

## LONG-TERM CARE AND COMPLICATIONS

### Monitoring Your Child's Health

One of the tools that you can use to help take care of your child is the log that your nurse coordinator provided. In it you can record your child's medicine doses, weight, temperature, blood pressure, etc. When your log runs out, feel free to ask your nurse coordinator for another.

You will need to monitor the following:

- Check your child's temperature twice every day, at the same time in the morning and evening. Notify the nurse coordinator if your child's temperature is greater than 100.5° Fahrenheit.
- Because your child's immune system is suppressed, he/she should avoid anyone who is sick with colds, the flu or other contagious illness.
- Check for signs and symptoms of infection. Notify the nurse coordinator if your child is experiencing any of the following:
  - Fever
  - Sores or rashes in mouth or on skin
  - Redness, swelling or draining around the incision site
  - Pain over the transplanted kidney
  - Burning with urination and frequent urination of small amounts
  - Blood in urine or stool
  - Persistent headaches
  - Sore throat
  - Nausea
  - Vomiting
  - Diarrhea
  - Productive cough
  - Earache
  - Any feelings of being "sick" that you cannot explain
- Check for possible side effects related to the medicines your child is taking.
- Check for signs and symptoms of rejection (See page 6)

### *Masks*

Masks should be worn within the first 12 weeks after transplant when in enclosed public spaces. There is often construction being done around Michigan Medicine. Our division has been advised by the hospital's Infection Control Program to begin preventative measures to protect our patients whose immune systems are compromised from infections carried by airborne dust particles. The yellow mask should be worn when the child enters/leaves the hospital or when the child enters any area of the hospital where there is obvious indoor construction. Masks will be provided for you before discharge from the hospital. Your transplant nurse will inform you when wearing a mask is no longer necessary.



## **Special Care and Potential Complications**

### *Injuries*

Cuts, scrapes and abrasions should be treated as you ordinarily would. Clean with soap and water and bandage if necessary. If your child has a severe or a non-healing wound, your local doctor should evaluate the wound and treat as necessary.

### *Ureteral Stent*

For more information on ureteral stents and its removal, please refer to page 1 of the After Transplant section.

### *Infections*

Patients who have had a kidney transplant require anti-rejection medicines, usually for their lifetime, to suppress their immune system. Since your child's immune system is inhibited by these medicines, he/she has an increased risk of getting infections. The risk is highest in the first three to six months after transplant or when higher levels of immunosuppression (anti-rejection medicines) are taken to treat rejection. For the first month after the transplant or after treatment of a rejection episode, avoid large crowds of people. If you want to take your child to a movie or out to the mall for a short shopping trip, go at times of the day when it is less crowded. Avoid people who are obviously sick. If there is an illness in the home, use good hygiene, especially hand washing. Do not share eating utensils, cups/glasses or toothbrushes with others since many viral illnesses are spread through saliva. More often, you will be the one sick and not your child. One thing you can do to help your child's transplanted kidney is to encourage your child to urinate every two hours to keep his/her bladder empty. The best advice is to be careful but realistic. Your child cannot enjoy life fully being overprotected.

### *Chickenpox & Measles*

Before the kidney transplant, your child's chickenpox (varicella) titer was checked. Titers are an indication of whether your child has had the chickenpox disease. You can ask the nurse coordinator for results of the titer on your child.

Chickenpox is contagious for 24 hours before the crusts and scabs form. Even though your child may have had the chickenpox, he/she can get it again when using immunosuppressive medications. However, it is more common for the chickenpox virus (varicella) to be reactivated in the transplant recipient in the form of shingles. Therefore, stay away from anyone who is infected with chickenpox or shingles. Notify the nurse coordinator or doctor immediately if you discover that your child has been exposed to either chickenpox or shingles.

It is considered a medical emergency if your child comes down with the chickenpox. Call your child's transplant medical team immediately. Your child will need to be admitted to the hospital for IV medications.

### *Shingles (Varicella Zoster)*

It is estimated that up to 50 percent of immunosuppressed patients develop shingles. Shingles is not caused by a new virus. It is caused by the reactivation of the chicken pox virus that remains in the body after the disease appears to have gone away. Even though patients recovered from chicken pox many years ago, the virus remains in the body without the patient being aware of it.

Shingles starts out as a pain or tingling sensation, followed by blisters. Shingles always follows a nerve pathway (e.g., down the hip and leg). It is treated with anti-viral medication (Acyclovir) and pain medications. Patients are contagious while they have the blisters. This means they can give the chicken pox virus to someone else who does not have adequate immunity for this virus.

### *Cytomegalovirus (CMV) and Epstein-Barr Virus (EBV)*

There are two viruses that are of concern and can affect the newly transplanted kidney. They are cytomegalovirus (CMV) and Epstein-Barr (EBV).

## **Cytomegalovirus (CMV)**

CMV is a common community-acquired virus and is not a serious illness for most people who are healthy. However, CMV may be of more concern to people who are taking immunosuppressive medicines (anti-rejection medicines).

CMV is a common infection that usually occurs within several months after transplant. Some patients are more at risk for CMV than others. The patients who are at the highest risk for getting CMV are those who:

- Are CMV negative and received a CMV positive kidney
- Receive high levels of immunosuppression
- Received treatment for rejection

Because CMV is such a common infection, transplant centers usually have treatments to prevent this infection, particularly in patients who are considered to be at high risk for this infection. Treatment of choice is using Valcyte for 90 days.

## **Symptoms of CMV**

- Fever
- Low white blood cells count
- Flu-like symptoms
- Vomiting, nausea, abdominal pain and/or bloody stools
- Increased liver function tests

CMV is often diagnosed by a blood test. It most commonly occurs within three to 12 weeks after transplant, but can occur at any time. If recognized early, CMV infection often responds well to medicine.

## **Epstein-Barr Virus (EBV)**

EBV is a virus that causes infectious mononucleosis (“Mono”) in healthy people. Most people have had an EBV infection by the time they become adults. It often presents as a cold. Children who have not had an EBV infection before transplant or received a kidney from a donor who had an EBV infection are monitored particularly closely post-transplant. Patients who develop EBV while on immunosuppression may develop a spectrum of EBV-related symptoms. EBV infection can range from:

- Non-specific viral infection
- Mononucleosis
- Post-transplant lymphoproliferative disorder
- Lymphoma

EBV is diagnosed by a blood test and by clinical examination. If your child develops EBV, he/she may be started on anti-viral medicine (Valcyte), and his/her immunosuppression may be adjusted. If your child develops any of the following, do not hesitate to call the transplant office:

- Fever
- Swollen glands
- Persistent cold symptoms
- Nausea, vomiting, diarrhea
- Weight loss
- Night sweats

When EBV infects children who are taking medicine to prevent organ rejection, the virus can cause certain white blood cells to divide and reproduce very rapidly resulting in a condition which is called post-transplant lymphoproliferative disease. PTLTD is a serious condition but is treatable in many cases. We will be monitoring your child frequently during the first year and yearly after transplant for evidence of the EBV virus. If an elevated EBV level is noticed, additional testing may be required to evaluate for PTLTD (i.e., CT scan and liver ultrasound). Your doctor will discuss further with you and your child if your child is at risk for an EBV infection or PTLTD.

### **Human Papilloma Virus (HPV):**

Transplant recipients are at an increased risk for contracting the virus that causes warts on the hands and feet. Scratching these warts or lesions can spread the virus to other parts of the body. Your pediatrician or dermatologist can successfully treat them. Current belief is that a transplant patient cannot transmit these warts to other healthy individuals but they may be capable of transmitting them to people with a compromised immune system.

HPV is also associated with skin cancer, cervical cancer and genital warts. It is recommended that all transplant patients between the ages of 12 and 18 obtain the HPV immunization. The immunization is given in two or three parts, over a period of six months. The immunization can be obtained either from the local pediatrician or health department. Some insurance companies have poor coverage for this immunization. For those patients with poor or no coverage, the immunization should be obtained at the local health department for a low fee. In addition, adolescent female transplant patients over the age of 18 should be seen yearly by a gynecologist for routine surveillance of the HPV infection.

### *Rejection*

“Rejection” is the body’s natural response to fight off foreign objects (e.g., your child’s new kidney).

Despite the medicines that your child takes to suppress his/her immune system, it is not uncommon for kidney transplant recipients to experience a rejection episode. It most frequently occurs within the first few months after your child’s transplant, but it can occur at any time after transplant. Many times your child may feel well but his/her blood tests may indicate a potential rejection episode. Therefore, be mentally prepared for the possibility of being admitted or needing a kidney biopsy any time after a blood test or clinic appointment.

It is important not to panic if your child has been diagnosed with a rejection episode. We have medicine to treat rejection, so it does not mean that your child will lose his/her transplanted kidney.

If the nurse coordinator or your child’s provider notes abnormal test results, additional blood tests and/or procedures may need to be done to evaluate for the possible cause. The most common tests and procedures include a kidney ultrasound and kidney biopsy. Many times the tests and procedures will be scheduled within days of the documented abnormal tests. The earlier the cause of the abnormal test result is found, the easier it is to possibly reverse the probable cause. For this reason our team performs kidney biopsies based on protocols as well as indications (i.e. an increase in creatinine).

Protocol biopsies are done six to eight weeks post-transplant and then possibly at 10-12 months post-transplant. Kidney biopsies can also be done at any time for medical indications.

The following are signs and symptoms that may indicate a rejection episode (although there are many other possible reasons for them):

- Fever
- Muscle aches (flu-like symptoms)
- Decrease in urine output
- Increased tiredness
- Increase in weight
- Swelling of feet or legs
- Pain or tenderness over the kidney
- Abdominal swelling
- Blood in urine
- Elevated blood sugars



If your child is experiencing any of these symptoms, you should contact the nurse coordinator.

### *Treatment for Rejection*

Rejection is usually treated by increasing the doses of the immunosuppression (anti-rejection medicines) or by adding or combining different anti-rejection medicines. Treatment for rejection depends on the type of rejection found. It may involve IV and steroids taken by mouth, and/or it may include IV anti-rejection medication such as Thymoglobulin. Both are managed inpatient and would require coming to the hospital. A rejection episode may also require outpatient infusions.

### *Chronic Rejection*

Chronic rejection is a slow process and can involve the body's own cells attacking the kidney or antibodies made against the kidney. It is usually seen on a biopsy as fibrosis (scarring) and damage to the small blood vessels within the kidney. It may result in a need for re-transplantation.

### *Cancer*

The risk of cancer is three to five times greater in a transplant patient than in the general population. This is primarily due to the use of anti-rejection medicines. The most common forms of cancers seen are:

- Lymphomas which make up 57 percent of all post-transplant tumors (i.e. PTLD)
- Skin and lip
- Colon cancer
- Breast cancer
- Uterine cancer

As your child progresses in age, the importance of routine cancer screening is recommended. Examples include:

- Self examination (breast and testicular examinations)
- Mammogram
- Gynecology
- Prostate
- Colonoscopy

## Immunizations

Your child should **never** receive immunizations that contain a live virus after transplant. If a live virus immunization is given, there is a potential risk that your child will contract that infection. This has potential for causing kidney dysfunction. The following immunizations contain a live virus and should not be taken:

- Small pox vaccine
- Oral polio vaccine
- MMR (measles, mumps and rubella)
- Varicella (chickenpox)
- Nasal Influenza (Flumist)

### You Should Know

Your child should NEVER receive immunizations that contain a live virus.

The following are acceptable immunizations for your child to receive, but you should contact your nurse coordinator or doctor first (typically no immunizations are given until your child is one year post-transplant, except the flu vaccine):

- Tetanus
- Typhoid
- Diphtheria



- Pertussis (dT or DPT) (whooping cough)
- Polio (killed virus)
- Haemophilus Influenza Type B (HIB)
- Annual Influenza (injected form only)
- Pneumovax
- Hepatitis A and B series
- Human Papilloma Virus (HPV)

It is necessary that your pediatrician have a copy of the immunizations that your child can receive. If a live virus immunization is given to your child after transplant, your child may get the infection that the immunization is trying to prevent.

Siblings and household contacts **should not** receive oral polio (Sabin) vaccine. Members of the household **can** get the MMR immunization but varicella vaccine may have to be withheld or special precautions put in place. This is also the case for the Rotavirus vaccine that may possibly be given to younger siblings. **Always** contact our office before giving siblings these vaccinations.

### *Flu Shots and Pneumonia Shots*

Transplant patients are encouraged to receive a flu shot every year and pneumonia shot every five years. Since high doses of anti-rejection medicines may lessen the effects of these vaccines, transplant patients are recommended to wait approximately three months after transplant before getting these vaccines.

### *Dental Care*

Because many infections start in the mouth, dental care is very important. Also, some medications such as cyclosporine and some blood pressure medications can cause gum hyperplasia (overgrowth of the gums). Here are some points that need to be done to promote good dental hygiene:

- Brush the teeth often – at least twice a day.
- Notify your nurse coordinator before making your child's first dental appointment after the transplant, which should not be scheduled for six months after transplant. Your child may need to take antibiotics before dental procedure (e.g., cleanings, fillings and gum surgeries). A prescription can be called into your local pharmacy.

- Your child should see the dentist every six months.
- Inform your dentist of your child's transplant and the special medicines that your child takes.

### *Eye Examination*

It is recommended that your child is seen by an ophthalmologist (eye doctor) on a yearly basis after transplant. This is to monitor for any chronic eye changes that can be noted as a result of the anti-rejection medicines, especially prednisone.

### *Sunscreen*

Because your child is taking drugs that suppress the immune system, your child has an increased risk of developing skin cancer. We suggest that your child take precautions, including using sunscreen (SPF 45 or greater), hats and long sleeves (if tolerated). Your child should avoid tanning salons and repeated long unprotected exposure to the sun.

## **Activity**

We encourage your child to resume normal activities as tolerated. However, use moderation in the early post-transplant period. Your child will feel better when participating in normal childhood activities. Exercise will help combat weight gain as well as decrease incidence of bone loss due to prednisone.



Ask your nurse coordinator/doctor/nurse practitioner about any activities in which your child would like to participate. In general, though, it may be best to avoid the following activities:

- Motorcycles, dirt bikes
- ATVs
- Contact sports such as football, hockey, karate, wrestling and uneven parallel bars
- Anything that would cause direct trauma to your child's transplanted kidney

Many activities do have an inherent risk to children with a kidney transplant and the ultimate decision is made between the patient, family and provider/transplant team. (Your child may be fitted for a kidney shield to provide extra protection). It is important that your child not lift anything heavier than 10 pounds (e.g., a six pack of pop) for approximately six weeks after surgery but this time frame may vary from child to child. Until that time, your child's abdominal muscles are not completely healed.

If your child is of driving age, he/she may resume driving approximately six weeks after surgery. Check with your nurse coordinator or transplant team before driving. Until that time, your child's reflexes may not be quick enough to drive safely. Your child should always wear a seat belt or be in a car seat.

## School

Your child should be able to return to school or work within six to eight weeks after transplant. Check with the nurse coordinator and school before his/her return to school. You should notify your child's school to make arrangements for home schooling once your child has been discharged from the hospital. Many times there are forms that need to be completed by the nurse coordinator/transplant team that you obtain from your child's school.

## Pets

Pets can be an important part of family life. Research has shown that pets help relieve stress and have positive physical and psychosocial benefits as well as possibly improving our quality of life.

Although animals do carry a number of diseases that can be transmitted to humans, few are life threatening. Some guidelines should be followed:

- Wash your hands after handling your pet, especially if you are going to eat, drink or handle any food.
- Your pet should have regular health visits to the vet and receive the required immunizations.
- Groom your pet on a regular basis. The nails of both the dog and cat should be trimmed on a regular basis to avoid scratches. If you do get a scratch, clean the wound with soap and water and apply antibiotic cream. If the scratch should become infected, seek medical treatment.

- All transplant recipients should avoid your pet's body fluids (urine, stool or vomit). If possible, have someone else clean up the accident. If necessary, use some gloves and clean the area with some disinfectant. Wash your hands with some antibacterial soap or hand sanitizer after the cleaning has been done.
- It is not recommended that a transplant recipient clean the litter box if at all possible. The litter and liner should be replaced frequently. The litter box should be cleaned at least every month with disinfectant soap or hot boiling water.
- Seek urgent medical treatment if your child should be bitten by any animal.
- Avoid having the pet lick your child on the face.
- Your child should avoid any stray or sick animal.
- Transplant recipients should avoid having an exotic animal as a pet (such as reptiles).

## Traveling

As soon as your child has recovered from the kidney transplant and moved to a more normal routine, you might consider traveling or going on a vacation. Please check with your nurse coordinator before leaving on a vacation to see if it is safe to do so. Most families wait until it has been six to 12 months after transplant.



General traveling tips:

- Notify your nurse coordinator of your destination or vacation site. If possible, give her a phone number where you could be reached if necessary.
- Carry a current list of all transplant medicines.
- Take at least one week of extra medicines with you in case of an unplanned extension of your trip.
- Always carry the medicines with you in a carry-on bag if flying.
- Take a list of important Transplant Center emergency phone numbers.
- Bring some bottled water and food with you to take medicine.
- If you plan on traveling outside of the U.S., contact your nurse coordinator for instructions regarding possible immunizations that might be necessary for your travel.

## Sexual Behavior and Reproduction

Males who have a kidney transplant are usually fertile and can father a child. For women, the possibility of conceiving is better than 50 percent.

Adolescent females, who have kidney failure before transplant, usually do not have a normal menstrual cycle. This does not mean that they cannot become pregnant during this time. After transplant and the kidney has returned to a normal function, menstrual cycles should return to normal. We recommend that women over the age of 16 see a gynecologist on an annual basis. Because of the immunosuppressant medicines, there is an increased risk of cancer.

To avoid becoming pregnant, we usually recommend a barrier method (sponge, jelly and diaphragm) plus a condom as a birth control. Condoms should also be used to protect both the man and the woman against any sexually transmitted infection. The possible side effects of oral contraceptives (the Pill) include increasing blood pressure and increasing the chance of blood clots. Therefore, they are not the first suggestion as a birth control method. Females will be referred to a gynecologist who can suggest suitable methods of birth control according to individual needs.

Each female is different when it comes to the effects of pregnancy and the health of the baby. A woman with a kidney transplant has a much higher rate of complications in pregnancy. However, her decision about pregnancy depends on how strongly she and her partner feel about having a family. Many women with stable transplants can have safe pregnancies. Consult with your transplant team before making this decision. In addition, the FDA now requires education and documentation of such, regarding females of reproductive age who are taking Cellcept (Mycophenolate REMS). The REMS documentation addresses the risks of birth defects and miscarriage if pregnancy occurs while taking Cellcept®. The FDA requires signed documentation for all females eight years or older.

### *Sexually Transmitted Infections (STIs)*

Everyone that is sexually active should be aware of and know about sexually transmitted infections (STIs). STIs can be passed from person to person in the following ways: oral, vaginal or anal (rectal) sexual activity. STIs can even be passed through kissing and intimate touching, or by sharing needles, body piercing or tattoos. The most common forms of STIs are chlamydia, herpes, HPV (Human Papillomavirus), syphilis, hepatitis B and HIV. People with STIs often have no symptoms and can pass the infection to another person without being aware of the STI. Most STIs can be treated and cured, but there are some that treatment can only help the symptoms. If the STI is left untreated, it could potentially cause serious health problems.

### **How to prevent STIs:**

The best way to prevent STIs is to abstain from oral, vaginal or rectal sex and **never** share needles. If you choose to participate in any form of sex, **always** use a latex condom.

**Prevention is the best practice!**

If your child thinks he/she may have an STI, seek medical care at once. Early treatment can prevent long-term complications. If your child does have an STI, be sure to tell his/her partner, so treatment can be given to that individual also.

### **Tattoos and Piercings**

Tattoos and body piercing are popular with young adults. The transplant team **only** recommends ear piercing.

There is some information that you should know before getting any tattoos or body piercings.

- There is a potential risk for serious infections such as hepatitis B, C and HIV (the virus that causes AIDS).
- Only use a professional tattooist or piercer. **Do not** try to do either a tattoo or body piercing yourself or by a friend.
- If a tattooist or piercer is not willing to talk to you regarding the sterilization process, then do not let that person do the tattoo or piercing.
- It is OK for you to ask to see their sterilizing equipment and how they process their equipment.
- Before getting a tattoo or piercing, you should watch the technician open the sterile instruments.
- **No** tattoo inks should be shared or reused between customers.
- Do not get a tattoo or body piercing from a person that has been drinking or using drugs.
- Remember, a tattoo is a big decision and will be with you forever!

**The Transplant Center does not recommend either tattoos or body piercing.**

## Drugs, Alcohol or Tobacco Products

It is the recommendation of the transplant team that **all** patients should refrain from using all forms of alcohol, street drugs, marijuana, tobacco products or other potential harmful drugs (such as huffing inhalants). The use of these products can lead to poor health and fatal damage to your body. As the pediatric transplant patient approaches legal drinking age, it is best that they consult with the transplant team before consuming alcoholic beverages.

## Medic-Alert Identification

It is recommended that your child wear a Medic-Alert bracelet or necklace. Your nurse coordinator will provide you with a form. The Medic-Alert Identification is ordered through the Kidney Foundation for a small fee. If your child would like one that is “fancier,” you can order this for him/her at a higher cost. The following information is needed:

- Child’s Name
- University of Michigan
- Kidney Transplant
- Name of Transplant Nephrologist
- Phone number **(734) 615-2040**

### You Should Know

Be sure to inform your child’s personal physician of **all** the medicines that your child is taking, since some drugs **cannot** be taken with immunosuppressive medicines.

### *Your Local Doctor*

It is a good idea to have a pediatrician, internist, general practitioner or family doctor see your child for routine medical issues other than your kidney transplant. Always make sure you inform us if you change your child’s personal doctor, since we will be keeping in touch with him/her every time you come to the Pediatric Kidney Transplant Clinic or are in the hospital.

Your nurse coordinator can provide you and your doctor a list of all medicines that interact with the immunosuppressive medicines.

