AFTER TRANSPLANT

The Kidney Transplant

Now that your child has received a new kidney, a new journey has begun, starting with the initial recovery phase after surgery. The newly transplanted kidney is placed into the left or right lower abdomen. The original kidneys are most often not removed, unless it is determined otherwise.

The incision for a kidney transplant is approximately four to 12 inches long and is located on the lower abdomen on the right or left side. The operation usually lasts two to four hours. After the transplanted kidney is connected to your child's blood supply, the transplanted kidney usually begins to make urine. The transplanted ureter is attached to the bladder. As the new kidney begins to work filtering waste products from the body, your child will begin to feel better.

Most of the time, the kidney begins to work right after the transplant, but there are times when the kidney takes a bit longer to start working. Rarely, there are some patients for whom the kidney does not work at all and they may need to return to dialysis to wait for another kidney.

Tubes and Lines

Your child will have various tubes and lines throughout the procedure, most of which come out fairly quickly when it is safe to remove. Some include intubation (breathing) tubes, peripheral and/or central IV lines, foley catheter (urine drain tube) and pre-existing peritoneal dialysis (PD) or hemodialysis (HD) catheters.

If your child has a peritoneal dialysis (PD) catheter in place, this will be removed when the transplant team feels appropriate, depending on how the new kidney is functioning, as well as the type of immunosuppression plan he/she is on.

Ureteral Stents

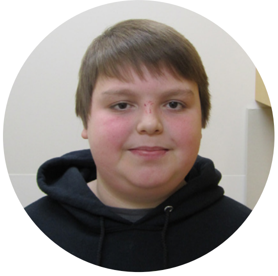
Most kidney transplant patients will have a ureteral stent placed during the operation. The stent placed in the ureter during surgery is usually removed four to six weeks after the transplant operation date. The procedure is done by a urologist. This may be accompanied by your child's dialysis catheter removal if appropriate. If your child is not on steroids (prednisone) as part of their immunosuppression, a biopsy of the transplanted kidney also occurs at this time and you can anticipate an overnight stay in the hospital.

What is a ureteral stent? A ureteral stent is a small, soft tube about six inches long and about as big around as a coffee swizzle stick. It is placed in the ureter, which is the muscular tube that drains urine from the kidney to the bladder. Each end of the stent is shaped like a J or a pigtail with one end of the tube sitting inside the kidney and the other end inside the bladder.

What does a stent do? The purpose of a stent is to help the body heal the connection between the transplanted kidney and the bladder. If this connection doesn't heal properly, urine may leak from the connection. If the connection heals too tightly, the urine cannot pass from the transplanted kidney into the bladder.

Does the stent guarantee the ureter will heal properly? No. However, it does decrease the likelihood of a problem.

Following Surgery – Pediatric Intensive Care Unit (PICU)



After surgery, your child will be taken directly to the Pediatric Intensive Care Unit in C.S. Mott Children's Hospital. The nurses in the PICU will need several hours to get your child settled before you see him/her for the first time.

Parents, legal guardians, spouses/significant others, and/or designated care-giving adults are welcomed in Mott 24/7. Other adults and all children, including siblings under 18, may visit at your discretion depending on the condition of your child, between 9 a.m. and 9 p.m. The number of family members and visitors at any given time is dependent on your child's medical needs and available space. All visiting children must be under constant adult supervision; parents are responsible for the behavior of visiting children at all times.

Visitation for patients in the PICU is somewhat more restrictive than the general care floor. Visitation is:

- Coordinated through the PICU clerk and your child's nurse.
- There is no visiting during patient rounds and shift change report.
- Limited to two visitors at a time.
- Not recommended for visitors who are ill. Sick individuals should not have direct contact with any patient.

If your child is in need of a procedure while in the PICU, you may be asked to leave and return after the procedure has been completed. The PICU staff's goal is to get you back with your child as soon as possible, but they need to care for your child first.

As your child improves, IV lines and tubes will be removed and he/she will be encouraged to become more active. Patient activity and mobility is important to prevent pneumonia, reduce the potential for blood clots, and to increase strength and conditioning. It will be important to encourage your child to take deep breaths and cough up the secretions that might be present. Blowing bubbles or using an incentive spirometer every hour while he/she is awake are two ways to take deep breaths. When coughing, use either a stuffed animal or pillow to "splint" the incision area and reduce the discomfort. Your child's nurse and care team will help you and your child practice these breathing activities.

For most children after their transplant, they will only need to stay in the PICU for one to two days, although some children require a longer stay because of monitoring needs. When your child is ready to leave the PICU, he/she will go to the general care unit that specializes in kidney transplants until he/she is ready to go home.

Pain Control

All parents are concerned about how much pain or discomfort their child will be in after the transplant or any procedure. Children are very resilient and can tolerate pain and discomfort better than adults. During the transplant, the pain service will be involved in recommending pain control for your child. Initially, the pain medicine will be given through his/her IV and then orally once he/she is on the general care unit. The pain medicine will be adjusted according to the amount of pain and discomfort noted. By the time they are discharged to go home, most children only need Tylenol to manage their discomfort.

Incision/Wound Care

The incision from the operation usually takes three to four weeks to heal. Clean your child's incision daily by sponge bathing him/her. By the time your child is ready to go home, it is okay to get in the shower with the incision unless told otherwise by your team. Most incisions are closed superficially by special glue or steri-strips. Do not pick at these, as they will peel off on their own over one to two weeks.

If there are any signs of new redness, swellings or drainage, notify the nurse coordinator. Your child **cannot** take a bath (in a bathtub) or use spas, hot tubs, or swim in a lake or pond until the incision is completely healed. Your child can swim in a chlorinated pool after the incision is completely healed. An exception to this is if your child still has a central line catheter in place.

Going Home

Preparing for discharge after a kidney transplant begins the first day after surgery. Slowly you will begin to learn about your child's medications and how to care for him/her after you leave the hospital. The transplant coordinator will have you start to review this education book when deemed appropriate, often before leaving the PICU.

While on the general care unit, some goals for your child will include achieving adequate:

- Immunosuppression (trough) blood levels
- Fluid balances (drinking fluids and making enough urine)
- Nutritional goals
- Pain control
- Activity level

In addition, vital signs and laboratory values must be acceptable. There may be reasons that your child may require a longer stay in the hospital if these goals are not met. Before being discharged, the transplant coordinator will meet with you and your family members to discuss the immediate and long-term care needs of having a transplant child at home.

Your child will not be sent home until he/she is physically able to leave the hospital and you have been taught all of the necessary care needs for your child.

Discharge Planning

Discharge planning is a team approach. You, as the parent, are an important part of this team. Before discharging your child from the hospital, there is much planning and teaching that needs to be completed. As a member of the team, it is your responsibility to actively participate in discharge planning so that you can learn how to maintain a healthy lifestyle for your child and care for the transplanted kidney. We are here to support you and answer any questions you have. We want you to feel confident and comfortable managing your child's health care needs when you leave the hospital.

Discharge Education for the Transplant Patient and Family Members

The transplant nurse coordinator will coordinate the following discharge information:

- Frequency of routine clinic visits and lab studies
- Review instructions for transplant medicines, including how to order refills
- Provide a personalized medicine schedule for home
- Teach how to monitor blood pressure and order equipment, as indicated
- Central line catheter care and how to order supplies for home, if necessary
- Arrange Home Care nursing, at parents' request
- Review short- and long-term complications after transplant
- Review basic health practices
- Transplant dietitian to review diet, formula and supplement as indicated

Routine Clinic Visits

Just like before your child's kidney transplant, on-going clinic visits are extremely important. These clinic visits allow us to ensure that the kidney transplant is functioning well. During these visits, we look for any complications that may have developed. Your child's lab studies give us information about any problems that may occur. We will review your child's medication and adjust doses, if necessary. You will meet with the transplant dietitian who may recommend nutritional changes after transplant. These clinic visits also allow you and your child to meet with our transplant social worker to help with any psychosocial issues. The transplant psychologist will also be available to assess patient emotional and behavioral functioning and provide brief interventions and/or referrals when indicated.

TIME POST-TRANSPLANT	CLINIC VISITS	LAB FREQUENCY
Months 1-3	**Weekly**	**1-2 times weekly**
Months 4-6	**Every two weeks**	**Every two weeks**
Months 7-15	**Monthly**	**Monthly**
Months 16-36	**Every two months**	**Monthly**
>36 Months	**Every three months**	**Monthly**

The schedule above is for an uncomplicated post-transplant course. There are many reasons that patients may require more frequent laboratory monitoring or clinic appointments. This decision is made on an individual patient basis and is at the discretion of the pediatric kidney transplant team.

Clinic visits will be weekly for the first three months. As your child recovers from the transplant, the clinic visits will become less frequent but start out with weekly appointments for 12 weeks and then move to every other week for another 12 weeks. See chart for outline of visit schedule.

All clinic visits will be in the Pediatric Kidney Transplant Clinic. Before each clinic visit, lab studies should be obtained. Once the lab studies have been obtained, check into the clinic area. It is important that you arrive to your child's clinic appointment **on time**. If you are having difficulties in making the appointment on time (such as being stuck in traffic), contact the Transplant Office to notify the team of your difficulties.

You should bring activities and snacks for your child during the visit and wait time.

Routine Calls

It is expected that you will have to call the pediatric transplant office. If you have some concerns or issues to discuss with the nurse coordinator, please don't wait until the end of the day to call.

Main reasons for possibly contacting the nurse coordinator during routine business hours:

- Any changes in your child's medical condition
- Persistent diarrhea
- Persistent vomiting. Always call if your child is unable to keep immunosuppressive medicines down.
- Problems with the IV access, if access is still present
- Problems with incision, if newly transplanted
- Concerns regarding medicines/needing refills
- Exposure to chickenpox
- Persistent fever greater than 100.5° Fahrenheit (38° Celsius) under the arm or by mouth
- Bloody, dark/tea-colored, foul-smelling urine or decrease in urine output
- Painful urination
- Jaundiced (yellow-colored) eyes or skin

- Abdominal pain or back pain
- Rash
- Dentist visit or any dental procedure, if questioned about prophylaxis antibiotics
- Your child is hospitalized outside of the University of Michigan Hospital
- Another doctor changes your child's medicine or prescribes a new medicine
- Your phone numbers change
- Your child's medical insurance coverage changes
- You need to go out of town
- You are concerned about your child's diet and would like to speak to the dietitian
- You are concerned about your child's mood behavior, school performance, insurance issues or need to speak to the social worker

Due to the high volume of telephone calls, you may need to leave a message on the answering machine. Messages are retrieved several times throughout the day. While every effort is made to return all calls on the same day, sometimes this is not possible. Telephone calls are prioritized – with calls from sick patients receiving the highest priority. To ensure the calls are prioritized appropriately, please include the following when leaving a message:

- Clearly state your name and child's name.
- Provide a telephone number(s) where you can be reached between 8:00 a.m. and 4:30 p.m.
- Briefly state the reasons for the call or concerns.
- If your child is sick, give the nature of the sickness.

If you need to reschedule or schedule a clinic appointment, this should be discussed with the transplant nurse before any changes in appointments.

Emergency, Night, and Weekend Calls

Emergency or urgent calls deal with problems that need to be addressed more quickly. If you believe that your child is having an emergency or urgent problem, you should make the transplant team aware of this problem at once.

If you are having a medical emergency, call 9-1-1 for assistance or go directly to the nearest emergency room for assistance. The emergency room physician may contact the Pediatric Nephrology attending physician who is on call and a transfer to the University of Michigan can be made at that time if medically necessary.

For those emergency phone calls during the weekend or evening hours, you may call the Pediatric Nephrology attending physician for assistance. Call the University of Michigan paging operator number at **(734) 936-6267** and ask for the Pediatric Nephrology attending on call.

Main reasons for contacting the transplant team for emergencies:

- Temperature greater than 100.5° Fahrenheit (38° Celsius) under the arm or by mouth
- Systolic or diastolic blood pressure greater than the level your physician told you it should be on two consecutive measurements
- Significant vomiting/diarrhea with signs of dehydration. Signs of dehydration include:
  - not making tears while crying
  - dry or sticky mouth
  - no urine in over eight hours or decreased number of wet diapers
  - dizzy or unsteady while standing or walking
  - less alert than usual
  - refusing to drink fluids despite encouragement or sunken "soft spot" (anterior fontanel) on an infant.
- Active chickenpox lesions
- Unusual irritability with sleepiness, shortness of breath or seizure activity
- Any critical changes in your child's condition
- Problems with central lines

To request a prescription refill, the office will coordinate the request, but will need the following information:

- Your name and child's name
- Your phone number
- Your pharmacy phone number
- The name of the prescription needing to be refilled
- The dose and how frequently the medicine is taken
- The amount of medicine remaining on the current prescription.

Please allow a minimum of three days for prescription refills to be processed.

Prescription Refills

It is **extremely important** not to wait until there are only one or two doses left in the bottle. This is especially important with compounded (liquid) medications. Compounds may take up to several days to make by the pharmacist.

Psychology Support in Pediatric Transplant

We recognize that a number of individual and family-related psychological and social problems may arise during the transplant process. It is important to address the psychosocial needs, as well as the medical needs, of the child and his/her family throughout the transplant process in order to promote the best health outcomes. Our team includes a pediatric psychologist with expertise in working specifically with young transplant patients. Our transplant psychologist works very closely with social work and the entire transplant team. The level of involvement by the transplant psychologist will likely vary across families. Below are some of the areas in which our transplant psychologist provides additional support and intervention for:

- Adjustment and Coping of the Child/Adolescent
  - Depression
  - Anxiety
  - Behavior Difficulties
  - Coping with Stress
  - Body Image
  - Developmental Issues
  - Sleep Disturbances
  - Transition to Adult Transplant Care

- Adjustment and Coping of the Family
  - Family Communication and Decision-Making
  - Sibling Coping
  - Parenting Challenges
  - Trauma Reactions

- Regimen Adherence
  - Medication
  - Pill Swallowing
  - Diet & Exercise
  - Attendance at Clinic
  - Lab Draws

- School Functioning
  - Section 504 Plan/IEP (Individualized Education Plan)
  - Homebound Services
  - School Re-entry
  - Cognitive Functioning
  - Peer Relationships

The psychologist(s) in our clinic are also involved in research, which is designed to help us learn ways to improve the long-term health of pediatric kidney transplant recipients. Research projects focus on quality of life, communication and decision-making, medication adherence, and the transition to adult transplant care.