

D U K E K I D N E Y T R A N S P L A N T A T I O N

KIDNEY TRANSPLANTATION

Introduction

Welcome to the Kidney Transplantation Program at Duke University Medical Center. This booklet will give you some information about kidney and pancreas transplantation. Please feel free to ask us questions. The more you know, the better you will be able to assist in your care.

The kidney transplant program at Duke began in February 1965. Since that time we have done over 2100 kidney and kidney/pancreas transplants. We are constantly working to improve kidney transplantation for our patients and families.

For many of our patients and families, the prospect of having a kidney transplant makes them a little anxious and uncertain. This procedure involves surgery. We hope this booklet will help to answer questions and relieve some anxieties. If you have more questions please ask us.

D U K E K I D N E Y T R A N S P L A N T A T I O N

The Kidney Transplant Team

The Kidney Transplant Team is made up of a varied and experienced team of health care professionals. These include doctors, social workers, nurses, and financial counselors. Initially these professionals will help you decide if a kidney transplant is the right treatment for you. If and when you receive a transplant, the same group of professionals will take care of you.

Transplant Nephrologist

This doctor specializes in kidney disease and kidney transplantation. He or she will evaluate your current medical condition, your kidney disease and will discuss the option of kidney transplantation with you.

Transplant Surgeon

This is the doctor that performs the kidney transplant operation.

Transplant Coordinator

This nurse is the main contact person on the Transplant Team while you are waiting. He or she will discuss the overall course of events before, during, and after transplantation.

Social Worker

This specialist will assess your ability to cope with effects kidney transplantation will have on you and your family. The social worker will ask you about your family life, social habits, and financial concerns. He or she will also be a resource person for coping, and returning to work/school after your transplant operation.

Psychologist

A specialist in human behavior, your transplant psychologist may talk with you regarding the stress and anxiety you may feel during the transplant evaluation process. He or she may ask you to complete questionnaires that will help determine how you might adjust to a kidney transplant.

Financial Coordinator

This member of the transplant team explains your insurance costs and coverage of the transplant procedure and medications. They also discuss with you the importance of fund raising before your transplant surgery.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Kidney and Kidney/Pancreas Transplant Office Address:

DUMC Box 3876
Durham, NC 27710
Office Phone Number.....919-684-5859
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Transplant Team Members

Transplant Coordinators

Carolyn Boone, RN
Kidney Transplant

Donna Greenwood, RN
Kidney Transplant

Leslie Hicks, RN
Living Donor Evaluations

Jennifer Thompson, RN
Kidney Transplant and
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Jan Krueger, RN
Pediatric Transplants

Transplant Nephrologists

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Transplant Surgeons

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Bradley Collins, MD.....919-681-3855
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Transplant Social Workers

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Transplant Financial Coordinator

Sarah Lawton.....919-684-4176
Nancy Shelton919-681-6457
Shelley Williamson.....919-681-5959

D U K E K I D N E Y T R A N S P L A N T A T I O N

About Your Kidneys

The kidneys are two bean-shaped organs located in the lower back along either side of the spine. Normally everyone has two kidneys but can live a normal life with only one kidney. Besides making urine, the kidneys do the following jobs:

- 1) They take waste materials and extra fluid from the blood.
- 2) They help regulate blood pressure and make red blood cells.
- 3) They regulate fluids and chemicals needed by the body.

Kidneys can stop working for several reasons. The two most common causes are hypertension and diabetes. End-stage kidney disease is where no matter the cause kidneys stop functioning and normal function will not return. There are two ways to treat end-stage kidney disease: dialysis or kidney transplant. Since we are able to function normally with one kidney, kidney transplant involves surgically removing a kidney from another person and placing it into you. This new kidney will perform all the functions your diseased kidneys did. Some diseases can come back in a transplanted kidney. Remember: a kidney transplant will not cure your kidney disease, it only treats the disease, as does dialysis.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Evaluation

The evaluation portion of a kidney transplant consists of coming to Duke to meet the members of the Transplant Team. On your visit to Duke you will have an opportunity to meet the transplant coordinator, social worker and financial coordinator who will all talk to you about different aspects of kidney transplant. Initially we will draw blood, do an EKG, and chest X-ray. The transplant nephrologist will talk with you about kidney transplant and examine you. Sometimes depending on your health history other tests may be needed to clear you kidney transplant. If other tests are needed we will order these tests to be done at a later time.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Kidney Donation and Selection

There are two sources of kidney donation;

Living donors—a family member, friend, or a person you share an emotional relationship with.

Cadaveric—persons who have died and had their organs donated for transplant.

When the kidney transplant team decides you are an appropriate candidate for kidney transplantation, your name is placed on a national transplant waiting list. All transplant candidates in the country are listed in a national donor computer system through United Network of Sharing (UNOS). Carolina Donor Services (CDS) works with UNOS to coordinate transplants in this area. Donor kidneys are matched with recipients according to the following criteria:

- 1) blood type: (O, A, B, AB)
- 2) HLA antigens: proteins located on cells of the kidney and blood cells. You are tested for 6 of these and are the basis for matching. 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.
- 3) Length of time on waiting list

Before the donor kidney is accepted for transplant it is thoroughly evaluated. This evaluation of the living or cadaveric includes examination of the donor's medical history, social history, and lab tests. Donors are carefully tested to be sure as possible that they have no transmissible diseases, such as HIV, hepatitis, or cancer.

Each blood type carries an approximate waiting time:

O→ 5-7 years

A→ 3-5 years

B→ 6-7 years

AB→ 1-7years

If you have a living donor then the only waiting time is the time to get the donor evaluation completed.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Waiting for your Transplant

The waiting period for a kidney is so uncertain and is the cause of much anxiety, frustration, and discouragement. It is important to remember during this difficult time, that no one has any control over when donor kidneys become available. We urge you to be patient, learn relaxation techniques, and other resources to help cope with the stress and uncertainty of waiting for an available kidney. You will be seen at Duke about every 12- 18 months until you receive a transplant.

While you are waiting, we strongly encourage you to remain as active as possible. Regular physical activity or exercise will help build your strength and endurance in preparation for your transplant and increase your chances to do well afterward.

We also encourage you to continue working as long as possible. If you are unable to work while on dialysis, you can use this “waiting time” to take classes at local community college, contact your Vocational Rehabilitation office, and make other plans to return to the workforce after your transplant. Remember your eligibility for disability payments will likely be reviewed one to three years after transplant, and these benefits may end.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Preparing for a Transplant

We want to help you and your family prepare for your transplant. Making plans to deal with your needs before your transplant can reduce the amount of stress you will have to cope with during the recovery process. You will have to make some changes in your plan over time as your situation changes. Please keep us up to date on changes as they occur.

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 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. You need to plan who can help you get here.

The following questions are to help in planning for your transplant. Please think about these questions carefully:

1. How will you get to the hospital when you are called for a transplant?

2. Who will stay with you and help take care of you after discharge?

3. Who will take care of your home (pay bills, maintenance), children, and pets?

4. Who will pay for your transplant?

Insurance Medicare Medicaid ÿ Other

5. Who will drive you to Duke for clinic appointments?

D U K E K I D N E Y T R A N S P L A N T A T I O N

6. How much are your deductibles or co-payments? (How much will you be responsible for?)

7. How will you pay for medicines after your transplant?

8. Do you have concerns about your situation or your family in preparing for kidney transplant?

9. What questions do you want answered by the transplant team?

D U K E K I D N E Y T R A N S P L A N T A T I O N

Kidney Transplant

At Duke we perform cadaveric and living donor transplants. Cadaveric kidney transplant is the kind of transplant that happens when someone is declared brain dead and their family decides to donate. When you match a donor from the waiting list, the transplant coordinator will call you. He/she will tell you when to come to the Emergency Room at Duke Medical Center and when to stop eating and drinking. There will be a blood test done before you go to surgery to make sure the kidney will be compatible with you.

Once you arrive at the Emergency Room, you will be prepared for surgery. A chest x-ray, EKG, and blood tests will be done. You will be seen there by the transplant doctors who will examine you to make sure you are ready to go to surgery.

The living donor transplant differs in that the transplant comes from a living family member or friend. This surgery is arranged in advance and you will not come to the ER. Instead you and the donor will arrive the day of surgery at the Operating Room.

The surgery itself takes about four hours. An incision will be made above your groin on either the right or left side. Your own kidneys will not be removed and only one kidney will be transplanted.

The kidney will be attached at three connections. 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 incision is closed and you are taken usually to the Post Anesthesia Care Unit, the Surgical Intensive Unit, or a stepdown unit.

D U K E K I D N E Y T R A N S P L A N T A T I O N

What to expect during the hospital stay

Patients are usually in the hospital for 4-6 days. You will have an IV tube in your neck at first, then in your arm. Usually after kidney transplant, we have to give you lots of fluids for the kidney to work well. You will have a catheter in your bladder to drain urine from your new kidney. We will be monitoring you for signs of rejection from the kidney. Urine output is important as well your laboratory values to tell us how the kidney is doing.

Initially you may be receiving pain medication through your IV. As surgeries go, a kidney transplant is not very painful. You will soon be taking pain medications by mouth as well fluids and food. You will need to walk soon after surgery. You will be receiving anti-rejection medications after surgery. Once you learn your medications, tolerating food, walking, you will be ready to go home.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Pancreas Transplant

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

These can be done two ways:

1. Combined kidney–pancreas transplant: Both the kidney and pancreas come from a cadaveric 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 six 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.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Caring for yourself after the transplant

There are many issues to consider regarding follow-up care after kidney transplant. These include:

Medications: Now that you have a kidney transplant, you will have to take special medications for the rest of your life. These are anti-rejections drugs that are expensive and have some side effects. If you have limited insurance coverage for medications, you will need to fundraise for future costs.

Monitoring: You will be asked to record your fluid intake and output, blood pressure, temperature each day.

Health Habits: After the transplant, you will be expected to maintain a well-balanced diet, drink plenty of fluids, and exercise regularly to keep yourself in good physical condition.

Frequent Check-ups: You will need to return to Duke frequently for clinic visit. You will need to have laboratory values checked frequently. These can be done locally and results sent to us. We need you to keep in close contact with us regarding changes in your health status.

D U K E K I D N E Y T R A N S P L A N T A T I O N

Medication Costs

We just want you to realize how much a burden a transplant is for one with Medicare only. Even those persons with insurance coverage can face added costs. The cost of the immunosuppressant drugs after transplants are very expensive.

Two of the drugs required are approximately \$1000.00 a month for each drug and Medicare only pays 80% of these drugs for 44 months or $\approx 3\frac{1}{2}$ years. That is about \$300 –\$400 you would be responsible for each month in addition to the other medications you would be taking. After 44 months, Medicare will not cover those two expensive immunosuppressant medications and you would be totally responsible for the cost.

There are limited drug assistance programs but the income requirements are such that many people have difficulty meeting the requirements. Fundraising is another option to cover the costs of these necessary but expensive medications. Some insurance plans have a cap on how much they will pay. We encourage you to investigate your prescription plan.

We just wanted to give you a good idea of some of the costs you will be facing post transplant. At Duke, unfortunately we do not have the resources to provide the medications for you. Please call our financial counselor Sarah Lawton at 919-684-4176 if you have questions or if we can be of assistance.

D U K E K I D N E Y T R A N S P L A N T A T I O N

INFORMATION AND RESOURCES

Duke University Health System
www.dukehealth.org
www.organtransplant.duke.edu

Organ Donation
United Network for Organ Sharing
1-888-894-6361
www.unos.org

Carolina Donor Services
1-800-200-2672
www.carolinadonorservices.org

Kidney Disease
American Kidney Fund
1-800-729-6682
www.kidneyfund.org

National Kidney Foundation
1-800-622-9010
www.kidney.org

Diabetes
American Diabetes Association
1-800-DIABETES
www.diabetes.org

Insulin Free World
www.insulin-free.org

Transplant Information
www.transplanthealth.com
www.transweb.org

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

National Clearing House for Alcohol and Drug Information
1-800-729-6686
Brochures and pamphlets on alcohol, tobacco, and other drugs

D U K E K I D N E Y T R A N S P L A N T A T I O N

Social Security Disability Hotline

1-800-638-6810

N.C. statewide information and assistance related to Social Security, Disability, or SSI

Medicare

1-800-672-3071

Information on Medicare coverage

County Department of Social Services(DSS): Medicaid persons with low income and few assets may apply in the county in which they reside for assistance with medical expenses. DSS also manages food stamps, AID to Families with Dependent Children, Fuel Assistance, and other emergency funds.

Social Security Administration

1-800-772-1213

Assists with applications for retirement, survivorship, disability, and supplemental security income and Medicare benefits.

Veteran's Administration Benefits Office

1-800-827-1000

Veteran's Affairs Medical Center (Durham)

(919) 286-0411

N.C. Division of Veteran's Affairs

(919) 733-3851

N.C. Division of Vocational Rehabilitation

(919) 733-3364

A state-sponsored program that provides services to help disabled persons obtain jobs. Services include evaluation, special training, job counseling, and funding for services to help you get back to work