

**RECIPIENT
&
DONOR**

**PATIENT
INFORMATION**

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INTRODUCTION

Today kidney transplantation is accepted as the best treatment for most patients suffering from end-stage renal disease (ESRD). The Dallas Pre Transplant Group recognizes that the decision to have a transplant is a very important and sometimes difficult decision for you and your family. The Dallas Pre Transplant Group also recognizes that you will have many concerns, questions, and fears as you face this decision.

This manual has been developed by the Dallas Pre Transplant Group of Dallas Nephrology Associates to try to answer questions that are often asked about kidney transplants and living donation. We hope that this information will help improve your understanding about transplantation, and assist you in making a choice that will be right for you and your family.

This manual tries to anticipate all of the questions you may have. It has an enormous amounts of general information, including answers to possible questions for potential recipients AND donors.

Another very important source of information is www.pretransplant.com, the website of the Dallas Pre Transplant Group.

It is important that you have as many facts as possible:

- Information about who the entire transplant team is
- What is involved in the medical evaluation necessary to be considered for a transplant
- Information about the actual transplantation procedure
- Requirements for follow-up care after your transplant.

We at the Dallas Pre Transplant Group believe that the decision to pursue a transplant or especially to donate a kidney is a very serious and life changing process. We are committed to making that as comfortable as possible.

The decision to pursue transplantation will take a significant commitment from you and your family. This commitment should be considered very carefully before you make this decision.

A BIT OF HISTORY

Dallas Nephrology Associates (DNA) is the largest Nephrology practice group in the United States, having been in existence for over 35 years. Some of the most highly trained and qualified Nephrologists from all over the US are part of this group. They understand the vision and the possibilities of health care delivery. The physicians of DNA have been very involved in all of the major aspects of Nephrology, including complicated consultation, hemodialysis and peritoneal dialysis patients, as well as kidney transplant patients. They are highly involved the care of kidney disease, stone disease, hypertension, and complicated medical disorders. They have active practices in all of the major hospitals in Dallas, many having leadership responsibilities in the Nephrology departments. The physician group has multiple office practice locations located throughout the city, including the Dallas Transplant Institute.

Importantly, they also serve as nephrologists and Medical Directors in over 30 dialysis facilities in virtually every neighborhood in the Dallas Metroplex.

DNA physicians assisted in the initial development of the transplantation program at Parkland Memorial Hospital in the early 1970's. They later developed the Methodist Medical Center transplant program, which performed their first kidney transplant in 1981. DNA physicians also serve as Medical Directors in the Baylor University Medical Center, Baylor All-Saints (Ft. Worth) and Medical City Dallas transplantation program. Dallas Transplant Institute, owned and operated by DNA, opened in June 1981. Dallas Transplant Institute provides one of the most complete and up-to-date transplant programs in the world. DTI provides medical evaluation to patients who are being considered for a kidney transplant and also provides follow-up medical care to patients who have received a transplant. Additionally, DNA physicians participate in immunosuppressive and medical management in the liver and heart transplant programs throughout the city.

DNA has a very active research department. The physicians in this group have published in excess of five hundred papers and textbook chapters. The Research Department has a full-time staff devoted to research projects. Many of the DNA physicians take a very active role in research. They have teaching positions at Southwestern Medical School, holding professorships, and also have teaching responsibilities at all of the major teaching hospitals in Dallas.

Dallas Nephrology Associates has been able to enjoy their reputation for excellence with the support of a loyal and supportive staff, some of which have been with DNA since their beginning in 1971 and many who have been here ten to twenty years.

DALLAS TRANSPLANT INSTITUTE

Dallas Transplant Institute

**3601 Live Oak, Suite 100
Dallas, Texas 75204
(214) 358-2300**

Dallas Pre-Transplant Group

**1420 Viceroy Drive
Dallas, Texas 75235
(214) 358-2300**

Dallas Transplant Institute (DTI), located on Live Oak opened in 1981 to provide services to patients requiring transplantation. Since that time it has grown to meet the many needs of transplant patients with a commitment to provide complete services for kidney and kidney/pancreas transplant patients. The Dallas Pre Transplant Group, a component of DTI, relocated, in 2004, its primary location to Viceroy Drive to provide consultation to potential kidney transplant recipients and potential donors.

Services provided at DTI include the following:

- Evaluation of potential recipients
- Evaluation of living donor candidates
- Maintenance of computerized records and data base
- Transplant Committee approval process
- Post-transplant follow-up by Transplant Nephrologists
- Social Services Consultation
- Medical Nutrition Therapy
- Full-service Medicare approved laboratory
- Radiology/Sonography
- Echocardiography
- Vascular Laboratory
- Bone Densitometry
- 24-hour access to physicians
- Research in immunosuppressive therapy
- Coordination of care with referring physicians and transplant programs at Baylor University Medical Center and Methodist Medical Center.

DTI is a one-of-a-kind outpatient medical facility and has been a pioneer in the provision of optimal medical care to the patient receiving a transplanted organ. It was developed and continues to be managed to provide safe, effective, comfortable care to those who have selected the option of transplantation.

An Overview of How Dallas Pre Transplant Group Works

When patients are approved to begin the medical evaluation for transplantation, one of the first appointments will be at the Dallas Pre Transplant Group located on Viceroy Drive. The patient will be scheduled for an orientation/education session, will be provided with educational material and will be given an opportunity to ask any and all questions. A Pre-Transplant Coordinator will meet with the patient to discuss what tests or procedures will be necessary during the medical evaluation. Patients will be scheduled for a Transplant Nephrologist consultation in the same location. Appointments for social worker assessment, laboratory testing, x-ray and sonograms will be scheduled at DTI located on Live Oak.

After a potential transplant recipient has been approved as being medically suitable for transplantation, if they feel that they may have a suitable living donor candidate, they can approach that potential donor about contacting the Dallas Pre Transplant Group regarding information about being a donor. After this initial contact, the potential donor will be given information regarding donation and how to proceed with an evaluation.

Donor candidates will also be scheduled to attend an orientation/education session and for a Transplant Nephrologist consultation at the Dallas Pre Transplant Group located on Viceroy Drive. Laboratory testing, x-ray and sonograms, and social work assessment will be scheduled at DTI located on Live Oak.

Dallas Transplant Institute
Dallas Pre-Transplant Group
(214) 358-2300

Transplant Nephrologists:

Thomas Parker, MD, Medical Director
Ruben Velez, MD
Freda Levy, MD
Jose Castillo, MD
Pedro Vergne, MD
Kosunarty Fa, MD
Larry Melton, MD, PhD
Kim Rice, M D
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Teresa Metz, RN Ext. 6113

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Patient Insurance:

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Pre Transplant Coordinators:

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Secretarial Staff:

Suzanne Moffitt Ext. 6037
Margie Deal Ext. 6011
Marcella Ford Ext. 6029
Dena Lambert Ext. 6024
Michelle Ross Ext. 6044

Nurse Practitioner:

Denise Kay Martelli, RN Ext. 6008

Social Workers:

Mary Beth Callahan, LMSW Ext. 6290
Marianne Moncrief, LMSW Ext. 6286

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Suzanne Adams, LMSW Ext. 6078

Puerto Rico Transplant Staff

Mayaguez: (787) 255-2727
Sixto Acosta, RN:
Jessie Bonilla, Sec.

San Juan: (787) 756-6560
Astrid Morales, RN
Cheila Planas, Sec.

DALLAS PRE TRANSPLANT GROUP RESPONSIBILITIES

Pre-Transplant Nurse Coordinators

- When your application is received, you are assigned a Pre-Transplant coordinator.
- The Coordinator will obtain all of your pertinent medical information, then determine what studies need to be performed to prepare you for a transplant
- You will be given a series of appointments for required:
 - Education
 - Medical tests
 - Medical consultation
- On completion of these studies, the records will be presented to the respective hospital transplant committee who will determine the acceptability of your being a transplant candidate.
- You will be advised of these decisions.

Pre-Transplant Secretaries

- Each Coordinator works with a Pre Transplant Group Secretary to coordinate many of the studies. The Pre Transplant Group Secretary will be responsible for scheduling your evaluation appointments.

Social Workers

- Social Workers will interview all potential kidney transplant recipients to evaluate patient's suitability for transplantation as it relates to lifestyle issues, compliance, psychosocial issues, financial concerns, etc.

Registered Dietitian

- A Registered Dietitian is available with referral by Nephrologist

When working with a recipient or a donor, we, the Dallas Pre Transplant Group will:

- Assure you that we will make recommendations for the medical evaluation of both the potential recipient and potential donor according to the guidelines developed by The American Society of Transplant Physicians. These guidelines are considered to be the current standard of good care for consideration for transplantation and organ donation.
- Provide information to the potential transplant recipient regarding the protocols for the transplant work-up process.
- Provide information to the potential donor regarding protocols for the evaluation process.
- Provide education to both potential recipient and donor about kidney or combined organ transplantation.
- Provide the potential recipient and donor with information regarding both the pros and cons of organ transplantation.
- Provide information regarding potential complications of transplantation so that both potential recipient and donor can make informed choices of treatment.
- Discuss in detail what can be expected after the transplant for both recipient and donor.
- Schedule the various appointments for laboratory testing, x-rays, social services, physician consults, etc., that are required for the donor medical evaluation.
- Assist both the potential recipient and donor with arrangements for keeping appointments when necessary.
- Inform potential recipient and donor of their respective test results, requirements for additional testing, etc.
- Schedule appointments at the times most convenient for recipient/donor within our ability to do so and within established hours of operation for health care facilities, etc.
- Maintain the confidentiality of both the recipient and donor communications and health records. We will not discuss the medical evaluation results of the donor with the recipient. We will not discuss confidential health information of the donor with the recipient or confidential health information of the recipient with the donor. We will not discuss private health information with family members unless the patient gives us permission to do so in writing.
- Expedite the pre-transplant medical evaluation within our ability to do so.
- Keep recipient/donor/physicians/insurance case managers, etc., informed of the status of the medical evaluation.
- Return phone calls in as timely a manner as possible, realizing that patients and family members are anxious about the status of the evaluation.
- Treat patients and donors with respect, consideration, and dignity.
- Participate in continuous quality improvement efforts of the Dallas Pre Transplant Group.

PATIENTS' RIGHT AND RESPONSIBILITIES

Patient's Bill of Rights

Patients have the right to be treated with respect and courtesy and to be given prompt and reasonable responses to their questions and requests. Patient's dignity must be safeguarded and their personal values and beliefs treated with respect.

Each patient has the right to privacy and to confidential handling of all records and communications regarding his or her healthcare. Medical records cannot be released without the written consent of the patient or the patient's legal guardian.

Patients (families or other designated persons when appropriate) have the right to a full explanation of diagnosis and proposed treatments and procedures in terms that are easily understood. The explanation must include benefit of the treatment, the risks involved, possible significant complications, the probable outcome of the treatment and the alternative treatments available. The patient has the right to an interpreter if necessary in order to understand all pertinent communication.

The patient has the right to review any records pertaining to their healthcare and to have any information explained or interpreted as necessary.

The patient has the right to know, at all times, the identity and professional status of all individuals providing any type of service, and to know which physician is primarily in charge of their care.

The patient has the right to be informed of any affiliations existing between their healthcare facility and any educational institutions. Patients must be informed if their healthcare facility proposes to engage in or perform research associated with their care or treatment. This research must be fully explained to a patient before consent is sought, and the patient's written permission must be obtained.

Patients have the right to be involved in all aspects of their care. The patient has the right to exclude any and all family members from participating in his or her care decisions.

Patients have the right to an advance directive such as a living will, healthcare proxy or a durable power of attorney for healthcare. Through the advance directive, the patient can make their wishes concerning medical treatment known to their healthcare providers in case they become incapacitated.

Patients have the right to be given impartial access to healthcare regardless of race, national origin, religion, age, creed, sex or sources of payment.

Patients have the right to be informed of healthcare facility policies and procedures and practices that relate to patient care, treatment and responsibilities, including financial responsibility. Patients have the right to obtain a full explanation of the total bill for health services rendered.

Patients have the right to communicate with persons outside any facility in which they are seeking healthcare.

Patients Also Have Responsibilities:

In order to receive the best care, patients and their families must fulfill certain responsibilities. Patients, or other designated persons, are responsible for:

- Providing accurate information about their present illness and past medical history
- Seeking clarification when necessary to fully understand their health problems and proposed plan of action
- Following through on the agreed plan of action
- Following the rules and regulations of the healthcare facility and considering the rights of others
- Providing information for insurance claims and working with the healthcare facility to make payment arrangements when necessary
- Adhering to appointment schedules

Patients have certain responsibilities to assist the transplant team during and after your medical evaluation for transplantation. The decision to pursue transplantation requires a great deal of commitment and dedication from the patient during the medical evaluation phase.

- It is mandatory that each recipient and donor attend the orientation session provided by the Dallas Pre Transplant Group, ask pertinent questions, and try to get as much information as possible about transplantation. It is also expected that the patient and family members will read and review frequently the *Patient Information Book* provided by the Pre Transplant Group.
- It will be necessary to make numerous appointments for you for diagnostic tests, physician consults, etc. It is important that the potential kidney recipient understands the importance of keeping appointments and following direction from the healthcare team. The consequence of non-compliance during this medical evaluation may result in delay in being approved for a transplant.
- Inform us of any change in your address, telephone number, employment information, insurance coverage, etc. It is very important that we have correct phone numbers to reach you in case appointments need to be changed, etc. Additionally, after you are on the transplant list, it is very important that we have your correct telephone number in case a kidney becomes available for you.
- It is important that you inform us of any change in your insurance coverage. Changes may require additional approval in order to proceed with the medical evaluation or for you to stay on the transplant list.
- It is important that you keep us informed about any changes in your health status during your medical evaluation and after you are on the transplant list. (This would include any infections, admissions to the hospital, surgical procedures, etc.) Changes in your health status may make you unsuitable for a transplant until the situation is resolved. It may be necessary to place you on work-up hold status or RenTran (Transplant List) hold status due to changes in your health status. The Dallas Pre Transplant Group will ensure that the appropriate follow-up tests are ordered to change you from a hold status to an active status as soon as possible when you keep us informed of these situations.
- It will be necessary for you to have a periodic PRA (Panel Reactivity Antibody) test. If you are not a dialysis patient going to your facility regularly, this may require more frequent trips to your physician's office or DTI. These are important tests that you need to have done according to the instructions you will receive from your Transplant Coordinator.
- After your initial medical evaluation and approval to be placed on the transplant list, it will be necessary to have additional diagnostic tests each year in order to remain in an active status. It is very important that you keep appointments for this follow-up testing.

DALLAS TRANSPLANT INSTITUTE DALLAS PRE TRANSPLANT GROUP

Grievance Procedure

If situations occur in the course of your medical evaluation for consideration for transplantation under the direction of the Pre Transplant Group of Dallas Transplant Institute, which you question or about which you wish to complain, you are encouraged to speak with someone on our management staff. If you continue to feel that your complaint has not been appropriately resolved, our management staff can refer you to the Medical Director of the Pre Transplant Group, to the President of Dallas Nephrology Associates or one of the Vice Presidents of Dallas Nephrology Associates for further resolution of your complaint. It is the intent of Dallas Nephrology Associates and Dallas Transplant Institute to provide you with the best medical care within our ability, and we want to know when you feel that we have failed to provide this care.

Information is provided below regarding the appropriate people to contact if you wish to discuss your concerns or complaints about the progress of your Pre-Transplant medical evaluation.

Asst. Director of Clinical Operations:	Teresa M. Metz, RN, BSN, CCTC 1420 Viceroy Drive Dallas, Texas 75235 (214) 358-2300, Ext. 6113
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End-Stage Renal Disease Network 14	(972) 503-3215
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United Network for Organ Sharing (UNOS)	(804) 330-8500
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To the best of our abilities and in our own individual capacities, each staff member is here to assist in your medical care. If you have a special problem or concern that has not been solved to your satisfaction, we have provided you with this established grievance mechanism under which patients can participate without fear of reprisal. We have also placed Suggestion Boxes at each clinical location. We hope that you will utilize this mechanism to make suggestions to us about how you feel we can improve our services to you.

GENERAL INFORMATION

What are the options if I have renal failure?

Dialysis is a way to clean the blood of waste products and excess fluid when your own kidneys fail to work properly. This can be done by **hemodialysis** (using an artificial kidney machine) or **peritoneal dialysis** (using the lining of your abdomen).

Kidney transplantation is the surgical placement of a healthy kidney into your body. **Transplant is not a cure for end stage renal disease; it is a form of treatment.**

What are the advantages of a successful kidney transplant?

A successful kidney transplant allows most patients to feel better and have an improved quality of life. Although medical supervision will continue after the transplant, you will no longer be dependent upon dialysis. There may also be fewer dietary and fluid restrictions.

Are there risks with a kidney transplant?

There are risks associated with having a transplant. Your body may try to reject the transplant. You may experience side effects of the medications. There are surgical risks with all surgical procedures. The Transplant Surgeon and/or Transplant Nephrologist will discuss this with you. Some patients have died as a result of complications from a kidney transplant, although the incidence is quite low.

It is important that you ask the physicians that you see during the medical evaluation to answer any of your questions regarding complications of the transplant procedure.

Where do kidneys for transplant come from?

Kidneys used for transplant are donated from:

- A person related to the recipient (called a living related donor or LRD)
- A person not blood-related to the recipient, but who has close emotional ties such as a spouse, in-law or close friend. (Called a living unrelated donor or LuRD)
- A person who has recently died and whose healthy kidneys have been donated (called a deceased donor). A deceased donor is someone who has had an unforeseen accident that has rendered them brain dead. The family has given permission for the organs to be donated.

How successful are kidney transplants?

The success rate is dependent upon many factors, one of which is the type of kidney received. It is difficult to predict for each individual, therefore we can only give you general statistics.

- A living related donor kidney that is a “complete match” has about a 95% chance of working at one year after transplant and about an 85% chance of working at five years after transplant.
- A living donor kidney (either related or unrelated) that is a “partial match” has about a 90% chance of working at one year after transplant and about an 80% chance of working at five years after transplant.
- A deceased donor transplant has a 90% chance of working at one year after transplant and a 75% chance of working five years after the transplant.
- If you would like center specific transplant success rates, you may contact the individual transplant programs. ***Information about transplant facility statistics is also available on the UNOS web site @ UNOS.org.***

APPLYING FOR A TRANSPLANT

Where are kidney transplants performed in the Dallas area?

There are four adult kidney transplant centers in the Dallas area: Parkland Memorial Hospital, Methodist Medical Center, Baylor University Medical Center (includes Baylor All Saints Medical Center in Ft. Worth), and Medical City Dallas Hospital. Children under the age of eighteen are transplanted at Children's Medical Center.

Dallas Transplant Institute coordinates medical evaluations for patients referred to these transplant programs: Methodist Medical Center and Baylor University Medical Center.

How do I know if I am eligible for a transplant?

To find out if you are eligible for a kidney transplant, first talk with your physician.

For some people, a kidney transplant may not be an option due to other medical problems.

Some of the most common reasons you would not be eligible for renal transplant include the following:

- Significant cardiovascular disease
- Active malignancy or history of cancer within the last five years
- Alcohol and drug dependency or abuse
- Psychiatric (Mental) disorders that are not controlled by treatment
- Non-compliance with medication and physician treatment recommendations
- Obesity (Overweight patients will be evaluated by the Transplant Surgeon and weight reduction programs may be recommended before the medical evaluation can be initiated or completed.)
- Severe liver disease
- Severe lung disease
- Active infection

How do I apply for a kidney transplant?

First, talk with your physician. If your physician feels you are a potential candidate for transplantation, he will refer you for a medical evaluation to the transplant center of your choice. The choice of the transplant center is a decision made between you, your physician and your insurance company. Many insurance companies have contracts with specific hospitals for transplantation. You may call the customer service number on your insurance card to get this information. You may call the transplant center for specific information as to the number of transplants performed, outcome statistics, waiting times, etc. ***Information about transplant facility statistics is also available on the UNOS web site @ unos.org.***

Do I need to be on dialysis before I can get a transplant?

You do not have to be on dialysis to be evaluated for or receive a transplant. However, your kidney function (creatinine clearance) must be less than 20.

What happens once I send in my application?

Upon receipt of the transplant application, the Pre Transplant Group will forward the application to the Transplant Center and to DNA Billing Department for processing.

The hospital financial department and DNA Billing will contact the patient's insurance carrier to obtain financial approval for the medical evaluation.

The patient will receive a letter from Pre Transplant Group regarding receipt of the application and will also be sent additional forms to be completed by the patient and returned to Pre Transplant Group.

When the hospital receives verification of financial coverage for the medical evaluation from the patient's insurance company, the Pre Transplant Group will be notified.

The Pre Transplant Group will then notify the patient that the evaluation has been approved. This verification process can be lengthy, depending on the type of insurance, type of transplant, etc. Patients should be aware of the fact that this financial approval process can be as short as two weeks and as long as several months.

Following financial approval verification, the patient will be contacted by one of the Pre-Transplant Coordinators with information about the medical evaluation and to make arrangements for an orientation/education session. The orientation session will include other potential transplant recipients and family members who will be given information about transplantation, what is required for the medical evaluation, what can be expected during the work-up process and the opportunity to ask questions.

Can I go see or tour the transplant center I have chosen?

The transplant centers have informational sessions that are scheduled on a regular basis. It is recommended that you attend one of these meetings. You will be provided with information about calling the Transplant Center for this information.

PRE-TRANSPLANT MEDICAL EVALUATION

Why do I need a pre-transplant medical evaluation?

Dallas Pre Transplant Group uses the American Society of Transplantation (AST) clinical practice guidelines for the evaluation of renal transplant candidates and living renal transplant donors. These guidelines were designed to assist the healthcare team in the evaluation process that leads to renal transplantation and in the evaluation process of potential living kidney donors. They are very comprehensive; however, they do not cover every possible contingency, since each potential transplant recipient and each potential living donor have unique characteristics that require specific evaluation and intervention.

Every patient's evaluation will include the following:

- Transplant Nephrologist evaluation
- Transplant Social Worker evaluation
- Blood work which will include: Routine blood chemistries; tests to rule out active hepatitis, syphilis, and AIDS; blood typing and tissue typing tests which will help the transplant team find the best possible kidney match for you.
- Chest X-Ray, renal sonogram
- Electrocardiogram, TB test and stool test for blood.

Other parts of the evaluation will depend on the patient's diagnosis, age and past medical history. The Pre-Transplant Coordinator will discuss these individually with each patient.

How long will my evaluation take?

The pre-transplant medical evaluation may take only a few weeks or it could possibly take several months, depending on the complexity of the patient's medical problems. Cooperation in keeping appointments and responding to requests from Dallas Pre Transplant Group staff can greatly reduce the time in the work-up process.

What if I miss appointments?

Compliance is an important part of the transplant evaluation. Potential recipients who are not compliant with their dialysis treatments, medications or evaluation appointments risk not being accepted for a transplant. Patients should review the non-compliance policy and make every effort to be compliant. **The single most prevalent reason that the hospital transplant committees do not accept patients for transplantation is non-compliance to dialysis prescriptions and keeping appointments.**

Dallas Pre Transplant Group **Non-Compliance Policy**

If a patient fails to keep either a scheduled DTI appointment or a consultant appointment and does not notify the Pre Transplant Group or the consultant office that they cannot keep the appointment, the patient will be sent a letter. This letter will also be sent to the referring physician/dialysis center. The letter will inform them of the appointments that were missed. The letter will also state that if they have not contacted our office within thirty days to re-schedule these appointments, their case will be presented to the appropriate Transplant Committee for inactivation.

If the patient responds to the letter within thirty days, a second set of appointments will be made for the patient. If the patient fails to show up for the second group of appointments, the patient will be presented to the Transplant Committee. The Transplant Committee may recommend inactivation for compliance reasons.

If the Transplant Committee inactivates the patient, a letter will be sent to the referring physician/dialysis center with a copy to the patient. This letter will inform the physician that the patient's case has been inactivated due to non-compliance. In order to be reconsidered for a transplant in the future, the patient will have to re-apply.

If the patient has been unable to keep the first set of appointments due to extenuating circumstances, hospitalization, etc., exceptions to this policy can be considered on a case-by-case basis.

If the patient has been notified of appointments made and calls the Pre Transplant Group to re-schedule appointments because of unavoidable circumstances, we will assist the patient in re-scheduling appointments as necessary.

HOSPITAL TRANSPLANT COMMITTEE

What happens when I complete my evaluation?

Once you have completed your evaluation, your Pre-Transplant Coordinator will gather all of the information and present your case to the Transplant Committee.

The Transplant Hospital Centers have Transplant Committees, composed of Transplant Nephrologists, Transplant Surgeons, Transplant Coordinators (non-voting members) and other physician referral sources. The committee makes a recommendation based on all testing results to either “approve” or “deny approval” of the potential recipient for transplantation.

If approved, the patient’s medical records are submitted to the transplant center. After final financial approval has been obtained their name will be placed on the United Network of Organ Sharing (UNOS) active transplant candidate waiting list. **You will be notified by the transplant center within 10 days of being listed.**

The Referring Nephrologist at the dialysis center or office practice will be sent a letter from the Transplant Committee regarding the committee approval, and a copy of this letter will be sent to the patient.

If the committee denies approval of transplantation, the Referring Nephrologist will be sent a letter of explanation, and the patient will also receive a copy of this letter. It is also possible that further diagnostic testing will be recommended. The case would then be re-presented to the committee upon completion of the additional testing.

What do I do once I am listed?

If your home address or telephone number changes please contact the pre-transplant office immediately. It is important that you keep us informed of how you can be reached by telephone at all times.

If you have any illnesses or hospitalizations please call the Pre Transplant Group or have one of your family members call. We must be able to locate you and know what is going on with your medical status at all times.

It is also important to notify the pre-transplant office if your insurance coverage changes. This may necessitate financial approval from your new insurance carrier.

THE WAITING LIST

How long will I have to wait for a kidney transplant?

Your tissue typing and blood type are entered into a computer with others who are waiting for a kidney, both locally and nationally, so that it may be reviewed when a kidney becomes available for transplantation. The waiting time for receiving a kidney will vary from a few weeks to several years. Blood type, availability of cadaver kidneys, and your antibody reactivity are some of the factors, which play a part in the wait time.

There is a severe shortage of kidney donors nationwide. Due to this, we encourage you to consider pursuing living donation from a family member or non-related living donor.

How do they decide who gets a kidney?

The “waiting list” is actually a nationwide computerized network called UNOS (United Network for Organ Sharing), to which all transplant centers in the United States belong. All patients awaiting organ transplantation are registered and listed nationally with UNOS. UNOS, which is supervised by the federal government, helps ensure that patients throughout the country receive healthy organs as soon as they become available. All deceased donor kidneys available for transplantation are initially registered with the UNOS national computer to determine whether there is a perfectly matched recipient listed.

If a perfect match recipient is not available, kidneys are then allocated based on a point system. Many factors --such as your blood type, the number of markers that match your tissue typing, how long you have been on the waiting list—influence the national allocation formula for kidneys. For each available kidney, points are assigned according to this allocation formula, and patients are placed in order based on these total points.

What if I have a Living Donor?

It is necessary that anyone who is interested in donating a kidney to you make the initial approach to the Pre Transplant Group with a telephone call to your Transplant Coordinator. The potential donor is then required to complete an application for financial approval and complete a health history for review.

After your medical evaluation is completed and the Transplant Committee has approved you, your potential donors’ applications will be processed. Once financial approval for the donors has been obtained, they will be schedule for the initial blood work. Blood samples are taken from you and your potential donors to determine if the kidney is a good match. Once the results are back, the medical evaluation of the donor will begin.

Please read more about living donors later in this manual.

What is “tissue typing”?

This is a blood test used to look at specific “markers” on your white blood cells, which are part of your immune system. These “markers” are assigned three sets of paired numbers, which are important, when we are matching you for a kidney transplant.

Other transplant related blood tests are:

Blood type – Your blood type is used to match you to a potential donor.

PRA (Panel reactive antibody) – As a part of your pre-transplant evaluation, blood tests are routinely drawn to test your immune system’s reactivity. This test should also be drawn on a monthly basis at your dialysis center or physician’s office and sent to the transplant center. This will help the transplant center know what percentage of the general population you are likely to have a crossmatch with that will be positive.

Crossmatch – This is a blood test that is done at the time of the transplant regardless of whether it is a cadaveric transplant or a living donor transplant. This test takes your blood and tissue from the donor and puts them together. If the crossmatch is “negative”, your blood did not react to the tissue of the donor. If the crossmatch were “positive”, your blood reacted with the donor’s tissue and you would reject that donor’s kidney. **The transplant can only be done if the crossmatch is “negative”.**

What does it mean to be placed on “HOLD”?

You may be placed on “hold” status from time to time.

- Work-up “hold” status is used when we place your pre-transplant medical evaluation on hold, usually due to a change in your medical condition or change in your insurance plan.
- RenTran (Transplant Waiting List) “hold” is used when you have already been approved for a transplant and are on the waiting list, but something changes with your medical condition that makes you unsuitable for a transplant at that time or if there is a change in your insurance plan.
- Anytime you have a change in your medical condition, an infection, surgery or admission to the hospital, it is your responsibility to notify the Pre Transplant Group. When the Pre Transplant Group is notified, they will ensure that the appropriate follow-up tests are ordered to change you from a hold status back to an active status as soon as possible. If you are on “hold” status, your physician will be notified. If you believe you should not be on “hold” status or have any questions about your status, please call your transplant coordinator to discuss your case.

Will I need to have additional tests after the initial medical evaluation?

Patients have the responsibility to assist us in keeping their medical evaluation in a current status.

After your initial medical evaluation, we will continue to need update testing so that we know your current medical condition as long as you remain on the transplant waiting list. This update testing will be done on a yearly basis. Some testing may be required every six months.

PLEASE NOTE - Failure to keep annual update appointments will also result in you being placed on “hold” status until your medical update appointments and testing are complete. The purpose of this is that we must ascertain that your medical status remains suitable for transplantation on an annual basis.

At regular intervals while you are in the transplant work-up process and until you are transplanted, it will be necessary for you to have one blood test performed. It is a PRA/Lymph Antibody Screen (blood that is sent to the transplant center to screen for antibodies that could cause problems when you get a transplant.) If you are a dialysis patient, or being seen frequently in your physician’s office, arrangements can be made to have your blood drawn for this test at one of those locations. If not, we will have to make special arrangements to have this blood test done at specified intervals.

How will I be contacted when a kidney is available for me?

A member of the transplant team at the Transplant Center will call you when a kidney is available for you.

You are responsible for keeping the Pre Transplant Group informed of any changes you have in your name, your address, your phone numbers, your employers, and your insurance coverage. If a kidney becomes available for you in the middle of the night and we cannot reach you because you have moved, you could conceivably be passed up for transplantation and the organ given to someone else. Also, if your insurance company changes, we have to seek another insurance approval for the transplant. It is very important that you advise us of any change in this information.

Is it necessary that I have a pager or cellular telephone while I am on the active transplant list?

We do not require that you carry a pager or a cellular telephone; however, it is advantageous to have one or the other if possible. We do need to have telephone numbers where you can be easily reached at all times while you are on the transplant list.

What should I do if I get a call or am left a message?

- **Methodist Medical Center**
During regular business hours 8:00 am to 4:30 pm Monday through Friday, call the Transplant Services office at (214) 947-1800. If it is after business hours or on the weekend, call the transplant unit (4 Bed tower) at MMC (214) 947-4099 and ask for the Charge Nurse.
- **Baylor University Medical Center**
During regular business hours 8:00 am to 4:30 pm, Monday through Friday, call the Transplant Services office at (214) 820-2050. If it is after business hours or on the weekend, call the main number at BUMC (214) 820-0111 and ask for the Transplant Coordinator on call.

If personnel at the Transplant Center are unable to locate you on the first telephone call, they will make additional attempts to reach you by telephone. They will try alternate telephone numbers if available, etc. When possible they will call the Dallas Pre Transplant Group to verify numbers. If they continue to be unable to locate you after **one hour**, they will call the next available patient. *This is why it is very important that you keep us informed as to changes in your telephone numbers, when you are going to be out of town, etc.*

How long do I have to get to the hospital after I have been called and told that a kidney may be available for me?

You can discuss this with the physician or hospital personnel who call you to advise you that a kidney may be available for you. As a general rule, if you live in the Dallas area, you should make every effort to get to the hospital within one hour after you are called if possible.

Note: Patients who live outside the Dallas area will receive special instructions regarding how much time they have to travel to the hospital after they are informed that a kidney may be available for them.

What else should I know before I come to the hospital?

If you are called in for a cadaver transplant, it is very important **not to eat or drink** anything until you get to the hospital and receive further instructions from the transplant staff.

It is possible that you could be asked to report to the Transplant Center as a back-up candidate for one kidney. This means that some other potential recipient(s) have been called also. The Transplant Center Immunology Laboratory will do a crossmatch on each of you. If the patient(s) who were called in as the first transplant candidate(s) has a positive crossmatch and your crossmatch is negative, you will get the kidney. If one of the first person(s) has a negative crossmatch, one of the first candidate(s) will get the kidney and you will be sent home.

What are “Expanded Criteria Donors”?

“Expanded criteria” kidneys are kidneys from deceased donors that had certain medical problems that could have damaged the kidneys. Due to this, these kidneys are considered inferior to kidneys obtained from deceased donors with no medical issues. The donor medical issues that make them “expanded criteria” kidneys are:

- Donor was greater than 60 years old
- Donor had high blood pressure
- Donor died due to a stroke
- Donor had reduced kidney function (blood creatinine level was over 1.5)

You will be told if you are being offered a kidney from an “Expanded Criteria Donor”. You do not have to accept this type of donor kidney. However, if you do, you will have **less time waiting for a transplant and increased survival compared to staying on the list.**

The disadvantages of receiving a kidney from an “Expanded Criteria Donor” is potentially **shorter lifespan of the kidney transplant compared to an ideal kidney. It may also take longer for the expanded criteria donor kidney to start working. There is also a small chance that an expanded criteria kidney transplant may never work (5%).**

You are encouraged to discuss this issue with your physician, the Transplant Nephrologist and the Transplant Surgeon before you make a decision related to this option.

What do I need to bring to the hospital?

Most people prefer to bring their own slippers, robe and pajamas, as well as their own personal toiletries. In addition, you may want to bring reading material, hobbies or crafts, puzzles, or anything else that would interest you.

What happens once I get to the hospital?

You will be facing a four to five hour wait time after you arrive at the hospital before you will know if you are a candidate for the kidney. The first thing that will be done is that you will have blood drawn for a crossmatch. The crossmatch will take about four hours.

While you are waiting for the crossmatch results, the physician will evaluate you to be sure you do not have any infections or other medical problems that would interfere with the transplant. If this does occur and you have an infection or a new medical problem, the transplant will be cancelled and you will be sent home. You will have blood drawn for routine tests as well as the crossmatch (as discussed earlier), an ECG, and a chest x-ray.

At the hospital you will be asked to sign operative permits agreeing to surgery. Dialysis may also be required prior to surgery.

If no problems are discovered from the blood tests results and from your medical evaluation, and if the crossmatch is negative, the transplant surgery will be performed.

THE TRANSPLANT

Where is the new kidney placed? How long does the surgery take?

The kidney is usually placed in the front on either side of the lower abdomen (pelvis). The area is selected for several reasons:

- It is easier to connect the tube that carries the urine from the kidney to the bladder (called the ureter).
- This is the best position for the doctors, nurses, and you to feel the new kidney to determine size and whether there is tenderness.

The actual kidney transplant surgery usually takes two to four hours.

Where will I go after surgery?

Immediately after the surgery, you will be cared for in a special care unit. When medically stable, you will return to your room on the transplant unit.

When will my transplant kidney begin to function?

Your kidney may make urine immediately. The nurses will be measuring this often. It may also be bloody. This occurrence is considered normal for the first few days and is due to the surgery.

In some cases, the kidney may not make urine right away. This may be due to acute tubular necrosis (ATN), which is a period of shock after the kidney has been transplanted. ATN is a condition that usually gets better with time. If your new kidney is experiencing ATN or a severe rejection, dialysis may be required until the kidney starts to work. Dialysis will not damage the kidney, and it will clear the harmful waste products from your body until your new kidney can start to work.

In rare cases, the kidney does not work at all following the transplant. There are no guarantees.

Who will take care of me after the surgery?

The transplant team will provide your care in the hospital. They have received specialized training in caring for transplant patients. Members of the team include doctors, nurses, and physician assistants, transplant coordinators, a dietitian and a social worker. A chaplain is available as well. You will see most of these people daily, especially when rounds are made. Every member is there to care for you, so do not be surprised when this big group comes to see you.

Who will take care of me when I go home following the transplant?

You and your family will be responsible for your care when you go home.

How long will I be in the hospital?

It is difficult to give an exact length of time that you will be in the hospital. If your new kidney makes urine immediately and there are no rejection episodes, you could possibly be discharged five to seven days after transplant. It may be longer. You will only be discharged when you are medically ready.

Can I have visitors?

Yes, you may have visitors, but they should be limited. You will be very susceptible to infections when you are on higher doses of immunosuppressive medications. Children under twelve years of age are not allowed. People who are ill or who have an infection should not visit you.

What kinds of things do I have to do and learn before I go home?

As soon as you are up and around, it will be time to start learning how you will take care of yourself when you go home. Before you are discharged from the hospital, you will be expected to:

- Know your medicines – how to take them, dosages, side effects and purpose
- Take your own temperature
- Weigh yourself
- Check your blood pressure
- Measure your fluid intake
- Measure your urine output
- List the signs and symptoms of rejection.

Do I need any special equipment when I go home?

You will need to have the following equipment:

- Blood pressure monitoring kit for checking blood pressure
- Oral thermometer to record your daily temperature
- Bathroom scale to record your daily weight

When can I drive a car?

Check with your physician as to when you can drive your car. It is important to talk to your family and friends to make arrangements before the transplant regarding who will be available to take you to and from the clinic for those first few weeks.

If I am from out of town, how long will I have to stay in Dallas?

If you live out of town, you need to plan to stay in Dallas for at least four to eight weeks after being discharged from the hospital. The transplant center social worker or hospital discharge planner will help you with these arrangements. This time may vary depending on any complications you might have had during or after your hospitalization. It will also depend on how far away you live.

POST TRANSPLANT INFORMATION

After I am discharged, when will I be seen at DTI?

After you are discharged from the Transplant Center, you will be seen an average of three times a week at Dallas Transplant Institute for the first several weeks. You may need to come to the clinic between visits for blood tests to check your medication levels. When your kidney function has stabilized, you will be seen less often, but followed closely. The physician will determine your next appointment after examining you and reviewing your laboratory tests.

You will also be examined by the Transplant Surgeon one or two times after your transplant for evaluation of your condition after a major surgical operation.

You will need to be seen regularly by a physician as long as you have your transplanted kidney.

Where will I go for clinic? Who takes care of me at the DTI clinic?

Dallas Transplant Institute is located at 3604 Live Oak, Suite #100. When you come to the clinic, you will be weighed, have blood drawn, and asked to give a urine sample. One of the nurses will review your medicines and any problems you might have. Then you will be seen and examined by one of the Transplant Nephrologists, Physician Assistants and/or Nurse Practitioners in clinic.

You will more than likely **not** be seen by the same Nephrologist on each of your clinic visits. Several Nephrologists routinely see patients at DTI, and patients are not assigned to see a specific physician. These doctors may be different than the ones who took care of you in the hospital. Assisting in your post-transplantation care is a dedicated staff of physician assistants, nurses, social workers, dietitians, and laboratory and clinic personnel who are trained in the area of transplantation.

Will I have any special tests after I leave the hospital?

A Glofil test (measurement of kidney function) will be scheduled periodically to give us further information about how well your kidney is functioning. Other diagnostic tests such as EKG's, x-rays, etc. will be ordered as necessary. Routine blood chemistries and medication blood levels will be performed on most of your DTI visits. If you are being followed by your physician out of the Dallas area, some of these tests may be done in his/her office. You may need to come to DTI periodically for some of these tests.

What medications will I be on after the transplant?

You will take a combination of several medicines after surgery to help your body accept the new kidney. Every patient is on a customized medication schedule. It depends on how you do with a particular medication.

IT WILL BE NECESSARY FOR YOU TO TAKE YOUR IMMUNOSUPPRESSIVE MEDICINES AS LONG AS YOU HAVE YOUR TRANSPLANTED KIDNEY.

Listed below are the most common medications being used at DTI at this time. You may be on any combination of these medications after transplant; it depends on what is best for you. **(All of the immunosuppressive drugs increase the risk of infection and the risk of cancer.)** There is a constant amount of research going on every day to better the outcome of transplants.

- **Prograf (tacrolimus)** – acts to depress the body’s immune system. This drug is a small capsule. Side effects include tremors, possible toxicity to your kidney, high blood pressure, and increased stomach upset and diarrhea. (You may be taking either Prograf or Cyclosporine but not both medications.) The approximate cost per month for this drug is about \$900.
- **Sandimmune/Neoral (cyclosporine)** – acts to depress the body’s immune system. This drug is a gel capsule or liquid. Side effects may include excessive hair growth, increase in gum tissue, tremors, possible toxicity to your kidney or liver, and high blood pressure. (You may be taking either Cyclosporine or Prograf but not both medications.) The approximate cost per month for this drug is \$750.
- **Cellcept / Myfortic (mycophenylate)** – decreases your body’s ability to fight the new kidney. This drug is available in both tablet and capsule. Side effects of this medication may include decreased white cell count (WBC) increased risk for infection and increased stomach upset and diarrhea. (You may be taking either Cellcept / Myfortis or Imuran but not both medications.) The approximate cost per month for this drug is \$575.
- **Imuran (azathioprine)** – decreases your body’s ability to fight the new kidney. This drug is a tablet. Side effects may include decreased white cell count (WBC), and increased risk of liver abnormalities and hair loss. (You may be taking either Imuran or Cellcept but not both medications.) The approximate cost per month for this drug is \$45.
- **Rapamune (sirolimus)**-acts to depress the body’s immune system. This drug comes in both liquid and tablet form. Side effects may include increased cholesterol level and decreased platelet count. (You may be taking this medication along with Neoral, Prograf, CellCept and Prednisone.) The approximate cost per month for this drug is \$425.
- **Prednisone or prednisolone** – reduces your body’s chance of attacking your transplanted kidney. This drug is a tablet. The dose of Prednisone or Prednisolone is high at the time of transplant but is tapered quickly to a lower maintenance dose. Some of the more common side effects are: fluid retention, weight gain, night sweats, joint pain, mood swings, increased risk of bleeding ulcer, changes in eyesight, weakness of bones, and increases in blood sugar. Many of these side effects will decrease as the dose of the medication is lowered. The approximate cost per month for this drug is \$10.
- You may be asked to participate in research studies involving investigational transplant medicines. If so, you will be provided information about these medications and will be asked to sign consent forms prior to taking any research medications. This decision will be entirely up to you and can be discussed with your transplant physician.

You may receive additional medications to prevent complications or to treat a current problem:

- **Insulin** - there is a possibility with the increased blood sugar seen with the steroids that you may need to take Insulin to control your blood sugar.
- **Antacids** – coats the stomach to prevent stomach ulcers while you are on higher doses of steroids. Antacids can cause either constipation or diarrhea, which can be controlled by changing the dosage.
- **Mycostatin mouthwash (nystatin) or Mycelex Troches (clotrimazole)** –helps prevent a fungal infection called thrush. Usually this medication is discontinued when steroid doses are reduced. Side effects may include nausea.
- **Cytovene or Valcyte** – helps to prevent or treat cytomegalo virus (CMV) infections. Some patients may need this, while others will not. Usually this medication is taken from one to three months. The approximate cost per month of this drug is \$1800.
- In addition, you may need to take medicines that reduce your blood pressure and medicines to increase your urine output. Many patients have taken these medications before transplantation and will continue to do so after their transplant.
- You may be prescribed an antibiotic as a preventative measure now that you are taking immunosuppressant medications.

Although many insurance plans cover medications, be prepared to spend several hundred dollars on medication when you leave the hospital.

Who will take care of me when I return to my home if I am an out-of-town patient?

The physician who referred you for transplant will be responsible for your medical care when you return to your home. At first, you will alternate visits with your physician and DTI physicians. As your kidney function stabilizes, the visits to Dallas will become less frequent.

You will be asked to return to Dallas should certain problems arise, or perhaps at regular intervals for check-ups.

When may I resume sexual relations?

After you are discharged from the hospital, you may resume sexual activity when your physician feels you are ready. Female patients need to use a reliable birth control method. (Please discuss this subject with your physician). Females are also instructed to empty their bladder completely after intercourse (to lower the incidence of urinary tract infection). There are increased potential health problems in homosexuals.

Will I be allowed to drink alcoholic beverages?

Alcoholic beverages in small quantities will do no harm unless liver problems have been diagnosed. Ask your physician or nurse before drinking any alcohol after transplant.

When can I go back to work? Are there any restrictions?

One of the goals of transplantation is to help patients return to a productive lifestyle. It is possible to return to work after the first six to eight weeks post transplant – some patients return to work sooner. Consult with your physician for a “Return to Work” statement.

- If you are unable to return to your previous job for whatever reason, there is vocational training available through the Texas Rehabilitation Commission (TRC). If you were unemployed before the transplant, TRC is a good option for training and placement.
- If you are receiving Social Security Disability at the time of a successful transplant and if your disability is based on your kidney disease, you will need to begin to plan to return to work. Usually, you can begin to think about returning to work approximately three months after your transplant. You can discuss this with your physician and the DTI Social Worker.
- Social Security will review your disability status at approximately **one year** after your transplant.
- Medicare insurance coverage will end three years after transplantation. With a successful transplant, you will hopefully be able to begin employment that will offer insurance benefits.

Should I tell the dentist I have had a kidney transplant?

Yes. If you have an appointment with the dentist, please notify the nurses at DTI. The risk of infection is increased if you are having dental work or even cleaning done. Antibiotics will be prescribed for you to take.

What happens if I go out of town and have an emergency?

Go to an emergency room. Tell them you are a transplant patient. Tell them the phone number of DTI or your Transplant Center. You should always tell the doctor what medicines you are taking.

Can I be around large groups of people?

Avoid large crowds for the first few weeks after your discharge from the Transplant Center and any time you are treated for rejection. (DTI Clinic will be the exception.) Avoid contact with persons who have a communicable disease or infection (cold or flu). This is because of the high doses of immunosuppressant medicines that you take.

What is rejection?

Rejection is the body's natural tendency to fight off your new kidney because it is foreign tissue. Rejection can prevent your kidney from working and even damage it permanently. Almost everyone has a rejection episode.

The two types of rejection usually seen are:

Acute – occurs most frequently during the first three months of transplantation but may occur after many months or years. (Rejection is often associated with failure to take immunosuppressant medications as prescribed.)

Chronic – continuous tendency to reject the kidney. Very often there are not signs or symptoms of rejection. This rejection is usually diagnosed by repeated laboratory tests. With careful medical treatment, this type of rejection process is often slow. The transplanted kidney may continue to function for several years.

To help prevent rejection episodes:

- Take your medicines exactly as your physician tells you and record them daily.
- Never stop taking or change your medicines unless instructed to do so by your physician or nurse.
- Do not take any prescription or non-prescription drugs (such as cold medicine, ibuprofen or aspirin) unless ordered by or approved by your Transplant Nephrologist or one of his/her staff.
- If any physician outside of DTI or the Transplant Center where you receive your post-transplant follow-up care wants to put you on any additional medications for any reason, call DTI or your Transplant Center before you have the prescription filled.

Acute rejection often causes no symptoms. Occasionally some of the following signs and symptoms of rejection will occur:

- Pain and swelling over the kidney
- Decrease in urine output
- Fever over 100 degrees
- Sudden swelling especially in the face, hands and feet
- Rapid weight gain
- Increase in blood pressure
- Cough or shortness of breath
- General malaise – “just not feeling well” or “flu-like” symptoms

How is rejection diagnosed?

Rejection is usually diagnosed from both the signs and symptoms of rejection, laboratory studies, and often a kidney biopsy.

What is a kidney biopsy?

A kidney biopsy is the microscopic examination of kidney tissue.

The traditional type of kidney biopsy is done with a biopsy needle, and a small piece of kidney tissue is removed. This procedure is done in the hospital to help detect rejection.

How is rejection treated?

There are several medications available to treat rejection episodes. These medicines are given intravenously. These are very potent immunosuppressive drugs, which target the cells that are causing the rejection. The medicines you have been taking by mouth may be increased, decreased or discontinued during this therapy.

What happens if the transplant kidney fails completely?

If the kidney fails completely, the anti-rejection medications will be discontinued. In some cases, the transplanted kidney will be removed surgically because of possible complications. You will be placed on dialysis, and following a full recovery, you may be considered for another transplant.

If I lose my kidney, may I receive another?

You can be evaluated to determine the risks involved in giving you a second or even third transplant. It will be necessary to repeat a complete medical evaluation just as you did before your first kidney transplant.

LIVING DONOR INFORMATION

What are the advantages of a living donor transplant?

The advantages of a living donor transplant are:

- They have better results
- The recipient spends less time on dialysis. This prevents complications that can be associated with dialysis.
- It is a planned procedure.

Are there other alternatives for the potential recipient?

The recipient will be on the deceased donor waiting list. There may also be other potential living donors. The recipient also has the option of hemodialysis or peritoneal dialysis.

Who can be a living donor?

Potential living donors can be related (family members) or non-related (friends, coworkers, church members, etc). Methodist Medical Center and Baylor University Medical Center have policies in place that do not allow the use of donors found on Internet sites.

What is the first step for a living donor?

The donor must take the first step and call the Pre Transplant Coordinator before the donor process can begin. It is required that the donor submits an application, which will be sent to the Transplant Center for financial approval. Most insurance companies do pay for donor medical evaluations; however, there are some that do not. If the insurance company denies financial approval, it will be necessary that the recipient make a cash deposit for the evaluation.

What is expected of a living donor?

Not everybody can give a kidney for donation. Donors need to be healthy individuals with two normal kidneys, compatible blood type with the recipient, and the tissue typing crossmatch must be negative.

What tests are included in the donor medical evaluation?

The evaluation for a living donor is very similar to the evaluation for the recipient. This is a very thorough medical and psychological evaluation. The results of the living donor's medical evaluation will also be presented to the Transplant Committee of the Transplant Center. The Transplant Committee will then either approve or disapprove the living donor as a candidate for donation of the kidney.

How long will the evaluation take?

Donor evaluations also take varied times, depending on the individual and his/her medical condition. Only one donor at a time will undergo medical evaluation. An estimation of the length of time that is required for the donor's medical evaluation is approximately one month. After the completion of the medical evaluation, the donor test results will also be presented to the Transplant Committee. If the living donor is approved, a transplant date can be scheduled at a time that is mutually convenient for the recipient, donor, Transplant Center, Transplant Surgeon, and donor surgeon. (The transplant date is usually four to six weeks following the committee approval.)

What would prevent someone from being a donor?

Issue that would prevent someone from donating include:

- Hypertension or high blood pressure
- Diabetes
- History of cancer or current cancer
- Pregnancy
- Kidney stones, recurrent kidney infection or history of surgery on the urinary system
- Hepatitis
- HIV positive
- Overweight as to jeopardize their health
- Severe heart, lung or vascular problems
- Unresolved stomach ulcers
- Psychosocial issues that do not meet criteria guidelines

What type of surgery will the donor have?

There are two types of surgical procedures for obtaining the donor kidney:

- **Open Nephrectomy:**

The donor will have an incision in his/her side just under the ribs.

Average hospital stay is 5 to 7 days.

Usual recovery time is 4 to 6 weeks.

- **Laparoscopic Nephrectomy:**

A fiber optic instrument is inserted through small incisions in the abdomen to visualize the surgical removal of the donor kidney.

Average hospital stay is 2 to 3 days.

Usual recovery time is approximately 10 days less than with open nephrectomy.

The donor surgeon will explain these procedures to the donor in detail so that the decision can be made as to which procedure is the best option for the donor.

What are the risks for a donor?

The risks for donating a kidney are greatly reduced because of careful medical evaluation before donation. Risks may still be present as in all surgical procedures. These risks will be discussed in detail with the potential donor when the patient is seen both by the Transplant Nephrologist and the donor surgeon.

After surgery for removal of the kidney, the donor is at risk for:

- wound infection
- pneumonia
- blood clots in the legs
- internal bleeding

Though the risk factors are very low, you need to be aware of them. If the donor's remaining kidney is injured in an accident or becomes diseased, the donor will no longer have a second kidney and may even need dialysis or transplantation.

What can the donor expect after surgery?

If the donor has had an open nephrectomy, the donor will have a larger incision than if he/she has laparoscopic surgery. Pain medication will be available after surgery for the discomfort.

The nurses will remind the patient to breathe deeply and cough frequently. This helps prevent pneumonia. The donor will be getting out of bed soon after surgery to help prevent lung and other problems.

To make sure that the donor receives adequate fluids and nourishment, intravenous fluids will be given until normal oral intake is established.

A catheter will be placed in the bladder for 24 hours after the surgery.

Will the donor have a special diet or medicines?

The donor will usually not need a special diet, although it is strongly advised that the donor eat a well balanced diet. An iron supplement may be needed for a short time, but it will not be necessary for the donor to take medications because he/she donated a kidney.

The donor should avoid non-steroidal anti-inflammatory medications (i.e.: Motrin, Ibuprofen, Aleve, etc) and certain antibiotics. We recommend that donors thoroughly discuss any medications with their doctor prior to taking.

Donors should also make sure that they drink lots of water and do not allow themselves to get dehydrated.

When can the donor travel long distances and/or go home?

Generally within one to two weeks following the surgery the surgeon will see the donor again as an outpatient in their office. If the donor is from out of the Dallas area and is healing well without problems, the surgeon will release the donor to go home.

Does the donor need follow-up evaluations after giving a kidney?

Yes, the donor will need to have a follow-up visit three months after the surgery to see the Transplant Nephrologist for a follow-up evaluation. It will also be necessary for some follow-up testing which will include a CBC, routine blood chemistries, urinalysis, urine culture, 24-hour urine for protein and creatinine, and a Glofil test. The recipient's insurance will pay for these follow-up tests.

If the donor lives in the Dallas/Fort Worth area or will be traveling to the area, these tests will be set up through DTI. If the donor lives out of town, these follow-up tests can probably be scheduled with their physician at home, but this is dependent on financial approval from the recipient's insurance or hospital contract.

It is recommended that the donor have annual follow-up examinations with their primary care physician. This examination may include a urinalysis, routine blood chemistries and blood pressure check. The donor will be financially responsible for the annual follow-up examinations.

There are usually no restrictions to activity. Some physicians may recommend that the donor refrain from contact sports following the donation of a kidney.

What else should the donor know?

The donor evaluation process will be kept confidential. No information will be given to the potential recipient without prior approval of the donor.

Donors are strongly encouraged to have individual health insurance. This recommendation is based on the possibility that the donor's ability to obtain insurance after donation may be more difficult. Donors should be aware that future health problems related to the donation may not be covered. These factors should be thoroughly considered prior to donating.

Finally, donors have the right to stop the donation evaluation process at any point along the way for any reason.

NUTRITION/LIFESTYLE INFORMATION

What about my diet right after transplant surgery?

After any surgery, you need a few weeks to heal and recover. During this time, a high protein diet will speed the healing along. High quality protein comes from animals. Good high protein choices after a kidney transplant are nonfat and low fat dairy products, lean meats, fish and poultry and eggs. Vegetable foods that are high in protein include various beans and nuts. Your dietitian in the hospital will help start you on this phase of your care.

If your new kidney does not work well right away, then you will probably follow a diet like the one you followed before your transplant. This type of diet is often low in potassium and phosphorus.

I have heard that my new medications could have nutrition-related side effects. What kind?

Here are some short-term nutritional concerns:

- **Sugar** – some people may develop intolerance to sugar, this is known as diabetes. This problem might be temporary and is due to the high doses of Prednisone. It is more likely to happen if you have a family history of diabetes, and may improve as your drugs are adjusted.

If you already have diabetes, then you will notice that your insulin dose will increase. Your dietitian will help you work through any changes in your usual food and drink choices.

- **Salt** – Prednisone and other drugs can cause fluid retention. It is wise to avoid a lot of salt since this can make fluid retention worse in some people. Some of the saltiest foods are soups, cured meats and many snack items. Ask your dietitian for a more detailed review.
- **Minerals** –Some medications can cause minerals to be lost in your urine. Special supplements may be needed to be sure your body gets enough minerals. These supplements may include phosphorus, calcium, or magnesium. Occasionally a patient may have a high potassium blood level after transplant. This is usually temporary and related to medication doses. If that occurs, a few weeks on a low potassium diet may be helpful. Ask the dietitian for reminders about high potassium foods.
- **Stomach Upset** – Some medications may cause different problems with your digestion. Whether you have indigestion, diarrhea or other concerns, let the doctor know so that your medicines can be adjusted. Some people are sensitive to caffeine. If your stomach is sensitive, choose caffeine-free drinks.

What are some long - term nutrition side effects of transplant medications?

Some of the “short-term” problems you just read about may continue. Your dietitian will assist you and your family work through these short-term and long-term concerns.

- **Weight gain!** –Many people gain more than they ever imagined after a kidney transplant. Better food choices, low fat cooking and more exercise will be very important to keep your weight under control.
- **Diabetes** – Intolerance to sugar may be caused by Prednisone. It may happen soon after your transplant or may occur at a later time. Having a family history of diabetes is one risk factor. The chance for diabetes usually increases if you gain weight. There are several approaches to help manage blood sugars. Regular meals are important. Learning about carbohydrates in foods and drinks will be helpful.
- **Cholesterol** – Neoral (cyclosporin) and prednisone can increase your cholesterol level. A low saturated fat diet is good, and if you also want to control weight, meals low in total fat are your best bet. Ask your dietitian to explain about the different kinds of fat and how to read food labels and how to change your favorite recipes into healthier meals.
- **Bone changes** – A high calcium intake is helpful to keep bones as healthy as possible. When you do not have to worry about potassium, non-fat and low fat dairy products are great sources of calcium. Talk to your dietitian about more high calcium ideas.

Why is unwanted weight gain such a big problem after transplant?

There are several reasons why people tend to gain weight after getting a new kidney.

- A person usually feels better and has a better appetite.
- The sense of taste also improves.
- Some people think they no longer need to watch what they eat.
- Prednisone can be an appetite stimulant.

It may not happen right away, but may wait until you have had the new kidney for a few months. You may even want to gain weight! Talk with your dietitian about what you want for your future and ways to make it happen.

What about exercise?

Until your incision has healed, slow walking is enough. After healing, it is time to gradually rebuild your muscle strength. If you did not have much energy before your transplant, you may be surprised that after you recover from your transplant you are ready for more activities. Choose one or more activities that could be fun for YOU! Talk with your doctor about all your options now that you have a transplant. Whatever you decide, a regular schedule of activity will give you the best results.

Will it be necessary to take vitamin supplements after a transplant?

Before your kidney transplant, you were probably on a vitamin/mineral supplement especially designed for people with kidney disease. With a transplanted kidney that is working well, your appetite will be much better and a supplement may not be necessary. You, your doctors and dietitian may decide that supplements could be of benefit. Usually, a general multivitamin with 100% of RDA is adequate. Sometimes extra minerals are recommended, such as phosphorus, magnesium, calcium or iron.

Is it safe to take herbal preparations/supplements after a transplant?

You may have heard or read about many different kinds of herbs and botanicals. It is true that herbs are the basis for many medicines, but at this time, the FDA does not regulate the ones sold as supplements at drug stores and health food stores for dose or potency. Some products are even advertised to enhance the immune system. Since this is unknown, a person with a kidney transplant patient would NOT be wise to use these products. Your immune system is being suppressed intentionally by your post-transplant medications. Herbal products may interfere with medications you are taking after your transplant.

It is recommended that you do not take any herbal preparation without first discussing this with your physician and dietitian.

How much fluid should I drink each day after my transplant?

After a transplant, intake of liquids is very important. At least 2 quarts (2 liters) is the minimum amount. For some people who have been drinking very little on dialysis, this is quite a change! Keep a large container handy throughout the day. This is even more important in hot weather.

If you are trying to control your weight, choose drinks without calories. Even fruit juices can be high in calories!

I have heard that grapefruit juice does not mix with some medicines.

Research has found that grapefruit juice can change the way some drugs are absorbed by the body. One group of drugs that may be affected is your transplant medicines. Because of this, grapefruit products are not recommended after a transplant.

What about other nutrition problems?

The dietitian at Dallas Transplant Institute will be available to help you and your family to discuss nutrition and lifestyle changes after your transplant. Ask to see the dietitian when you are at DTI. You could also leave a message on her extension and she will call you back. An appointment with the dietitian can be made through the appointment desk at DTI.

SOCIAL SERVICE AND FINANCIAL INFORMATION

Why do I see a social worker as a part of the pre-transplant work-up?

A social work assessment is a part of every pre-transplant medical evaluation. The social worker will try to understand the impact kidney disease has had on your life, and your thoughts and feelings about having a kidney transplant. This information will also help the social worker help you in planning for a transplant. The information also helps the transplant team to better understand any special needs or problems that you might be having. Kidney disease can affect not only a person's medical condition but often brings about changes in other areas of your life—your employment, your finances, your support system, etc..

How can the social worker assist me during pre-transplant evaluation?

The social worker can help you to use your strengths and resources to plan to meet your needs after transplant. You will receive information about the following:

- Benefits of Medicare, Medicaid and the Texas Kidney Health Care
- How insurance works to meet your needs for medications and housing after transplant
- Medication costs and side-effects
- Managing depression and/or anxiety
- Working while awaiting transplant and preparation for return to work after transplant
- Financial issues
- Transportation and lodging needs after transplant
- Life changes after transplant

How can the social worker assist me after transplant?

Kidney disease can change your life. Transplant is another change and can bring new challenges. As a member of your health care team, the social worker can work with you to return to many of your normal activities. You may also want to try new activities, such as volunteering or a job change.

Your social worker can help you to understand your feelings and adjust to your new lifestyle in the following areas:

- Concerns about your job
- Your marriage and family life
- Information about healthcare decisions
- Changes in your role in your family
- Finding outside help when needed
- Dealing with all of the changes in your life

A social worker can guide you to community resources that may help you and your family:

- Find employment or return to employment
- Make the best use of your medication coverage
- Assist you in wellness and exercise

Social workers are a resource, an advocate and a link between patients and services that have been designed to assist them. There may be difficult social, personal and financial issues that transplant patients will face, and social workers can help with these issues. Working as part of a team, with *YOU* as an active member, the transplant social worker can help you live life to the fullest!

Who pays for transplant?

You may already be covered under a group or individual insurance policy – check with your employer or your spouse’s employer. If you have end-stage renal disease (ESRD), you may also be eligible for coverage for Medicare and/or Medicaid.

Private insurance

Policies vary on how they pay for transplant. Approval from your insurance company for the transplant is always necessary. It is important that you review your policy carefully for a clear understanding of your transplant benefits.

Coordination of Benefits with Employer Group Health Plans

When you are eligible for Medicare because of kidney failure, there is a period of time when your employer group health plan will pay first on your healthcare bills and Medicare will be the secondary payer. This period of time is called a 30-month coordination period. At the end of the 30-month coordination period, Medicare will become your primary payer and will pay first for all Medicare covered services and may include anti-rejection medications. Your employer group health plan coverage then becomes a secondary payer

Medicare

Medicare is a federal health insurance program for people who are disabled, retired, or have permanent kidney failure and who have paid into the Social Security system. Dependents may be eligible if a spouse or parent has paid into Social Security.

If you become entitled to Medicare because of kidney failure, Medicare coverage generally starts at one of three times.

- The fourth month after first chronic hemodialysis treatment
- The first month of dialysis if you participate in a self dialysis training program and are expected to complete the training and self-dialyze thereafter
- The month you are admitted to an approved hospital for a kidney transplant

Medicare hospital insurance (Part A) covers most but not all of the services you receive as an inpatient. You will be responsible for a Medicare deductible for each 60-day “benefit period” when you are admitted to a hospital. This will need to be paid when you enter the hospital for a transplant unless you have been in the hospital some time within that 60-day benefit period. If you also have private insurance or Medicaid, the deductible may be billed to those sources.

Medicare medical insurance (Part B) pays 80% of most outpatient services and clinic visits. To obtain additional information regarding Medicare benefits, you may contact the Social Security office at (800) 772-1213 and request a copy of the booklet “Medicare Coverage of Kidney Dialysis and Kidney Transplant Services—A Supplement to your Medicare Handbook”. You can also review information about Medicare at www.Medicare.gov.

Medicaid

Medicaid is a state health insurance program for people who are disabled or retired and have limited income and resources. If you are eligible for Medicaid, this program will help pay for your transplant and decrease the cost of medications.

Fund Raising

The cost of medication co-pays, lost wages during your recovery, possible lodging and food expenses can cause additional stress during your recovery from transplant. To help you prepare for post transplant expenses, organizations are available to help you raise money.

If I receive a kidney from a living donor, who pays the donor’s expenses?

Application for financial approval is necessary for potential living donors, just as it is for the potential kidney transplant recipient. The Pre Transplant department will discuss this with your potential donor when the donor calls to express interest in donating a kidney to you. It will be necessary for the donor to complete an application and send to the Pre Transplant Group, and after review, it will be forwarded to the appropriate Transplant Center.

Private Insurance

Policies vary on whether or not they will pay for living donor medical expenses. Approval must be obtained before the medical evaluation for the donor can be initiated. The recipient’s insurance will be reviewed to see if it will cover the donor medical evaluation.

Medicare

If the potential recipient is eligible for Medicare, Medicare will pay for donor evaluation, and hospitalization. Medicare will not pay for transportation, lodging or outpatient medication.

Medicaid

Medicaid does not cover living donor evaluations and other donor medical expenses.

If there is no coverage for the living donor, a cash deposit will be required by DTI for the donor medical evaluation. The Transplant Center will also require a cash deposit for the surgery and hospitalization expenses.

Where will I be able to get my medicines and how will they be paid?

Transplant medications, especially immunosuppressant (anti-rejection) drugs, can be very expensive. All together, they can be easily more than \$4000 per month.

It is important that you know your insurance benefits for medications including what is paid for generic brands versus name brand medications. It may also be important for you to know if your insurance carrier considers a particular medication as a “formulary” item or “non-formulary” item (covered or not covered on the drug list.) The co-pay amount is usually more if the prescribed drug is not on the insurance formulary.

You need to know what pharmacies are included in your insurance plan. This is information that you will need to find out BEFORE your transplant so that you can be prepared to pay for these medications if necessary when you leave the hospital. It is important that you find out if you have mail order pharmacy benefits with your insurance plan because such a plan can save you money on your medications.

- If Medicare is your primary insurance, you will be able to use the Medicare benefit to pay for the immunosuppressant medications. Medicare will pay for 80% of the cost of these medications for the length of time that you have Medicare, if you use a Medicare Part B provider pharmacy. Many pharmacies are not Medicare provider pharmacies. The Social Worker who sees you during your pre-transplant evaluation can give you information about these Medicare Part B provider pharmacies.
- If Medicare is your primary insurance and you also have another insurance plan, the Medicare Part B provider pharmacy may be able to bill for the cost of your immunosuppressant medication first to Medicare, which will pay 80% of the cost, and then to your secondary insurance, which will pay the remaining 20% of the cost. You must be sure that your insurance plan will coordinate benefits secondary to Medicare for immunosuppressant medications or you could have to pay a larger bill.
- If you have Medicare and Medicaid, the immunosuppressant medications can be billed to Medicare, which will pay 80% of the cost, and then to Medicaid, which will pay the remaining 20% of the cost. You must go to a Medicare provider pharmacy in order to do this.
- If you have Medicaid only and are taking a medication regularly, you can often get a six-month’s supply at a time through Medicaid. It is important that you ask your physician to write the prescription as a 180-day supply in order to maximize this benefit.
- Usually, Medicare ends three years after a successful kidney transplant unless you are disabled for some other medical reason or unless you are 65 years of age.
- If you have the Texas Kidney Health Care Program (KHC), and do not have other insurance plans that pay for medications, you will be able to use this program to pay for some medications that are on the program’s approved list of medications. Certain pharmacies are Texas Kidney Health Care provider pharmacies and will bill directly to Texas Kidney Health Care. KHC can also help you pay Medicare Part D copays and premiums. In some cases, it may pay the 20% remainder after Medicare for anti-rejection medications.

- Medicare Part D plans are available to people that have Medicare with no “creditable” employer group health plans. If you have a transplant with Medicare and had your transplant at a Medicare covered facility and had (or got retroactively) Part A at the time of your transplant, your anti-rejection medications are not covered under Medicare Part D. Immunosuppressant (anti-rejection) medications are covered under Medicare Part B.

If I am from out of town, what additional expenses will I have after I leave the hospital?

It is recommended that transplant recipients who live outside the Dallas area remain in town for four to eight weeks following surgery so that they can be closely followed at DTI. Expenses that you will need to plan for during this time include lodging, transportation, and food. Some private insurance companies will help with these expenses. Medicare and Medicaid will not. If you have relatives or friends in the Dallas area, you might consider staying with them for a few weeks to assist you with your expenses.

How long is Medicare in effect after my transplant?

Medicare coverage ends 36 months after the month of a kidney transplant. Medicare will continue past the 36 months only as long as you are receiving Social Security Disability benefits or are 65 years of age or over.

How long is Texas Kidney Health Care in effect after my transplant?

Under the current Texas Department of Health policy, Texas Kidney Health Care is a lifetime benefit for people who are either on dialysis or have received a kidney transplant. To qualify for this benefit, you must be a resident of Texas and have a household income of less than \$60,000 annually.

If I no longer have Medicare or other insurance, how will I pay for services when I come to the clinic?

Hopefully, the transplant will allow you to return to a productive lifestyle and employer insurance will be available. If not, patients will be personally responsible for their costs from DTI. Arrangements may be made for a special payment schedule.

Is there a member of the transplant team who can help me find financial assistance if I need it?

A Social Worker is available to provide information regarding resources for financial assistance as well as other concerns that accompany the adjustment to having had a kidney transplant.

Who do I call if I have questions about the bills that I receive from Dallas Nephrology Associates/DTI?

If you ever have questions about your billing statement you may contact the Billing Representative at DTI or call the Billing Department at (214) 358-2300. It is important that you notify us of changes in your insurance so we can avoid billing problems.

IMPORTANT ADDRESSES AND TELEPHONE NUMBERS

DALLAS TRANSPLANT INSTITUTE

3604 Live Oak
Suite 100
Dallas, Texas 75204
(214) 358-2300

DALLAS TRANSPLANT INSTITUTE

Pre-Transplant Group
1420 Viceroy Drive
Dallas, Texas 75235
(214) 358-2300

BAYLOR UNIVERSITY MEDICAL CENTER

3500 Gaston Avenue
Dallas, Texas 75246
(214) 820-0111

BUMC TRANSPLANT DEPARTMENT

3500 Gaston Avenue
Dallas, Texas 75246
(214) 820-2050

METHODIST MEDICAL CENTER

1441 N. Beckley
Dallas, Texas 75201
(214) 947-1800

METHODIST MEDICAL CENTER TRANSPLANT SERVICES

(214) 947-1800
4 BED TOWER (Transplant Unit)
(214) 947-4099

BAYLOR ALL SAINTS MEDICAL CENTER

1400 8th Avenue
Ft. Worth, Texas
Transplant: 1st Floor C Bldg
(817) 922-4650