Patient Education Class

Slide 1: Patient Education Class

This is the Patient Education Class for kidney and/or pancreas transplants. You are here today to be evaluated for a kidney and/or pancreas transplant.

Slide 2: Patient Education

The Patient Education Class is designed to provide you with information about transplantation. Today we will review a slide presentation of the facts you will need to determine whether transplantation is right for you. As we review the slides in class today, you may want to use the space provided next to each slide to make notes or jot down questions you want to ask.

You will receive a Patient Education Guide that explains transplantation in detail and will be a long-term reference guide for you through the phases of transplantation. You can add information and contact numbers to this guide. It is important to bring your Patient Education Guide with you for every clinic visit and when you are admitted to the hospital for your transplant. Portions of this guide will be used during your inpatient stay to teach you about medications and post-transplant care.
Slide 3: Basic Organ Function

The basic functions of the kidneys are to filter poisons out of your blood and to regulate water balance. The basic functions of the pancreas are to secrete digestive juices and to secrete insulin which assists in the regulation of blood sugar.

Slide 4: Pancreas Transplants

Pancreas transplants may be helpful for patients who have Type 1 Diabetes, indicating their pancreas has lost its ability to make insulin and won’t ever be able to make insulin again. There are three types of pancreas transplants: a) simultaneous pancreas and kidney (SPK), b) pancreas after a kidney transplant (PAK), c) pancreas alone which is rare. Very specific criteria determine when a pancreas transplant is appropriate. If you have any questions regarding pancreas transplant, discuss them with the doctors during your evaluation appointment.

Slide 5: Why a Kidney Transplant?

Chronic kidney disease is the slow loss of kidney function over time. Chronic kidney disease is also known as chronic kidney failure or chronic renal insufficiency. The main function of the kidneys is to remove wastes and excess water from the body. When your
kidneys do not work correctly, wastes build up in your blood and they make you sick. The most common causes of chronic kidney disease are high blood pressure or high blood sugar (diabetes). Kidney failure is defined when the kidney function falls below about 15 percent (GFR is less that 15 mL/min/1.73m2). When you are in kidney failure, you will have two treatment choices: to start dialysis or have a kidney transplant. Most patients experience an improved quality of life with transplantation compared to dialysis. On average, patients will live longer (approximately twice as long) after a transplant than if they had stayed on dialysis. Some patients may be able to avoid dialysis by having a living donor transplant before they need dialysis. Some patients are not interested in pursuing either dialysis or transplant, choosing not to pursue treatment for their kidney disease. It is important to discuss this decision with a physician.

Slide 6: Where Do Kidneys Come From?

Donated organs can come from deceased donors and living donors. Gift of Life Michigan (GOLM) is the Organ Procurement Organization (OPO) that coordinates deceased donors in our area. There are two ways donated organs are received from deceased donors. The first is called Donation after Brain Death (DBD) and occurs when the family chooses to donate their loved ones organs after a devastating brain injury from which their loved is declared brain dead. The other is called Donation after Cardiac Death (DCD). In this situation the donor has suffered a devastating medical event that they will not recover from. With the families approval the patient is withdrawn from life support and cardiac death will occur prior to organ donation. If cardiac death does not occur within a designated time frame following withdrawal from life support, organ recovery will not occur.

Donated organs may also come from living donors who may be related or unrelated to the recipient. Some living donors choose to remain anonymous.

All donors (deceased and living) are screened very carefully prior to donation. When a donated organ is offered to the Transplant Center for you, the coordinator contacting you will inform you of the information regarding the organ, and you have a choice to accept or decline the offered organ.
Slide 7: Why it is Important to Consider Living Donation

Transplants using living donor kidneys last longer. On average living donor kidney transplants last for 15 years compared to an average of 10 years for a kidney transplant from a deceased donor.

Living donor transplants can be done sooner than deceased donor transplants. The time to a living donor transplant is from one to three months. The time to a deceased donor transplant can be from four to seven years. The sooner a patient can be transplanted the better their outcomes will be after transplant.

Living transplantation improves the likelihood that a transplant will be done. Only about 50 percent of patients that are put on the wait list ever get a deceased donor transplant. Many patients die before an organ becomes available or become too ill to allow them to be a viable candidate. The risk of dying on the waiting list is approximately 8 percent every year.

Slide 8: Living Donors

Living donors need to have a blood type (ABO) that is compatible with the intended recipient. The donor and recipient’s blood are cross matched to ensure the recipient’s blood does not react to the donor’s blood in a detrimental way. Since everyone’s blood antibodies change over time, cross matches are done routinely to ensure no detrimental reaction occurs.

Surgery can be planned in advance around the donor and recipient schedules.

Our paired donation program offers possibilities of finding a suitable match, when no known match exists.
Slide 9: Living Donors (2)

Our first priority in assessing a person to become a living donor is their safety. To ensure the donor’s needs are met they will meet with our Living Donor Advocate. If the transplant team, including the living donor advocate, does not feel you can donate without causing you harm they will not accept you as a donor.

Donors must take four to eight weeks off work, depending upon how quickly they heal and what type of work they do. The risk to a donor is low: the risk of death within 90 days of donation is about 1 in 3,000, but one in 15 will experience some complications related to the operation that requires some care, such as a bladder infection or a wound infection.

The Transplant Center pays for the cost of the donor evaluation, the operation and any complications related to the donation.

Slide 10: Desensitization

Many patients who are waiting for a kidney transplant may not be able to receive one because they are considered "sensitized." Other patients cannot receive a kidney transplant because their blood is incompatible with the donor. Sensitization and blood incompatibility are caused by antibodies against human cells or blood types. Antibodies are proteins made by white blood cells generally used to help the body fight infection.

If a kidney transplant is performed in a patient with antibodies against human cell or blood types, the antibodies will bind to the transplant causing severe rejection and destruction of the kidney.
A process called "desensitization" removes unwanted antibodies from the blood stream using medications and a process similar to dialysis (dialysis removes chemicals from the blood, while this process removes harmful antibodies). The process prepares the patient for a successful transplant and occurs as a monthly infusion process for the first six months, followed by two additional infusions at 9 months and 1 year after treatment begins. The success of desensitization depends on the amount of antibodies.

For more information on desensitization, please refer to page 5 of the Before Transplant section of this guide.

**Slide 11: Paired Kidney Donation**

Our paired kidney donation program offers new hope to patients needing a kidney transplant. Often a patient who needs a kidney has a family member or a friend willing to donate one of his or her kidneys, but it cannot be done due to tissue or blood type incompatibilities. Paired donation seeks to match individuals who do not have a compatible donor/recipient with others in the same situation.

If you and your intended donor do not match by either blood type or cross match, you may benefit from the paired donation program.

**Slide 12: Altruistic Donor Begins Chain**

Altruistic donors come forward with an offer to donate an organ, often without an intended recipient. Altruistic donors receive no financial or other incentives to donate: their offers stem from a selfless regard for the welfare of another.
One donation can begin a chain of organ matches in the paired donation program that may allow for many transplants to occur.

One kidney is donated, and…

**Transplant One**
- Is matched and transplanted to recipient A
- Recipient A had a donor who was not compatible, but now…

**Transplant Two**
- Matches with and donates to recipient B
- Recipient B had a donor who was not compatible, but now…

**Transplant Three**
- Matches with and donates to recipient C
- Recipient C had a donor who was not compatible, but now…

**Transplant Four**
- Matches with and donates to recipient D
- Recipient D had a donor who was not compatible, but now…

And so on, and so on and so on…

The gift chain of donations continues as long as there are suitable donors and compatible recipients.

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**Slide 13: Expanding the Deceased Donor Pool**

There are not a sufficient number of donated organs to transplant all the patients who need a transplant. Some donor kidneys are suitable for certain patients and can allow those patients to get a transplant sooner:

**Expanded Criteria Donors (ECD):** the age and health history of the donor and recipient are considered.
Hepatitis B Core Antibody +: for recipients who have been immunized against hepatitis B or may have had an exposure in the past, may be able to receive a kidney that is from a donor who has been exposed.

Hepatitis C positive: organs from donors who have been positive for Hepatitis C may be transplanted safely to recipients who also have Hepatitis C.

Center for Disease Control: High-risk behaviors involves using donated organs from a patient with a history of one of the following:

- Sexually transmitted diseases
- High-risk sexual behavior in the last five years
- Injection drugs
- Been in jail or a mental institution in the past 12 months

When the recipient is placed on the wait list they will specify whether to consider organs from these types of donors for you. The coordinator will discuss this with you at the time of listing and again at the time of the offer. The recipient can then make an informed choice and can either accept or decline the organ offer.

Another way the number of organs available has increased is through Paired Donation. Often potential donors come forward wishing to donate to their loved one and learn they cannot because their blood type is not compatible. Paired donation allows two sets of mismatched donor/recipient to come together with the donor of the first pair giving their organ to the recipient of the other pair, and vice versa.

Slide 14: Pre-Transplant Evaluation

Your evaluation appointment today will take approximately five to six hours. You have already had your labs drawn and your chest x-ray. Following this class you will go to the clinic where you will have an EKG, have your picture taken and you will meet with members of the transplant team. It is important to understand that no patient is ever listed for
transplant on the day of their evaluation appointment. There are several more steps to the process before anyone could be listed.

The evaluation process is an opportunity for the transplant team to assess whether transplantation may be beneficial to you and an opportunity for you to assess whether you feel transplantation is right for you.

**Slide 15: Transplant Evaluation Team**

You will meet with the following members of the transplant team during your evaluation today:

**Transplant Nephrologist** – specializes in kidney disease and will focus on assessing your overall health in preparation a transplant.

**Transplant Surgeon** – specializes in performing kidney and pancreas transplants and will focus on whether the surgery can be performed on you.

**Social Worker** – specializes in helping patients and their families understand and cope with the issues they may face (emotional, family, financial and vocational)

**Transplant Coordinator** – a professional who facilitates your journey through the transplant process.

You will also have access to a Financial Coordinator who will assist you in understanding and facilitating the financial aspects of transplantation and your insurance coverage.

**Slide 16: After Today’s Evaluation**

After all the testing results are obtained, your case will be reviewed by the Transplant Evaluation Committee. The Committee includes the nephrologists, the surgeons, the social workers, the financial coordinators, dietitians, pharmacists, living donor advocate and the transplant coordinators. All listing
decisions are made by this committee which meets each week. The committee will review your case and make one of the following decisions: Continue the Evaluation Process, Do Not List or List for Transplant.

**Slide 17: After Committee Meeting**

Following the Transplant Evaluation Committee meeting, your Transplant Coordinator will write a letter to advise you of the committee decision and notify you of the next steps to take. You should receive this letter within two weeks following the meeting. If you do not receive the letter, please contact your Transplant Coordinator.

It will be very important to keep your Transplant Coordinator informed about any changes in your life that may impact your listing and/or transplant. These may include changes in your address, phone numbers, insurance, health conditions, hospital admissions, surgeries, accidents and/or blood transfusions.

**Slide 18: Decision: Continue Evaluation**

You may receive a letter advising you the team requires additional testing before they can make a recommendation on whether you meet listing qualifications. In addition to the letter, your Transplant Coordinator may contact you by phone to explain the results and the additional testing you need and answer any questions you may have. The letter will include the specific testing you will need to complete before the committee can review your case again. The letter will also include the contact information where you should have the testing results faxed to us. You may also be contacted by your social worker regarding social goals to complete prior to being listed. Once the results from the additional testing are received your
case will be reviewed again by the committee. Another letter will be sent to you following the review of your case, notifying you of the final decision and any steps that should be taken.

Slide 19: Decision: Not To List

You may receive a letter that indicates your records were reviewed by the committee and our team feels that a kidney and/or pancreas transplant is not in your best interest and does not recommend you proceed with transplantation. While this may be disappointing to learn, it is important to remember the committee only advises transplantation when it appears it will benefit – and not harm – the patient.

Slide 20: Decision: To List

You may receive a letter indicating you meet all the listing qualifications and are being listed for a deceased donor organ transplant. The letter will include all the information you need to remain in an “active” status on the wait list. It will be important to contact your transplant coordinator when specific health issues arise. Since obtaining an organ from a living donor may be your best opportunity, you will be encouraged to pursue this option.
Slide 21: Where Are You Listed?

You will be listed on a national list that is administered by UNOS (United Network for Organ Sharing). Your listing will reflect the University of Michigan Transplant Center as your service center. UNOS facilitates the organ matching and placement of donated organs. Gift of Life Michigan (GOLM) is the only Organ Procurement Organization (OPO) federally designed organ and tissue recovery program in Michigan. When an organ becomes available the local OPO, which is GOLM, runs the match list using the UNOS database and places offers to the transplant centers who serve the patients being offered the organ.

Slide 22: UNOS Requirements to List

To place your name on the wait list for a deceased donor organ UNOS requires the following:

**Confirmation of Blood Type** – Two separate tests are required to confirm your blood type.

**Panel Reactive Antibody (PRA) Levels** – This identifies the antibodies you have that would cause a reaction against certain donors. Samples are only good for 60 days from the draw date.

**Antigen data – genetic markers** – For matching purposes six specific antigens are considered in the recipient and the donor. A six antigen match is considered a “perfect” match.

**Type of Transplant being listed for** – kidney, SPK, PAK, PA.

**Dialysis Start Date** – The dialysis start date will be entered for patients listed in the State of Michigan. For patients listed after they are on dialysis, their wait time will accrue from their dialysis start date – not their listing date.
It is our policy to list every patient for a deceased donor kidney even those planning for a living donor transplant. Doing so protects the patient by allowing them to accrue wait time while they pursue living donation. Occasionally, living donor transplants cannot be accomplished and the accrued wait time has value for the recipient.

**Slide 23: Multiple Listing**

Multiple listing allows a patient to be listed at two or more transplant centers in different donation service areas (DSA). Our transplant center receives organs through Gift of Life Michigan (GOLM), so our patients interested in multiple listing would need to list with a transplant center outside the GOLM area.

Wait time with each center begins as soon as the center lists you for an organ transplant. Primary waiting time is the longest you have waiting at any center. You cannot add up or split up the total waiting time among centers. Many factors beyond multiple listing impact waiting times. There is no guarantee that multiple listing will shorten your wait time, although it is possible that it will. Multiple listing may be very appropriate for patients with antibodies.

**Slide 24: Multiple Listing Considerations**

If you are interested in multiple listing, you may want to consider the following:

- You must be considered and accepted at each transplant center that lists you.
- Each transplant center sets their requirements for listing.
- You will want to be sure your insurance coverage will cover you at each transplant center where you will be listed.
• You will need to consider transportation time and your mode of transportation to each center.
• You will need to identify a primary site if a “perfect” six antigen matched kidney is identified for you.
• You will need to consider where you want to receive your post-transplant care.
• You will need to maintain current labs and contact information at each transplant center that lists you.

You should know:
• You can multi list.
• UMTC accepts multi-list patients.
• UMTC will transfer your records to other centers upon request.
• UMTC requires a written request for transfers, switches in wait time or primary wait time.

Slide 25: To Stay “Active” on the List

Being “active” on the list means that your name would appear on a match list if an organ becomes available and that you would be able to come for a transplant. To remain active on the list you must have an annual visit in our pre-kidney clinic. You must complete all requested and ongoing testing and have the results approved. You must use the kit we send each month to have your blood drawn monthly and sent to our lab for tissue typing which screens for new antibodies since your last sample. We will not receive an offer if your sample is greater than 60 days old. If you have a live donor in the evaluation process you will be asked to submit monthly sera before being added to the wait list.
Side 26: Listed – Status is “On Hold”

Being on the list with a status of “On Hold” means that if an organ becomes available, your name would not appear on the match run so you would not be offered the organ. Patients still accrue wait time while they are “on hold.” You may be placed “on hold” for a variety of reasons, which may include a change in your health status, no current blood work, social goals that are incomplete, requested testing has not been completed, you are on a planned vacation out of the area or we are unable to contact you. Your monthly blood draws are still required while you are “on hold.” Your listing will be returned to "active" status when you have met the criteria specific to your situation.

Slide 27: While You Wait…

You will want to use the time you are waiting for your transplant to learn about transplantation. We suggest that you read your Patient Education Guide each month. It provides the information you will need to know in the general order it will occur. There is a list of transplant-related websites in the resource section of your Patient Education Guide. These websites provide a wealth of information on a variety of aspects of transplantation. You may also find it helpful to attend support groups. Your social worker can assist you in finding a support group. It is important to keep all your clinic appointments. Stay in contact with your transplant coordinator, your financial coordinator and your social worker. If you have questions, please contact your transplant coordinator.

Having a stable support system is crucial in maintaining a positive attitude while you wait for a transplant. Make every effort to maintain strong connections with your family and your friends. If the support people who planned on helping you can no longer do so, please contact your Transplant Center social worker.
Slide 28  Be Prepared for “The Call”

The Transplant Coordinator has one hour to reach you and to accept the organ that has been offered for you. There are many steps to coordinate this process that must occur within that hour. It is imperative that the coordinator knows how to reach you. Please keep your contact information up to date. It is helpful to have developed your own plan for how you will get to the hospital when the call comes. In life not everything goes as planned, so it is important to have a back up plan in case your first choice is not possible.

As you think through what will need to occur when you get the call to come to the hospital, don’t forget to plan for child care, pet care, temporary lodging and meals for your family during and after your transplant. Don’t forget to plan for added expenses, such as the costs of parking at the hospital. Consider whether you will have a loss of income during this time and plan for how to manage your expenses during this time.

It is important to think through what will happen when the call comes and to have made plans for handling the specific details. Be prepared! Review your plan periodically and make changes as necessary to stay prepared.

Slide 29: When the Call Comes

The call to offer you a donated organ can come at any time, but often it comes in the middle of the night. The coordinator works in collaboration with the transplant surgeon to coordinate the offer. The coordinator has only one hour to complete the process, to find you, and to accept or decline the offer. It is important to always answer your phone even when you do not recognize the caller’s telephone number. Since the call can come at any time, the coordinator may be calling you from any location they are at – not just from the hospital. Be sure you keep your transplant coordinator informed of your current contact information. If you are away from home, be sure others know how to reach you. If the coordinator cannot reach you, you will miss the opportunity to receive that donated organ.
Slide 30: Arriving at the Hospital

Do not rush to the hospital. While the coordinator has only one hour to accept or decline the organ offer, they will give you plenty of time to arrive at the hospital. The donated organ will be packed in cold storage and will remain viable for up to 24 hours. We prefer to perform surgery as soon as possible and to have you at the hospital six to eight hours before the surgery. Even so, you will have plenty of time to get to the hospital. Drive carefully and wear your seat belt.

Be sure to bring the essentials you have packed for this trip – including telephone numbers you may need and money for parking. Please bring your Patient Education Guide as that will be used after your surgery to teach you about the medications you will take and how to care for yourself when you go home.

When you arrive at the hospital proceed to the area of the hospital as instructed by the transplant coordinator who called you.

Slide 31: Transplant Research

A clinical trial (also called a research study) is a study that helps test whether a new treatment or medication is safe and effective, or whether older treatments produce the best results. In organ transplants, previous studies have been very important in finding the best way to care for your new organ. Clinic trials have been found to be the best way to make sure new drugs, devices and procedures are safe and effective.
Slide 32: Clinical Trial – To Join or Not?

You are not required to join; you must volunteer in order to be able to take part in a clinical trial. A decision should be made after you have full knowledge of what is involved. Taking part in a clinical trial may or may not improve your health. You may be one of the first to try a promising new drug or you might receive the standard or regular therapy. All clinical trials are reviewed and approved by a safety and ethics board before any patients can be enrolled in a study. Patients will meet with a member of the Clinical Research Team who will explain the studies and answer questions, before the patient makes a decision. Many studies provide free medications after transplant. Each patient enrolled in a clinical trial is monitored very closely while participating in the study. Whether you choose to join a study or not, you will be cared for by the Transplant Center team of dedicated professionals who are interested in your health. One of the most important reasons for joining a clinical trial is a desire to help advance what is known about new treatments.

Slide 33: The Transplant Operation

The length of time a recipient spends in the operating room varies, but generally is between two to four hours. The new kidney will be placed in the lower abdomen, either on the left or the right side. The existing kidneys (called native kidneys) usually aren’t removed, although they can be if they are causing problems.

The length of time a donor spends in the operating room varies, but generally is between two to four hours. Almost all donors have the procedure done laparoscopically as it may cause less pain and may require less recovery time. With a laparoscopic procedure, you will have several small incisions in your abdominal area from which the organ will be removed.
Slide 34: Ureteral Stents

A ureteral stent is a small, soft tube about six inches long and about as big 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. The surgeon may place a ureteral stent during the surgical procedure to help the body heal the connection between the kidney and the bladder. The ureteral stent should be removed between three and eight weeks by the urologist following surgery.

Slide 35: During Your Hospital Stay

After the operation, transplant patients must get out of bed and walk three times each day, beginning the day after transplant. Walking soon after surgery will speed 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. It is suggested you get out of bed and sit in your chair to eat meals at breakfast, lunch and dinner.

You will need your support person while you are hospitalized. Patients 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 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.

During your inpatient stay you will be cared for by a team of professionals. At times it may seem confusing or overwhelming to have so many different caregivers coming and going from your inpatient room. Be assured each team member has a specific purpose and they are all working together to provide you the best possible care.
Slide 36: Immune System

Your immune system protects you by fighting infections and foreign bodies. Your immune system will recognize a newly transplanted organ as a foreign body and will fight against it. Medications, called immunosuppressive drugs, are used to prevent your body from “rejecting” your newly transplanted organ. You will need to take immunosuppressive medications for your lifetime. These medications are very expensive – costing between $2,000 and $4,000 every month. You will need to work with your Financial Coordinator to develop a sound insurance and financial plan to cover the cost of these medications.

Slide 37: Medications after Transplant

As a transplant recipient you will begin taking new medications the day of or the day after your transplant. You will take medications to prevent rejection, to prevent infection and other medications as well. You will need to take some combination of medications for the remainder of your life or your kidney will fail. To prevent rejections you will take a combination of three medications after surgery; prednisone (steroid), mycophenolate, cyclosporine or tacrolimus. Valcyte is a very expensive medication, approximately $1,500 a month, which may be indicated to treat or prevent infection. This medication may or may not be covered by insurance.

A steroid avoidance protocol is available for some patients who meet the qualifications. If you are interested in avoiding the use of steroids, please discuss this with your transplant physician.
Slide 38: Learning About Medications

You must learn about each of your new medications before you can be discharged from the hospital. You will need to know the drug name, the purpose of the medication, the side effects and the dosages of each medication. The nursing staff will work with you and your caregiver to develop a “Self Medication Schedule.” Your support person must participate in learning about your medications. To ensure you can safely manage your own medications at home, you and your support person will be quizzed to demonstrate your knowledge about your medications prior to discharge.

Slide 39: Side Effects of Medications

All medications have possible side effects. Not all patients experience all the side effects of every medication. Not all patients will experience the same level of intensity of each side effect. Many of the medications must be tapered (slowly reduced). DO NOT independently withdraw from taking any medication. Discuss any concerns you have with your transplant nurse or physician.

Slide 40: Some Possible Side Effects

Medications have the potential to cause a variety of side effects. You are not likely to have all the side effects or have them all at a high intensity. If you have any concerns about side effects, you should discuss your concerns with your transplant nurse.
**Slide 41: Mycophenolate Mofetil (Cellcept®) / Mycophenolate Sodium (Myfortic®)**

These medications are used in combination with tacrolimus or cyclosporine. Their main toxicities are diarrhea and suppression of bone marrow. These medications could cause serious harm to the baby if taken while pregnant. Women of child bearing ages should have a negative pregnancy test within a week of starting this medication and should use two forms of contraception, unless abstinence is the chosen method. They should begin the two forms of contraception four weeks before beginning the medications, continue during therapy and for six to 12 weeks after they stop taking the medication. If you have any questions regarding these medications or pregnancy, please discuss it with your transplant coordinator or physician.

**Slide 42: Pain Management**

The transplant team is committed to providing the best care for our transplant recipients, including the effective management of postsurgical pain. We acknowledge that some patients may have chronic pain issues and are on maintenance pain medication. Managing postsurgical pain and chronic pain can be challenging. As we make a plan for your surgery and recovery needs, the evaluation team will also discuss your use of pain medications for management of chronic pain. Our goal is to understand our patient’s long term pain management plan and coordinate care with the physician who will be prescribing their pain medications during their post surgical recovery. While the transplant physicians will provide pain medications for a few weeks after the transplant surgery, our goal is to facilitate a smooth transition for chronic pain management to your identified pain specialist or local physician.
Slide 43: Steroid-Free Protocol

Due to their anti-inflammatory and immunosuppressive properties, steroids have been a main component in the immunosuppressive regimen for the prevention and treatment of acute rejection after kidney transplantation. Prolonged exposure to steroids results in significant side effects which include worsening cholesterol levels and high blood pressure, and the development of post-transplant diabetes mellitus, weight gain and osteoporosis. While our standard protocol is designed to minimize these effects by keeping the maintenance steroid dosage low, some patients may be interested in an alternative steroid free approach. For select patients the steroid-free protocols have comparable outcomes in regards to patient and graft survival, rates of acute and chronic rejection, and transplant renal function, while minimizing the above adverse events.

Not all patients qualify for the steroid-free protocol. Patients who are interested in the steroid-free protocol should discuss it with their physician during their clinic appointment.

Slide 44: Hospital Stay

The average length of stay for kidney recipients is two to three days, for kidney living donors is one to two days, and for pancreas recipients is four to seven days. Prior to discharge all patients receive training in how to care for themselves following surgery, including wound care, nutrition and medications.
Slide 45: Discharge

On the day of discharge you will be focused on “let’s go home.” While we 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 you can “go home.” After your physician tells you that you can go home today, the staff must be sure you have a 30-day supply of medications before you are discharged, 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 prior to 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 early evening. Patients should make plans to have someone stay with them to provide around the clock support for the first weeks after going home.

Slide 46: Outpatient Follow Up

Living donors will need to return to the clinic for a follow-up visit two weeks after the surgery. Barring any complications, after that appointment the donors will return to the care of their primary care provider. Total recovery time for living donors is usually four to eight weeks.

Recipients will return to the clinic for their first appointment after surgery within a few days after discharge and will visit the clinic weekly for the first six weeks. Each recipient will have an individualized clinic visit schedule based on their needs after the first six weeks. Blood draws will need to be done twice weekly for the first three months after discharge. The total surgical recovery period is six to eight weeks. Recipients will need to plan transportation to their lab and clinic appointments during the surgical recovery period.
**Schedule for biopsies:** To evaluate the condition and health of the transplant before irreparable damage occurs, we do frequent biopsies in the first year following transplant. A biopsy will be performed in the operating room at the time of transplant, and then at three, six and 12 months after transplant. A biopsy requires a needle puncture in the area of the transplanted kidney.

**Slide 47: Rules We Must Follow…**

It is important for patients to understand that we are bound by the regulations set forth in the Health Insurance Portability and Accountability Act (HIPAA). We cannot share your medical information with anyone – without your express written permission. We cannot tell your spouse, father, mother, sister, brother, daughter, son, friend or neighbor anything! We cannot answer any question from the donor about the recipient. We cannot answer any question from the recipient about the donor. If you want us to be able to talk about your medical care with another person, you need to ask to sign an authorization that we will keep on file.

**Slide 48: You are Listed When?**

You are not listed on the day of your evaluation. You will only be listed when you have completed all the requested testing, your case has been reviewed by the transplant evaluation committee, and it has determined you meet all the criteria for listing. You will know you are listed when you receive a letter from your coordinator informing you the committee has made the decision to list. You should receive a letter within two weeks of the evaluation meeting stating what the next steps are. If you do not, please contact your transplant coordinator.
Slide 49: **Who to Contact?**

Your Patient Education Guide includes a listing of the key players and their telephone numbers. Many support groups are available and some are listed in the Patient Education Guide.

The United Network for Organ Sharing provides a toll-free patient services line to help transplant candidates, recipient and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. Phone: 1-888-894-6361.

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Slide 50: **Questions?**