

*Living Kidney Donation
Patient Education Handbook*



*Transplant Services
Charlottesville, Virginia*



LIVING KIDNEY DONATION

Introduction

This handbook was developed to provide information to those individuals considering donating a kidney to a family member or friend. The information provided might not answer all the questions that you or your family members may have and it may also stimulate new questions. This handbook is meant to be a supplement to the discussions with the doctors and nurses involved in your care. You may find it useful to read parts of this at a time or refer back to the handbook at different points in time. It is important that you fully understand how donating a kidney will affect you and your family. Our staff is available to help you make your decision, as well as explain required tests and their results. Please do not hesitate to contact the Transplant team members at any time you would like more information.

The Transplant Team

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Transplant Nephrologists

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Transplant Office Access

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Kidney (Renal) Failure and Transplantation

Kidney, or Renal, failure occurs when the kidneys are unable to perform their normal function of filtering out waste products and excess water from the body. When a patient loses 90-95% of his or her kidney function, life-saving treatment becomes necessary. The treatment options currently available include hemodialysis, peritoneal dialysis, and kidney transplantation.

Dialysis can replace some, but not all of the normal kidney functions. Hemodialysis involves use of an artificial kidney where an individual must commit 12-20 hours per week for regular treatments. There is often limited flexibility in scheduling these treatments, which may pose an inconvenience to the individual and/or their family. In addition to these treatments, there are some necessary diet and fluid restrictions. Peritoneal dialysis involves the instillation of a special solution into the abdominal cavity through a permanently implanted catheter. This fluid remains in the abdomen for a designated period of time and then is drained into a bag connected to the catheter. Considerable treatment time is required even when the treatments are done at home. Neither the use of a dialysis machine and artificial kidney, nor using the abdominal cavity as a substitute filter, can completely replace the normal functions of a kidney.

Transplantation, when successful, provides an opportunity for the individual with renal failure to be free from a regular dialysis regimen. The normal hormonal functions of a kidney will occur, and the individual will have fewer dietary and fluid restrictions. The downside of transplant includes a requirement for the transplant recipient to take medications to suppress the body's natural tendency to reject the transplanted kidney for as long as the kidney is in place. In addition, some of the medications may be associated with undesirable side effects such as infection, stomach ulcers and weight gain. The decision to pursue transplantation as a treatment option should be made by the individual with renal failure and their family after discussing all treatment alternatives with their doctor and the Transplant team.

LIVING KIDNEY DONATION

The Transplant team at the University of Virginia encourages living donor transplantation for various reasons. Currently, kidneys from living donors have a better long-term survival rate than kidneys from deceased donors, and the waiting time for a deceased donor kidney is approximately five years. A living donor transplant is scheduled and planned for, so the surgery takes place at a convenient time for everyone concerned. The waiting time for the recipient is minimal. In addition, the donor and recipient operations take place at the same time, which means that the kidney is outside of the body for a short period of time, thus it is still warm when placed into the recipient's body. Kidneys from living donors usually start working immediately in the operating room whereas cold kidneys, or kidneys that have been out of the body for a longer period of time, may take several days to fully function.

It is important to remember that living donor transplant is one option for someone with kidney failure. Possible alternatives to living donor kidney transplant include the potential recipient being placed on a waiting list for a deceased donor kidney transplant and/or to start, or stay, on hemodialysis or peritoneal dialysis.

WHO CAN BE A LIVING DONOR?

In addition to parents, children and siblings, living donors can also include distant relatives, adoptive relatives, in-laws, friends, co-workers, etc. Ideally, the potential donor and recipient have compatible blood types. There is a protocol however, that can be used for *some patients* whose donors have an incompatible blood type.

Selection Criteria

A living kidney donor must be willing and in excellent health, both physically and psychologically. Individuals with a history of high blood pressure, diabetes, recurrent urinary tract infections, kidney stones, blood in the urine, cancer, heart disease, or liver disease cannot be considered as donors because of the potential health risks to themselves and the kidney recipient. Obesity (a body mass index of greater than 35) and previous surgeries may also exclude a donor because of the increased surgical risk. Donors can be between 18 and approximately 70 years of age. In addition, all donors must complete and pass a thorough medical and psychosocial evaluation that is described further in this handbook.

THE DECISION TO DONATE

Being a living donor is a rewarding experience. It is a sharing of life and a giving of oneself to someone you care about. Donating a kidney, however, is also a choice that *only* the donor can make. Some people make the decision instantly with few worries or concerns. Others may go through some soul searching before deciding. It is very normal to be afraid of giving a kidney and to experience guilt about not wanting to be donor. The Transplant team is available to assist you with this choice by making sure that all of your questions are answered and by providing any additional information necessary to help you make your decision. A psychological evaluation is required to help you determine your real feelings about being a donor and to assess coping skills in case complications occur with either you or the recipient. It is also our responsibility to protect the privacy of each donor because everyone always has the right to say no, no matter what the circumstances. Remember that the only “right” decision is the one that makes the donor most comfortable.

Hospital personnel who are involved in the course of your care may review your medical record. They are required to maintain confidentiality as per law (HIPAA) and policy of this hospital. If you do become a donor, data about your case, which will include your identity, will be sent to a Federally-designated organization called UNOS (United Network of Organ Sharing) and may be sent to other places involved in the transplant process as permitted by law. *Communication between the transplant center and yourself will remain confidential, but will be subject to authorized release of information. Your evaluation results and records will be kept confidential from the intended recipient.* Should you decide not to donate, your reasons for not going forward will be kept confidential and not shared with the potential recipient

THE PRELIMINARY EVALUATION PROCESS

Should an individual decide to become a kidney donor, he or she must contact the Transplant Office to speak to the Living Donor Nurse Coordinator. The nurse coordinator will obtain a health assessment over the telephone.

Blood Typing

Blood typing is always the first step in the evaluation process. Listed below are blood type compatibilities.

DONOR		RECIPIENT
O	→	O
A, O	→	A
B, O	→	B
O, A, B, AB	→	AB

HLA Tissue Typing

Tissue typing is a *blood* test that identifies the genetic components in each individual that helps us determine how well the donor and recipient match. Every person inherits genes from each of their parents, half from the mother and half from the father. People from the same family may share all or some of the same genes. *Living donor transplants can be done when all, some, or even none of the genes match.* Better matches may prevent or decrease the incidence of rejection after transplant however; even perfectly matched kidney recipients may experience some rejection. The tissue-typing test may help decision-making when multiple members of a family want to be donors. The tissue-typing test must always be performed at UVA.

Crossmatching

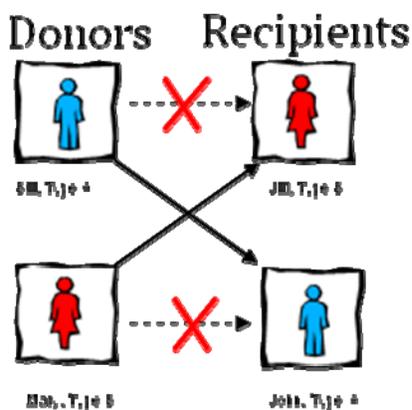
The crossmatch is a blood test that mixes white blood cells from the donor with the recipient's blood and looks for any reaction. Any reaction, or a positive crossmatch, indicates that the immune system of the kidney recipient would not accept a kidney from this donor. A negative crossmatch means that no reaction has taken place, which is the result that the Transplant Team is looking for to determine if a particular recipient can receive a kidney from a particular donor. The crossmatch test is done at the beginning of the evaluation process and is also repeated before the transplant operation to make sure that the initial negative results have not changed. The second test is known as the final crossmatch and is done approximately two weeks before the scheduled surgery. It is rare, but possible, to have a negative crossmatch initially and a positive crossmatch right before the operation. This can occur as a result of the recipient receiving blood or having an infection. The transplant cannot be done if the final crossmatch is positive.

If a donor and recipient have incompatible blood types or an incompatible crossmatch, donor-recipient pairs have two options to proceed with living donor transplantation:

1. Desensitization
2. Paired Donor Exchange

Desensitization involves the recipient candidate receiving specialized medical treatment before and after the transplant to decrease the chance of rejection. In this type of transplant, the incompatible donor donates his/her kidney to his/her intended recipient.

Paired Donor Exchange involves two pairs of potential living donors and recipient candidates who are not compatible. The two pairs exchange or “trade” donors so that each recipient candidate receives a kidney from a compatible donor. See the figure and example below.



In this example, Jill and her donor, Bill, are not compatible and John and his donor, Mary, are not compatible. By choosing to participate in the Paired Donor Exchange Program it is determined that Bill is compatible with John and Mary is compatible with Jill. The recipients trade or swap donors.

The Transplant Team reviews each pair's compatibility to determine the best option(s) in each individual case. There are additional educational materials about the University of Virginia's Paired Donor Exchange Program that you will receive if you and your recipient are found to be incompatible AND if this is an option you are interested in learning more about.

Urine and Blood Studies

The next step in the evaluation is to determine whether the donor's kidney function is adequate for donation. The nurse coordinator will arrange the following tests at any local hospital, or at UVA:

1. Comprehensive Metabolic Panel, a blood test to check kidney function and other lab values
2. Urinalysis and urine culture-to check for bacteria, blood, and protein in the urine
3. 24-hour urine collection for creatinine clearance and total protein – this test looks for normal kidney function over a longer time period than the blood tests
4. Urine microalbumin/creatinine ratio, another test to look for protein in the urine

If the donor's kidney function is not acceptable, he/she will be ruled out for donation. It is critical that the donor be able to sustain himself/herself for his/her lifetime with the *one* remaining kidney.

THE REMAINDER OF THE EVALUATION

Once the preliminary blood and urine testing is done, and the potential donor's kidney function is found to be adequate, the potential donor will be further evaluated by the Donor Evaluation Team. This team is a group of UVA family medicine physicians, psychologists, and a social worker that meets and evaluates each donor. A review of past and current medical problems and surgeries is done to be sure that there are no concerns that would place the potential donor at any risk. Physical exams include measurement of blood pressure to make sure that there is no evidence of hypertension (high blood pressure).

This team is not involved in the care of the potential recipient and will only look after the potential donor's health, safety and interests throughout the kidney donation process. This team will decide if there are any medical or psychosocial problems that would prevent someone from being a living donor. One member of this team is the Independent Donor Advocate. This person advocates for potential donors' needs, rights, and interests and will help potential donors to understand the informed consent, evaluation, surgery, and follow-up processes.

Please note: At this point in the donor evaluation, only one potential donor will be evaluated for a given recipient at a time. At any point in the evaluation process, if a potential donor is deemed inappropriate for donation, another potential donor may be considered for evaluation.

The other evaluation tests and studies included in the evaluation are listed below:

1. EKG
2. Chest X-ray
3. Routine lab work – studies include screening for kidney function, liver function, and hepatitis, HIV, diabetes and other viruses and infections.
4. 2-hour oral glucose tolerance test - this test is done when there is a family history of diabetes.
5. Renal Ultrasound – this test looks for the presence of two normal looking kidneys without stones or masses.
6. Tissue Typing and Crossmatching (as previously described)
7. If you are over the age of 50, you will need to have a cardiac stress test, which will be scheduled for a different day either locally or at UVA.

THE FINAL EVALUATION PROCESS

Renal CTA or MRA

The renal CTA or MRA is the last procedure in the evaluation process. This test is done *only* if all prior test results are normal. It evaluates the blood vessels that supply the kidneys, which helps the surgeon determine which kidney is the best one to remove. This test may show some blood vessel abnormality, which would make removing the kidney and transplanting it into the recipient technically impossible. The results of this test will be reviewed with you once the reading has been confirmed with the radiologist and transplant surgeon. Our department will schedule an appointment in our clinic the same day as the CTA or MRA for the potential donor to meet with a living donor transplant surgeon. The surgical procedure and the risks associated with being a donor will be discussed at this time.

One benefit of the donor evaluation is the potential for finding out about health problems that you did not know you had but may need treatment for. Your ability to get health and life insurance in the future may be affected by finding out about these health problems. Future kidney disease or abdominal problems may not be covered by your insurance. If these problems are not related to the surgery and are not covered by your health insurance, you will be responsible for all costs. Your future health, disability, and life insurance premiums may be altered due to being a donor. You also may not be able to get health, disability and life insurance in the future if you lose my current insurance or if you are not now insured.

Although the University of Virginia is a Medicare-approved provider, I understand that if my intended recipient's transplant is not provided in a Medicare-approved transplant center it could affect his/her ability to have his/her immunosuppressive medications paid for under Medicare Part B.

THE SURGICAL PROCEDURE

The operation to remove a kidney can be done in one of two ways. The preferred method for removing a kidney involves the use of a laparoscope, which contains a miniature camera. Four or five small incisions are made and the abdomen is inflated with carbon dioxide gas to better visualize the anatomy. The surgeons watch what they are doing on a video monitor. The kidney is cut free and then removed through a slightly larger incision in the lower abdomen. This surgery takes approximately 3 hours.

The alternate way to remove the kidney is done with an incision about 10-12 inches long made along the patient's side near their waist, between the ribs and hip. In some cases a rib or part of a rib may be removed to provide better access to the kidney. The entire operation takes 3-4 hours. There is a longer recovery time, and oftentimes more pain, associated with this method when compared to the laparoscopic procedure.

The laparoscopic technique will be utilized whenever it is appropriate and possible for a donor. It is possible; however, that the laparoscopic surgery might not be the best option for a donor based on his/her anatomy. Before surgery, the surgeon will review all of the advantages and disadvantages of each surgical technique so the most appropriate approach is selected for each donor.

THE SURGICAL EXPERIENCE

Living kidney transplants at the University of Virginia are done on Thursdays. Approximately two weeks prior to the scheduled surgery date, both the donor and the recipient will come to the transplant clinic for a pre-operative visit. During this visit the donor will have a history and physical exam performed by a surgeon, receive pre-operative instructions, and have pre-operative blood drawn for the final crossmatch and other blood tests. Consent for the donation surgery will also be obtained at this clinic visit. You will also be evaluated in the Pre-Anesthesia Evaluation and Testing Center where anesthesia screening will occur. You will not actually be admitted to the hospital until the morning of the surgery. If you live far away and want to stay in Charlottesville prior to surgery let us know and we can help you find accommodations.

The day of surgery you and the recipient will go directly to the Surgical Admission Suite. The staff there will start an intravenous (IV) line through which medications will be given to you during surgery. You will then be taken to the operating room where the anesthesiologist will give you a medication through your IV line to put you to sleep. You will wake up in the Recovery Room where your blood pressure and other vital signs will be closely monitored by the nursing staff. You will feel very groggy and may have some discomfort. A catheter will be draining urine from your bladder and frequent urinary output measurements will be taken.

Once you are sufficiently awake and your vital signs are stable, you will be transferred to the nursing unit 5-West. Your family members may visit with you. The IV will remain in place until you are able to take in fluids and food by mouth. Medicine for pain will be available when you need it. You will have sequential compression devices on your legs, which inflate with air, to prevent blood clots in your legs. Once able, you will be encouraged to get out of bed, usually on the evening of surgery or the following morning. During your hospital stay, you will be encouraged to move around as much as possible. You are likely to have some pain the first several days, which is completely normal. You will remain in the hospital two to four days and at the time of discharge, you will be given narcotic pain medicine to be taken by mouth once you are at home.

RECOVERY AND FOLLOW UP

The recovery period will be different for each individual and may vary based on the surgical technique used to remove the kidney (open -vs- laparoscopy). Once home, your activities will be somewhat limited. You may not drive for two weeks from the date of your surgery and you may not lift anything heavier than ten pounds for the first three weeks. You may find that you tire easily for the first couple of weeks. Most active sports, such as jogging, tennis and exercise class should not be resumed before four weeks after discharge. Walking is very good exercise and is

encouraged. You will be instructed to call the Transplant Nurse Coordinator if you have any questions about your care. You should plan on returning to work four to six weeks after surgery and when the Transplant Surgeon approves your return. For individuals who do heavy lifting or manual labor for their jobs, the length of time off of work will be eight to twelve weeks.

The Transplant Team will provide your medical care for the time period immediately following donation surgery. You will be scheduled an appointment for 2-3 weeks post-operatively and then one month after that appointment. At that time, you will be released from our care. It is expected that you will have long-term medical care provided to you by your family physician.

Please note that UNOS, the United Network for Organ Sharing requires that Transplant Centers submit information pertaining to living donors addressing the health information of each living donor at *6 months, one-year, and two-years* following the donation. Donors may be contacted by phone and/or mail asking for an update on your health.

COMMONLY ASKED QUESTIONS

Who pays for the evaluation and surgery?

The Transplant Program covers all *medical* costs associated with your donation. This includes all medically necessary preparatory procedures, the surgery, postoperative medical recovery expenses, and any medical complications that may occur related to donation. The surgery, hospital stay after surgery and immediate post-operative care is covered by the recipient's insurance. Costs that are *not* covered include, but are not limited to, loss of salary due to time off from work, hotel and transportation costs, and personal expenses. Donors should explore their employer's sick leave policy, since they will not be able to return to work for approximately four to six weeks, perhaps longer. If you have financial concerns you should discuss these issues with the Donor Evaluation Team and/or the Transplant Team prior to donation. It is the responsibility of the potential donor to make the Transplant Program aware of any financial concerns prior to the surgery date.

What are the health risks to a kidney donor?

The operation involves the same level of risk for the donor as any other major surgery. The risk of death associated with having a kidney surgically removed is 1 in 4000. Donors may experience some complications as a direct result of the surgery, the majority of which are relatively minor such as treatable infections and persistent tenderness around the incision. Research has shown, and continues to show, that kidney donation does not appear to put donors at any increased risk for future health problems.

Some of the possible risks of being a kidney donor include bleeding requiring transfusions, infection, chronic pain, blood clots, damage to abdominal organs, incisional hernia, bowel obstruction, future kidney failure, and major anesthetic complication such as heart attack and/or stroke.

There is also the potential for psycho-social risks, such as depression, post Traumatic Stress Disorder (PTSD), generalized anxiety, anxiety regarding dependence on others while recovering from the donation and possible feelings of guilt.

Does kidney donation affect lifestyle?

A person can lead an active, normal life with only one kidney. After recovery you can work, drive, exercise and participate in sports as usual. You can continue all types of occupations, including military duty. There is also no evidence to suggest that female donors suffer any effect on their ability to become pregnant or bear children.

What if I change my mind about having this surgery?

A potential donor should never feel pressure to donate. At any point in the evaluation process, you have the option to change your mind. Even if you get through the entire donor evaluation, you still have the opportunity to change your mind. You can put a stop to the surgery up until the point you are put to sleep in the operating room! The transplant team will support whatever decision you make, at whatever time you make it. Your decision will be confidential and not shared with the intended recipient, or anyone else.

Want more information?

You might find the following web-sites helpful regarding living donation and kidney transplantation, in general:

www.kidney.org/transplantation/livingDonors
<http://www.transplantliving.org>

In addition, we also have available to you, a DVD titled “Living Kidney Donation: What You Need to Know” that you can check out from our office if you wish. This video was created by The American Society of Transplant Surgeons through an educational grant by Wyeth Pharmaceuticals. Please let us know if you are interested in viewing this optional educational video.

****Thank you for taking the time to carefully read the information in this handbook. Please contact our office with any questions you might have about living kidney donation and/or if you wish to be evaluated as a donor.****

Patient Rights and Responsibilities

The University of Virginia Health System is committed to providing an environment, which fosters quality health care for its patients as described below. Employees are expected to assist patients in understanding and exercising their rights. Likewise, patients are expected to understand their responsibilities to their caregivers and other individuals attempting to provide services to them.

Patient Rights

- The UVa Health System is dedicated to giving you the best health care and service possible. As a patient here, you may expect to receive considerate and respectful care. We will honor your rights to be informed and to be involved in making decisions about your care. You have the following rights as a competent adult patient:
- You have the right to know about your illness and proposed treatment and to participate in the development of your plan of care. Information will be given to you by your doctors and other members of your health care team in language you can understand.
- You have the right to make decisions about your care, including the right to know why you need an operation or treatment and who will perform that operation or treatment. This includes the right to refuse care or treatment and to know what may happen if you do not have this care or treatment.
- You have the right to develop Advance Directives and to have hospital staff comply with those directives.
- You have the right to access all information contained in your medical record. This includes the right to know the name of the doctor who is in charge of your care and the names of all other Health System staff taking care of you.
- You have the right to have a family member or representative and your own physician notified promptly of your admission to the hospital.
- You have the right to receive treatment in a safe, abuse-free environment without discrimination as to race, color, religion, sex, national origin, disability, sexual orientation, or source of payment.
- You have the right to personal privacy while in the hospital and to have all information about your illness and care treated as confidential.
- You have the right to be free from restraints of any form that are not medically indicated.
- You have the right to receive appropriate assessment and management of pain.
- You have the right to agree or refuse to take part in any study or experiment related to your care or treatment.

- You have the right to review your bills and have any questions you have about them answered.
- You have the right to discuss your concerns or file a complaint with the hospital's Patient Representative Office regarding your experience as a patient of the Health System and to receive a response in a timely manner. You also have the right to an internal appeal to any response that you receive and a right to file a complaint with an external agency.

Patient Responsibilities

In order to receive optimal care, you and your family are responsible for:

- Providing accurate information about your present illness and past medical history and wishes for your medical care.
- Seeking clarification when necessary to fully understand your health problems and the proposed plan of care.
- Following through on your agreed plan of care.
- Considering and respecting the rights of others.
- Being courteous.
- Providing accurate information for insurance claims and working with the Health System to make payment arrangements when necessary so that others can benefit from the services provided here.
- Following visitation policies of University Hospital.
- Following the rules and regulations of the Health System and of the Commonwealth of Virginia which forbid:
 - Engaging in verbal or physical abuse,
 - Using alcohol or illegal substances,
 - Carrying weapons of any kind.