



Living Donor Transplant Team Members

Transplant Surgeons

Transplant surgeons meet with you during the evaluation process to perform a medical evaluation, explain the surgical process and review the risks of donation. The transplant surgeon performs the transplant donor surgery and works with the medical doctors to manage your care after the donation.

Transplant Nephrologists

Nephrologists are doctors who specialize in kidney disease. They assess your health to decide if donation is a good option. They stay involved in your care after donation.

Nurse Coordinators

Nurse coordinators are responsible for coordinating your transplant care before, during and after donation. They provide ongoing education and help arrange the required testing you need prior to being approved for donation. They will assist you through the evaluation process by working closely with you and communicating with your local doctors and health care facilities.

Clinical Social Workers

Clinical social workers conduct a psychosocial assessment, discuss available community resources, assist with financial resources and work with other members of the transplant team to support you emotionally throughout the donation process. The social worker will provide information and help you complete your advance directives paper work. They are also responsible for educating you about the financial aspects of donation, and are your best resource for help with any insurance related questions. They can also assist you with finding a support group for you and your family.

Living Donor Advocate

The living donor advocate is an independent advocate who is not involved in care of transplant recipients on a routine basis. The advocate's role is to serve as the representative for you, the living donor, to discuss any questions and concerns you may have and to ensure that your rights as a patient are protected; including the right to be free of any feelings of family pressure, undue emotional responsibility, need for recognition or reasons of financial gain. The living donor advocate can communicate with the medical team on your behalf and/or obtain additional information to ensure that your decision is informed and free from coercion.

Clinical Dieticians

Clinical dieticians work with you and your family to evaluate your nutritional status and develop a plan for good nutrition throughout the donation process.

Physician Assistants

Physician assistants assist with inpatient and outpatient care and help organize your discharge needs. Physician assistants monitor your recovery and assist doctors in every aspect of your care.

Surgical Residents and Transplant Fellows

Surgical residents and transplant fellows assist mainly with inpatient care including preparing you for surgery, assisting in the operating room and helping to manage post operative issues. Surgical residents and transplant fellows work with the surgeons and other team members to prepare you for discharge.

Discharge Case Managers

Discharge case managers work with you and your family to prepare you to leave the hospital.

Nurse Practitioners

Nurse practitioners assist with inpatient care and outpatient care following your surgery. A nurse practitioner assists the transplant doctor with long-term general health management. A nurse practitioner is available to see you in the transplant clinic on a long-term basis.

Transplant Pharmacists

Transplant pharmacists work closely with doctors, nursing staff and you to ensure you're your medications are used correctly. The pharmacists work with the rest of the transplant team to find the best way to diminish the side effects you may have due to medicine used during donation. They also help with managing medication schedules.

Inpatient Transplant Nurses

Inpatient transplant nurses specialize in the care and treatment of transplant patients during their hospital stay. You will be assigned a primary nurse for your inpatient nursing care who will work with your doctors, coordinators and other health care disciplines to prepare you for your discharge.

Transplant Clinic Nurses

Transplant clinic nurses care for you during clinic visits and assist with numerous outpatient procedures. The clinic nurses provide care and support for you during your recovery period after procedures, and assist in setting up required follow-up care. They also provide ongoing education for you and your family.

Office Support Staff

Members of the transplant office support staff provide phone triage to coordinators and other staff and assist in management of outpatient medical information. They help coordinators manage patient lab results and daily patient issues and concerns.

Pastoral Care

Chaplains help many patients and families receive comfort and meaning from their faith during illness recovery. Our chaplains provide spiritual and emotional support and perform sacraments. Faith and medicine opportunities are provided at the hospital chapel. Catholic and Protestant services are held on Sundays.

Other Doctor Consultations

UW Hospital and Clinics have many specialized expert doctors that can be consulted to work together to provide the best care possible. Infectious disease, dental, endocrine, cardiology, hepatology, gastroenterology, dermatology, urology and rehabilitation experts are just a few of the teams that are available to assist in your care.

Other Services

Other services are available to provide assistance to you and your family. For example, interpreter services can be made available for anyone needing translation services. Housing assistance can help you and your family, should temporary housing be needed.

The Living Donation Process

Living Kidney Donation: The Pre-Evaluation

If you are interested in learning about being a living kidney donor, it is extremely important to obtain the facts about this process from our transplant program. You can do this in one of the following ways:

- You may call the UW Kidney Transplant Program at (608) 263-1384
- You may accompany your intended recipient during their kidney transplant evaluation appointment, where you can share your interest in learning more about living donation
- You may get the nurse coordinator's name and phone number from your intended recipient and call them after the recipient has been to their evaluation appointment. You should initiate this contact or phone call yourself. This will ensure that you are in a comfortable place, both physically and emotionally, to begin to learn about being a kidney donor

Once you express interest in donation, one of the nurse coordinators will ask you questions about your general health. Remember that your answers to these questions, as well as all of your health information, are protected under the Health Insurance Portability and Accountability Act (HIPAA.) HIPAA laws protect your privacy and ensure you have control over your health information. We will not share your information with anyone who is not a member of your UW Health care team, including your intended recipient.

If it appears that you are in good general health, a blood sample can be drawn and we can see if you are a good “match” for your intended recipient. A nurse coordinator will assist in arranging the blood draw at a lab close to where you live, if you didn't come to the intended recipient's evaluation appointment. Your blood type will be tested, as well as other matching (compatibility) testing. The chart below explains which blood types are compatible with each other. The negative and positive Rh factor within a blood type does not matter with kidney donation.

If a RECIPIENT is blood type:	The DONOR must be blood type:
O	O
A	A or O
B	B or O
AB	A, B, AB or O

The other compatibility testing involves measuring donor specific antibody levels using the recipient's blood. This allows the transplant team to see if the intended recipient has any antibodies that may react with you. This is called the Donor Specific Antibody Level, or DSA. The DSA needs to be at an acceptable level for us to proceed with the transplant.

Your nurse coordinator will let you know the results of the blood tests. It typically takes about one to two weeks for these results to be completed. Once everyone who is interested in being tested as a donor for your intended recipient has received their test results, the most suitable donor can be identified. The most suitable donor can then schedule a full medical evaluation. This full medical evaluation is completed with one potential donor at a time. If, for some reason, the first person to undergo the full medical evaluation is not able to be the donor, another suitable person can then be evaluated.

Living Kidney Donation: The Donor Evaluation Day

The evaluation day will take six to eight hours and you will be meeting with many different members of the transplant team including a nurse coordinator, a transplant surgeon, a transplant medical doctor, a dietitian, a social worker and a living donor advocate. During the day you will also go to the lab to have blood drawn and to the radiology department to have x-rays. Your evaluation day will consist of the following medical tests and screenings:

- Complete history and physical
- Urinalysis with urine culture
- Chest x-ray
- EKG
- Social work/health psychology evaluation
- Dietary consult
- Interview with a surgeon
- Interview with a medical doctor
- Interview with a living donor advocate
- Spiral CT/CAT scan of your abdominal organs, your kidneys and the kidney's blood vessels
- Blood tests including:
 - A glucose tolerance test (a screen for diabetes)
 - Routine chemistry and hematology panels
 - Clotting studies
 - Additional matching/compatibility tests
 - Viral infection screening: hepatitis panels, CMV and EBV screens, HIV testing and syphilis testing

The additional blood tests are done to confirm that you will be a good match to your intended recipient. The other blood tests are to make sure you are in good health. The urine samples are collected to see how your kidneys are working and to detect any problems or infection. The chest x-ray and electrocardiogram are done to make sure there aren't any problems with your heart or lungs. The glucose tolerance test will make sure you don't have diabetes and to determine what your risk of having diabetes in the future may be. The spiral CT/CAT scan will look at where your kidneys and blood vessels are situated in your abdomen, which helps the surgeons decide which kidney should be used and which type of surgery should be done (laparoscopic or open.) Before the CT/CAT scan, it is important to let us know if you have any known allergies to contrast dyes, seafood or shellfish. If you have any of these allergies, you will receive medication before the test, or you will receive a different type of test, called an MRI scan.

Living Kidney Donation: After the Evaluation

After your evaluation day, it takes about one week for the lab to send us all of your test results. More tests or consults with other doctors may be needed once your test results are reviewed. These often, but not always, can be done at facilities closer to your home. Your transplant coordinator will discuss your results with you, and arrange any additional tests you may need to complete.

Before being declared a living donor candidate, your records will be reviewed by a multidisciplinary team called the Donor Selection Committee. This committee completes an additional review of your medical records and test results to make sure nothing was missed on your evaluation day.

Once you are approved to donate, the date for the nephrectomy (surgical removal of your kidney) can be scheduled.

If you are not suited to donate a kidney, we may suggest that you schedule time with your local doctor to discuss any issues that were discovered during your evaluation process. The cost of this follow-up care will be your responsibility. With your permission, records from the donor evaluation will be sent to your local doctor. Having certain diagnoses could make it harder for you to obtain private health or life insurance in the future.

Living Kidney Donation: Preparing for Surgery

Once we have arranged the date for your surgery, a pre-surgery clinic appointment will be scheduled. This appointment will typically be the day before your surgery, and is done at the UW Health Transplant Clinic. During this appointment, we make sure there hasn't been any change in your general health since your evaluation day. You will have another physical, more blood tests and an appointment with our anesthesia team. You will be taught deep breathing and coughing exercises that you will need to do after your surgery, to prevent pneumonia.

The evening before surgery, you will take a medicine to cleanse your bowels, and you will shower using a special soap. You will not be able to eat or drink after midnight. If you do not live near Madison, hotel accommodations for the night before your surgery will be provided. You should plan ahead to determine what you want to bring with you to the hospital.

We require that you bring:

- Any medicines you take daily
- Comfortable clothes that will not be too tight over the incision
- Walking shoes

And we recommend that you bring:

- Personal and comfort items (toothpaste, shampoo, pillows)
- Books or other things to keep yourself busy

Remember: The hospital is not responsible for lost or misplaced items, so please do not bring items of value to the hospital.

Living Kidney Donation: The Surgery

The day of your surgery you will check in at the UW Health First Day Surgery Center. (You will be admitted to your hospital room after the surgery.) While in the surgery center, an intravenous catheter (IV) will be inserted into one of the veins in your arm or hand. You will be given fluids for hydration through this IV.

The nurses will continue to prepare you for your surgery, and will take you to the operating room at the appropriate time. During surgery, a small rubber tube called a Foley catheter will be placed in your bladder. This allows us to monitor the amount of urine your remaining kidney is producing. The Foley catheter will stay in place until the day after surgery. The surgery will take about three hours. There are two different types of donor surgeries: laparoscopic and open. About 90-95 percent of donor surgeries are done with the laparoscopic method.

Laparoscopic surgery

This surgery is less invasive, and often patients will have a shorter recovery time and less pain. Special instruments and a video monitor are used to look at the kidney and blood vessels, and to remove the kidney. A donor must meet certain standards for this type of surgery, and not all donors are able to have their surgery done this way. For example, a person who has already had major abdominal surgery, and/or has complex left and right-sided kidney anatomy, may not be able to have this type of surgery. Your transplant coordinator and doctor will discuss this with you.

The laparoscopic method uses four small incisions on the abdomen (each about an inch in length) to place the instruments and the tiny camera. There is also one larger incision (about three to four inches long) made below the belly button. This is where the kidney is removed. Internal sutures that will dissolve over time are used to close these incisions. Laparoscopic surgery may take about three hours to complete, which is slightly longer than the open method. Even though this is a more technical surgery to perform, most donors at our center have their nephrectomy via the laparoscopic surgery method. It is important to know that if problems occur during a laparoscopic surgery, the surgeon may have to convert to the open method to remove the kidney. This rarely happens, but is a possibility. For some individuals a single port laparoscopic surgery may be an option. This is where the entire surgery is done through a belly button incision. Your doctor will discuss this with you.

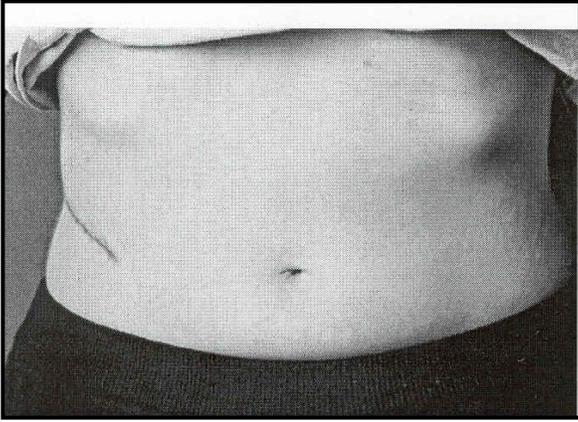


These photos show scars typical for patients who donate a kidney via laparoscopy. This patient was photographed two weeks after donation. *Temporary skin abrasions, caused by the patient's sensitivity to surgical tape, were removed from these photos.*



Open surgery

Open surgery allows the surgeon to directly see the kidney and blood vessels. This surgery is used on patients with more complex kidney anatomy, and/or on those who have already had major abdominal surgery. With open surgery, the incision is on the right or left side of the abdomen and extends around the side of the body. The doctor will decide which kidney is best to remove. The open incision is about eight to ten inches in length. Both the skin and muscle need to be cut to remove your kidney. The lowest rib on that side may be removed. Loss of this rib will not cause any disability or extra pain. Typically internal sutures that will dissolve over time will be used to close the incision. Open surgery will take about two to three hours.



This photo shows the scar that is typical for a patient who donated a kidney who experienced an open surgery.

Living Kidney Donation: After Surgery

When your surgery is completed, you will be taken to the recovery room. After one to two hours you will be moved to your room on the nursing unit. When you arrive in your room, you will still be quite sleepy. You will still have the IV and Foley catheter in place. Because anesthesia can increase your lung secretions-which can stay in your lungs and may lead to pneumonia-you will be asked to cough and do deep breathing exercises at least hourly, while you are awake. By breathing deeply, air reaches the area where the secretions collect- and coughing helps to bring them up. A small plastic tool (incentive spirometer) will be used to help you take deep breaths.

Typically, you will be required to get out of bed to walk about six hours after you return to your room. Walking will help prevent many problems that can occur after surgery. These include pneumonia, blood clots and bowel problems. You should walk at least every one to two hours, while you are awake, during the first few weeks. You will be given TED socks (elastic stockings) and leg SCDs (sequential compression devices) to wear. The SCDs will provide a constant massage to your lower legs, to help the blood flow to and from your legs, which helps prevent blood clots. While you are in the hospital, you will also receive heparin (a blood thinner) via an injection in your stomach, twice a day, which also helps to prevent blood clots.

Your urine output will be measured hourly for the first day. When the Foley catheter is removed, we will measure your output every time you void. This helps us know that your remaining kidney is working well.

Your doctor will decide when you can resume eating. Surgery and pain medications can slow the wave-like action of your bowels for a short time. As bowel activity and sounds return and you start to pass gas, you will be given liquids. Slowly you will advance to eating regular food. Walking as early as you are able will help your bowel function return to normal.

It is important for you to look at your incisions each day, and to watch for signs of infection such as redness, swelling and/or drainage.

You will go home three to four days after surgery. The length of stay may be shorter if you had laparoscopic surgery. Your nurse and doctor will give you additional instructions before discharge. You will also have pain medicine ordered, and you will want to take it home with you. Pain medicine can cause constipation because it slows down bowel movements as they travel through the intestine. This causes the stool to become hard. If you have hard bowel movements, have trouble passing bowel movements and/or the movements are not often enough, then you are constipated. After surgery, you will be started on stool softeners to help avoid constipation. These suggestions may help you avoid constipation:

Eat foods that have helped you to relieve constipation in the past

- Eat foods high in fiber, as long as they have been approved by your doctor. This includes foods such as uncooked fruits, raw vegetables and whole grains and cereals. Prune juice is high in fiber. If you are not hungry, do not force yourself to eat fiber.
- Drink plenty of liquids. Eight to ten eight-ounce glasses of fluid each day will help keep your stools soft. Warm liquids often help with bowel movements.
- Walk as much as you are able each day. Increase the amount you walk as you are able.
- Plan your bowel movements for the same time each day, if you can. Set aside time for sitting on the toilet.
- Aim for a bowel movement every second or third day rather than every day.

After surgery you will need to restrict your activities and driving, but walking is a good exercise anytime. Do not lift more than ten pounds for the first four to six weeks after an open surgery- and for three to four weeks after laparoscopic surgery. After four to six weeks you may begin to exercise with moderation and to lift objects heavier than ten pounds. Remember to increase to more strenuous activities slowly. You cannot drive if you are still taking pain pills. In most cases, you may return to work after four to six weeks. Some people may go back to work as early as two weeks. This will depend on your occupation, and what exactly you do while working. Please discuss with your doctor your options for returning to work.

Prior to being discharged from the hospital, you should know the date and time for your first follow up appointment at the transplant clinic. This will be scheduled for you approximately three to four weeks after your surgery. Further activity and work guidelines will be discussed at this clinic visit. If any questions or problems arise before that visit, please call the transplant coordinator. Between four-six months after surgery, we will schedule your second routine check-up, either in the transplant clinic or with your local physician. We will then want you to have additional one year and two year post- surgery check-ups. These can be done either in the transplant clinic or with your local physician. If you do the one and two year follow-up visits locally, you are responsible for those costs. Your coordinator will review and assist you with our check-up visit recommendations.

We suggest that your routine annual physical with your local doctor include a physical exam, a blood pressure check, blood creatinine level test and urine testing to see how your kidney is working. The cost of the annual local check-ups will be your responsibility.

After kidney donation your life style should be unchanged. You will not need to follow any special diet or take any medicine because you donated a kidney. We suggest that you avoid long-term or heavy use of any medicines that can affect kidney function. A common type of medicine we recommend avoiding is the class called nonsteroidal anti-inflammatory drugs (NSAIDS). Examples of such medicines are: naproxen, ibuprofen and aspirin. Ibuprofen is found in many over-the-counter medicines such as Advil[®], Motrin[®], Midol[®], Nuprin[®] and Rufen[®]. Naproxen is also known as Aleve[®]. These medicines may also be combined with many other over-the-counter cold medicines. If you have any questions about a medicine that may contain ibuprofen or naproxen, as well as any other medicine or over-the-counter product, consult your pharmacist. If these medicines are used over a long period of time, or in excess, they can harm your kidney. Before taking any medicine, you should always ask your doctor or pharmacist about how it may affect kidney function.

Living Donor Mentor Program

About the Program

The University of Wisconsin Transplant Program has a mentorship program that links people who have already donated an organ with those who are considering donation. This happens via the telephone. We believe our donors know better than anyone what donation is actually like, and can be a valuable source of support, encouragement and information for people going through the donation process.

Our mentors have been chosen for their positive attitude and willingness to share their time and experiences. We have assembled a group of mentors from a variety of ages, religious and cultural beliefs, ethnicities and socioeconomic backgrounds; as well as those with unique factors that affected their donation. Each mentor has completed a thorough training program taught by our staff of nurses and social workers. On-going support and guidance is always available to our mentors. Our staff carefully pairs each mentee with a mentor based on factors such as age, gender, race, organ donated, relationship to their recipient, and similar concerns that have been shared.

Your mentor will be given your first name, phone number and a brief account of your situation. Your last name, address, and date of birth are kept confidential.

By linking people who have already donated an organ with those who are considering donation, the University of Wisconsin Transplant Program Living Donor Mentor Program provides potential donors additional support and information. Mentors' real-life stories are an invaluable source of insight and comfort to those still weighing the decision about living organ donation. In turn, the mentoring experience provides previous donors the opportunity to reflect on their experiences and to stay connected with the transplant community.

To Enroll in the Program

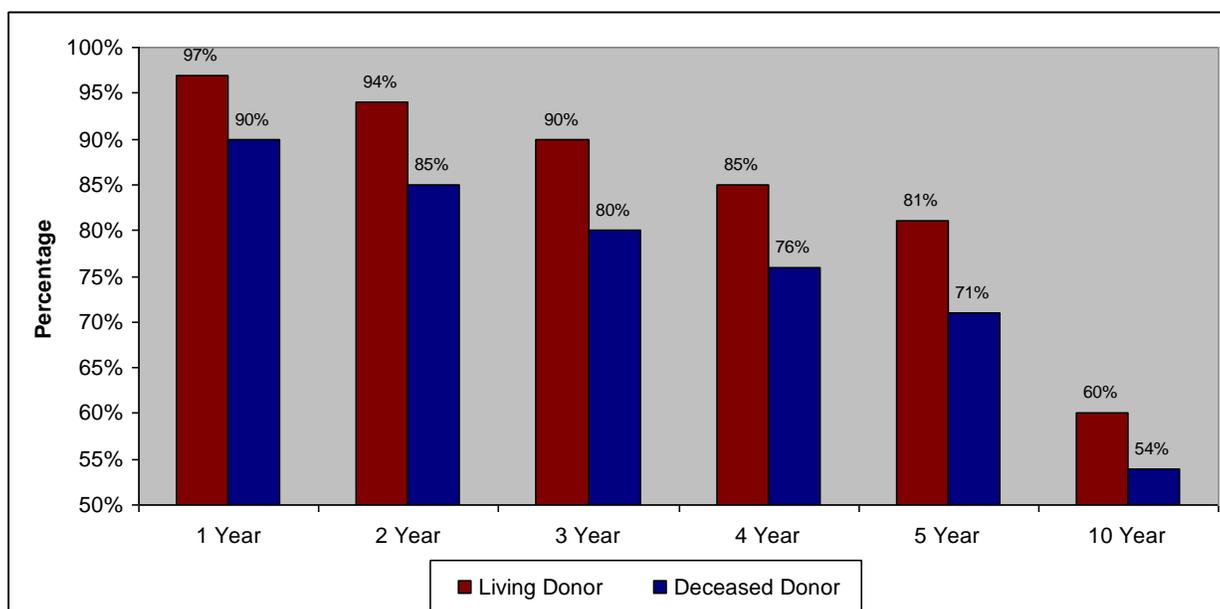
If you are interested in being paired with a mentor, please call (608) 261-0516 and ask to speak with someone about the living donor mentor program. For more information, please visit uwhealth.org/livingdonor.

Kidney Transplant Statistics

“Graft survival” means the length of time the new kidney works after the transplant surgery. This is different than “patient survival” which refers to the patient being alive. Many things affect how long your new kidney will work. For example, if your kidney came from a living donor it will typically last longer than a kidney that came from a deceased donor.

Below are the adult kidney graft survival rates for living and deceased donor kidneys at UW Health. For the most up to date information on both patient and kidney graft survival rates here and at other transplant centers please refer to our website: www.uwhealth.org/transplant or the United Network for Organ Sharing (UNOS) website: www.unos.org.

Adult Kidney Graft Survival Rates 2000 - 2010



Source: UW Health Transplant database.

Represents the total number of kidney transplants from 1/1/2000 through 12/31/2010. Includes all kidneys transplanted including multi-organ transplants.

The Non-Medical Risks of Living Donation

Financial strain and potential impact on your job

Living kidney donation will involve an absence from your job for, on average, four to six weeks. If your job includes doing heavy lifting, you may need to take more time off from work. In rare instances, donors require a longer recovery period. The living donor social worker will help you explore what impact this may have on your income and what options (if any) you may have for income continuation. If you will not be paid during your recovery, a state tax credit or deduction may be available. If finances will be tight during recovery, donors are encouraged to develop plans for this ahead of time, with help from the social worker.

It is important to find out ahead of time whether donating a kidney will jeopardize your job. Depending on your job, you may have Family Medical Leave Act (FMLA) protections during your recovery period. If not, your employer may still choose to 'support' your decision to donate by authorizing your time off. However, it is also possible that donating a kidney will affect your employment status. The living donor social worker will help you explore options and potential impact.

Disruption in family obligations

During surgical recovery, you will be limited from activities like driving and lifting. This means that if you typically care for someone else (a child or an elderly relative, for example) you will not be able to do this for several weeks after donation. It may be eight weeks before you can lift anything heavier than 20 pounds. The living donor social worker and your transplant coordinator will ask you about any dependents you have, and will encourage you to develop a support plan for your recovery.

Body image

You will have scars on your abdomen after organ donation. The surgeon will be able to describe their appearance once the decision is made regarding which surgery technique is best for you. Some people describe changes in how they feel about their bodies with these scars. This is particularly true for people who have tattoo work across their bellies that may be affected by the scar.

Mood disruption

Donation is an emotionally-loaded decision and you may experience a variety of feelings both before and after donation. There is a risk of experiencing depression, or low mood, after living donation. This can be considered an after-effect of anesthesia. Sometimes this occurs because donors are temporarily unable to do many of the activities that they typically enjoy, which are good for your mental health, such as exercising, working and active play with your children. Living donation may weigh you down emotionally, especially if you have a history of coping with depression or anxiety. Many emotions may be riding on the outcome of your own surgery as well as the recipient's surgery. It is common to experience a flood of feelings during recovery, particularly during a complex recovery. Some people have described relationships within their family, or with their recipient, changing. This may include a new sense of closeness, but may also include new challenges, particularly if you see the recipient having difficulty taking care of him/herself. The social worker and/or health psychologist will talk with you about these emotions, and other risks you might experience, during your donor evaluation.

Substance abuse relapse

If addiction or substance abuse issues have been a problem for you in the past, surgical recovery can include a risk of relapse. If chronic pain is a problem for you, managing the pain medication during surgical recovery may be challenging.

Impact on future insurability

Although the costs of living donation are covered by the recipient's insurance, donating an organ can still affect how you obtain insurance in the future. Kidney donation can be considered a pre-existing condition when you

apply for either health or life insurance. This means that you might have higher premiums, and/or there might be a ‘rider’ placed on your coverage so that kidney donation-related needs are excluded, or that you might be denied insurance coverage.

If you have a group health insurance policy in place now, you have some portability protections, and your current insurance will probably be unaffected by donation. The living donor social worker can help you explore this possibility during your evaluation.

Relationship changes

Some people describe relationship changes in their family following donation, sometimes in ways that surprise them. People who donate kidneys hoping to repair a past painful relationship may be disappointed that changes don’t happen. Other people describe feeling disappointed in how the person who received the kidney (the ‘transplant recipient’) takes care of the new kidney. Yet others describe new feelings of closeness or intimacy after transplant. It can help to think about what your hopes are for the donation, and sort out ahead of time how much is within your control, and how you’ll cope if someone doesn’t respond in the way you hope.

What if I am “Ruled Out” as a Potential Living Donor?

During the living donor evaluation process, it is the medical team’s job to be more conservative with your care, and the decisions that are made, than you may want to be with yourself. The medical team must first consider what they learned about your specific health situation, and compare that information to what they know about living donor outcomes. This means that it is possible that the medical team may tell you that, at this time, the risks of living donation are too high for you to be a donor.

This careful evaluation of potential living donors is important for several reasons:

- It helps make sure that living donors have good surgical outcomes
- Donors are more comfortable with their decision to donate when they know that the medical team takes donor candidacy very seriously
- Transplant recipients tell us that they feel better accepting the kidney knowing that the donor’s medical evaluation is very thorough

Transplant recipients have often stated that it was the desire of their loved one to help them that was the most meaningful to them. Because you took the time and made the effort to explore living donation, even if you are unable to actually be their living donor, is a powerful act of support for your loved one.

Of course, you may still experience a range of emotions if you are ruled out as a potential donor. These may include sadness, disappointment, relief and confusion.

Try to remember there will continue to be meaningful ways for you to provide support, even if you are not able to be the living donor. You can give the transplant recipient key support during the time leading up to transplant and during surgical recovery (including help with transportation, food preparation, fundraising and/or child care). If another person is able to become their living donor, you can serve as a key support person for them as well.

Finally, if you are ruled out as a potential living donor, you can still be a living donation champion. You can help others learn about living donation and, with your loved one’s permission, you can tell other people about their need for a living donor. You can provide basic information about the donor evaluation process and you can help out with logistics. These steps will help your loved one get a living donor transplant.

What if I decide not to be a living organ donor?

Living organ donation is voluntary. You are not obligated to become a living donor. Your transplant coordinator will frequently talk with you about this as you start your journey to learn about living donation, and as the evaluation tests continue. Likewise, during your medical evaluation, an independent living donor advocate will talk with you about your decision to donate. This person is available to help you walk away from the process if at any time living donation doesn't feel right to you.

People approach living donation in a variety of different ways. Some just know that it is right for them. Others struggle dealing with emotions related to competing obligations, concern, love, and/or fear. As time passes, it is not uncommon for feelings about this decision to change.

The donor evaluation process is designed to help you make a thoughtful, informed decision:

1. **Confidentiality.** Your medical record is private. This means that your intended recipient, and other members of your family, will not be told anything about the status of your donor evaluation. This also means that if you decide not to donate, the transplant team can help you do so in a private, safe way that protects relations with your recipient.
2. **Education.** The medical team will provide education about the risks and benefits of living donation. They will combine data about living donor outcomes with your health information and test results. Sometimes, by learning more, you can better sort through your feelings. In addition, if members of your family or support system have anxiety or concerns about you becoming a living donor, we invite them to join you at this session.
3. **Careful process.** There are several steps to the donor evaluation process. This helps the medical team make careful determinations, and allows you time to make a thoughtful decision.
4. **Donor advocate.** You will meet with someone who works with UW Health, but is not a member of the transplant team. She is there to talk with you about donation decision-making, to help you get all of your questions answered and can help you walk away from the process at any time.

Resources to Reduce the Financial Burdens of Living Organ Donation

Costs of living kidney donation

The medical costs related to the process of becoming a living donor are covered under the organ recipient's insurance plan. There may be some routine preventive care, such as a Pap smear for women, which are part of the evaluation process but are not covered by the recipient's insurance plan. If this is the case for you, please speak with the donor social worker to see if there are resources for reduced-fee care in your area.

Payment of travel costs

In some cases, the recipient's insurance covers travel expenses for living donors.

Travel grants

For those who do not have coverage for travel costs, The National Living Donor Assistance Center can pay for up to three trips to the transplant center, including your evaluation visit, surgery and follow-up visit. This grant includes reimbursement for mileage, airfare, hotel, food and other incidentals. The living donor social worker

can determine if you are eligible for this grant program, and can help you apply for the grant. For more information, go to the web site: LivingDonorAssistance.org.

Tax credits/ deductions

Many states now offer tax credits and/or deductions for living donors to offset costs associated with living donation, such as lost wages or travel costs. This includes Wisconsin, Minnesota and Iowa. You must itemize your state income taxes to take advantage of this option. The donor social worker can help you learn more.

Role of the living donor social worker

As you explore living donation, you will meet with a social worker who will help you explore the 'non-medical' parts of your life that may be affected by living donation. This includes the impact on your job, family activities, finances, insurance and mood. This will also include looking into resources that may reduce the incidental costs of living donation.

Internet Resources for Transplant Patients and Living Organ Donors

UW Health: uwhealth.org/transplant

Information about the UW Transplant program as well as online patient education videos

UNOS (United Network of Organ Sharing): unos.org

Information and people profiles. The Transplant Patient Database contains center-specific waiting list and transplant data

Transplant Recipients International Organization, Inc.: trioweb.org

Transplantation/organ donation information for patients, donors and families

Living Donors Online: livingdonorsonline.org

Specific information for those considering living organ donation, both kidney and liver. Includes question and answer, process, and stories.

American Society of Transplantation: a-s-t.org

An international organization of transplant professionals dedicated to advancing the field of transplantation through the promotion of research, education, advocacy and organ donation to improve patient care

American Society of Transplant Surgeons (ASTS): asts.org/ResearchEducation/PatientEducation.aspx

Information and online videos for patients needing transplant and those considering living donation

Healthy Transplant: healthytransplant.com

Developed to help patients learn about transplant so they can take a more active role in their cares

Organ Transplant Support: otsfriends.org

A non-profit organization that aims to provide support and comfort to transplant patients and their families as they experience the trials of an organ transplant, to give support to future transplant recipients and to promote donor awareness

Transplant Buddies: transplantbuddies.org

A discussion and bulletin board site for recipients and donors

Transplant Living: transplantliving.org

Transplant Living is a project of the United Network for Organ Sharing (UNOS), a nonprofit organization that

maintains the national Organ Procurement and Transplantation Network (OPTN) under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services

Transplant Wisconsin: transplantwisconsin.com

Transplant Wisconsin provides organ transplant recipients, donors, families, friends and interested persons a forum for exploration, education and support

TransWeb: transweb.org

A non-profit serving the world transplant community, aimed at young people. Includes *The Transplant Journey*, a multimedia trip through the transplant process, and lists of support groups by state.

Kidney Disease-Specific Sites

American Association of Kidney Patients: aakp.org

Non-profit that helps patients to learn more and become active participants in planning/managing treatment. Focus on rehabilitation, lobbying, and emotional support

Hereditary Nephritis Foundation: www.cc.utah.edu/~cla6202/HNF.htm

Hypertension Dialysis and Clinical Nephrology (HDCN)

Renal Disease Electronic Journal: hdcn.com

Articles on clinical nephrology and dialysis issues, published online

Ikidney.com: ikidney.com

Worldwide resource for kidney patients and professionals.

Interstitial Cystitis Association: ichelp.com

Kidney Cancer: oncolink.org

This site also has information in Spanish about kidney cancer

National Institute of Diabetes, Digestive and Kidney Disorders: niddk.nih.gov

National Kidney Foundation: kidney.org

Comprehensive information on the many forms of kidney disease, organ donation and transplantation

Polycystic Kidney Research Foundation: pkdcure.org

Renalnet: renalnet.org

Urological Sciences Research Foundation: usrf.org

USRF is a non-profit group which studies the major urological diseases

The Whole World of Nephrology: nephroworld.com

Liver Disease-Specific Sites

American Liver Foundation: liverfoundation.org

Pediatric Liver Disease: childliverdisease.org

Liver disease information site: cpmcnet.columbia.edu/dept/gi/disliv.html

This resource, designed by Columbia University, is a list of liver diseases and conditions with links to sites that provide relevant information

Children's Liver Association for Support Services: classkids.org

Non-profit group which serves the emotional, educational, and financial needs of families coping with childhood liver disease and transplantation

Other health sites that may be of interest

American Diabetes Association: diabetes.org

This site has information about diabetes in English and Spanish

Centers for Disease Control (CDC): cdc.gov

Medline: nlm.nih.gov

The world's most extensive collection of published medical information; coordinated by the National Library of Medicine

Healthfinder: healthfinder.gov

A gateway site to help consumers find health and human services information quickly

National Institutes of Health Information Page: health.nih.gov

Restless Legs Syndrome Foundation: rls.org

Fund-raising sites

Children's Organ Transplant Association: cota.org

Non-profit that provides fund-raising assistance for children needing transplant

National Transplant Assistance Fund, (800) 642-8399, transplantfund.org

Non-profit that provides fund-raising expertise for patients, \$1,000 challenge grants for eligible patients, and educational information

If you have questions about planning for surgery and recovery, please contact the social workers or your coordinator at the Transplant Clinic Office at (608) 263-1384. The information here is provided to help patients seek general information and resources. This list is not all-inclusive and is subject to change. **Information and advice that is found in any of these resources are not intended to be used in place of professional medical advice.** Ask your doctor before acting on any advice to be sure that it is right for you.

Living Kidney Donation Patient Stories

Laina's Story

"She has twice the energy as before and has grown so much that she's literally gone through full sizes of clothing!"

- Penny Koenig, talking about her daughter Laina, who underwent a kidney transplant at UW Hospital.



Kidney disease isn't just an illness that affects adults or the elderly. In the United States, more than 1,000 children are awaiting life saving kidney transplants, 17 in Wisconsin today. This fact became a startling reality for the Koenig family of Buffalo City, Wisconsin, after a routine trip to the pediatrician. When Penny and Jason Koenig brought their daughter Laina to her six-month check-up, the news they received about their baby shocked them. During the examination, the pediatrician noticed swelling in Laina's abdominal area. An ultrasound soon revealed that Laina had polycystic kidney disease (PKD), which is an inherited renal disorder characterized by the presence of multiple cysts on the kidney. In patients with PKD, normal kidney tissue is replaced by fluid-filled sacs or cysts of varying sizes that become larger as the disease progresses. Often abnormally high blood pressure (hypertension) and the progressive loss of kidney function, leading to end-stage renal failure are associated with the disease.

Laina's mother Penny explains that although she and Jason were shocked by the initial diagnosis, they were thankful that Laina fared quite well with the use of medication up until her second birthday. Then her energy level began to dip as Laina began to experience the symptoms of kidney disease. Throughout the rest of her toddler and early childhood years, Laina was tired and inactive, and not at all able to enjoy the experiences common to young healthy children. When Laina turned 5 and was entering end-stage renal failure, the family began planning for a kidney transplant. Both Laina's parents and her maternal grandmother tested. Her mom, Penny, was a match, and on March 4, 2010, Laina received her mother's kidney. Penny and Jason are so appreciative of the compassionate care they received from the entire hospital staff.

Now, more than a year after her transplant, Laina most typical 6-year-olds. And though she still doesn't like to take her medications, she doesn't the trips back to Madison for her scheduled check- These visits often include a trip to the zoo and a for ice cream - simple experiences that Laina now the good health and energy to enjoy. As Laina recovered, her parents saw a gradual change in their daughter's energy level - as she went from tired to having the energy of a typical 5-year-old girl. Now, Penny says, "She has twice the energy as before and has grown so much that she's literally gone through full sizes of clothing!" Laina now has the energy to live the busy and fun life of a healthy kindergartner. She's even learned how to ride her bike, and plans to take her training wheels off this summer.



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Jim's Story

Jim's brother-in-law completed the desensitization process prior to receiving Jim's donated kidney.



I have lived a full and rewarding life. I'm one of thousands of people who went to college at UW-Madison and never left Madison. I enjoyed school, and ended up with two degrees from the UW: a B.S. in Education (Natural Sciences) and a J.D. I've been married to Kathy for 35 years, and we both recently retired, me after 30 years of service at the University of Wisconsin-Madison and Kathy after 30 years as a nurse. In 2008, when I learned that Kathy's brother needed a kidney, I stepped up to donate. The team at UW Hospital discovered that he and I were not a great match, so they offered him the option of going through the desensitization program. We were only the second non-matched kidney transplant at UW Hospital and Clinics, so I think it is important

to get the word out that non-matched transplants are possible and that they work. My brother-in-law, who has polycystic kidney disease, is now leading a much better life. To improve awareness about organ donation, I serve as the living donor representative on the Donate Life Wisconsin collaborative. I also serve on several other boards, and enjoy a healthy, active lifestyle including biking, hiking, cross-country skiing, bird watching and hunting.

Sue's Story

Sue is married to Travis, a kidney desensitization and transplant patient. A caring wife, Sue was also a kidney donor for Travis.

Travis and I were married in 1992, at a time in our life when we were both very active people. Travis taught aerobics for over 18 years and worked a full-time job before his life changed due to Wegener's Granulomatosis. I was told at one point in the hospital that he probably wouldn't be able to receive a transplant. That was such an extremely difficult time because Travis was in an unconscious sedated state so he could heal. It was so hard to not be able to talk to him.

At that time I was told that I couldn't give Travis a kidney because I wasn't the same blood type, but we were told to call UW Hospital to see about getting Travis added to their list. The staff at UW Hospital told us about a new procedure that involved plasmapheresis. We couldn't believe it when we were told it could happen in two months time. Our experience with surgery was so positive. I am so proud of Travis and glad that I could help better his life. We felt that there was no downside to our surgeries. For me, there wasn't really pain, only some discomfort. After my surgery, I was walking up and down the hall within 24 hours visiting Travis. We went walking several times a day for about 40 minutes at a time and ate at the cafeteria every day. It helped that both of us have always been active.

We stayed in Madison for about two weeks after the surgery, to be close to the hospital for any problems or questions that arose. This allowed us to concentrate on healing. We came back to take the classes that were offered and with our hotel being so close, we were able to go and rest when needed.

The staff members in the transplant clinic and the inpatient transplant unit were extremely helpful. We even had what we considered a tag-team of coordinators working with us. I am very fortunate to work for two companies that were very supportive, and we're blessed with a great family and a family of friends. It was awesome to have so many people there for us."

To view more living kidney donor patient stories and videos, visit: uwhealth.org/livingdonor

Living Kidney Donation Frequently Asked Questions

What are the advantages to having a living donor?

Advantages include:

- Better short-term and long-term outcomes, as living donor kidneys usually last longer
- Decreased wait time resulting in a quicker return to an improved quality of life, especially for patients on dialysis
- Scheduled surgery, making it more convenient for patients and their families
- More complete medical testing is possible with living donors, helping to ensure the highest quality kidneys for transplant
- Receiving a kidney transplant sooner often means patients are in better health, which makes recovery easier and improves the outcomes of the transplant
- The kidney is transplanted into the recipient immediately after the donor surgery, which helps preserve kidney function and results in reduced complications

What are the risks involved with a living donor?

The risks with kidney donation are minimal. There are surgical risks related to the use of anesthesia, and possible bleeding or clotting. Research indicates that the long-term medical risks of having only one remaining kidney are low. Although most of us are born with two kidneys, only one working kidney is needed to sustain life. This allows a healthy person the chance to donate a kidney to someone in need.

Does the donor need to be a relative?

People can donate a kidney to a friend, spouse or any other non-blood related person, as well as to a relative. While the best matched kidney may come from a full-blooded sibling, many donors are not related and may only be an acquaintance of the recipient.

What does a donor have to do to be tested and approved for organ donation?

The UW Transplant staff carefully reviews each person's situation to see if the person is a suitable donor. Donors should be in good health, both physically and emotionally, and of an appropriate age. Certain medical problems such as high blood pressure, diabetes, heart disease, cancer, and urinary tract or kidney problems could make someone ineligible for donation.

A donor can come with the recipient to UW Hospital and Clinics for the recipient's evaluation. Blood samples will be drawn from a donor to ensure compatibility. If the donor is compatible, a medical work-up of the donor will be completed at a later date. Donors are educated on the risks associated with surgery, hospitalization and recovery. In addition, every donor has a "living donor advocate" assigned to them who meets with them to discuss their decision to donate to ensure that their questions have all been answered and that they are comfortable with their decision.

How is the donor's surgery performed?

The surgery to remove the donor's kidney is usually done using a laparoscope, a surgical instrument that is connected to a video camera. Inserting the laparoscope requires a smaller abdominal incision and a few small "keyhole" incisions around the navel. This results in less pain and scarring and a more rapid recovery. The laparoscopic surgery takes about three hours and the donor often goes home three days after surgery.

What are the costs for the donor?

The recipient's insurance or Medicare pays for all donor medical expenses. Travel costs and time away from work are often not covered by insurance and need to be considered. In the state of Wisconsin, donors may subtract up to \$10,000 from their federal adjusted gross income for these costs on their state income tax form. An employee of the state of Wisconsin may also receive 30 days paid leave of absence for donating a kidney.

What about donor care after donation?

During recovery, the donor will be seen for follow-up care at the UW Health Transplant Clinic. After that, as with all individuals, it is good to obtain routine annual medical examinations, including blood pressure and urinalysis screening, with a local physician. There are no special diets or medicines that need to be taken after kidney donation.