

## **Introduction**

For patients with early onset, insulin-dependent diabetes (Type 1), pancreas transplantation may prevent or slow the progression of the long-term complications of diabetes. Long-term complications include neuropathy (loss of feeling or burning in the hands and feet), retinopathy (disease resulting in blindness), vascular disease (clogging of the arteries in the legs leading to amputation), and nephropathy (disease of the kidney leading to failure). Pancreas transplantation may be an option to reverse or halt these long-term complications and can be performed 1) as an isolated pancreas transplant; 2) at the same time as a kidney transplant; or 3) after a kidney transplant.

Most pancreas transplants are done at the same time as a kidney transplant because clinical studies show better survival rates after a simultaneous kidney/pancreas transplant. Taking this into account, our recommendation at the Tulane Abdominal Transplant Institute is to transplant both organs together, from the same donor, whenever possible. However, we will consider isolated pancreas transplant in selected cases. Usually this happens when someone has already received a kidney transplant from a living donor. We will consider an isolated pancreas transplant, when kidney failure is not present, if diabetes management is difficult or when the patient is under threat of complications such as blindness or severe vascular disease.

## **Evaluation**

Usually your nephrologist (kidney doctor) or endocrinologist (diabetes doctor) will make the transplant referral, but anyone, including you, can call to make the transplant appointment. Sometimes insurance companies will tell the policy holder which transplant centers are covered in their network. Our financial counselor can also check on this for you.

A transplant evaluation is the process by which you prepare for transplant. It includes a history and physical, psychosocial assessment, nutritional consultation, and financial evaluation. The first appointment will take approximately 4-6 hours. This is just the first step in the evaluation for many patients, as you may need additional tests and consultations with other physicians. Your Transplant Coordinator will be able to tell you what additional tests you may need before you leave after this first appointment, but sometimes we may not be able to tell you until after the whole team reviews your case.

The transplant coordinator will be your guide through this transplant appointment. Some of it will depend if you are being evaluated for a pancreas-only transplant or more commonly, a combined kidney-pancreas transplant. While you are here you will be given information about transplant and living kidney donations, see a film, and talk with all of us about transplantation. After you have seen everyone in clinic you will be directed to the laboratory, the radiology department for your chest x-ray, and to cardiology for your EKG. Please have your parking validated before leaving the clinic.

You will not leave without a plan for completing your workup. If you are un-sure, ask us to review it again *before* you leave.

### **What To Bring**

You will need to bring your insurance, Medicare or Medicaid card for us to copy for our records. You also must present a picture ID so we can verify your identity. You also need to bring

1. A complete list of all the medications you are currently taking, including the amount you take and how often you take them.
2. A copy of your most recent blood test results from your dialysis center or primary doctor.
3. A complete list of all the doctors that you see for your healthcare. We will need the doctors full name, mailing address, and telephone number. Otherwise we will not be able to communicate with your doctors.
4. A list of any surgeries you have had.
5. A list of your major medical problems and approximate years they developed.
6. If you have had any heart tests or procedures, know the name and telephone number of the doctor so we can request a copy on your behalf.
7. Most importantly, bring a list of the questions you want to ask us.

It will be easier for you if you have a family member who can come with you to this appointment – there will be a lot of information given to you during the evaluation. One of the important aspects of undergoing a kidney/pancreas transplant is having people around you to help you in your recovery. We need to meet these people so they too can be educated about what you will need. Our Social Worker will also want to meet with a family member or friend who is your close support.

Your Transplant Coordinator will call you after all your results have been received and have been reviewed by our team at our Candidate Selection Meeting. This is a meeting of the whole team to review your case and to make a decision about transplant for you. We meet every week so within a week or two after we have received all the results of your tests, you can expect to hear from us. After we discuss your case at the Candidate Selection Meeting and make a decision to place you on the UNOS/OPTN national waiting list, the Transplant Coordinator will call you to let you know of our decision. We will first get clearance from your insurance carrier before we place you on the waiting list. Once we do, you will get a letter in the mail telling you this. We will also send a letter to your kidney & diabetes doctors and to your dialysis unit. If you do not receive a letter from us, you should call us.

## **Schematic of the Evaluation**

Referral from nephrologist (kidney specialist) or endocrinologist(diabetes specialist)



Call to set up appointment for education seminar and clinic visit



Education seminar



Clinic appointment (full day)

1. meet with
  - Pre-transplant coordinator and/or nurse practitioner
  - Nephrologist and/or surgeon
  - Social worker
  - Financial coordinator
  - Dietitian
2. initial lab work, chest x-ray, and EKG
3. set up appointments with necessary consultants (endocrinologist at Tulane, cardiology, gynecology, gastroenterology, etc...)



Once complete, your case will be presented at our weekly candidate selection committee meeting. We will then call to notify you of your status.

For referral please call (504) 988-5344 or long distance (888) 988-5344. Our operator will direct you to the proper person.

## **Waiting List**

After your pre-transplant evaluation, if the selection committee determines that you are a good candidate for transplant, you and your referring physician will receive a letter stating that you have been placed on the United Network for Organ Sharing (UNOS) computerized national list.

Waiting times for deceased donor transplants can range from 6 months to 6 years. If you need both organs and have a living kidney donor, then we can proceed with the kidney transplant first. Once you have recovered (usually 3-6 months after)-you will be placed on the pancreas-alone waiting list which fortunately is much shorter. Therefore, patients often are transplanted within 6-12 months.

Once on the list, our protocol requires you to keep in touch with us to update your medical conditions. Depending on your health, you may have to see us as little as once a every two years, or we may need to see you every 6 months. Your Transplant Coordinator will be able to advise you of this also after you have been listed. Staying on the list also requires you to keep your blood samples updated. It is very important that

you regularly send a blood sample that can be used to check if you would match with any potential donor kidneys that become available. Each month, blood tubes with return mailing labels are sent to your dialysis unit or to you if you are on peritoneal dialysis or not yet on dialysis. To remain eligible for a transplant, you must send in this blood sample every month.

It is impossible to say exactly where a patient is on the list. Pancreases are given out by a formula based upon age, blood group, Panel Reactive Antibody (PRA) matching, and time on the waiting list. Each time a deceased donor pancreas becomes available, tissue typing is performed and the UNOS computer system produces a list of possible recipients unique for each donor based on these factors.

### **Living Donor Kidney Transplant**

There are several advantages to the recipient of a living donor kidney transplant. First, the operation can be scheduled when it is convenient for the donor and recipient, and when both are in their best state of health. Second, the kidney function after a live donor transplant (either from related donors and unrelated donors) last significantly longer. On average, they last 15 years as compared to kidney from deceased donors (7-10 years average function).

Living donor transplantation is possible because we are born with two kidneys. After removal of one kidney, the remaining kidney takes over completely. Recent studies that examined the long-term effects of kidney donation have not demonstrated any increased risk of kidney disease or decreased lifespan compared to the general population.

The donor must be more than 18 years of age and must either be related to the recipient, or have a close emotional attachment. An example of an unrelated donor would be a spouse. The donor's medical expenses related to the evaluation, surgery, hospitalization, and immediate postoperative care are covered by the recipient's insurance company. If any problems arise in the future that are directly related to the kidney donor surgery, these expenses are covered as well.

If you know someone who is interested in donating a kidney to you, ask them to call us at our toll free number and ask to speak to our living donor coordinator. The potential donor *must* call us; we cannot call potential donors on your behalf. Please keep in mind that a phone call to the transplant center does not commit you to becoming a donor. We would be happy to answer any questions you may have to help you make a decision about wanting to go through with the donor evaluation.

## **Being Called in For Transplant**

Nurses are on call 24 hours a day to accept offers of organs for transplant. Our doctors screen these offers to accept the best possible organs for our patients. A transplant nurse will call you by telephone to tell you when an organ has become available for you. It is very important to make sure we can get in touch with you 24 hours a day, 7 days a week. If your telephone number changes or if you will be out of town, be sure and notify your coordinator of the telephone numbers where we can reach you. You should pack a suitcase to stay in the hospital about two weeks. Bring all medications you are currently taking and anything else you will need for a week in the hospital. Come to Tulane University Hospital as soon as possible. The transplant nurse coordinator will guide you through this process when you are called in for transplant. Sometimes, multiple patients are brought in for a transplant. We do this in order to “back-up” the first person on the list.

You will be admitted to the Abdominal Transplant Unit where a nurse who will prepare you for your transplant surgery will greet you. The nurse will get you settled into the room and will take several vials of blood. Some of the blood will be sent to the HLA lab where a final cross-match will be performed. A doctor will complete a history and physical to update your medical information and to be sure that you do not have any new medical problems that will make the transplant operation unsafe. Depending on your medical history, kidney specialists, diabetic specialists, heart specialists or other types of specialists may be consulted to be sure all aspects of your medical care are addressed.

Before we know that we can absolutely do the transplant, a final test (crossmatch) must be performed. The final cross-match is a test in which your blood is mixed with cells from the donor. A negative cross-match means that when your blood was mixed with the donor’s cells there was not a reaction, and your body should accept the new organ. A positive cross-match means that the blood reacted and that this organ would not be acceptable for you.

The organ cannot be given to you if you have a positive cross-match; it could be life threatening to receive an organ that has reacted positively with your blood. A member of the transplant team will tell you that unfortunately you reacted positively to the cross-match. This does not mean that you will never receive an organ. You will be called in again when another organ is found for you and the process will start again. Do not be discouraged, some patients are called in several times before an acceptable organ is found.

It takes approximately 6-12 hours to complete the transplant evaluation, preparations for surgery and the final crossmatch. You will probably not be allowed to eat during this time.

## **Pancreas Transplant Surgery**

A pancreas transplant operation lasts about 3 hours and is performed under general anesthesia. Combined kidney-pancreas transplants usually take 5 or 6 hours. Typically, a vertical incision in the midline of the abdomen is made. The pancreas is connected to an artery and vein and also to your intestine in order to drain the digestive enzymes the pancreas produces. On some occasions, the pancreas enzymes may be drained into the bladder. They will then pass with the urine. Patients after a pancreas transplant are taken from the recovery room directly to the Abdominal Transplant unit. The pancreas is a very fragile organ and it is not uncommon to return to the operating room sometime in the first few weeks after surgery.

## **Hospital Stay**

You will return to the transplant unit after surgery, and will probably be very groggy from the anesthesia. You may remain on the ventilator until you are awake enough to breathe safely on your own. During this time, fluids and medications will be given to you through an IV. You will also have a tube in your nose that goes down into your stomach to help drain the stomach juices until your bowels start to work on their own (usually 2-3 days after transplant). You will have one nurse devoted to taking care of you. These nurses are specially trained to care for transplant patients. He or she will be in your room frequently monitoring your progress. After you have been settled into your room, your family will be asked to join you.

Deep breathing and coughing are important exercises right after surgery. Once you are taken off of the ventilator and are breathing on your own, your nurse will give you a breathing device that is used to encourage deep breathing. Deep breathing and walking are the keys to a speedy recovery. Throughout your recovery after surgery, physical therapists will work with you to build your strength and help you to start walking again. Both deep breathing and walking will decrease the chance of developing pneumonia which is a common complication after surgery. Walking will also decrease the chance of developing a DVT (deep vein thrombosis). If you do not move and walk enough, there is a chance of blood clots getting stuck in the veins. This is called a DVT and can cause pain, swelling of the extremities, and decreased blood flow.

Most patients experience pain mainly over the incision site after liver transplant. You will be given IV pain medication that you can control. It is called a PCA (patient controlled analgesic). The pain medication is on a pump and you will have a button to push when you want the pump to deliver more medicine. The pump is set so that you cannot get too much medication, but just enough to keep you comfortable.

After the transplant surgery, it may take a few days before your bowels begin to function. During this time you will not be able to eat or drink anything. IV fluids are given to keep you hydrated until you are able to tolerate liquids by mouth. A tube is inserted through your nose into your stomach during the transplant surgery to help empty your stomach

while your bowels are not functioning. This tube will help to minimize nausea and will prevent you from vomiting after surgery. Once your bowels start to work, you will be able to resume drinking liquids and gradually you will be able to eat a normal diet.

The usual length of stay following a pancreas/kidney transplant is 1-2 weeks. Of course, this depends on how well the new pancreas (& kidney) works and whether there are any complications. If you have a complication after surgery, you may need to stay longer. The transplant team will not keep you in the hospital any longer than necessary. Leaving the hospital as soon as you are ready will decrease the chance of getting an infection.

Before you leave the hospital you will be assigned to a transplant coordinator. Your coordinator will monitor your blood work and medications throughout the life of your transplant and will be available to you if you have any questions or concerns. A transplant coordinator is available even at night and on the weekends. You will always have someone to help you if you have any questions or concerns about your transplant.

### **After Your Transplant**

Before you leave the hospital you will be assigned to a transplant coordinator. Your coordinator will monitor your blood work and medications throughout the life of your transplant and will be available to you if you have any questions or concerns. A transplant coordinator is available even at night and on the weekends. You will always have someone to help you if you have any questions or concerns about your transplant.

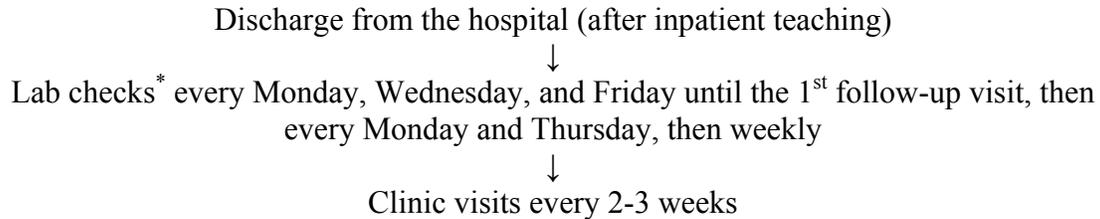
You will be sent home with a one month supply of the medications you will need and with orders for frequent blood tests. You should talk with your transplant coordinator about how you will get your medications filled, where you will have your blood work drawn, and how the results will be sent to your transplant coordinator. You will need to monitor and record your weight and blood pressure in your notebook when you get home. This information is important to your transplant coordinator and your transplant physician. You should bring it with you to your follow-up transplant appointments.

Even after your transplant you still need to be followed by your nephrologist or primary care physician. You should go to their clinics for regular check-ups and health maintenance. The transplant team will follow your transplant health; however your primary physicians need to be involved in your care as well.

It is your responsibility to take good care of your transplant by taking all medications when you should, getting your blood tested regularly, and by keeping in touch with the transplant team. Eating a healthy diet and staying active will help to keep your whole body healthy and give your transplant kidney/pancreas a good environment to work well. The transplant physicians, coordinators, dietitian, and social workers will work with you to help you to get the most out of your new organ.

## Protocol

At Tulane Abdominal Transplant Institute, we pride ourselves on our patients' success. We are a team, however, which requires that we all participate. On our end, we have developed a general protocol for patient follow-up that at times may seem rigorous, but is what we believe is safe and in your best interest. We expect our patients to respect their new organ by adhering with our required outpatient visits, medication regimen, and lab checks. Our basic protocol for uncomplicated patients in the first 3 months is as follows:



\* Remember, if taking Prograf or Neoral (cyclosporine), DO NOT take morning dose until after your blood draw

## Bloodwork

Initially, you will have blood work done 3 times a week. These laboratory levels will be sent to your coordinator and he or she will contact you regarding these results. By 1 year after your transplant, you will have your blood work drawn only once a month, but if there are any problems, you may have to have blood drawn more often.

Your laboratory orders are based on the type of transplant you receive and the medications you are taking. Blood work may include: complete blood count (CBC), renal profile, Prograf level, Neoral level, urine analysis (UA), liver function test (LFT), and cholesterol level. Prograf and Neoral are two of the main anti-rejection medications and they need to be monitored very closely; the doses of these medications may be raised, lowered, or changed based on the results of your blood work.

### Drug Levels

If you are taking Prograf, cyclosporine or rapamune as one of your immunosuppression medications, the level of this medication in your blood must be monitored. If the level is too low, you are at risk for rejecting the transplant, however, if it is too high, it could cause toxic side effects. The dose of your medication will be raised or lowered to maintain the level in a certain range.

### Blood Counts

The CBC includes multiple blood levels. The main levels we check are the hemoglobin, hematocrit, and white blood cell count. A low hematocrit and hemoglobin is called anemia. Patients with kidney failure are usually anemic and may be taking iron pills or another medication to treat this problem. Anemia often gets better after transplant. We

monitor your CBC to make sure your hematocrit and hemoglobin are within normal limits. Included in a CBC test is your white blood cell count. This number usually is slightly low when you are taking immunosuppression or anti-rejection medications. However, if it is too low, you may need to have the doses of your immunosuppression medications adjusted. Some types of infections may decrease the white blood cell count. In this case, the transplant team will want to check for infections in order to treat them as quickly as possible. It is very important to keep in contact with your transplant coordinator and to have your blood drawn as scheduled.

### Chemistries

The kidneys filter the blood and remove toxins. The pancreas regulates your blood sugar by producing insulin. The renal profile blood test monitors how well your transplant kidney is filtering out toxins. The BUN (blood urea nitrogen) and creatinine levels reflect how well the kidneys are functioning. These numbers are monitored to ensure your transplant kidney is working properly. The renal profile blood test also monitors your electrolytes (such as potassium and phosphorus) as the kidney plays an important role in balancing the electrolytes. Most of your medications are broken down in the liver. Liver function tests are done every 3 months to make sure your liver is healthy and able to break down these medications well. You will not need to check daily finger stick blood sugars at home.

Some of the anti-rejection medications may increase your cholesterol. If your cholesterol is too high, you may need to take a cholesterol lowering medication. High cholesterol levels are directly related to plaque formation in your arteries. This problem can occur in the brain (leading to a stroke), in the heart (leading to a heart attack), and in your new transplant (leading to early failure of your transplant kidney).

### **Medications**

In addition to your previous medications, you will be taking immunosuppression medication. Your immune system recognizes foreign bodies that are not its own and tries to fight to get rid of it, kill it or reject it. The immune system sends out white blood cells to combat what it sees as an intruder. The transplant kidney is seen by the body as an intruder. To minimize the body's ability to reject your new organ, you will be given medication that will decrease the body's ability to make white blood cells. These medicines will also decrease your body's ability to fight infection. It is a delicate balance to give you enough medication to limit your body's ability to reject your new organ, and its own ability to fight viruses, bacteria and other things you come into contact with on a daily basis. Because of this delicate balance, your immunosuppressive medication doses will be increased or decreased based on blood levels and how your body reacts to the medication. You must take these medications every day for the rest of the life of your transplant organ. Your risk for rejection is much higher if you do not take your medications as prescribed.

### Immunosuppression

There are a variety of different medications that can be used to suppress the immune system and prevent rejection. Most patients take at least 2 or 3 of these special medications. The Tulane Abdominal Transplant Institute has developed our own guidelines for immunosuppressive medications. We also tailor these guidelines to individual patient's needs when appropriate.

The main immunosuppressive medication is either Prograf (Tacrolimus) or cyclosporine (Neoral). These are the most important medications in the prevention of rejection. Sometimes Rapamycin (Sirolimus) is used in place of or along with Prograf or Neoral; this is usually done to help avoid side effects from the other immunosuppressants.

Steroids have always been used to prevent rejection in transplant patients. Gradually the dose of steroids you take is decreased (usually during the first 3 months after transplant). In some cases we consider early withdrawal from steroids or using no steroids at all in patients who have had bad side effects. In our experience, this small amount of steroids is an important part of preventing rejection and most patients have very few side effects at such small doses.

Another type of immunosuppressive medication that you take is called Cellcept or Myfortic. Research shows that patients who take this type of medication in addition to the other immunosuppressants will have transplanted organs that work better for longer.

This method of using a combination of medications helps to decrease the possible side effects from any 1 medication.

### Other Meds

We prescribe other medications for our transplant patients that include antibiotics to prevent infection, blood pressure medications, and medications to prevent stomach ulcers that may be caused by the new medications.

Your blood pressure medication may be changed after transplant depending on the type of medication you used. Some blood pressure medications do not work as well after transplant or some may need to be changed due to side effects.

## **Special Considerations**

### Rejection

Rejection occurs when your immune system discovers your new organ and sees it as foreign and tries to attack it. Your body's response is similar to what happens with infections. Your white blood cells try to attack and destroy your new transplant organ. Rejection is most common within the first six months after transplant, but it can occur at any time. Rejection is often treatable, especially when caught early. Having rejection

does not mean that you will lose your transplant as long as you receive treatment as soon as possible.

If your transplant team suspects that you have rejection, they may do additional tests such as repeating your blood work, obtaining an x-ray study or ultrasound of your transplant, and, in many instances, also a biopsy of your transplant. Most patients are hospitalized whenever rejection is suspected in order that these tests may be completed as soon as possible and that treatment is not delayed.

Rejection is often determined on your routine blood work. This is one of the most important reasons to get your laboratory tests regularly as directed by the transplant center.

Some signs of rejection are:

1. Fever over 100.5°
2. Flu-like symptoms: chills, aches, pains, fatigue, headaches, nausea, and vomiting
3. Fluid retention with weight gain, swelling, increased blood pressure
4. Pain, tenderness or fullness over the area of your transplant
5. High blood sugar

The treatment of rejection is additional immunosuppression which can come in several forms depending on how severe your rejection is. In addition, your maintenance immunosuppression doses may be adjusted by the transplant team.