

PATIENT GUIDE

LIVING KIDNEY DONOR

pennstatehealth.org/services-treatments/transplant-surgery

PENN STATE HEALTH MILTON S. HERSHEY MEDICAL CENTER | TRANSPLANT PROGRAM
717-531-6092 or 1-800-525-5395

TABLE OF CONTENTS

Welcome	5
Abdominal Transplant Program	7
The Transplant Team	9
Transplant Surgeon	9
Transplant Nephrologist	9
Transplant Nurse Practitioners/Physician Assistants	9
Transplant Coordinators	9
Transplant Social Workers	10
Transplant Financial Counselors	10
Transplant Dietitian	10
Transplant Pharmacists	10
Transplant Office Assistants	10
Introduction to Living Kidney Donation.....	11
Eligible Donors	13
Donor Requirements.....	13
Paired Kidney Donation.....	15
Living Donor Evaluation	16
Before Your Clinic Visit	16
During Your Clinic Visit.....	18
Donor Advocate Team	21
The Surgery.....	22
The Surgical Procedure: Donor Nephrectomy	22
Surgical Risks	23
After Surgery	23

Healthy Living..... 26
 Follow-Up in Clinic:..... 27
Other Things To Consider 29

PENN STATE HEALTH MILTON S. HERSHEY MEDICAL CENTER
LIVING KIDNEY DONOR
TRANSPLANT PROGRAM

Welcome to the Penn State Transplant Program at Penn State Health Milton S. Hershey Medical Center. This guide is designed to be a resource for you that will answer many questions you may have about being a kidney donor. It will also address questions you may have about the donor work-up process, expectations and care after your surgery.

It is normal to experience some stress and anxiety about your decision to donate a kidney. You may have questions and concerns about your own health, as well as the impact kidney donation will have on your family.

The Transplant Program at the Milton S. Hershey Medical Center is committed to providing you with the finest in medical services, as well as the emotional and practical support that is needed to get through the donation process successfully.

If you have any questions during any point in the process, do not hesitate to contact our office. We are here to answer your questions and support you and your family.

:: **The Abdominal Transplant Program**

Please direct all routine calls and questions to the living donor coordinator at 717-531-6092. Refer to the business cards given to you during your evaluation for the name of your coordinator, social worker and/or the living donor advocate. Our living donor administrative assistant is also available if you have general questions or are not sure to whom you should speak.

Location: Penn State Health
Milton S. Hershey Medical Center

Telephone: 717-531-6092 or 1-800-525-5395

Fax: 717-531-3717 or 717-531-0124

Address: Penn State Health
Milton S. Hershey Medical Center
Solid Organ Transplant
90 Hope Drive, MC A520
Hershey, PA 17033

Office Hours: Monday to Friday, 8 a.m. to 5 p.m.

After Hours: If you have problems related to surgery after donation on holidays, evenings and weekends, call 717-531-8521 and ask for the kidney transplant coordinator on call.

You can find us online at
pennstatehealth.org/services-treatments/transplant-surgery

:: **The Transplant Team**

Transplant Surgeon

Our transplant surgeons have advanced training in surgeries related to transplant. The surgeon will meet with you before the transplant surgery to determine, with the help of other members of the medical team, whether donation is safe for you. The surgeon will speak to you about the risks of the surgery and answer any questions you may have about the surgery or follow-up care. The transplant surgeon will assist the minimally invasive surgeon with your surgery and oversee all aspects of your care during your hospital stay.

Transplant Nephrologist

The transplant nephrologists specialize in the medical treatment of kidney disorders. This physician will meet with you to complete a physical examination to determine if it is medically possible and safe for you to be a kidney donor and to discuss the risks associated with donation. The nephrologist will also discuss any medical issues with you and your family. The transplant nephrologist monitors all nonsurgical aspects of your care while you are in the hospital and, later, in the outpatient clinic. He or she will monitor your kidney function to identify any problems.

Transplant Nurse Practitioners/Physician Assistants

Our transplant nurse practitioners (NPs) and physician assistants (PAs) are advanced practice clinicians who have received training in the care of donors and transplant patients. The NPs and PAs work closely with the transplant surgeon and transplant nephrologist to monitor your recovery and kidney function.

Transplant Coordinators

Transplant coordinators are the main source of contact with the transplant team. These coordinators are highly trained registered nurses who are an integral part of your care both before and after donation. Before donation, your coordinator

will guide you through the education and work-up process and is your contact person for any questions or concerns. Your transplant coordinator is separate from your recipient's coordinator and cannot share information about you with your recipient, nor can he or she provide you with any confidential health information about your recipient. After transplant, your coordinator will monitor your care and educate you on how to care for yourself. The coordinator also reviews your lab work in conjunction with our physicians and answers any questions that may arise.

Transplant Social Workers

Transplant social workers provide support, education, counseling and assistance throughout the evaluation and donation process. Your social worker can also discuss transportation and lodging options with you and your family.

Transplant Financial Counselors

Transplant financial counselors review your insurance coverage and explain what is covered by the recipient's insurance.

Transplant Dietitian

Our transplant dietitian provides nutrition counseling for patients awaiting transplant, post-transplant patients and living donors. Nutrition support is tailored to meet the needs of each patient.

Transplant Pharmacists

Transplant pharmacists have an in-depth knowledge of medications, side effects, dosing and medication interactions. The transplant pharmacists provide education to patients on medications that they will be taking after surgery.

Transplant Office Assistants

Transplant office assistants work closely with our transplant coordinators, providing administrative support, such as answering phone calls, scheduling and entering test results and patient information.

:: Introduction to Living Kidney Donation

Living kidney donation occurs when a living person donates a kidney for transplantation into another person with end-stage renal disease. Thousands of living donor kidney transplants are made possible every year. More than 80,000 people are on the kidney transplant waiting list, and many people wait years for a kidney from a deceased donor. To shorten the waiting time, people like you offer to be living donors.

Kidneys from living donors generally have high success rates:

- More than 98% of kidneys transplanted from living donors are still working one year after transplant.
- On average, living donor kidney transplants work longer than kidney transplants from deceased donors.

The National Scientific Registry of Transplant Recipients (SRTR) is a database of information on transplant donors and recipients. More information regarding transplant outcomes can be found at srtr.org.

There are several advantages to the kidney recipient when receiving a kidney from a living donor.

1. Recipients can avoid the long wait for a deceased donor kidney to become available.
2. The living donor kidney usually begins to work immediately, while the recipient is still in the operating room. A deceased donor kidney may not work right away.

3. Recipients of living donor transplants tend to have fewer episodes of rejection. As a result, living donor kidneys tend to last longer.
4. Living donor transplant surgery is scheduled in advance, which allows both the donor and the recipient to plan for absences from work, child care and other social concerns.
5. Use of living donors decreases the number of recipients on the deceased donor waiting list.

Transplant hospitals use existing hospital-specific guidelines or practices and clinical judgment to determine who is a candidate for transplantation.

Living kidney transplant is considered an elective surgery (nonemergency procedure). If you choose not to donate, the intended recipient can remain on dialysis and also on the waiting list for a deceased donor kidney.

You should not feel pressured to donate. If you do, please contact our office and ask to speak to the living donor advocate.

:: **Eligible Donors**

Living donation is a very safe procedure for donors, who can live a long and healthy life with one kidney. All donors are screened and tested thoroughly before donation to ensure that removing a kidney will not negatively impact their physical or mental health. If we feel that kidney donation would place you at any unnecessary risk, we will not proceed with donation.

Donor Requirements

Donors:

- Should be between the ages of 18 and 70. However, donors between the ages of 18 and 20 will be considered on a case-by-case basis.
- Should not have a history of uncontrolled high blood pressure, any cancer or diabetes.
- Must be free of coercion and inducement, which means they are willing to donate of their own free will.

In order to donate to a particular person, a donor must be a compatible blood type with the recipient.

Donor blood type	Can donate a kidney to patients with blood type
A.....	A, AB
B.....	B, AB
AB.....	AB
O.....	A, B, AB, O

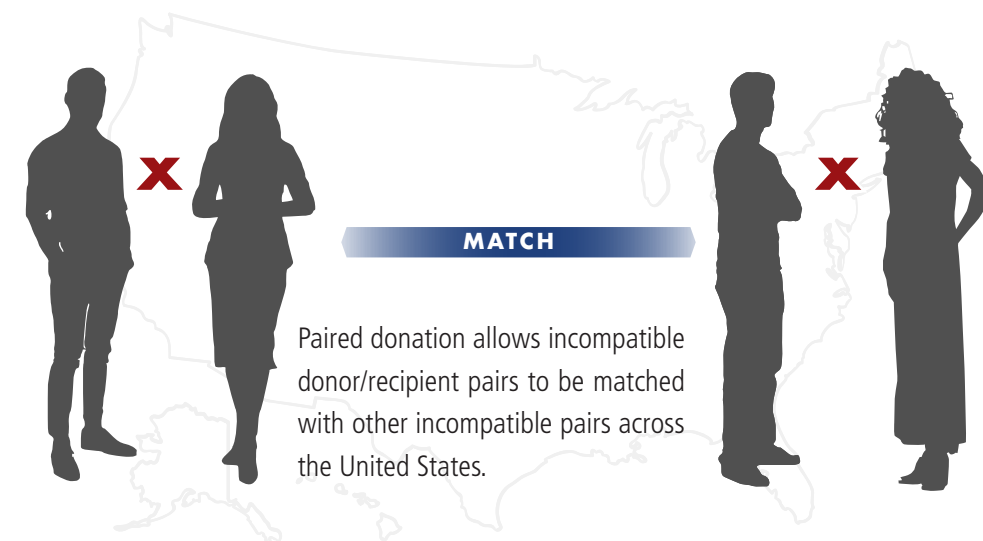
Rh factors (+, -) do NOT need to match

Another important part of donor and recipient compatibility is a white blood cell crossmatch. This is done to determine if the recipient has any antibodies against the donor kidney. A preliminary crossmatch is done at the time of the donor evaluation. If this crossmatch is positive, the recipient's antibodies could attack the donor kidney. This is an incompatible crossmatch, and the donor would not be suitable for the recipient.

If the donor is compatible, the work-up will continue and a final crossmatch will be performed again just before the surgery to make sure the recipient has not developed any antibodies against the donor since the last test. If the final crossmatch is positive, the surgery will need to be canceled, but you may still be able to donate through the paired donation program, which is explained in the next section.

:: Paired Kidney Donation

Penn State Health participates in a paired transplant donation program for donors and recipients who are not compatible. Paired donation allows incompatible donor/recipient pairs to be matched with other incompatible pairs across the United States. Participation in the paired donation program is voluntary and will allow your recipient to receive a living donor kidney from another donor while you donate to another incompatible recipient.



The surgery to remove the donor kidney is completed at the transplant center where the donor was evaluated and then sent to the other recipient's center. Similarly, the other donor's kidney is removed at the transplant center where they were evaluated and then sent to our center for transplantation.

Your coordinator will discuss this option with you in more detail, if appropriate.

For more information, you may also visit the National Kidney Registry website at kidneyregistry.org.

:: Living Donor Evaluation

As a potential living donor undergoing evaluation, you should understand the following:

- Both you and the transplant hospital staff must decide whether living donation is right for you.
- Going through the donor evaluation process does not guarantee that you will be approved by the donor team as a donor.
- The living donor evaluation may reveal previously unknown medical conditions. If any further follow-up is necessary, we will ask your primary doctor to arrange it.
- Occasionally, testing may reveal information that could be emotionally upsetting. It is important to consider this before going through the testing.
- Living donor evaluation testing results are not shared with the recipient. It is up to you to decide whether you wish to share any of this information.
- You may choose to stop the donation process at any time, and this decision will be kept confidential from the potential recipient.

We welcome all questions you may have at any time during the evaluation and donation process.

Before Your Clinic Visit

An independent living donor advocate (ILDA) will send a letter to you with their contact information before your visit with us. The ILDA will explain the ILDA role as your advocate during the donation process and how to contact the ILDA for assistance.

We will schedule most of your evaluation and testing to be performed on a single day at Hershey Medical Center. However, we will need to receive the following test results and records BEFORE your formal evaluation in our clinic:

- **Blood type.** If you have previously had your blood type tested, we will request those official results. If you have not had blood typing or are unsure of your blood type, we will mail you a laboratory order to have this testing done.
- **Blood pressure readings.** We need two readings, usually done on two separate days, to see if you have high blood pressure. These results can be collected from doctor's office visits or notes.
- **24-hour urine collection for protein and creatinine clearance.** We will ask you to collect your urine in a special container for 24 hours and take it to the lab to determine how well your kidneys are working. We will provide you with an order for this test.
- **Review of records.** With your consent, we will request medical records from your family doctor, specialists or any other relevant providers for review. These records may include counseling and psychiatric records, if applicable.
- **Age and gender-appropriate cancer screenings.**

For women:

- Recent gynecological exam and Pap test
- Over age 40: Recent mammogram
- Over age 45: Colonoscopy
- Over age 50: Colonoscopy (unless strong family history then over age 45)

For men:

- Over age 50: Blood test for prostate specific antigen
- Over age 50: Colonoscopy (unless strong family history then over age 45)

Once these are completed and reviewed, you will be scheduled to complete the rest of your testing in our living donor clinic.

During Your Clinic Visit

The testing process requires your permission. You will be asked to sign a consent for the release of medical records and the agreement for living donor evaluation. You will be provided with a copy of this agreement.

During the evaluation, you will also be asked personal questions regarding your behavior and social history to determine your risk for disease transmission, including human immunodeficiency virus (HIV) and hepatitis. If you are deemed a donor at increased risk for transmission of a bloodborne disease, the intended recipient will need to be informed of the risk. This may rule you out as a donor.

You will have several tests scheduled on the day of your clinic visit.

They include:

- **Blood tests**, which provide information about your body chemistry and past infections, as well as hepatitis and HIV status.
- **Chest X-ray**, which allows us to look for heart and lung abnormalities.
- **Electrocardiogram (EKG)**, which shows whether your heart function is normal. If this test reveals abnormalities, further testing will be done. Depending on your age or medical history, additional testing may be ordered.

- **Stress echocardiogram**, which is generally ordered for potential donors over age 50. You will undergo an ultrasound of your heart after exercising on a treadmill. This study allows us to look at how your heart functions under physical stress.
- **Computerized tomography (CT) angiogram**, which will show us kidney size, presence of any kidney stones and any abnormalities in the blood vessels to your kidneys. This CT scan requires intravenous (IV) injection of dye into your blood, which will allow us to study the anatomy of your urinary system – the kidneys, ureters and bladder.

The final results of your testing are usually completed within a week and will be shared with you when available.

In addition to the testing, you will be examined and/or interviewed by several members of our transplant team, including:

- **Transplant social worker.** You will meet with our social worker to confirm your motivation for wanting to donate, determine your ability to understand the process and risks associated with donation and assess your ability to cope with the stress of donation. You may also be required to see one of our transplant psychiatric providers during a separate visit.
- **Independent living donor advocate (ILDA).** You will meet with a special team member who has no personal interaction with your recipient. The ILDA will talk with you to confirm that you understand the process and risks. The ILDA's responsibilities include:
 - Promoting the best interests of the donor
 - Advocating for the donor's rights

- Assisting the potential donor in getting and understanding information regarding the donation and transplant process
- Answering any questions the donor may have
- **Transplant surgeon.** A transplant surgeon will meet with you to go over the surgical procedure and the risks of the surgery in detail.
- **Transplant nephrologist.** A transplant nephrologist will review your testing, assess your physical and emotional readiness to donate and share more information with you about the risks of donation.

:: **Donor Advocate Team**

Once the tests are complete, we will discuss your donation with a group of team members at a Donor Advocate Team (DAT) meeting. These meetings are held every other week. Our DAT includes the transplant surgeons, minimally invasive surgeon, transplant nephrologist, transplant coordinators, ILDA, transplant social workers and a member of the hospital's Ethics Committee.

The DAT will make one of three recommendations when your case is discussed:

1. **Approval**
If you are approved for donation, we will speak with you about scheduling a surgery date.
2. **Further testing is needed**
We will let you know what additional testing is needed and make arrangements to complete this testing.
3. **Donation is not recommended**
If you are denied, you may choose to be evaluated at another center.

The living donor coordinator will contact you by phone after the meeting to inform you of the team's decision and to discuss the next steps.

:: The Surgery

On the day of surgery, you will report to the Admissions desk in the main lobby of the hospital. Once you have registered, you will be taken to the preoperative area, where an IV will be inserted in your arm to infuse fluids during and after your surgery. When you are wheeled to the operating room, your family and friends will be escorted to the surgical waiting area where they can follow your progress.

In the operating room, an endotracheal tube will be inserted through your mouth and into the trachea to help you breathe while you are asleep. A Foley catheter will be inserted into your bladder after you are asleep to keep an accurate account of your urine output during and after surgery.

The Surgical Procedure: Donor Nephrectomy

There are two surgical approaches used to remove a kidney for transplantation:

- **Laparoscopic donor nephrectomy.** The donor's kidney is removed using small cameras and instruments inserted through three to four very small incisions in the abdomen to free the kidney, which is then removed through another small incision, either just above the pubic bone or the bellybutton. The surgeon may perform this surgery using only the instruments and very small incisions, or may need to make a slightly larger incision to remove the kidney if he is using the hand-assisted technique. The laparoscopic approach results in less pain and discomfort, a short hospital stay (two to four days) and a rapid return to normal activity. You are usually ready to return to work and normal activity within about four to six weeks after surgery.
- **Open donor nephrectomy.** The donor's kidney is removed through an incision that runs along the lower edge of the rib cage, from the middle of the abdomen to the back on the side where the kidney is to be removed. The donor kidney, its blood vessels and the attached ureter are removed during

the two- to four-hour surgical procedure. This approach is used ONLY in the event that it is unsafe to continue laparoscopically and is VERY RARE. It can be associated with more pain and a longer recovery period – often a five- to seven-day hospital stay, with an eight- to 12-week recovery period.

Surgical Risks

The risks for donor nephrectomy are very similar to risks for any other surgery. The detailed list of potential complications is included in the special consent for Living Kidney Donor Evaluation. Complications such as blood clots, pneumonia, infections and a chance of death (this risk is estimated to be three in 10,000 procedures, or 0.03%), are typical of any surgical procedure. The surgeons responsible for the kidney removal will discuss the specific risk factors. The surgical risks and potential medical, financial and psychosocial risks are covered in more detail in the Agreement for Living Donor Evaluation.

After Surgery

Immediately after surgery, you will be in the recovery room for approximately one to two hours, then transferred to your room once you are awake. The surgeon will meet briefly with your family and friends in the surgical waiting area to let them know how the surgery went, and your family and friends will be directed to your room at that time. It is not unusual for your face, arms and legs to be a little swollen. You will be given a lot of fluid intravenously during the surgery, and it will take your remaining kidney a little time to remove the excess fluid after surgery.

Routine postoperative care will include:

- Frequent checking of vital signs, including blood pressure, pulse, respirations and temperature.
- The Foley catheter will remain in your bladder to measure urinary output for the first day. It will be removed once you are fully awake and able to walk to the bathroom.

- You will be encouraged to use incentive spirometry, which helps you take deep breaths to expand your lungs and prevent pneumonia.
- You will be encouraged to get out of bed and start walking as soon as you are alert in order to prevent blood clots.
- You will be given pain medications as needed.
- Your IV will remain in place until you are able to drink adequate fluids to flush your remaining kidney.

Following your discharge from the hospital, you will be asked to report any of the following to the Transplant Office:

- Increased urinary frequency
- Increased urgency to urinate
- Burning on urination
- Blood in the urine
- Temperature of 100° F or greater
- Swelling, redness or tenderness along the incision

The following restrictions will be placed on you after surgery:

- **No lifting of anything greater than 10 pounds (a gallon of milk) for four weeks after surgery.**
- **You may NOT drive for two weeks following surgery.**

- You are the best indicator of the appropriate time to return to work. Most patients return to work four to six weeks after surgery, depending upon the occupation.
- You should return to normal activity as soon as you can tolerate it.
- After your incision has healed, you should experience no difference in your energy level, ability on the job, life expectancy, susceptibility to illness or sexual function.
- You will not need any special diet or medications long term.

:: **Healthy Living**

Hypertension (high blood pressure) and diabetes are the leading causes of renal failure. Uncontrolled hypertension or diabetes can damage your kidneys and lead to kidney failure.

The risks associated with being a living kidney donor are low, and you have been carefully screened. If you have been approved as a donor, you do not have either of these conditions at this time. However, since you are going to donate one of your kidneys to a family member or friend, we recommend that you maintain a healthy lifestyle to prevent hypertension, diabetes or vascular disease, which could result in stroke or heart disease developing later in your life.

We recommend the following:

- Maintain your ideal body weight. This is a body mass index (BMI) between 19 and 25. Reduce stress through regular exercise.
- Keep your diet low in saturated fat and cholesterol.
- Avoid excessive salt intake (foods such as pickles, canned soup, potato chips, cold cuts, etc.), excessive alcohol intake and excessive caffeine intake.
- Drink a minimum of eight 8-ounce glasses of water each day.
- Avoid high-risk behavior, such as smoking, alcohol or drug abuse.
- Avoid overusing over-the-counter medications, such as ibuprofen (Advil, Motrin) and naproxen (Aleve).

- Seek prompt treatment of urinary tract infection or kidney stone symptoms (painful urination, inability to pass urine, pelvic pain, pain in the mid-back under the ribs on the side of the remaining kidney, urine that does not look or smell normal or bloody or dark urine).
- If you smoke, we would **STRONGLY** advise you to stop smoking. Please note that we may require you to stop smoking prior to surgery.
- See your family doctor for an annual physical to check blood pressure, blood sugars and urinalysis.
- Be sure to inform any health care providers you see that you have only one kidney.

Follow Up in Clinic

We ask that you follow up with us in clinic for a period of at least two years. Generally, this is only four visits, scheduled as follows after surgery:

- Four weeks
- Six months
- One year
- Two years

During these visits, we will also collect data to report to the United Network for Organ Sharing. This information is collected and analyzed to monitor the long-term implications for living donation.

Please contact our office if you are diagnosed with any infectious disease or malignancy (cancer) within the first two years after surgery. We are required to report this information to the Organ Procurement and Transplantation Network and may need to share this information with the recipient of your kidney for treatment and/or testing.

:: **Other Things To Consider**

- Some living donors have had challenges getting life insurance and coverage of disability claims after donating.
- It is a felony to be paid in any way for donating an organ. Doing so will make it difficult for any future recipients, as well as have serious legal consequences for you.
- While donation is highly successful, there are times that the kidney may not work or may not work properly after transplant. Your recipient may develop complications. The immediate loss of kidney function in the recipient is very rare.
- During the living donor evaluation process, a deceased donor organ may become available for your recipient, and the living donor surgery may be canceled.
- Deceased donor organs may become available for another recipient that may require the surgery time to be changed or postponed.
- If, for some reason, a donor's remaining kidney fails and must be listed for transplant, special consideration is given to that donor to allow the transplant to happen more quickly.
- You may choose to stop the evaluation process or decide not to donate at any time. If you do so, your choice will be kept confidential. We only share that a donor has stepped forward for the recipient. It is your choice how much you choose to share.

- Hershey Medical Center will take all possible precautions to provide confidentiality for you as the donor and also for the intended recipient.
- Hershey Medical Center is a Medicare-approved transplant center. It is our duty to inform you that if we were to lose our Medicare approval, it could affect the transplant recipient's coverage of immunosuppressive medication under Medicare Part B. Additionally, we are required to notify you if we do not meet the outcome requirements for transplant centers.

Living donors save lives.

***Thank you for considering living
donation and choosing Penn State
Health.***