

VA Pittsburgh Transplant Center

Living Kidney Donor Guidebook



VA



U.S. Department of Veterans Affairs

Veterans Health Administration
VA Pittsburgh Healthcare System



VA



**U.S. Department
of Veterans Affairs**

**Veterans Health
Administration**
*VA Pittsburgh
Healthcare System*

**VA Pittsburgh Healthcare
System provides solid
organ (kidney and liver)
transplants to eligible
Veterans. This guide is
about VA's living kidney
donor process.**

Table of Contents



LIVING DONOR GUIDE INTRODUCTION

Eligibility and Requirements4-7



YOUR TRANSPLANT TEAM

About Your Team Members 8-9



BENEFITS, RISKS, AND COMPLICATIONS

Benefits of living donation.....10

Risks of living donation10-11

Potential complications with living donation....11



WHAT TO EXPECT

Pre-Evaluation12-13

Post Evaluation.....14

Pre-Surgery.....14

Recovery15



ADDITIONAL INFORMATION

Kidney Knowledge.....16-17

Registries and Data17

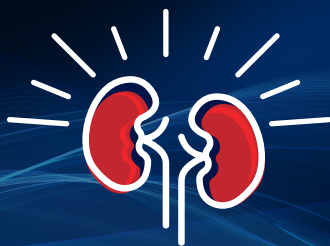


CONTACTS/NOTES/REFERENCES

Contacts.....18

Notes.....18-19

References.....19



Introduction

Who can be a living donor for a Veteran?

Non-Veterans and Veterans can register as living organ donors for the Veteran of their choice. VA lists living donors as “transplant collateral” to the recipient. The designation allows the donor to go to any VA medical center (VAMC) for VA-provided testing, medical care and treatment for all donor-related care before and after the transplant surgery. Care provided to Veterans who are living donors is separate from their other VA benefits.

Are you able to become a living kidney donor?

Becoming a living donor is a serious decision: you are asking to have major surgery that has no medical benefit to you. VA Pittsburgh Healthcare System’s (VAPHS) Living Donor Transplant Team takes a cautious approach when approving someone to be a living kidney donor. We are careful to select donors who are able to live happy, healthy, successful lives while living with one kidney.

Living kidney donors must be 21 or older and in excellent health. Donors cannot have diabetes, a history of diabetes or high blood pressure.

You should:

- Discuss your decision with family and friends who can help you make an open and fair-minded decision.



- Consider talking with other living donors through the National Kidney Foundation's peer mentoring program. For more information, call **855-653-7337** or email **nkfpeers@kidney.org**.
- Evaluate whether you can afford to take time off work to recover from surgery. Most short-term disability policies do not cover time off work for living-donor surgery and recovery. Talk with your employer's human resources department and your health insurer about possible benefits available to you. Find out if becoming a donor will impact your ability to obtain health, life and disability insurance in the future.
- As a living organ donor, you will undergo a medical evaluation that is more detailed than a general physical. During the evaluation, undiagnosed medical conditions may be found that you are not aware of. For this reason, anyone interested in becoming a living donor must also have private insurance. Your insurance company will never be billed. If another medical condition is found during the evaluation, VAPHS is confident you will receive care and treatment through your primary care provider (PCP).
- Know that even if you meet the minimum requirements to be a donor, the transplant team makes the final decision on whether you can be a donor.
- Understand you can withdraw as a donor at any point during the process. We will support your decision and keep it confidential. Please discuss any concerns with the living donor transplant coordinator or independent living donor advocate.



Introduction (cont.)

You must have a support person.

If you are able to donate and are selected, you must have a support person. Donors who have a good support person do much better than those without support. Your support person will:

- Help you understand the risks and benefits of donor surgery.
- Keep you safe during travel and after your surgery: you will stay in a hotel as you recover.
- Help you cope with possible complications.
- Make a positive difference in your emotional well-being.

Ask your living donor transplant coordinator for information you can give to your support person to help them understand their role.





Ready to find out more?...



Your Transplant Team

If you are selected, a team of health care professionals will manage your care and answer your questions. Team members include:

Living Donor Transplant Coordinator

Registered nurse and your primary contact. Experienced in the care and management of transplant patients and living donors. Acts as a liaison between you, the transplant team and the referring VAMC.

Independent Living Donor Advocate

Social worker. Works independently from the transplant team. Meets with you to review your personal concerns about kidney donation. Helps you find support and financial resources. Works with you on planning for recovery after donation.

Transplant Nephrologist

Physician who specializes in kidney disease. Assesses you for donation and may recommend more testing and/or consultations with other health care providers. Follows up with you throughout the transplant process.



Transplant Surgeon

Physician who performs transplant surgeries. Meets with you to discuss your surgery, including the process, risks and side effects. Makes recommendations about your suitability to be a living donor.

Pharmacist

Medication expert. Meets with you during your evaluation and after your donation. Reviews your current medications and provides direction on the proper use of any new prescriptions your physician might order.

Psychologist

Speaks with you about your decision and goes over your knowledge of the process, risks and complications. Asks you about your psychosocial history, your mental and physical health, and how you deal with stress. Helps you understand any psychosocial risks related to kidney donation.

Other Staff as Needed

You may need to meet with other health care professionals, including a dietitian, pulmonologist (lung doctor) or cardiologist (heart doctor). Staff may ask you to sign a release of medical information so they can get information from other health care providers such as your primary care physician (PCP).



Benefits, Risks and Complications

What are the benefits of living donation?

- Generally, a lower risk of rejection if the donor is a relative.
- Immediate kidney function. Surgery to remove the donated kidney is done in an operating room next to the recipient. Deceased donation may have a delay in kidney function that may require dialysis for a short period of time.
- Increased organ supply. Each living donation removes another person from the transplant wait list.
- Longer-lasting kidney function. Although not guaranteed, living-donor kidneys can last 15 to 20 years on average. Deceased-donation kidneys last 10 years on average.
- Healthy, normal life after giving; studies show donating a kidney is safe.
- Sense of satisfaction in knowing you helped someone by donating an organ.

What are the risks of living donation?

Short-term risks:

- › Post (after)-surgery pain
- › Infection
- › Blood loss requiring a blood transfusion
- › Blood clots including deep vein thrombosis (DVT) and pulmonary embolism (clots in your lungs)
- › A poor reaction to anesthesia
- › Need to change from a simpler to a more involved procedure
- › Pneumonia
- › Injury to surrounding organs and structures
- › Death (extremely rare)

Long-term risks:

- › High-blood pressure
 - › Kidney failure leading to dialysis or transplantation
- Note:** High priority is given to previous living donors on the transplant waiting list if kidney failure develops



Psychological risks:

- › Body image issues because of scars at the surgical site
- › Depression (can happen years after donating)
- › Feelings of resentment, anger, regret, and/or guilt if the recipient rejects the organ, has organ failure or loss of the donated organ.

Important Information for Living-Donor Women of Childbearing Years:

- › If a human chorionic gonadotropin pregnancy test is positive, your donor work-up will be put on hold.
- › Two-hour glucose test to check for diabetes and a 24-hour ambulatory blood pressure test to check for high blood pressure required.
- › History of diabetes mellitus or gestational diabetes poses greater risk for kidney disease
- › There is a greater risk for gestational diabetes, high blood pressure, preeclampsia, and other serious pregnancy-related health issues after donating. Tell the transplant team if you have a history of pregnancy complications.
- › Inform obstetrician/gynecologist of prior donation if you become pregnant.

What are common potential complications with living donation?

- Blood clot (embolism or thrombosis) or pneumonia
- Stomach problems including distention/bloating or an ileus (a buildup of food caused when the intestines do not contract normally.)
- Infections involving the wound and urinary tract.
- Other complications that vary from patient to patient. Please tell your living donor transplant coordinator of anything that doesn't feel normal.

For more information on other potential complications, please speak with the transplant team.



What To Expect

What can you expect during your evaluation for living donation?

Pre-evaluation

You will meet members of the transplant team and be evaluated to make sure you can donate safely. You will undergo imaging scans and bloodwork, some of which will be done at a VAMC near you.

Common medical tests include:

Chest X-ray

Looks at your lungs.

Electrocardiogram (EKG)

Records your heart's electrical signals to see if your heart is functioning normally.

Carotid Dopplers

Uses harmless sound waves to assess blood flow inside your blood vessels and check for narrow or blocked carotid arteries.

Ultrasound of the Abdomen

Uses sound waves to form pictures of your abdominal organs to look for problems such as gallstones, kidney stones or liver disease.

Echocardiogram

Uses ultrasound to look at how well your heart works.

Split Renal Function Scan

Looks at the function of each of your kidneys.

CT Angiogram

Looks at your kidneys' blood vessels.

24-Hour Ambulatory Blood Pressure Monitor

You will wear a blood pressure cuff for 24 hours. It will take and record your blood pressure every 20 to 30 minutes to see if you have high blood pressure during a normal day and overnight while sleeping.

Blood work

Blood work includes but is not limited to:

- Electrolytes
- Magnesium
- Cholesterol
- Lipase
- Urine Microalbumin
- Hemoglobin A1C
- Phosphorus
- Triglycerides
- Cystatin C
- 24-hour Urine Study
- Complete Blood Count
- Uric Acid
- High Density Lipoprotein (HDL)
- Blood Typing x2
- Prostate-Specific Antigen (PSA) (men)
- Amylase
- Gamma-Glutamyl Transpeptidase (GGT)
- Low Density Lipoprotein (LDL)
- Urinalysis
- Human Chorionic Gonadotropin (HCG) (pre-menopausal women)

Cross-matching

Checks to see if you are a match to the Veteran to whom you wish to donate. If you are not a match, you can volunteer for the kidney paired exchange program (KPD) or become a donor for a different Veteran. Ask your living donor transplant coordinator for information on the KPD program. If you are a match, a final cross-match will be completed one to two weeks prior to the scheduled surgery date to confirm compatibility.

Infectious Disease Testing

Looks for viral illnesses you can pass to the recipient. Prevents the Veteran from getting potentially dangerous or life-threatening viruses from their donor.

Genotyping

Genotyping determines differences in your genetic makeup. It is not required, but we offer apolipoprotein genotyping to all donor candidates with sub-Saharan African ancestry. A person who has this genetic composition has a higher risk of developing kidney failure. To learn more, speak with the living donor transplant coordinator.

Health information obtained during your evaluation is subject to the same regulations as all medical records and could reveal certain conditions that must be reported to local, state or federal public health authorities. Ask your living donor transplant coordinator for more information.



What To Expect (cont.)

What happens after your completed evaluation?

Post-Evaluation

The living donor transplant coordinator will review your results and discuss them with the transplant team. Results of crossmatch testing can take up to 10 days. Your living donor transplant coordinator will contact you to tell you if you are a match.

If you are a match, we may require more tests or ask for additional information. Once you complete the tests and provide the information, the transplant committee will review your case. The committee is made up of all members of the transplant team. The living donor transplant coordinator will contact you with the results of the meeting. If you are approved, a surgical date will be selected and the coordinator will contact the Veteran to whom you wish to donate.

What to expect in the days leading up to the surgery.

Pre-Surgery

SUNDAY

The Sunday prior to surgery, you and the recipient arrive in Pittsburgh.

MONDAY:

Undergo testing, blood work and a clinic visit with the transplant team.

TUESDAY:

Undergo more tests as needed. Meet with the pre-surgical team and transplant physician assistant to discuss and sign forms and complete your medical/health history and a physical exam.

WEDNESDAY:

Give blood to be stored for 10 years as per organ transplant national policy.

THURSDAY:

Undergo surgery with your own surgical team at VAPHS in an operating room separate from the recipient. The most common surgical method is a laparoscopic nephrectomy, which uses four small incisions to remove your kidney. This method allows for a shorter hospital stay, requires less pain medication and allows for a faster return to normal activities. Your surgeon will talk with you if a different method is found to be necessary at the time of surgery.

What will your recovery be like after surgery?

Recovery

The living donor transplant coordinator will give you discharge instructions prior to your surgery. They will go over them with you and your support person at discharge. We will then discharge you to a local hotel.

The transplant team will follow up with you the next week before you are cleared to go home. If there are any complications related to your surgery, you must receive care at a VAMC. If you receive care at a community hospital (outside of VA), you cannot be reimbursed for the cost of the treatment provided. Any treatment obtained outside of VA will be at your own expense or using your own insurance.

Normal recovery time varies. Most donors stay in the hospital for one to two nights. They can return to normal activities within four to five weeks, and begin lifting objects greater than 10 pounds between six to 12 weeks. Please discuss return to driving and any other concerns with the living donor transplant coordinator.

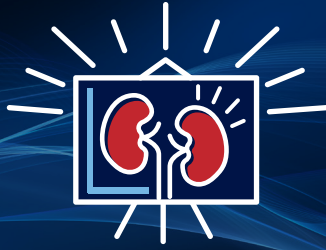
After discharge, the **United Network for Organ Sharing (UNOS)** requires you to have mandatory visits with the VAPHS transplant team at six months, one and two years after donation. We will take your vital signs and you will provide blood work and urine samples. We will ask a series of questions and report your answers to UNOS. The living donor coordinator will provide the questions to you before your appointment. We may require more tests.

You can see your own PCP for follow-up care, but it will be at your own expense and through your own insurance. You must submit private (outside of VA) provider results to VAPHS's Transplant Center.

After the first two years have passed, we encourage you to see your primary care provider for follow-up care.

If you develop any infectious disease or cancer related to your donation during the first two years after surgery, notices will be sent to you, VAPHS's transplant center and UNOS.





Additional Information

Kidney Knowledge

- **All people have two kidneys that:**

- › Remove waste and excess fluid
- › Filter blood
- › Make red blood cells
- › Make vitamins
- › Regulate blood pressure

- **Chronic kidney disease (CKD)**

- › Occurs when one or both kidneys stop working.
- › Has five stages based on glomerular filtration rate (GFR).
GFR is a percentage of how well a kidney is working.
- › Requires possible transplantation when a patient is in stage 4 or stage 5 CKD.

Treatment options for stage 4 or 5 CKD

- **Living Donation**

Patient receives a kidney from a living donor. Recipient must take lifelong medications to stop the immune system from rejecting and damaging the donated kidney.

- **Deceased Donation**

Organ donation can be designated by the deceased on their driver's license or if the donor's family gives permission. There are longer wait times for deceased donor transplant. Speak with the living donor coordinator for average wait times. Clock starts either when dialysis treatment begins, or when a patient who is not on dialysis is placed on the list. The recipient must take lifelong medications.

- **Hemodialysis**

A machine cleans the patient's blood. Done at home or in a clinic.

- **Peritoneal dialysis**

The lining of the abdomen or peritoneum cleans the patient's blood. Done at home or in a clinic.

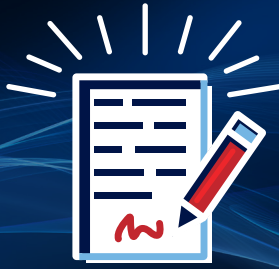
Registries and Data

- **The Scientific Registry for Transplant Recipients** collects data on living donors at every transplant hospital in the U.S. For more information, see www.srtr.org.
- **The Organ Procurement Transplantation Network** posts various data on transplant surgeries. To search the site for VAPHS's data on living donors:
 1. Go to <https://optn.transplant.hrsa.gov/data/view-data-reports/>
 2. Click "Center Data"
 3. Click on the map of Pennsylvania and choose "PAVA" from the drop-down menu



SCIENTIFIC
REGISTRY OF
TRANSPLANT
RECIPIENTS





Contacts/Notes/References

Living Donor Team Contacts and Notes

Living Donor Transplant Coordinator

Name: _____

Phone: _____

Independent Living Donor Advocate

Name: _____

Phone: _____

Living Donor Surgeon

Name: _____

Phone (emergencies only): _____

NOTES: _____

NOTES: _____

References

General information on living donation. National Kidney Foundation. (2021, September 17). Retrieved from <https://www.kidney.org/transplantation/livingdonors/general-information-living-donation>.

How to find a living donor. Transplant Living. (2018, February 21). Retrieved from <https://transplantliving.org/kidney/how-to-find-a-living-donor/>.

Lerret, S., Cupples, S. A., Lerret, S., McCalmont, V., & Ohler, L. (2017). Chapter 7 Care of Living Donors. In *Core Curriculum for Transplant Nurses* (2nd ed.). Lippincott Williams & Wilkins.

Organ Procurement and Transplantation Network. OPTN. (n.d.). Retrieved from <https://optn.transplant.hrsa.gov/governance/policies/>.

Organ Procurement and Transplantation Network. OPTN. (n.d.). Retrieved from <https://optn.transplant.hrsa.gov/learn/patient-education/living-donation/>.

Treatment of kidney failure. Treating kidney failure | Kidney failure - American Kidney Fund (AKF). (n.d.). Retrieved from https://www.kidneyfund.org/kidney-disease/kidney-failure/treatment-of-kidney-failure/#medical_management.

Veterans' Health Library. Ileus. (n.d.). Retrieved from https://www.veteranshealthlibrary.va.gov/Encyclopedia/142,40392_VA.

Online Resources

transplantliving.org

[kidney.org](https://www.kidney.org)

[srtr.org](https://www.srtr.org)

www.va.gov/health/services/transplant

VA



U.S. Department of Veterans Affairs

Veterans Health Administration
VA Pittsburgh Healthcare System

University Drive
Pittsburgh, PA 15215

412-822-2222 | 866-482-7488
www.pittsburgh.va.gov

Connect
with us!



VAPHS



VAPittsburgh

*Please do not make copies. Contact Public Affairs
or Reproduction Center for current document.*

646 -112F-U-241 | 02-23