

## Patient Education Guide

All kidney and/or pancreas transplant recipients must bring their Patient Education Guide to the hospital with them when they come to be admitted. The Patient Education Guide contains information the patient must know to care for the newly transplanted organ and to care for themselves. The inpatient transplant education nurse will use this guide as the basis for teaching the patient how to care for the new organ when they go home.

### You Should Know

Bring this Patient Education Guide with you to the hospital.

## Inpatient Team

Many caregivers will be involved in the transplant patient's stay in the hospital. The transplant surgeon will be responsible for making decisions regarding the patient's care while in the hospital. The patient is also seen by a nephrologist who will make recommendations to the surgeons regarding the patient's plan of care. In addition, the inpatient team includes transplant education nurses, physician assistants, nurse practitioners, bedside nurses, lab technicians, dietitians, social workers, pharmacists and other hospital staff. They may also see a nurse case manager, and a physical therapist and/or an occupational therapist.

At times it may seem confusing or overwhelming to have so many different caregivers coming and going from the inpatient room. Be assured each team member has a specific purpose and they are all working together to provide the best possible care to each patient.

## Following Surgery

After surgery, the transplant recipient will stay in the Post Anesthesia Care Unit (PACU) for approximately four hours. The PACU nurse will monitor the recipient's vital signs, urine output and comfort status until he/she is fully recovered from the anesthesia. Family members usually are permitted to visit on a limited basis while the patient is in PACU. Family members are recommended to wait in the Surgical Family Waiting Room on the first floor of University Hospital. The Surgical Family Waiting Room is where the surgeon will look to update the family following the operation. Updates on the patient's condition during the operation are often available while waiting in the Surgical Family Waiting Room.

After PACU, the transplant recipient will be transferred to the Inpatient Transplant Surgery unit in area C on the 5th floor of University Hospital. The transplant recipient will remain on 5C throughout the hospital stay. Healthy visitors are welcome on 5C between the hours

of 9 a.m. and 9 p.m. One adult family member is welcome to stay at bedside 24 hours a day/ seven days a week to promote communication and to meet the cognitive and emotional needs of the patient. Individuals who feel sick, are experiencing cold symptoms or other contagious illnesses should not visit a transplant recipient.

After the operation the transplant recipient will have several IV lines, usually in the arm. You will also have an indwelling urinary catheter (called a Foley catheter). These lines and tubes will stay in place for an average of two to three days or more after surgery, depending upon the recipient's condition. The kidney transplant recipient is usually allowed to eat on the first day after the operation, starting with a clear liquid diet and progressing to solid food as tolerated. Please refer to the Nutrition section. If the recipient received a pancreas transplant, they may have a nasogastric tube in place for several days, until bowel function returns and the patient is able to begin eating again.

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 incision for a pancreas or a combined kidney/pancreas transplant is located in the mid abdomen and is approximately eight to 12 inches long. The actual size of the incision depends on several factors, including the size of the recipient. Most patients will have their incision closed with surgical glue.

#### *After Surgery: Patient-Focused Pathway*

On 5C, we follow a patient-focused pathway, which will be reviewed with you daily. This will help you and your family be more involved and informed about the progression of your hospital stay and better prepare you for discharge. A copy of the pathway will be provided to you by your nurse on 5C after surgery.

## **Pain Management**

After your operation a pain-controlled analgesic device (referred to as a PCA) is used to help control any post-surgical pain. This device administers pain medication through your IV line. The PCA will be set up to administer a prescribed dosage of medication at pre-set intervals. You will use the control button to administer the medication within the prescribed limitations. The use of a PCA is generally discontinued the day after your surgery. At that time you will begin taking oral medications for pain control on an "as needed" (PRN) basis.

## Complications From Surgery

In general, complications of kidney transplant surgery are similar to those of other major operations on the abdomen. These can include wound infection, bladder infection, pneumonia, and blood clots in the legs. Some complications are unique to the kidney transplant operation, or can happen more frequently.

### *Delayed Graft Function (DGF)*

While not technically a complication, delayed graft function is a fairly common occurrence after kidney transplantation. Most kidney transplants make urine and begin to function immediately or soon after the transplant surgery. However, some transplants may need time to recover and may not function right away. This happens in about 25% of transplants from deceased donors, and 5% of transplants from living donors. Some types of deceased donor transplants, such as expanded criteria donors (ECD) or donation after cardiac death (DCD) transplants, have higher rates of DGF than others.

If your kidney transplant experiences DGF and you were on dialysis before surgery you may need to continue to receive dialysis until the kidney recovers. Your transplant team will make this decision based on your clinical condition, lab testing, and the extent to which the kidney transplant is functioning at the time. If you are ready for discharge from the hospital but the kidney transplant has not recovered, your transplant team will arrange for you to continue dialysis as an outpatient, and the recovery of the kidney can be monitored as an outpatient. Most kidney transplants with DGF recover within a week, but occasionally may need weeks or even months to recover. It is extremely rare for a kidney transplant not to recover completely.

### *Wound infection*

Infection of the surgical incision occurs in approximately 15% of kidney transplants. Most of them will develop during the first week after the surgery. Most are superficial infections that can be treated with antibiotics. Occasionally, a deeper infection may be present that requires the surgical incision to be opened so the infection can drain outside the wound. In this case, the wound may need to be left open and packed with gauze dressing. In these situations, the wound gradually contracts and closes over time, usually requiring several weeks. For certain large wounds, a device called a wound vac can be used to help speed up the healing process.

### *Bleeding/Anemia*

About 10% of kidney transplant recipients require a blood transfusion after the surgery. Sometimes the blood count is low because of the effects of the anti-rejection medications or due to the body's response to surgery. Other times there is bleeding that has occurred that lowers the blood count. If this happens it usually stops on its own and doesn't require surgery. On rare occasions where it does not, or if the blood flow to the kidney is compromised, surgery may be required to remove the blood and stop any bleeding that is still present. This will not usually affect the outcome of the kidney transplant. If you are on blood thinners and these need to be resumed early after the transplant, the risk of bleeding may be higher.

### *Fluid Collections (Lymphocele)*

Sometimes after surgery, collections of fluid called lymph can develop near the kidney transplant. These are called lymphoceles. Most of these collections are benign and do not cause any symptoms or problems. They are often identified by chance during an ultrasound of the kidney that is done for another reason. On occasion, they may cause discomfort, pressure, or leg swelling on the side of the kidney transplant. They can also slow urine from exiting the kidney into the bladder. These can occur within the first few weeks after the transplant surgery. These symptoms occur in <5% of transplants. If they do, then the first step is to have the radiologists remove the fluid using a needle with local anesthesia. If the fluid comes back and continues to cause problems, a small procedure is performed in the operating room which will usually solve the problem.

### *Urine leak*

A urine leak occurs when the connection that is made between the bladder and the ureter of the kidney transplant does not heal properly. Urine accumulates around the kidney and the bladder. This may cause pain, pressure, the urge to urinate, and can affect kidney function. Urine leaks occur in about 3% of transplants, and generally occur within the first three weeks of the transplant procedure. Most are extremely small (pinhole sized), and can be managed by having our interventional radiologists place a stent through the kidney down the ureter and into the bladder. This stent, which is larger and different from the one placed at the time of surgery, helps the leak to heal itself. This may require several weeks to even several months, but does not affect the long-term survival of the kidney transplant. Larger leaks may require surgery to repair.

## Steps to Speed Your Recovery and Prevent Surgical Complications

While you are in the hospital there are several important things that you can do to speed your recovery and to prevent common surgical complications.

**Preventing Blood Clots in Legs:** During and after the operation you will wear self-inflating stockings which promote blood circulation in the legs. The stockings help prevent blood clots (deep vein thrombosis or DVT) from forming in the legs. Even though you may be walking frequently, the stockings still need to be worn while in bed.

**Preventing Pneumonia:** Taking deep and frequent breaths and trying to cough will help prevent pneumonia after surgery. You will also be taught how to use an Incentive Spirometer (IS). This device will be used every hour while awake to keep the lungs clear of congestion.

**Walking:** Walking soon after surgery speeds recovery in many ways. It encourages an early return of your bowel functions, it promotes effective breathing, it mobilizes secretions from the lungs, it improves circulation, it prevents stiff joints and it relieves pressure. The morning after surgery you will be instructed to be out of bed at least three times a day. It is suggested you get out of bed and sit in your chair to eat meals at breakfast, lunch and dinner. Being out of bed more often is encouraged but must be accomplished at least three times a day. You may request pain medication to make walking more comfortable. Please bring to the hospital with you any assistive devices that you use at home, such as a cane, walker or wheelchair. After you are discharged, it is very important to continue to walk with the goal of walking up to one mile each day.



## Your Support System While Hospitalized

Patients will need their support person while they are hospitalized. Patients who are recovering from surgery are not at the top of their game. The support person can be helpful in assisting with the walking sessions, being present at the learning sessions about how you will need to care for yourself following discharge, and learning about your medications. Teamwork is essential, so we encourage the patient and the support person to approach this as a team.

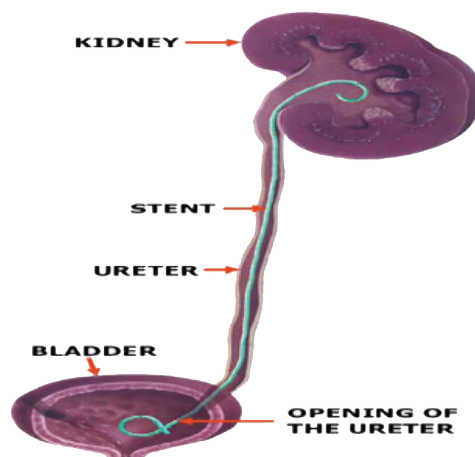
## Your Support System When You Go Home

At your evaluation appointment, the social worker discussed the importance of support when you are recovering from surgery. Now is the time to call upon your support team and make a plan for 24-hour support for one to two weeks after discharge.

## Ureteral Stents

Most kidney transplant recipients will have a ureteral stent placed during the operation.

**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.

**Does the stent ever pass by itself?** Yes, but this is uncommon. If you notice that the stent passes with your urine, please save the stent and show it to the nurse in the clinic.

**Does the stent cause symptoms?** Most patients do not feel the stent. Some patients can have urinary tract infections associated with the stent, or can have bladder irritations from the stent.

## Learning about Your Medications

Transplant patients will begin taking many new medications related to their transplant on the day of, or the day after, their operation. Since your hospital stay may be only a few days, the amount of time you have to learn about your new medications is limited. Including a support person in this process will be helpful since you will need to learn many new things.

The nurses on the inpatient transplant unit will teach you the name, purpose, side effects and administration schedules of all your new transplant medications. Under nursing supervision, you will set up and take your medications according to a “self medication schedule” that will be personalized for you.

Before discharge you and your support person will be expected to read and discuss how you will care for yourself following discharge. You will be given a “quiz” to verify you have correct information about caring for yourself. Your support person is encouraged to participate in completing the quiz.

Before you leave the hospital you will be given prescriptions and a schedule for all the medications you will be taking at home. If you are participating in the UMHS Transplant Specialty Pharmacy Services, your medications will be delivered to you while you are still in the hospital – before discharge. It is important to take all your medications exactly as they are prescribed in order to protect your new kidney and/or pancreas. Sometimes you will be away from home when it is time to take your anti-rejection and other medications. **Therefore, you will have to get into the habit of carrying your medications with you so that your medication schedule will not be interrupted.**

You will need to take some medications for the life of your transplant. Never stop taking your anti-rejection medication because of insurance coverage problems. Skipping doses or decreasing the doses of any medications can endanger the proper functioning of your new kidney and/or pancreas. If you are unable to pay for your medications, please contact the Transplant Center at **(800) 333-9013** and ask to speak with the post-transplant nurse or the social worker for help in developing a plan to continue your prescriptions.

When traveling, things don't always go as planned. Sometimes flights are delayed, cars break down and plans are changed. For this reason we recommend you always take extra medications with you when you travel – even to local destinations. If there is ever a chance you won't be home by bedtime, take extra medications with you. It is important to note that some pharmacies may not be able to fill your prescription for transplant medications.

For a comprehensive review of medications please refer to the Medication section.

## **Transplant Specialty Pharmacy Services**

The University of Michigan has a Transplant Specialty Pharmacy whose only focus is to serve transplant patients, ensuring they have ongoing and timely access to their medications. The specialty pharmacy makes available financial counseling and support services to help transplant patients in navigating through the complexities of insurance coverage and allows patients to obtain answers to questions regarding their medication regimen and medication side effects. A representative from the Transplant Specialty Pharmacy will meet with you while you are in the hospital to review the program and discuss your pharmacy options. If you have questions about the UMHS Transplant Specialty Pharmacy, please call **(866) 946-7695**.

## Planning for Nutrition and Weight Control After Transplant

During your inpatient stay a registered dietitian will visit with you to discuss diet, weight control and exercise following transplant. The dietitian will develop with you an individualized diet plan to use when you go home from the hospital. If you have questions after you go home, you can call the dietitian at **(800) 333-9013** or make an appointment to see her in the renal clinic.

## Length of Stay

The ranges for an anticipated length of stay are:

Kidney, recipient .....	2 to 3 days
Kidney, living donor.....	1 to 2 days
Kidney and pancreas, recipient .....	4 to 7 days
Pancreas, recipient .....	4 to 7 days

## Medic-Alert Bracelet or Necklace

After you leave the hospital you are encouraged to order a Medic Alert bracelet or necklace to identify yourself should you become ill or get into an accident and are not able to speak for yourself. Your nurse will help you in completing the order form. Be sure that the following information appears on it:

- Your full name
- Type of transplant
- Your UMHS nephrologist's name
- University of Michigan Health System
- **(800) 333-9013**
- Any known allergies

Please wear your Medic Alert bracelet or necklace at all times.

## Wearing Masks

Wearing a mask protects you from airborne contaminants.

**In the Hospital:** While you are in the hospital, we recommend that you wear a mask in waiting rooms. If you leave your hospital room for a test and will be in a waiting area, it is our suggestion that you wear a mask. It is recommended that you wear a mask in the hospital, in clinic waiting areas and construction areas for three months after your transplant. You will be given a supply of masks when you go home. Below you will find information about where you can purchase more masks and the approximate cost.



**In clinic waiting rooms:** The transplant clinic will have masks available to you while you are in the waiting room.

**Transplant Ambulatory Care Unit (TACU):** There is no waiting room in the TACU. Masks are not required, but will be available to you upon request.

**Construction areas:** It is also suggested that you wear a mask when around construction sites. With ground excavation, it is possible that particles will be in the air that may cause you to become sick.

Suggested suppliers for face masks include:

- Mitchell Home Medical  
(734) 572-0203  
(800) 420-0202 toll free  
Procedure Ear Loop Face Mask (34 cents per mask, may order individually)
- Masters Medical Supply  
(800) 286-9989  
Procedure Ear Loop Face Mask (50 per box = \$8.95)

## Going Home

Your kidney and/or pancreas transplant has been successful and it is now time for you to leave the University of Michigan Hospital.

- During your stay in the hospital, you and your caregiver have learned how to care for your transplant.
- You are able to administer your own medications. You have been taught to recognize the signs of infection and rejection.
- You are able to care for any tubes that must remain in place when you leave the hospital.
- The dietitian has discussed any necessary dietary restrictions with you.

With 24 hour support from family and friends for the first two weeks you are able to care for yourself and you're ready to go home.

Once you leave the hospital, it is your responsibility to take care of yourself and your new kidney and/or pancreas.

### You Should Know

Patients are not able to drive following surgery until the surgeon gives approval. This is usually a period of three to four weeks. Patients cannot drive while using narcotic medication.

## The Day of Discharge

On the day of discharge you will be focused on “Let’s go home!” While we will do our best to help you accomplish your discharge efficiently, it is important for you to know there are many processes that must be completed before a patient can “go home.” After your doctor tells you that you can go home today, the staff must be sure all your medications are ordered and have arrived, your inpatient lab tests are completed, the lab tests for your first outpatient clinic appointment are prepared, and that your follow-up appointments to the clinic are made. The staff must review discharge instructions with you before your departure. Patients who must travel long distances to get home may want to stay in a local hotel the night of discharge since discharges may occur late in the afternoon or into the evening. For your safety it is important to wear your seat belt when traveling by automobile following surgery.

Patients are not able to drive following surgery until the surgeon gives their approval. This is usually a period of three weeks after transplant and when you are no longer using narcotic pain medication. Patients cannot drive while using narcotic medication. During this period, the patient must have a support team that can help in doing his/her errands and providing transportation to clinic and lab appointments.

### Who to Call (after discharge and before your first clinic visit)

- (800) 333-9013
- After 4 p.m., weekends and holidays: (734) 936-6267 and ask for the STX intern on call.

### You Should Know

During this period, the patient must have a support team that can help in doing his/her errands and providing transportation to clinic and lab appointments.

## Clinic Visits

After you leave the hospital, your progress will be followed closely in the outpatient clinic. You will need to come to the Transplant Clinic within a few days of discharge for your first clinic visit. An individual plan for frequency of clinic appointments will be developed for you. Eventually, you will be in the care of your local nephrologist, who was caring for you before your transplant. At that point you will still need a transplant clinic visit at University Hospital every year.

### *What to Bring to Your Clinic Visit*

- Your Patient Education Guide (this book)
- Your daily dose of cyclosporine, tacrolimus or sirolimus to take after your blood is drawn, plus other medications that are due
- Transplant medication schedule
- Daily record of weights, temperatures, etc.
- Note of any medications for which you will need new prescriptions
- Pain medication and a snack
- A list of questions you have
- Any paperwork given to you at discharge
- Your support person

Occasionally a patient is admitted to the hospital from a clinic visit. For this reason you are advised to keep a small bag packed in your vehicle with some of the things you would need to make you comfortable in the hospital. In your bag you need to bring your medications and you may want to include your personal toiletry items, such as a make-up case or a shaving kit. It is wise not to make plans for an activity following your clinic visit. If you must make plans, we suggest you have an alternate plan in the event your appointment runs late or you are admitted to the hospital.

You should get into the practice of always carrying your medications with you so you are always prepared in the event you cannot return home as you planned.

For more comprehensive information on clinic visits and your care following transplantation, please refer to the Post-Transplant Care Section.

