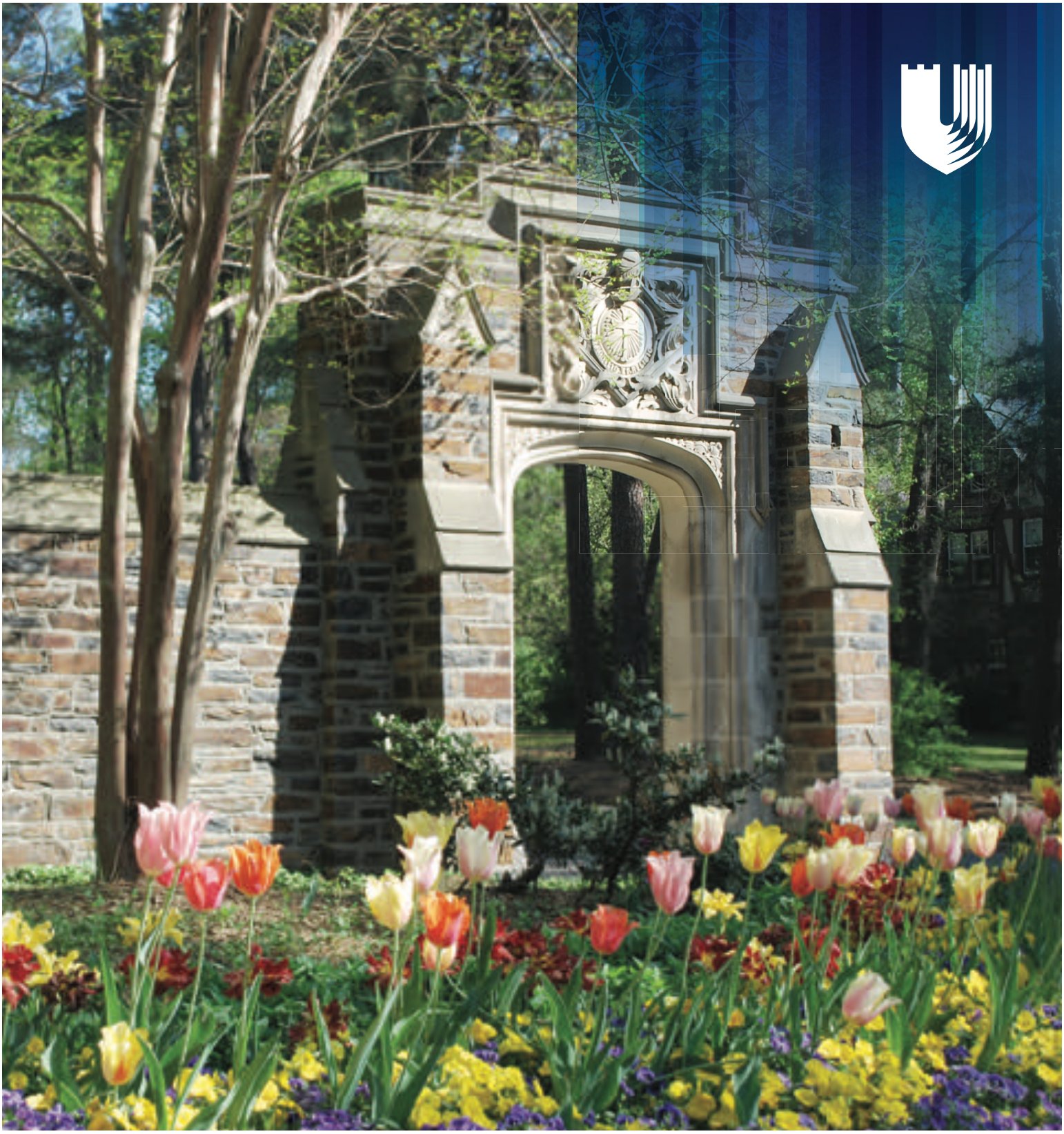


KIDNEY TRANSPLANT PROGRAM

Before your transplant

Duke Transplant Center

Table of Contents

Welcome to Duke Kidney/Pancreas Transplant Center!

You are here today seeking kidney/pancreas transplant and we are here to serve as your guide for understanding your kidney disease, how to get on the transplant list and the follow-up needed to stay on the transplant list. This booklet will guide you through the various phases of transplant and provide additional resources for transplant.

Our hope is that you will use this booklet as your transplant resource to find answers to your questions. If you are unable to find what you are looking for, we are always available as a resource for you.

Duke Transplant Center

Toll free:	1-800-249-5864
Local number:	(919) 613-7777
Fax number:	(919) 668-3897
USPS:	DUMC Box 102347 Durham, NC 27710
UPS/FedEx:	330 Trent Drive Durham, NC 27710
Transplant Clinic:	40 Duke Medicine Circle Suite 2B/2C Durham, NC 27710

Transplant Coordinators

Today you will be assigned a pre-transplant coordinator to serve as your personal resource through the transplant process. All transplant coordinators are nurses that are trained in the field of transplant. Your transplant coordinator will be your point of contact during the entire transplant process.

My Pre-Transplant Coordinator: _____

Once you are transplanted, your transplant coordinator will change to our inpatient transplant coordinator during the course of your hospital stay.

Inpatient Transplant Coordinator: _____

Once you are discharged, you will be assigned a post-kidney transplant coordinator. This coordinator will follow you for the remainder of your time as a transplant patient.

My Post-Transplant Coordinator: _____

Once you identify a living donor, your donor will be assigned a separate transplant coordinator from your assigned coordinator. Similar to the process for recipients, donors will have a coordinator that works with them to determine if they are a candidate for donation.

Kidney Function

Normal Kidney Function

Regulates

- Blood pressure
- Water/fluid
- Electrolytes: Potassium, glucose, sodium, phosphorus, calcium

Filters/Eliminates waste

Hormonal functions

- Sends a signal to the bones to stimulate the production of red blood cells.
- Works with the parathyroid gland to regulate the amount of calcium and phosphorous in the body.

Fischer, H. (2013). Cross section of a kidney. Retrieved from https://www.drugabuse.gov/publications/health-consequences-drug-misuse/kidney-damage

Kidney Dysfunction

With kidney dysfunction, the kidneys slow down and eventually stop working. This dysfunction can be caused by several disease processes including high blood pressure (hypertension), high blood sugar (diabetes), polycystic kidney disease, kidney cancer (renal cell carcinoma) and many more. The most common causes of kidney failure are diabetes and hypertension.

Treatment Options

Dialysis

- Dialysis takes over a portion of the kidneys' function and helps regulate and filter electrolytes (salts) and water. While your native kidneys work continuously (every day, every hour), dialysis is only completing these functions for a few hours, 3-4 times a week. Dialysis does not contribute to the hormonal functions performed by functioning kidneys; most dialysis patient will require a medication called erythropoietin to help with blood counts and vitamin D and phosphorus binders to help with bone health.

Kidney Transplant

- Kidney transplant is also a treatment, not a cure to kidney disease. Whatever health problem caused your kidney failure will not necessarily go away with a kidney transplant. A kidney transplant will continuously filter and regulate your blood. With a good functioning kidney transplant, you will be getting blood filtering/cleaning around the clock, which often helps patients maintain more consistent amounts of fluid in their bodies, better blood pressure control, improved blood counts, etc.

Transplant Candidacy

Kidney Transplant Selection Criteria and Suitability

Not everyone will be a candidate for transplant. We assess and review you as a candidate through our evaluation process to ensure it is safe and beneficial for you to receive a kidney transplant. We want to enhance the quantity and quality of your life. If it is determined that a kidney transplant would achieve that goal, then we are happy to get you listed. However, there are situations where a kidney transplant would not benefit you or improve your quality of life and in those instances you would not be deemed a transplant candidate.

Kidney Inclusion Criteria

In order to be considered for kidney transplant you must meet the following criteria:

- Expressed interest in transplant
- eGFR* $\leq$ 20mL/min/1.73m2
- For **deceased donor** recipients, legal resident of the Unites States (citizen or legal alien)
- If patient has HIV, must have CD4* count consistently > 200 and clinical clearance by Duke Infectious Disease physician
- Patients > 70 years old must have a potential living donor or one or more years of dialysis.
- Presence of a consistent and reliable support system, enabling the patient to obtain anti-rejection medications after transplant and providing reliable transportation.
- Ability to arrive at Duke Hospital within 6 hours ground travel time of initial notification.
- Candidates must demonstrate financial resources sufficient to support post-transplant care (Including, but not limited to medication costs, travel and lodging expenses, and medical devices)

* See glossary

Kidney Exclusion Criteria

If you meet any of these criteria you may be excluded from kidney transplant:

- A history of cancer for which the type or stage would compromise patient or kidney graft survival after transplantation.
- Body mass index (BMI) > 40
- Patient with liver disease who has not been cleared by the Duke Hepatology team.
- Active substance abuse (alcohol or other)
- Inability or unwillingness to perform self-catheterization in the setting of an unsatisfactory urinary drainage system
- Persistent non-adherence with medications, dialysis treatment, and/or medial recommendations
- Any cardiac condition that would make transplant surgery unsafe or that would compromise post-transplant survival.
- Transient ischemic attack or stroke within the last 6 months
- Severe restrictive or obstructive pulmonary disease
- Systemic infection
- Non-healing ulcer or wound
- Medical or psychosocial risk factor(s) that make transplant surgery unsafe.
- Untreated or uncontrolled psychiatric disorders that would negatively impact the patient's ability to care for self.
- Patients in an institutional setting that cannot meet the requirements outlined in the criteria above
- Deconditioned state or degree of frailty that would prevent the patient from safely tolerating surgery or complications after surgery in the presence of immunosuppression.

Pancreas Selection Criteria

In order to be considered for pancreas transplant you must meet the following criteria:

- Expressed interest in transplant
- Age 21-55 years
- Intended recipient must be post kidney transplant or have experienced life-threatening complication of Type I Diabetes.
- Confirmation of Type 1 diabetes (serum C-peptide level < 1).
- Legal resident of the United States (citizen or a legal alien).
- Estimated GFR* > 60 ml/min/1.73 sq meter (native kidneys or renal allograft).
- If patient has HIV, must have CD4 count consistently > 200 and clinical clearance by Duke Infectious Disease physician
- Candidates must demonstrate financial resources sufficient to support post-transplant care (including, but not limited to medication costs, travel and lodging expenses, and medical devices)
- Ability to arrive at Duke Hospital within 6 hours ground travel time of initial notification.

Kidney/Pancreas Selection Criteria

In order to be considered for kidney/pancreas transplant you must meet the following criteria:

- All inclusion criteria listed for Pancreas
- GFR* < 20 ml/min/1.73m^2

Kidney and pancreas inclusion and exclusion criteria are general guidelines used by our transplant team. Every patient is considered on an individualized basis and the decision to list or not list is based on an overall assessment of the patient.

Alternatives to Transplant

Dialysis and continued medical management.

*See glossary

Evaluation Process

Physical Testing

A series of studies will be required to determine your overall health and ability to survive after transplant. You will be given a list of items to complete at the end of your evaluation visit today. Your coordinator can assist in scheduling necessary testing here at Duke or you may make arrangements to get them scheduled at a facility closer to home. Some of these studies may include:

- CT scan
- Stress test
- Echocardiogram
- Chest x-ray
- EKG

Routine Health Maintenance Cancer Screening

As part of your evaluation, we require you to keep your cancer screenings up to date. This will be your responsibility to maintain through the transplant process. As these screenings are needed whether you are a transplant patient or not, these screenings are **scheduled by you** with your local providers. You can work with either your dialysis center or your nephrologist to get these scheduled if this is your first time doing so.

Mammogram

- Females > 40 years old, required yearly or as directed by your physician

Pap smear

- Females > 18 years old, required every one to three years or as directed by your physician

Colonoscopy

- All patients > 50 years old, required every ten years or as directed by your physician

Follow Primary Care Provider (PCP) recommendations; they are your primary physician. We are your transplant team. We will follow you for your transplant needs only. If you have other issues or health problems that need to be addressed, you should refer to your primary care provider (PCP).

Psychosocial Evaluation

Our social workers will meet with you today to assess your ability to cope with the many stresses associated with transplant. They will contact your dialysis center to better understand your adherence with dialysis and their recommended medical regimen for you. This will give us insight into your ability to follow a complex & stressful treatment plan. Our social workers will also work with you to help you identify your caregiving team.

- Need for social support and care giving
    - A social support system is required for transplant. This includes two caregivers that can provide assistance with transportation, new medications, emotional support and wound care. They need to be aware that this is a 24/7 time commitment for several weeks after your transplant.
- Lifelong immunosuppression
    - It is necessary for you to follow a strict medical regimen after transplant, including monitoring the effects of medications and taking your immunosuppression medications consistently.
- Financial considerations
    - You need financial coverage for immunosuppression drugs, related expenses such as travel, lodging and medications not covered by insurance.

Transplant Team Members

Transplant Nephrologist
A transplant nephrologist is a physician who specializes in kidney disease and kidney transplants. They will evaluate your current medical condition and your kidney disease. They will discuss whether transplant will be safe for you or if dialysis is the better alternative.

Transplant Surgeon
A transplant surgeon is the physician who will perform the kidney transplant operation. They will discuss whether a transplant is right for you from a surgical perspective.

Social Worker
A social worker will meet with you to evaluate your ability to cope with the many stresses of associated with transplant. They may require follow-up visits with them or other providers to ensure a complete assessment.

Finance Coordinator
A financial coordinator will explain your insurance coverage and the cost of the transplant procedure, as well as discussing the cost of post-transplant medications. You may be asked to apply for additional insurance coverage or to save or fundraise funds for post-transplant costs.

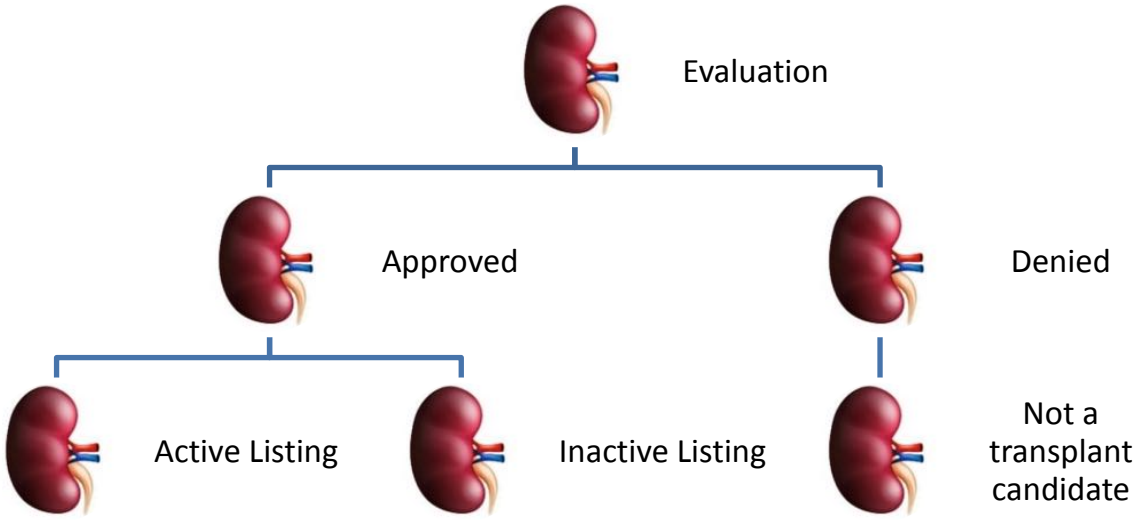
Pharmacist
Pre-transplant, a pharmacist is available as a resource to you while you learn about immunosuppression medications. Post-transplant, a pharmacist will meet you and educate you on your specific medication regimen and the side effects.

Dietician
A dietician is available as a resource to you for dietary education. They will make recommendations about the best diet, exercise and weight for you to be the optimal transplant candidate.

Medical Psychologist
A medical psychologist is a mental health expert with whom we may ask you to speak about the stress or anxiety you may experience during the transplant process. They are a resource to help with adherence, compliance and adjustment to kidney transplant

Evaluation Outcome

Once you have completed all the studies and appointments required for your evaluation, your coordinator will present your case to the selection committee. The selection committee is composed of all the members of the transplant team. Once a decision is made, you will be notified by letter of the decision.



Listing Process

If our multidisciplinary selection committee decides that you are a candidate for kidney transplant, you will be placed on the national waiting list for kidney transplantation after your insurance company gives us authorization to put you on the list. This means you will begin accruing wait time on the transplant list for a deceased donor kidney.

All transplant candidates in the United States are listed in a national donor computer system through the United Network of Sharing (UNOS). Carolina Donor Services (CDS) works with UNOS to coordinate transplants in this area. Deceased donor kidneys are matched with recipients according to the following criteria:

- Blood type: O, A, B or AB
- HLA antigens: Proteins located on cells of the kidney and blood cells. You are tested for 6 of these and they are the basis for matching your donor kidney to you. If your transplanted kidney has some of these proteins (antigens) then your body is less likely to see this kidney as foreign and reject it. We require a monthly blood sample (serum sample) while you are listed to ensure we have material for crossmatches when an organ becomes available.
- Length of time on the waiting list varies for each patient according to blood type, dialysis time, and other factors.
    - Each blood type carries an approximate waiting time:
        - **O**→ 5-7 years
        - **A**→ 3-5 years
        - **B**→ 6-7 years
        - **AB**→1-7 years

If you are on dialysis, once you are listed your waitlist start date will be your dialysis date. If you are not on dialysis, your waitlist start date will be the date we list you.

At the time of listing you are listed either ACTIVE (status 1) or INACTIVE (status 7) on the transplant list. No matter which status you are listed under, you will still begin accruing time on the transplant list.

- Status 1: Active on the list and ready to receive organ offers at any time
- Status 7: Inactive on the list, not eligible to receive organ offers, but still accruing time

UNOS Multiple Listing and Transfer of Time Process

Included in your packet is the UNOS booklet on multiple listing.

Multiple listing involves registering at more than one transplant center. Wait time can vary from one section of the state depending on the number of candidates on the list in that area. For example in this area, we share our list with 3 other transplant centers so listing at two of those offers no benefit as you already are on the list. We share our organ offers with three other transplant centers in our organ procurement organization (OPO):

- Wake Forest Baptist
- Vidant
- UNC

If you are interested in multiple listing, have your dialysis center or kidney doctor send a referral to the center you are interested in.

Types of Kidney Donors

High KDPI Score Donors

Every kidney offered for transplant has a Kidney Donor Profile Index Score (KDPI). This is a percentage score that ranges from 0 to 100. The score is associated with how long the kidney is likely to function when compared to other kidneys. For example, a KDPI score of 20% means that kidney is likely to function longer than 80% of other available kidneys. The score is based on the characteristics of the donor: age, height, weight, ethnicity, cause of death, high blood pressure, diabetes, exposure to hepatitis C, serum creatinine and age. This score is ultimately used to describe the function of the donor kidney.

- KDPI 0-20% is used to describe kidneys that are likely to function the longest
- KDPI 21-84% is used to describe kidneys that are likely to function well
- KDPI > 85% is considered a High KDPI score. High KDPI score kidneys are offered for your consideration. You are not required to accept this type of kidney, it is optional. Due to the higher score, these kidneys tend to last less time than those < 85% KDPI. However, after careful review by our team, they will work well enough to get you off of dialysis. Depending on your circumstances, we may recommend that you consider these types of offers.

If you are offered an organ from a donor that has KDPI > 85 %, this will be discussed with you at the time of the organ offer and you can decline the offer with no penalty.

Public Health Service (PHS) Increased Risk Donors

An increased risk donor is a donor whose behavior or past medical history places them at a greater risk of having a chronic viral illness that could be transmitted through organ donation such as hepatitis, Human Immunodeficiency Virus (HIV) or other infections. During the donor screening process, donors or donor families answer questions about the donor's behavior. The Center for Disease Control (CDC) requires donors to be listed as increased risk if any of the following are answered "yes":

- Men who have had sex with another man in the preceding 5 years.
- Persons who report non-medical intravenous (IV), intramuscular (IM) or subcutaneous (SQ) injection of drugs in the last 5 years.
- Persons with blood disorders such as hemophilia who have received human-derived clotting factors.
- Men and women who have engaged in sex for money or drugs in the last 5 years.
- Persons who have had sex in the preceding 12 months with any person described in 1-4 above or with a person known or suspected to have an HIV infection.
- Persons who have been exposed in the last 12 months to known or suspected HIV-infected blood by sharing of needles, blood transfusions, or contact with an open wound.
- Inmates of any correctional system

Even when a potential donor is not rated increased risk, there is no guarantee that a donor is disease-free. Even though a donor may not be considered CDC increased risk, family members of deceased donors may not know about the donor's increased risk behaviors or the living donor may not disclose their behavior.

If you are offered an organ from a donor that is in the increased risk category, this will be discussed with you at the time of the offer and you can decline the offer with no penalty. At the time of a kidney offer from an increased risk donor, testing is performed on the donor's blood, looking for infection. If the test is positive (indicating infection), you will not get an offer from us. You would only hear from us if the test is negative (risk of test missing an infection is < 0.01%)

Living Donors

There are two types of kidneys that you may receive during for your kidney transplant:
Deceased donor—a person who has died and had their organs donated for transplant
Living donor—a person that is healthy enough and willing to donate their kidney

So far we have discussed deceased donor kidneys; those are kidneys that are allocated from the transplant list. However, we can also transplant living donor kidneys.

Living Donor kidney transplants differ from deceased donor transplants for several reasons:

- Decreased wait time to be transplanted (in place of waiting for around 5 years for a deceased donor kidney transplant, you will only have to wait for as long it takes to get you and your donor cleared.)
- Surgery can be planned at a time convenient for both the donor and recipient
- A living donor kidney transplant will likely last longer (usually around 5 to 6 years longer) depending on how well you care for yourself
- A living donor kidney is more likely to work immediately after transplant resulting in fewer complications for you after your transplant.
- A living donor kidney is likely to work better than a deceased donor kidney transplant meaning that it will filter more efficiently which will likely result in you feeling better for longer after your transplant.

Your living donor typically has a 1 to 2 day hospital stay, with a follow up appointment within 7 days after discharge. On average the living donor may return to work 4-6 weeks after discharge, depending on the type of work. After donation, living donors can resume their normal, pre donation life. In other words, donation is very safe for the donor.
Any person can be screened to be a potential donor; donors do not have to be related to you (anyone can donate, including family members, but also friends, members of social groups, etc.). However, living donors must also meet certain selection criteria, for their safety and yours.

Who are some potential living donors for you? List as many as you can think of:

_____ _____ _____

_____ _____ _____

_____ _____ _____

Once you have identified your living donor, don't ask them any questions about their health; let us do this as we know what questions to ask and what a safe response is for your donor and yourself. Your donor needs to call our living donor team to start the screening process. They will be assigned their own living donor coordinator and work with them to determine if they are a candidate to donate.

Potential Living Donors:

1. **Call (919) 613-7777**
2. **Identify yourself as a potential donor**
3. **Provide recipient name and date of birth (needed to link insurance information)**

If living donors prefer, they can complete our living donor form and fax it instead of calling to be screened: **https://redcap.duke.edu/redcap/surveys/?s=9EHPAAPMFM**

There is a great deal of information available on the web about living donation. Below are a sampling of web sites with additional information about living donation, how to find a living donor, etc. We cannot verify that all of the information on these sites is completely accurate, but it will serve as an information guide. If you have more questions, please call & we will get your questions answered.

https://www.kidney.org/transplantation/livingdonors
The National Kidney Foundation (NKF) is one of the largest kidney disease advocacy groups in the United States. This link provides useful information for living donors and recipients, including answers to commonly asked questions, myths and concerns about living donation.

http://www.kidneyregistry.org/living_donors.php?cookie=1
The National Kidney Registry (NKR) is an organization that helps facilitate kidney exchange (a process in which pairs of incompatible living donors and recipients can swap organs). This link has good general information about living donation and paired exchange.

https://www.americantransplantfoundation.org/about-transplant/living-donation/becoming-a-living-donor/
The American Transplant Foundation (ATF) is a group that helps living donors with non-medical expenses after donation. This reference provides great information about living donation; the information is mostly for people considering donation, but there is some information for recipients about living donation as well.

Waiting Period

Follow-up While Listed

All listed patients at our center are generally seen in clinic once per year for an annual update appointment to ensure that your health status remains good. You will be seen by either a transplant surgeon or transplant nephrologist and will then meet with a social worker, financial coordinator and transplant coordinator. Once you are listed, make sure you are always prepared for transplant, as you could be called at any time. Make sure you have a "transplant bag" packed with a change of clothes, any personal items needed, copies of updated insurance cards, medications list and disability letter (if applicable).

List Management

While you are listed, you need to notify your transplant coordinator of any changes to health status, contact information, caregivers, insurance, hospitalizations or blood transfusions.

Availability/Communication

- You need a cell phone with working voicemail available.
- When you are called to come to the hospital for your transplant, it is vital that we be able to find you quickly, at any time of the day or night. You will need to have phone capability with voice mail and you will need to check this as you could miss an organ offer call. You will need to provide other phone numbers where you can be reached, as you can receive an offer anytime of the day of night. Please keep the transplant coordinator updated about any changes in phone numbers and contact numbers that you can be reached at. Also, let your coordinator know when you are out of town or traveling.
- You will need to have a reliable plan for getting to the hospital on short notice. You will also be coming back to the clinic as often as once a week for one to two months after your transplant. You need to plan who can help you get here. Do not rely on options such as Medicaid Van as they will not be able to get you here in a timely and reliable fashion. Regular follow up in clinic is one of the most important parts of a successful transplant.

Waitlist Inactivation or Removal

Changes in health status, insurance, and/or psychosocial status may result in change in status or removal from the waitlist. If you are changed from active to inactive, you will still accumulate time, but you will not be receiving any organ offers. This status is used when a patient has a temporary problem that would make transplant unsafe. As soon as that problem is resolved, you can be converted back to active status. If you have a problem that is not anticipated to improve and that will make transplant unsafe, you may be removed from the waiting list altogether. You will be notified by letter if you are removed from the waitlist.

Kidney Transplant Surgery

Organ Call

A transplant coordinator will call you when you match a donor. They will ask screening questions about your health, insurance, and dialysis (if applicable) treatments. You may be told not to eat or drink after a certain time. You will also be told where you are on the list for a particular offer.

Pre-Operative Work-Up

- **Crossmatch:** Blood testing to ensure kidney is a match for you
- **Delays:** There may be a wait time period as the organs have to be removed, complete crossmatch with your blood and the donor's blood to check for any reaction.
- **Dry Run:** There is a possibility you may come to the hospital and not receive the transplant due to organ quality or a kidney that is not a good match for you.

Length of Surgery

- Kidney transplant surgery is normally about 4-5 hours, with placement of the kidney in the right or left groin area. Most often, your own kidneys will not be removed and only one kidney will be transplanted.
- The kidney will be attached in three places (see the figure). First, the donor artery is connected to your **iliac artery** (the artery going to your leg). Then, the donor vein is connected to your **iliac vein** (the vein coming from your leg). Finally, the **ureter**, the tube that drains urine to the bladder, is connected to your bladder. After all the connections are made, the surgical incision is closed and you are taken usually to the Post Anesthesia Care Unit (PACU), the Surgical Intensive Care Unit (SICU), or a stepdown unit.

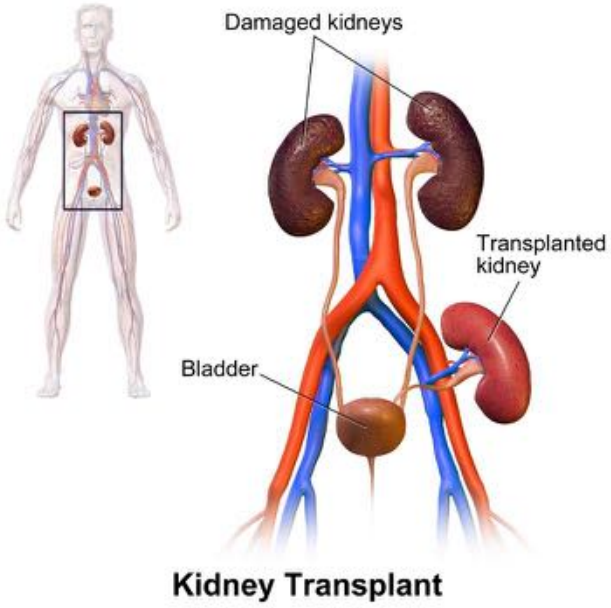


Diagram Of Abdomen Organs With A Pancreas And Kidney Transplant Kidney Transplantation (2017). Retrieved from: https://humananatomyly.com/diagram-of-abdomen-organs-with-a-pancreas-and-kidney-transplant/diagram-of-abdomen-organs-with-a-pancreas-and-kidney-transplant-kidney-transplantation/

Post-Op Recovery

ICU or Stepdown Unit, average stay 4-6 days

- You will receive IV fluids with close monitoring of fluid status and urine output. Your urinary catheter will remain in for 3-4 days. You will be out of bed the day after surgery. The transplant team (surgeon, nephrologist, advanced practice provider, coordinator, case manager, pharmacist and others) will be seeing you every day during your recover.

Surgical Risks

Any of these are potential complications after kidney transplant:

- Blood clots in leg, lungs, or renal vessels
- Bleeding
- Wound infection
- Pneumonia
- Stroke
- Heart arrhythmia or failure
- Delayed graft function (during which you may continue to require dialysis)
- Graft failure

Pancreas Transplant Surgery

A pancreas transplant can be done for patients with Type 1 (Insulin-dependent) diabetes who have renal failure or are close to needing dialysis. At Duke we only do whole pancreas transplants which must come from a **deceased** donor.

These can be done two ways:

1. Combined kidney and pancreas transplant: Both the kidney and pancreas come from a deceased donor and are transplanted at the same time.
2. Pancreas after kidney: This occurs when the patient receives a living donor kidney first and then has a pancreas transplant afterwards.

As in the kidney transplant, a final blood test will be done to be sure the pancreas is compatible with you. Your incision will be up and down the middle of your abdomen. Your own kidneys and pancreas will not be removed. Three connections also connect your new pancreas. The donor's artery and vein from the pancreas are connected to your artery and vein. Then the pancreas is attached to your small intestine so enzymes from the pancreas can drain through your GI tract. This surgery can take up to eight hours. Once your incision is closed, you will be taken to the Surgical Intensive Unit. You will be in the hospital for seven to ten days.

Post-Op Recovery

ICU or Stepdown Unit, average stay 7-10 days

- You will receive IV fluids with close monitoring of fluid status and urine output. Your urinary catheter will remain in for 3-4 days. You will be out of bed the day after surgery.

Surgical Risks

Any of these are potential complications after kidney transplant:

- Blood clots in leg, lungs, or renal vessels
- Bleeding
- Wound infection
- Fluid collections around pancreas
- Pneumonia
- Stroke
- Heart arrhythmia or failure
- Delayed graft function (during which you may continue to require dialysis)
- Graft failure

What to Expect After Transplant

Post-Transplant Care

We require adherence to a strict medical regimen

- You will need to follow the instructions given to you by our transplant care team to decrease your chances of rejecting your kidney or having other problems.
- You will be asked to record your fluid intake and output, blood pressure and temperature each day. If you have blood sugar control issues (diabetes), you will be asked to record your blood sugar up to four times per day.

Frequent Clinic Visits

You will have frequent clinic visits in the beginning to have laboratory values checked for medication levels and to monitor kidney function. Your first visit will be within seven days after your discharge. After your first visit, you will be seen weekly for the first month, and then appointments will be spaced out further. You may also be asked to complete a lab appointment without seeing a provider once you are post-transplant. We need you to keep in close contact with us regarding changes in your health status.

Diet

The renal diet you are currently following may no longer apply after your kidney transplant, as your kidney will now regulate your fluid and electrolyte levels. You will however, need to continue to follow any dietary recommendations that you currently do for other disease processes, such as diabetes. There are some interactions with certain foods, drinks, and medications that can alter the anti-rejection drug levels. We have included some of this information below, but you will receive a comprehensive education session during your hospitalization with specific nutrition instructions.

- First 6 weeks after transplant
  - You may need to eat smaller amounts of food more frequently (4-6 times per day). Eat a healthy diet with plenty of protein (found in red meat, chicken, & fish, but also in plant sources, like beans, lentils, & nuts) and continue to limit sodium <2300 mg per day.
  - Increase fluid intake by drinking water or unsweetened beverages. If blood glucose levels are high, limit juices to 4 oz. per day. Reduce sugar intake to 28 grams (4 teaspoons) per day. Dietitian appointments are available as needed.
  - Potassium and phosphorus diet restrictions are usually no longer needed with good graft (transplanted kidney) function. However, the transplant team may need to make restrictions for a short period of time.
- Food Safety and Drug: Nutrient Interactions
  - The following foods are **NOT** recommended after transplant due to concerns with decreased immune function:
    - No grapefruit or grapefruit juice, including sodas that may contain this. Examples: Fresca, Sundrop, Sunny Delight, Squirt, Ruby Red Squirt, Citrus Blast.
    - No pomelo fruit
    - No undercooked or raw meat, fish, poultry, or over easy /runny eggs
    - No raw sprouts: alfalfa, bean or other sprouts
    - Wash all raw fruits/vegetables well
    - No unpasteurized (raw) milk or cheeses
    - Cook all deli meats, hot dogs, and luncheon meats to steaming hot
    - No unpasteurized pates or meat spreads
    - Avoid all herbal supplements

Medications

- Immunosuppression is a concept with which you need to become familiar in order to understand your care. Your immune system is a part of you that is able to recognize when foreign substances (anything that might make you sick, like an infection) enter the body. Throughout your life, your immune system has been fighting off foreign substances by recognizing and destroying foreign matters such as bacteria and viruses.
- Your transplant organ (kidney and/or pancreas) is new and foreign to your body. If something is not done to stop the process, your body's immune system will recognize your new kidney or pancreas as foreign and soon begin to destroy them. Preventing this natural response of the body's immune system is called **immunosuppression.**
- Immunosuppression medication is given to transplant patients in order to decrease the body's ability to recognize and destroy foreign substances. Without these medications, rejection of the kidney would occur. Therefore it is critical that you take your medications exactly as prescribed for as long as you have a transplant. **If you stop taking these medications, your body will reject the transplant organ.** Every episode of kidney rejection is likely to decrease the life of your kidney.
- Being on immunosuppressive medications (anti-rejection) does mean that you will be at greater risk for developing infections. It is important to take some sensible precautions to avoid infection, including good handwashing (the most important precaution), limiting exposure to potential infectious sources and calling at the first sign of infection. All of these will decrease your risk of serious infection.
- The anti-rejections drugs are expensive and have serious side effects. If you have limited insurance coverage for medications, you will need to fundraise for future costs. If you have a change in insurance or an inability to cover medication costs, you must contact your transplant coordinator immediately.
- Other risks associated with immunosuppressant medications:
  - Increased risk of malignancy (cancer)
  - New onset diabetes mellitus
  - Nephrotoxicity (direct irritation to the kidney)
  - Hypertension (high blood pressure)
  - Bone marrow suppression (low blood counts)
  - Neuropathies (nerve irritation that can cause tremors in the hands, nerve pain in the legs, and changes in brain function)

One Year Patient and Graft Outcomes

- SRTR (Statistics included in your transplant packet)
- These are our current statistics and that change every 6 months. Once you are listed, you will receive a copy in the mail in January and July of each year.

Transplant Advantages: Years of Life Gained

Patient Age (years)	Number of Years Expected to Live on Dialysis	Number of Years Expected to Live with a Transplant	Years of Life Gained with a Transplant
45-49	7 years	18 years	+ 11 years
50-54	6 years	16 years	+ 10 years
55-59	6 years	13 years	+ 7 years
60-64	5 years	11 years	+ 6 years
65-69	4 years	9 years	+ 5 years
70-74	4 years	8 years	+ 4 years
75-79	3 years	6 years	+ 3 years

Resource Directory

We want to help you and your family deal with concerns that may arise before or after your transplant. Your social worker, transplant coordinator, and physician can give you information on resources for your particular needs. The following are a list of resources that may be useful. Please note that there are hundreds of websites about kidney disease and transplantation. We recommend only those we know will provide reliable information.

Duke Health
www.dukehealth.org

United Network for Organ Sharing
1.888.894.6361
www.unos.org

Carolina Donor Services
1.800.200.2672

Organ Procurement & Transplant Network
optn.transplant.hrsa.gov

American Kidney Fund
1.800.729.6682
www.kidneyfund.org

National Kidney Foundation
1.800.622.9010
www.kidney.org

American Diabetes Association
1.800.DIABETES
www.diabetes.org

Insulin Free World
www.insulin-free.org

Transplant Information
www.transweb.org

National Foundation for Transplant
1-800-489-3863
www.nft.org

Social Security Disability Hotline
1.800.638.6810

Medicare
1.800.MEDICARE (1.800.633.4227)
www.medicare.gov

Social Security Administration
1-800-772-1213

Veteran's Administration Benefits Office
1-800-827-1000

Veteran's Affairs Medical Center (Durham)
919.286.0411

NC Division of Veteran's Affairs
919.733.3851

NC Division of Vocational Rehabilitation
919.733.3364

Pharmacies

Many recipients must utilize special transplant pharmacies to obtain their medications. The benefits of such pharmacies are that they file insurance claims for you (including Medicare when eligible) and offer fast Federal Express services and competitive prices. You should check with your insurer to determine which one you are allowed to use. The Duke Cancer Center Pharmacy is our specialty pharmacy here at Duke. If allowed by your insurance company, your first 30 day supply of medications post-transplant will be filled at this pharmacy.

Patient Lodging

If you need assistance with travel planning you may contact Concierge Services: (919) 681-4947

Parking/Transportation

Hospital and clinic garage parking fees are based on an hourly rate. Discount parking books are available for inpatients and their families and can be purchased at the parking office or at the hospital gift shops. Please call the Medical Center Traffic Office at 919-684-5773 for more information.

Valet parking service is available at DUH, Duke Clinic, Duke Emergency Services, and Morris Cancer Clinic.

Duke University Hospital Valet Parking
M–F, 7 am to 10 pm; daily rate
Saturday – Sunday, 10 am–6 pm; daily rate

Duke Clinic Valet Parking
Entry 1 (main entrance)
M–F, 7:30 am–6 pm; daily rate

Duke University provides free bus service to all campuses and the Medical Center for students, employees, patients, and visitors. All routes served by Duke Transit are accessible to persons with disabilities. Accessible Duke University buses can be identified by the international accessibility symbol on the side of each bus.

Transit Information	Parking Services
919.684.2218 or 919.681.4001	919.684.5773

Glossary

BMI - The body mass index (BMI) is a screening tool to identify possible weight problems. It provides an estimate of body fat based on height and weight.

CD4 - This is a test used to measure the strength of your immune system. CD4 cells are a type of white blood cell that fights infection, and they play an important role in your immune system.

Catheterization - emptying urine from the bladder with a small, flexible tube (catheter). The bladder is an organ in the body that stores urine.

EKG - Electrocardiography (EKG or ECG) is a test used to check the heart. It looks at your heartbeat and heart size, and can tell if you have had a heart attack. No electricity will flow into your body during the test.

Echocardiogram - This is a test which produces images of the heart by using sound waves. The echocardiogram is simple, painless, obtained within a short period of time and offers valuable information to your medical team.

GFR - Glomerular filtration rate (GFR) is a measure of the function of your kidneys. Glomeruli are tiny filters in your kidney that allow waste products to be removed from the blood, while preventing loss of important proteins and blood cells. The rate refers to the amount of blood that is filtered per minute. GFR is considered the most accurate way to monitor kidney status.

HLA - Human leukocyte antigens (HLA) are a group of proteins that help the body's immune system to identify its own cells and to distinguish between "self" and "nonself." Everyone has an inherited combination of HLA antigens present on the surface of his white blood cells. While not as unique as a fingerprint, the presence or absence of each antigen creates a one-of-a-kind HLA combination for each person. (This is important when someone needs an organ transplant, as the donor's HLA antigens must match up with the recipient's.)

PTH - Parathyroid hormone (PTH) helps the body maintain stable levels of calcium in the blood.

Stress Echo - An exercise echocardiogram is a test to see how well your heart can tolerate physical activity. You will need to walk on a treadmill for this test. An echocardiogram looks at how the heart moves. An exercise echocardiogram is also called a stress echocardiogram.

Notes and Questions