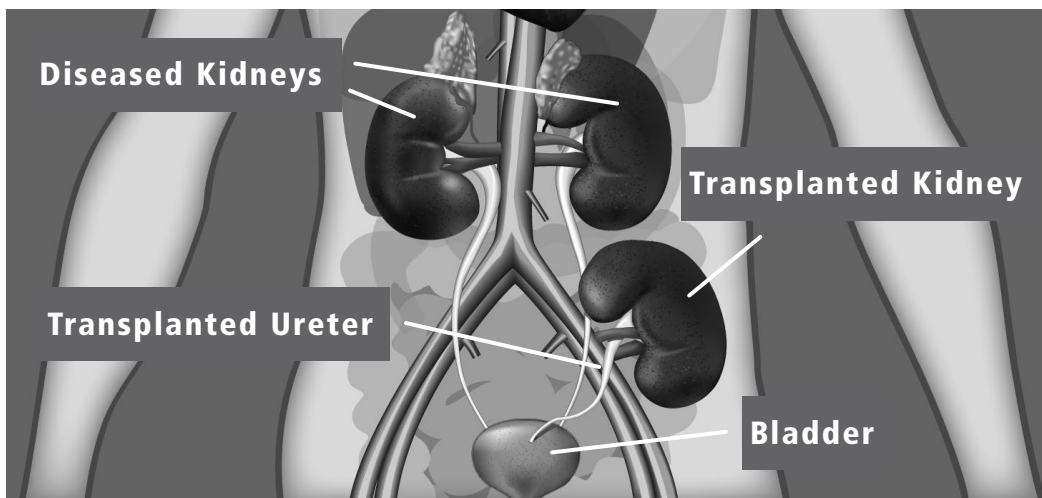
If your child has an approved living donor, the transplant surgery will be scheduled in advance. A final crossmatch will be performed the day before your child's surgery.

Arriving at the Hospital

When you arrive at the hospital, check in at the Admissions desk. After your child is admitted to a room, he or she will have blood drawn, a complete physical, EKG, chest X-ray and intravenous (IV) line placed to prepare for the operating room.

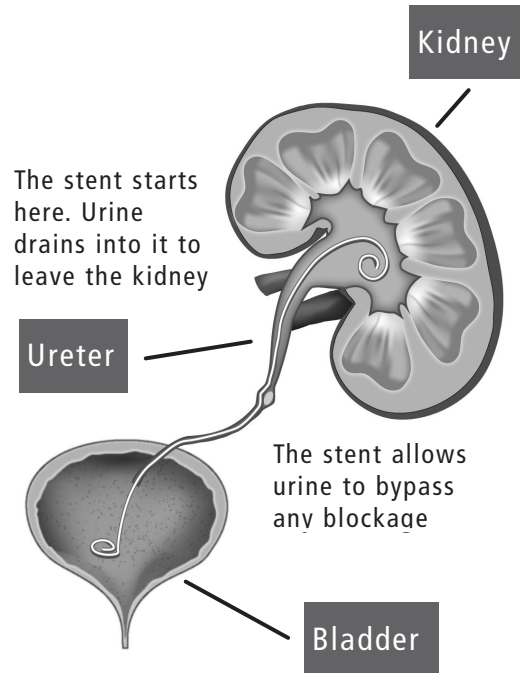
The Transplant Surgery

Your child's transplant operation will take four to six hours. The surgeon will make an incision between 6- and 8-inches long and place the transplanted kidney in your child's abdomen, in the middle or lower front side. The transplanted kidney will be connected to your child's bladder, as well as the main artery and veins in the lower abdomen. Your child's native kidneys will not be removed



during the transplant procedure. If a native nephrectomy (kidney removal) is required, your child’s nephrologist and surgeon will discuss this with you before the transplant.

We’ll insert a special IV, called a central line, near the collarbone while your child is under anesthesia. We’ll also place a plastic catheter, called a stent, in the ureter during the transplant surgery. The stent makes sure the ureter remains open, allowing urine to flow from the kidney to the bladder while everything is healing. You’ll receive an appointment with a specialist in the Penn State Health Department of Urology to have the stent removed around six weeks after the transplant.



Immediately After Surgery

Your child will wake up in the post-anesthesia care unit, which you’ll hear called the “PACU.” Your child will stay in the PACU for approximately two to three hours. During this time, we’ll closely monitor your child’s heart rate and blood pressure. Your child will also have a Foley catheter in his or her bladder, which will allow us to watch child’s urine output closely.

Next, your child will go to the pediatric intensive care unit, also called the “PICU.” We’ll monitor your child’s fluid levels, as well as administer fluids and medications, as needed, through the central line that was inserted during surgery.

Most children will be in the hospital approximately seven to 10 days after transplant. During this time, the transplant coordinators will teach you and your family how to care for your child and the newly transplanted kidney.

Before your child can leave the hospital, you must have a thorough understanding of how to take care of your child at home. The nurses and transplant coordinator will teach you on how to care for your child's new kidney and how to give your child's medications. A pharmacist will review your child's medications, a dietitian will give you dietary instructions and a social worker will visit you as needed.

:: Medications

Anti-Rejection Medications:

After transplant, the body's normal response to something it sees as foreign, such as a new kidney, is for the immune system to attack it. This is known as rejection. Anti-rejection medications decrease the immune system response and help the body recognize the new kidney as not foreign. Your child will need to stay on these medications for the rest of his or her life, although we will most likely be able to lower the dosage over time.

Not taking anti-rejection medications properly is a leading cause of your child's body rejecting the transplanted kidney.

Our pharmacist, your child's nurses and the transplant coordinator will explain what medications to take, what each one does and any common side effects before your child is discharged from the hospital. You will leave the hospital with all medications for the first month. You must become familiar with the names, dosages and schedule of all your child's medications. While the number and dosage of the medicines will be decreased over time, but never stop a medication without talking to the transplant team.

Anti-rejection medications can have side effects, and many other medications may have interactions with them. Notify your child's transplant coordinator before taking any new medications to make sure that there are no interactions or potentially harmful side effects.

Rules for Medications

- Always wash your hands before handling your child's medications.
- Take all prescribed doses each day on time.
- Keep all medications in tightly closed bottles and out of the reach of children.
- Store medications in a cabinet at room temperature, unless instructed otherwise.

- Do not store medications in the bathroom.
- NEVER run out of medication – refill prescriptions well ahead of time.
- Plan ahead for vacations and holidays. Take extra medication with you when traveling. Do not put medication in your checked luggage because temperatures vary or your luggage could be lost. We can provide letters for liquid medications.
- If a dose is missed and you remember within six hours, make sure your child takes it as soon as you remember. Then, take the next dose at the appointed time. If it has been more than six hours, wait until the next dose. If you are not sure, call the transplant coordinator.
- If you cannot remember if your child took the medication, do not give an extra dose, but give your child the next dose at the appointed time. **DO NOT give your child twice as much medicine.**
- Use Tylenol (acetaminophen) for headache or pain.
- **DO NOT** use ibuprofen or naproxen (Advil, Motrin, Aleve, etc.).
- We strongly recommend using a pill organizer.

Typical Medications

At the time of surgery, your child will receive one of the following:

Thymoglobulin (anti-thymocyte globulin [rabbit]) is given intravenously in the operating room and then for three to seven days after.

Possible side effects:

- Flu-like symptoms
- Nausea
- Vomiting
- Low blood pressure

- Allergic reaction
- Higher risk of infection and cancer

Campath (alemtuzumab) is given intravenously as a one-time dose.

Possible side effects include:

- Flu-like symptoms
- Shortness of breath
- Fluid in the lungs
- Allergic reaction
- Higher risk of infection and cancer

While in the hospital, your child may receive:

Thymoglobulin, Simulect, Campath, IVIG

These are all intravenous medications that may be used.

After surgery your child will be on some combination of the following medications:

Tacrolimus (Prograf, Envarsus, Astagra)

Tacrolimus is a potent anti-rejection medication. The prescribed amount can change according to the measured drug level in your child's blood and other medications can alter the absorption of tacrolimus. Please check with your child's transplant coordinator when being placed on any new medication by a doctor other than your child's transplant surgeon.

- Store tacrolimus in a cool, dark place at room temperature (do not refrigerate).
- Do not open, slit or crush capsules.

- If your child vomits his or her medication, call your child's transplant coordinator.
- On clinic days, hold your child's tacrolimus dose until after his or her blood is drawn. Then, give the dose.
- Do not allow your child to eat grapefruit or pomegranate, or drink grapefruit or pomegranate juice. These juices will increase the tacrolimus level.

Potential tacrolimus side effects:

- Nausea
- Diarrhea
- Tremors
- Hair loss
- Depression or other mental symptoms
- Kidney toxicity
- Headache

Cyclosporine

Cyclosporine is also a potent anti-rejection medication. The prescribed dosage will change over time to maintain an appropriate blood level. Other medications may alter absorption of cyclosporine.

- Store cyclosporine in a cool, dark place (do not refrigerate).
- Do not open the blister package until your child is taking the dose. Expiration dates should be marked on the capsule package.
- Repeat if the full dose is vomited within one hour, and call your child's transplant coordinator.

- On clinic days, hold your child's cyclosporine until after his or her blood is drawn. Then, give the dose.
- Do not allow your child to eat grapefruit or pomegranate, or drink these juices. This will increase the cyclosporine drug level.

Possible cyclosporine side effects include:

- High blood pressure (may require drug control)
- Kidney toxicity
- Increased hair growth
- Hand tremors
- Swollen gums
- Depression or other mental symptoms
- Tingling of hands and feet
- Headache

Mycophenolic acid or mycophenolate mofetil (Myfortic or Cellcept)

Your child will be on EITHER mycophenolic acid or mycophenolate mofetil, but should never take both at the same time. These medications are used to prevent rejection and help prevent harm to a new kidney by decreasing the number of white blood cells in the body. Your child will take this medication two times a day.

- Store in a cool, dark place at room temperature (do not refrigerate).
- Do not open, split or crush capsules.

Possible side effects include:

- Diarrhea or vomiting
- Decreased white blood cell count

- Increased risk of infection
- Increased risk of developing lymphomas and other malignancies, especially of the skin

If your child becomes pregnant while taking either of these medications, there can be serious birth defects. We recommend sexually active female transplant patients use two forms of birth control to prevent pregnancy while taking these medications.

Steroid (prednisone, Solu-Medrol (methylprednisolone), dexamethasone)

Steroids are used to prevent rejection.

Possible side effects include:

- Stomach ulcers; indigestion
- Salt and water retention
- Increased appetite and weight gain
- Increased blood sugar
- Increased susceptibility to infection; delayed wound healing
- Increased sun sensitivity, heat intolerance and acne
- Difficulty sleeping; mood changes
- Bone and joint changes
- Blurry vision – do not obtain new glasses until the dosage is stabilized
- Cataracts; glaucoma

Azathioprine (Imuran)

Azathioprine is an anti-rejection medication. The most common side effect of azathioprine is a low white blood cell count which could lead to an infection.

Possible side effects include:

- Decreased white blood cell count
- Increased abdominal pain
- Nausea and vomiting
- Hair loss

Sirolimus (Rapamune)

Sirolimus is an anti-rejection medication.

Possible side effects include:

- Increased cholesterol and triglycerides
- Increased blood pressure
- Diarrhea
- Low white blood cell and platelet count
- Acne
- Anemia
- Joint pain (arthralgias)

Your child will be on the following medications to prevent infections for six months to one year after transplant:

- **Bactrim** (trimethoprim/sulfa) to help prevent bacterial infections, especially pneumonia
- **Valcyte** to help prevent/treat viral infections like cytomegalovirus
- **Mycelex troche/Nystatin** to help prevent oral/mouth yeast infections (thrush)

Your child may still need to be on medications for other conditions that are unrelated to kidney disease, such as:

- Medication to decrease indigestion, such as Prilosec, Prevacid or Pepcid
- Medication for high blood pressure
- Injections to increase red blood cell count
- Injections to increase white blood cell count
- Stool softeners

Other important things to remember about your child's medications:

1. **NEVER** stop or change medications unless directed by your child's physician.
2. **If your child is having trouble with side effects, contact our office.**
We often can change your child's medication schedule or even prescribe medications to help ease some of the side effects.

Please check with our office if another doctor prescribes a new medication to be sure that it will not interfere with any of your child's transplant medications.

If you have a question regarding an over-the-counter medication, please contact your transplant coordinator.

:: **Follow-Up After Surgery**

Transplant Surgery Outpatient Clinic

After your child has been discharged from the hospital, the transplant team will monitor very closely for medical and surgical complications and problems. You must bring your child to the transplant surgery outpatient clinic on the Monday after being discharged.

Outpatient care for transplant patients is provided in a dedicated suite at this location:

University Physician Center
Penn State Health Surgery Specialties Clinic, Suite 3100
200 Campus Drive
Hershey, PA 17033

Hours: Mondays, 8–11:30 a.m.

Parking is available in a lot near the building.

Your child will need to have blood drawn here at the Hershey Medical Center on the day of his or her appointment. **Your child should not take cyclosporine, tacrolimus or sirolimus until the blood samples have been taken, and should not eat breakfast before lab work.**

- Take your child to the outpatient lab in Suite 520 of the University Physician Center about one-and-a-half hours before your clinic appointment.
- After blood is drawn, your child may take these medications and eat breakfast.
- Please return to the clinic at your scheduled appointment time.
- Bring your patient guide, medication sheet and vital signs log to these appointments.

During the visit, please ask any questions you have, and report anything of concern, including fever, headache, cough, weight gain, and wound drainage.

It is important to remember that rejection may occur with or without symptoms. That is why we draw and test your child's blood frequently and why it is important to keep your child's appointments. Sometimes we may need to readmit your child directly from the clinic, so you should be prepared to stay overnight, if necessary.

Once your child is cleared by Transplant Surgery, he or she will return to the Pediatric Nephrology Clinic. The following section outlines the schedule for long-term care.

Lab Work

Your child will have lab work according to this schedule, pending a complication-free, post-transplantation course of recovery:

- One to six weeks after transplant – labs every Monday and Thursday
- Seven weeks to six months after transplant – labs every Monday.
- Six to 12 months after transplant – labs every other Monday.
- After 12 months – monthly labs.

Transplant Clinic Visits

You may see us more frequently if you have complications.

For the first six weeks after transplant, your child will be seen every Monday in the Transplant Clinic

Pediatric Nephrology Clinic Visits

At two months after transplant, we will see your child in the Pediatric Nephrology Clinic, as follows:

- Every other week until three months after transplant.

- Monthly until six months after transplant.
- Then, every three months

Vital Signs

You will monitor your child's blood pressure, weight, and temperature daily for the first six weeks only. You may be asked to monitor these vital signs more frequently if your child is having complications or blood pressure problems.

:: **Life After Transplant**

A transplant is a very precious gift. It is your responsibility to take very good care of the transplanted kidney, and we are here to help you do that in every way we can. If a patient loses a transplanted kidney because they do not take care of it, they may not be considered for another transplant.

Although transplant may seem a long way off at this time, it's very important to read this section so you are informed about your child's care after transplant. Deciding if you are able to provide this care is an important part of the process in determining if transplant is the right treatment for your child.

Postoperative Guidelines

When you leave the hospital, you will assume the responsibility for monitoring your child's health and avoiding infection. Follow these guidelines in the immediate postoperative stage of your child's transplant:

- No lifting anything over 10 pounds, and no strenuous exercise for the first 12 weeks.
- If your child has a driver's license, he or she will not be allowed to drive for two weeks from the date of transplant.
- No tub baths for four weeks. Showers are acceptable.
- During the first six weeks after transplant, your child should avoid unnecessary contact with persons who are ill. If family members are ill, practice good hand-washing.
- You can expect your child to return to school after six weeks, but he or she will not be able to participate in physical education classes.

Care at Home

After receiving a transplant, there are several things you must do to keep the transplant working:

1. **Give your child’s medications as prescribed.** Your child will need to take these medications every day, at the same time each day, to prevent rejection of the transplanted kidney.
2. **Get your child’s blood drawn as ordered.** Initially after transplant, your child will need to have blood drawn twice a week. This allows us to keep a very close watch on the function of the transplanted kidney. The monitoring also allows us to see changes before they become big problems that permanently affect the transplanted kidney. The more time that passes from your child’s transplant date, the less often your child will need to get blood drawn.
3. **Keep clinic appointments for follow-up care.** See the “Follow-Up After Surgery” chapter for more information.
4. **Measure your child’s blood pressure, temperature and weight daily for the first six weeks after transplant.**
 - Take your child’s temperature in the morning and in the evening.
 - Call the transplant team if your child’s temperature rises above 100 degrees Fahrenheit. Do not give your child medication to lower his or her temperature unless instructed to do so by your child’s transplant physician.
 - Check your child’s weight every morning before breakfast, after going to the bathroom. Your child’s weight will help us determine if he or she is drinking the right amount of fluid.
 - Take your child’s blood pressure every morning and evening. Your transplant team will review your child’s blood pressure at each visit. If you have any questions or concerns about blood pressure readings, call your transplant coordinator.

These measurements help you monitor for signs and symptoms of infection and rejection. We will provide you with acceptable levels so you can report immediately if they are too high or too low. You will need to keep a log of this information, which can be found at the back of this guide, and bring it to the clinic when you have appointments.

Check with your child's pediatric nephrologist to see if you are to continue these measurements after returning to his or her care.

General Guidelines for Staying Healthy

The following guidelines should always be followed and should become a natural part of your child's lifestyle:

- **Your child should not handle pet waste or clean a cat's litter box.** It is advisable not to have birds or turtles as pets because their waste contains a high level of germs. If you have a pet, make sure a veterinarian carefully screens it.
- **Your child should shower or bathe regularly.** Also make sure your child washes his or hands with soap before meals and after using the bathroom.
- Your child should not handle the diapers of younger siblings, especially for 14 days after a sibling receives the rotavirus vaccine.
- Wash all fruits and vegetables thoroughly.
- Wash minor injuries, such as cuts and scrapes, immediately with soap and water. If they do not heal well, call your physician.
- Your child should avoid mold. Dust generated from construction may contain fungi (mold). Do not have any renovation work done in your home without first consulting the transplant team. Barns and sheds should be avoided due to dust, which may contain fungi. If your child must be exposed to any of these sites, he or she should wear a mask.

- Report any suspicious lumps or growths in the armpits, groin or elsewhere on your child's body to your child's nephrologist. This could be an indication of a serious transplant complication.
- Provide your child with a healthy diet, exercise and plenty of rest to help avoid illness.
- 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 child's transplant team for resources that may be available to help you quit.
- Discuss any travel plans with your child's transplant team. Always take an extra supply of medication with you.
- Your child may not swim for three months after transplant. After three months, your child may swim in the ocean or a pool. There is a risk of infection associated with swimming in fresh water (lakes or ponds), so particular care should be taken not to swallow water.

Vaccines

Many vaccines are very appropriate for your child after transplant. However, **your child must never receive a live or weakened virus vaccine** after the transplant.

This includes:

- MMR
- Nasal flu
- Rotavirus
- Smallpox
- Yellow fever
- Oral polio

This type of vaccination is a small dose of the actual virus, which could turn into a serious complication for a transplant recipient.

The majority of vaccines that are not safe for your child after transplant are listed above. Please call your child's nephrologist if you are uncertain. We recommend that your child receive the yearly flu, human papillomavirus and meningococcal vaccines, as directed.

Wait six months after your child's transplant date before scheduling any immunizations.

Medical Identification

We recommend that your child wear a medical alert bracelet or necklace that identifies him or her as a child with a kidney transplant. In case of an accident, it is helpful for health care personnel to know that your child has had a transplant. There is a pamphlet included in your teaching packet to order this identification.

Prohibited Sports and Activities

Use good common sense when choosing activities for your child. In general, patients are encouraged to remain active and to develop active lifestyles given the long-term health benefits of regular physical activities. Although aerobic exercises are good for children with kidney transplants, please discuss any new sports activities with your transplant team.

Sports and activities that must be avoided:

- Tackle football
- Boxing
- Karate
- Judo
- Martial arts
- Kickboxing
- Dodgeball
- Wrestling
- Rugby
- Lacrosse
- Ice hockey
- Trampolines
- Gymnastics (uneven parallel bars, balance beam, tumbling)
- Snowboarding
- Downhill skiing
- All-terrain vehicles/snowmobiles (due to the increased risk of high impact crash)
- Dirt bikes

Daily Hygiene

Dental care

Dental care, including routine brushing and daily flossing, is very important after your child's transplant.

Schedule regular dental checkups every six months, or more frequently if recommended by your child's dentist. Your child does not need preventive antibiotics for a routine dental visit because of transplant. However, if your child needs to take preventive antibiotics because of another condition, he or she will still need to do so. Your child should not go to the dentist within the first six months after transplant for routine dental care. If your child has an abscess or other dental issue within that time frame, however, please have it evaluated by a dentist.

In addition to daily care of the teeth, also check in and around your child's mouth for bleeding gums, lumps, blisters, cold sores and other signs of infection. Report any unusual findings to the transplant coordinator.

Your child should not have orthodontic braces placed within the first six months of transplant.

Skin care

The medications your child is taking may increase his or her susceptibility to skin problems, such as sun sensitivity, dry skin and acne.

Increased sensitivity to the sun means your child will burn more easily, even if this was not experienced before. Your child should always wear a sunscreen with SPF 30 or higher on all exposed skin before going outside. Make it a habit to apply sunscreen every day and have your child wear a hat that shades the face. The rays that can cause skin damage and skin cancer are present even on cloudy days. If at all possible, avoid exposure between the peak hours of 10 a.m. and 3 p.m.

Your child may have bouts of dry skin. Use a mild soap without perfume or deodorants. You may use any over-the-counter lotion that you prefer.

Most teenagers develop acne. To control acne, have your child wash his or her face and other affected areas at least three times a day with a mild cleanser, and

always use a fresh, clean washcloth. Do not rub or scrub the affected areas, as this will only increase irritation, and do not touch the affected areas. If these measures do not work satisfactorily, try using a lotion containing 10% benzoyl peroxide. If the acne becomes red and infected, consult your child's physician.

After the age of 18, your child will need to have a yearly skin cancer screening by a dermatologist.

Minor first aid

To treat cuts, scratches and other minor injuries, wash the area thoroughly with soap and water; apply a clean, dry bandage; and change the bandage frequently. Check the area daily for infection. If the area becomes warm or swollen and filled with milky fluid, or if your child develops a fever, call your child's physician.

If the cut is large enough to require stitches, alert the physician who is caring for your child's injury about his or her transplant.

Sexual Activity and Birth Control

For females who have begun menstruating before transplant surgery, menstrual periods usually resume two to 12 months after surgery. However, it is possible for your child to become pregnant before her period starts.

Some forms of birth control may not be appropriate after transplant. For example, the intrauterine device should not be used. Please discuss this with your physician.

Keep in mind that because of the immunosuppressive drugs your child is taking, he or she will be at greater risk for infection from sexually transmitted diseases (STDs), such as AIDS, gonorrhea, syphilis, herpes, etc. Remember that oral contraceptives do not protect against STDs.

Sexually active females should have regular Pap smears and gynecological exams.

Pregnancy after transplant is possible

Fertility may actually improve after transplant. However, we strongly recommend that pregnancy should be planned and discussed with your transplant team.

If your child becomes pregnant, you should contact the Transplant Office immediately. Several of the anti-rejection medications your child is taking may cause birth defects. If your female child is sexually active, two forms of birth control are recommended for those taking certain types of anti-rejection medication. See the Medications section of this guide and discuss birth control with the transplant team. **We strongly recommend use of birth control to prevent pregnancy during the first year after transplant.**

Diet

After transplant, a dietitian will meet with you and your child and may recommend dietary changes. Several restrictions will be necessary due to the anti-rejection medications your child is taking.

The main goal in your child's diet should be to promote sensible, healthy eating.

Occasionally, you may need to continue to restrict your child's potassium and phosphorus intake. We have included a guide for foods high in potassium to assist you with making good food choices.

High-potassium foods

Fruits

- Apricot, raw (2 medium),
diced (5 halves)
- Avocado (1/4 whole)
- Banana (1/2 whole)
- Cantaloupe
- Dates (5 whole)
- Dried fruits
- Figs, dried
- Honeydew
- Kiwi (1 medium)
- Mango (1 medium)
- Nectarine (1 medium)
- Orange (1 medium)
- Orange juice
- Papaya (1/2 whole)
- Prunes
- Prune juice
- Raisins

Vegetables

- Artichoke
- Bamboo shoots
- Beans, baked
- Beans, dried
- Beans, refried
- Beets, fresh and boiled
- Black beans
- Broccoli, cooked
- Brussels sprouts
- Butternut squash
- Cabbage, Chinese
- Carrots, raw
- Greens, raw except kale
- Kohlrabi
- Legumes
- Lentils
- Mushrooms, canned
- Parsnips
- Peas, dried
- Potatoes, white and sweet
- Pumpkin
- Rutabagas
- Spinach, cooked
- Squash, cooked acorn
- Squash, Hubbard
- Tomatoes/tomato products
- Vegetable juices

Other

- Bran/bran products
- Chocolate (15-2 ounces)
- Granola
- Milk, all types (1 cup)
- Molasses (1 tablespoon)
- Nutritional supplements: Use only under the direction of your doctor or dietitian,
- Nuts and seeds (1 ounce)
- Peanut butter (2 tablespoons)
- Salt-free broth
- Salt substitute/lite salt
- Yogurt

Hydration

It is important for your child to stay well hydrated. Drinking water and other healthy fluids will keep your child's creatinine level low to increase the life of the transplanted kidney. While in the past your child may have been on fluid restrictions, he or she now has a functioning kidney and no longer needs to restrict fluid intake. Encourage your child to drink more! **In fact, we encourage drinking approximately eight 8-ounce glasses of fluids a day.** You will need to accurately monitor your child's intake. A water bottle is good for this.

Drinking the proper beverages is an important part of hydration. Please avoid excessive caffeine, which is a natural diuretic and can actually cause the body to lose fluid. You can supplement water with juices, dairy products and some soda. Be aware that **your child must avoid grapefruit and pomegranate juices** because they can increase the anti-rejection drug levels in the blood. **Also avoid alcoholic beverages.**

There are times your child will need to drink even more than usual. Exercising; dry, cold weather; hot, humid weather; and being ill or having diarrhea can all increase the body's fluid needs. If your child is unable to drink enough to keep up with these needs, please call your transplant coordinator immediately to prevent dehydration.

Helpful liquid measurements and equivalents

5 mL = 1 teaspoon

15 mL = 1 tablespoon

30 mL = 1 ounce

Constipation

Constipation may become a problem due to your child's surgery and/or pain medications. To prevent or treat constipation, have your child drink plenty of water, and provide a diet that includes plenty of fresh fruits and vegetables. Remaining physically active is also an effective way to avoid constipation. You may use most over-the-counter products for constipation.

You should notify your doctor of stool changes, such as persistent diarrhea or dark, tar-like stools. Do not take over the counter medications for diarrhea unless instructed by the transplant team.

:: **Post-Transplant Complications**

Rejection

The biggest problem facing all transplant patients is the possibility of rejection. Rejection is the body's attempt to rid itself of a foreign substance, in this case the new kidney. There are several kinds of rejection, and rejection can be a common and lifelong issue.

- **Hyperacute.** This severe form of rejection happens within minutes or hours after transplant surgery. The new kidney and/or pancreas must then be taken out. This form of rejection is very rare.
- **Acute.** This is the most common type of rejection and, while it can happen any time, it more frequently occurs during the first six months after transplant.
- **Chronic.** This type of rejection can happen at any time, including years after the transplant.

Most rejections that happen shortly after surgery can be treated medically. If your child has rejection symptoms, call the Transplant Office. The more quickly your child receives treatment, the more successful the treatment is likely to be. The highest risk of rejection is during the first six months after the transplant surgery.

A few signs of rejection are:

- Fever above 100.4 degrees Fahrenheit
- Swelling or pain over the new kidney
- Flu-like symptoms
- Elevated blood sugar levels
- Fatigue/weakness

It is also important to remember that your child may be experiencing rejection without any obvious signs or symptoms. **That is why it is so important to have your child's blood tested on a regular basis.**

The bloodwork your child gets each week will give us information about the level of medication in the bloodstream and the activity of the immune system, which helps to maintain appropriate levels of anti-rejection medication. Your child may have frequent medication changes during the first few months after surgery. During this time, your child is recovering from transplant surgery, and his or her body is getting used to the new kidney and new medications. Giving your child the proper doses of medication at the prescribed times is the best defense against rejection. Even so, your child may still have rejection episodes. However, not taking medications as prescribed will very likely cause a rejection episode and possibly damage the kidney.

If we have concerns that your child's body is rejecting the new kidney, we will order a kidney biopsy. This can be done on an outpatient basis. If the biopsy confirms rejection, your child may need to have IV medication to reverse the rejection. The severity of the rejection will determine whether your child will be admitted to the hospital. See the "Treatment for Infection and Rejection" chapter for more information.

Infection

The medications your child takes to prevent rejection suppress the immune system, so they will place him or her at greater risk for infection. Infections may occur in the lungs, bladder or the incision site. Your child will be on medication for the first year to help decrease the risk of getting an infection. Be sure to tell your family and friends that people who are ill should not come to visit. As a reminder, there are signs and symptoms of infection that you should watch for and report to your child's transplant team:

- Fever above 100.4 degrees Fahrenheit
- Cold or flu-like symptoms
- Sore throat

- Skin rash or sores
- Sores in or around the mouth
- A cough that lasts longer than three days
- Shortness of breath with the cough or mucus that is green or yellow
- Pain or burning during urination
- Blood or blood clots in the urine or urine that becomes cloudy or foul smelling
- An incision or cut that becomes red, swollen or drains fluids

Although these signs and symptoms are associated with infection, they are also associated with common chronic illness. That is why it is important to notify your transplant team if they occur.

There are also “opportunistic infections” that can occur. These are viral or bacterial infections that are very common, and people are routinely exposed to them. These infections can cause problems once your child’s immune system is compromised by the anti-rejection medication. Your child will be on medication to protect him or her from several of these infections. However, at times this protection is not sufficient to keep your child from getting the actual infection.

Your child will be tested on a regular basis for some of these infections and may need to have treatment.

:: **Treatment for Rejection and Infection**

Your child's transplant coordinator will review his or her bloodwork when it is sent to our office. If there are any abnormalities, the coordinator will go over the results with one of our physicians, and you may receive a call requesting that your child come to the hospital the next day for a kidney biopsy. While bloodwork helps us monitor the kidney function, a biopsy is the most definitive way to determine exactly what is happening.

Your child will not be allowed to eat or drink anything after midnight the morning of the biopsy. We will ask you to take your child to the Outpatient Lab, Suite 520, in the University Physician Center two hours before the biopsy for lab work. You may give morning medications after your child has had his or her blood drawn, so please remember to bring all medications with you. You will then go to the Admissions Office to check in and be taken to a room.

Your child will receive sedation before the biopsy and a local anesthetic in the area over the kidney. An ultrasound exam during the biopsy identifies the precise location of the transplanted kidney and guides the biopsy needle used to obtain a tiny piece of tissue from the transplanted kidney. This tissue is sent to the pathology lab to be analyzed for signs of rejection. Your child will stay at the hospital until we have results from our pathologist. **Please plan to be at the hospital for a full day.**

It is important that a rejection episode is treated as soon as possible to minimize damage to the transplanted kidney. This may require a hospital admission because many of the treatments involve medication that is administered by IV therapy. While these complications can occur at any time, the first three months after transplant are the highest risk for recurrent biopsies and admissions. Depending on the type of rejection that is diagnosed, your child may need to have multiple treatments similar to dialysis, called plasmapheresis. **Please understand that, through these follow-up measures, our goal is to keep your child and the transplanted kidney as healthy as possible.**

Other Complications

Delayed graft function

Occasionally, a kidney transplant will not function immediately, and patients may require some dialysis after the transplant until the “sleepy” kidney wakes up. This is usually temporary, but is rare in pediatric kidney transplants.

High blood pressure

High blood pressure is also a common side effect of some of the medications your child will take. If this is a problem, we will prescribe medications to control blood pressure.

Cancer

Although it is rare in children, long-term treatment with anti-rejection medication increases the risk of cancer. Your child will need cancer screenings as an adult.

RESOURCES

:: When To Call the Transplant Team

The Transplant Program at Hershey Medical Center is committed to providing you with the care your child needs. The entire team seeks to provide you and your child with the support necessary to get through the transplant process successfully.

Your child's transplant surgeons and coordinators are available by calling the Transplant Office at 800-525-5395 or 717-531-6092, Monday through Friday, from 8 a.m. to 5 p.m. No question or concern is unimportant, so please call whenever you have a question, concern or symptom. If your child is having a severe emergency, such as chest pain or difficulty breathing, call 911 or take your child to the local emergency department. Please call with routine questions on a regular business day during office hours, and ask to speak with the coordinator assigned to your child's care.

There is a transplant coordinator on call 24 hours a day, seven days a week, should you have an urgent problem. You can contact the coordinator on call at 717-531-8521.

When your child is waiting for a transplant, you should continue to contact your child's primary care physician or nephrologist with health care questions. Please notify our office if your child is hospitalized, placed on an antibiotic for infection or sick.

:: **Writing to Your Child's Donor Family**

If your child has received a deceased donor kidney, you and your child will have the opportunity to write a letter to the family of the donor. Donor families often express their gratitude in hearing from the recipient of their loved one's kidney. While writing a letter is optional, we encourage all transplant recipients to do so. We certainly understand that everyone recovers at a different rate and may not feel up to writing a letter immediately. You and your child can write a letter to your donor family at any time after transplantation.

If you decide to write to your donor family, please don't include your name or any other identifying information. The letter must remain anonymous in an effort to protect the privacy of both you and the donor family. Once you complete your letter, give it to your transplant coordinator. We will check to make sure it meets the guidelines, then will forward it to the local procurement agency, the Gift of Life Donor Program, which will then forward it to the donor family. If the family chooses to respond to your letter, they will follow the same process, submitting a letter to the Gift of Life Donor Program, which will then forward the letter to you after screening it.

Writing Tips

When writing about your child:

- Include your child's first name only (and the first names of the family, if you choose to include them).
- Acknowledge the donor family's loss and thank them for their extraordinary gift.
- Describe your family, including your child's siblings, parents and grandparents. Describe the type of transplant your child received because one donor may have benefited many people.
- Use simple language. Avoid complex medical terms and too much detail about your child's medical history.

- Note how long your child waited for a transplant. What was the wait like for your child and your family?
- Explain how the transplant has improved your child's health and changed your child's life. Did your child celebrate another birthday?
- Share your child's hobbies or interests.
- Consider omitting any religious comments, since the religion of the donor family is unknown.

When closing your card or letter, please sign your first name only. Do not reveal your address, city, phone number, physician's name or the name of your hospital.

You may or may not hear from the donor family. Some have said that writing about their loved one and their decision to donate helps in their grieving process. Other donor families, even though they are comfortable with their decision to donate, may prefer privacy and choose not to write back.

We thank you for your thoughtfulness. We know the donor families appreciate hearing from recipients. Remember, the donor family may still be coping with the loss of their loved one, and individuals manage grief in different ways. While you may be celebrating the anniversary of your child's transplant, someone else is remembering a loss. Help the family understand the importance of the decision to donate. Let them know their loved ones will never be forgotten.

:: **Additional Resources**

Online Resources

Hershey Medical Center Transplant Program

pennstatehealth.org/services-treatments/transplant-surgery

Phone number: 1-800-525-5395 or 717-531-6092.

Gift of Life Donor Program

donors1.org

Organization responsible for the distribution of organs in the regions of eastern Pennsylvania, southern New Jersey and the state of Delaware.

Phone number: 1-800-DONORS-1. (1-800-366-6771)

United Network for Organ Sharing

unos.org

National organization responsible for overseeing the distribution of organs in the United States.

Patient information: 1-888-894-6361.

National Kidney Foundation

kidney.org

Phone: 855-NFK-CARES

(855-653-2273)

National Living Donor Assistance Center

livingdonorassistance.org

For information on financial assistance for living organ donors

Phone: 888-870-5002

American Kidney Fund

kidneyfund.org

Nonprofit with programs that support people with kidney disease, from prevention through post-transplant living.

Phone number: 1-800-638-8299

Where to stay

A hotel that consistently offers some of the best rates:

Simmon's Motel

355 W. Chocolate Ave.

717-533-9177

Lodging with special accommodations for children:

Ronald McDonald House, Charities of Central Pennsylvania

745 W. Governor Road

Hershey, PA 17033

717-533-4001

888-829-3545

If financial concerns make it difficult to find accommodations at an affordable rate, please contact your child's social worker for assistance.

Other hotels in the area

Guests can find hotels and other lodging establishments within a short driving distance. The hotels listed at pennstatehealth.org/locations/milton-s-hershey-medical-center/visit-patient/dining-lodging/places-stay are located near the Medical Center. Families should mention that they have a family member who is a patient at the Medical Center to receive possible discounted rates. Some facilities may offer transportation to and from the Medical Center.

Please note that this guide was created for our guests and is not an endorsement of the accommodations listed. This list is subject to change and may not include all lodging options.

:: **Glossary of Important Terms**

Acute tubular necrosis (ATN) – Reversible kidney damage resulting in delayed kidney function. ATN generally resolves on its own in a few weeks.

Antibody – A protein that is produced by the body’s immune system when it detects a foreign substance, such as a transplanted kidney.

Antigen – A substance, such as a transplanted kidney, that can trigger an immune response; an immune response may be the production of antibodies.

Biopsy – Using a needle to take a small tissue sample of the transplanted kidney so it can be examined under a microscope to look for signs of rejection.

Crossmatch – A test between the donor’s and the recipient’s blood to determine if any reaction occurs. A reaction indicates that the recipient’s body would attack the donor’s kidney immediately if it were transplanted and means they are incompatible.

Deceased donor – An individual who has died and donated his or her organs for transplant.

Graft – A transplanted organ, such as a kidney.

Immune system – The body’s natural defense to fight infections, such as bacteria, viruses and other foreign substances.

Immunosuppression – Using one or more medications after transplant to turn down the body’s immune response to foreign bodies to prevent rejection of the new kidney.

Living donor – Someone who donates an organ (such as a kidney) to a person who could be a relative, friend or even someone they do not know.

Noncompliance – Failure by a patient to follow instructions provided by his or her transplant team or center.

Organ Procurement Organization (OPO) – A local organization responsible for distributing organs to transplant centers in their region. Gift of Life is Hershey Medical Center's OPO.

Panel Reactive Antibody (PRA) – A measure of antihuman antibodies in the blood. This score can range from 0 to 99%, which is the likelihood that a recipient's blood will have an antibody against a particular donor. For example, a PRA of 30% means the recipient will have antibodies to approximately 30% of the population. PRA helps to predict the likelihood of a recipient's compatibility with a potential donor. Patients with high PRA levels may be difficult to match. PRA will increase because of previous transplants, blood transfusions, pregnancies or serious infections.

Rejection – Attempt by the immune system to attack and destroy a transplanted kidney. If not treated, it will result in the loss of the transplanted kidney.

Tissue typing – A test that evaluates the closeness of a donor's tissue with that of a recipient.



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