



**Clinical Transplant Services  
Kidney/Pancreas Transplant Program**

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## **Facts for the Kidney Donor: Information to Consider**

The gift of a kidney can significantly improve the health and lifestyle of the person receiving it. While being a kidney donor can be a very rewarding experience, it may not be a good choice for everyone. This handout provides information to help you decide if donating a kidney is a good choice for you. Some people feel that the information in this handout is overwhelming and discourages donation. That is not the intent at all. Rather, the intent is that you have accurate and complete information about donation so that you can make a decision that you feel is right for you. Every living donor has an “Independent Living Donor Advocate” (ILDA) who is your “point person” throughout the donor process from initial education through your post-donation follow-up. The ILDA’s job is to represent your interests and concerns: your ILDA has no responsibility for your recipient’s care and will support whatever decision you make with respect to donation.

### **What treatments are available for people with kidney failure?**

People with kidney failure can choose to have dialysis, a transplant or, rarely, choose not to treat their kidney disease. A transplant is the best choice for people with kidney failure who are determined by their transplant center to be healthy enough for a transplant. That’s because getting a transplant often results in a longer and more enjoyable life than long-term dialysis. Every recipient undergoes extensive testing by their transplant center to help decide if getting a transplant is a safe choice for them. The transplant center makes this decision based on existing center-specific guidelines or practices as well as their clinical judgment. Transplantation does require the recipient to have major surgery and take “anti-rejection” medications for the rest of their life. These medications can have some very significant side effects as they “suppress” the recipient’s immune system in order to reduce the risk of rejection. Donors are not on any long-term medications as a result of donation.

It is important to realize that there is no cure for kidney failure; every treatment choice has potential risks. Transplant recipients can have complications from the transplant operation. The anti-rejection medications can also make recipients more susceptible to infections and cancer. Even so, most patients do better with a transplant than they do with chronic dialysis. Any transplant candidate may have underlying health issues which increase their risk for complications up to and including death, but those conditions do not necessarily prevent them from being accepted as a transplant candidate. HIPPA laws prevent the transplant program from discussing these with potential donors unless the recipient gives permission to do so. OHSU takes all reasonable precautions to provide confidentiality for both the donor and the recipient.

### **How successful are transplants?**

National results as well as those for Oregon Health and Science University (OHSU) in particular are available online at <http://www.ustransplant.org/crs/current/crsDefault.aspx>; they are also included as a separate handout in your education packet.

### **Can anyone be a kidney donor?**

No; donors need to be in excellent health and be able to make an educated and voluntary decision to donate. Nationwide, only 15-20% of people who express an interest in living kidney donation actually become donors. The sale or purchase of human organs or profiting from donation is a federal crime. This includes receiving anything of value, including but not limited to money, property, and vacations. Living donors undergo very extensive education, medical testing and psychosocial screening to determine if donation is a safe choice for them.

### **What happens to my kidney function after donation?**

Within a few weeks, your remaining kidney will recognize that it is on its own and compensate somewhat for the loss of its partner, but your overall kidney function will be permanently reduced after you donate. Most donors have between 65-75% of their original kidney function after donation. Most people do not feel any symptoms of kidney disease until they are down to about 30% function and dialysis is rarely needed until kidney function is down to about 15%. If a person develops kidney disease, it is most often first recognized when they are in their 40s or 50s. Dialysis or transplantation is usually not necessary until they are in their 60s. As kidney problems are often “under the radar” (you don’t feel sick from them until they are very advanced), it is essential that donors are tested on a regular basis after donation to keep track of how their remaining kidney is doing. Every transplant center is required to report living donor follow-up information to UNOS at specific times, currently 6, 12, and 24 months. A living donor must commit to follow-up testing coordinated through OHSU at those times. After two years, we recommend an annual blood and urine test coordinated through your own healthcare provider for the rest of your life to monitor your kidney function after you donate. That way, if you do develop kidney problems, you and your doctor can address them early and minimize the effect on your remaining kidney. If you do develop a kidney problem in the future that does not respond to treatment, your progression to kidney failure (needing dialysis or a transplant yourself) may be faster than if you had not donated a kidney. If your remaining kidney suffers damage (trauma or cancer, for example) you might also progress to kidney failure. The chances of this are quite low. We cannot predict the long-term consequences of donation in younger donors as they have not lived long enough to develop their own “medical history”. Pre-existing medical conditions (including but not limited to high blood pressure or obesity) can increase your risks with donation. The donor physicians will discuss these with every donor candidate during their evaluation. Remember, the donor team’s primary concern is your health and well-being. Developing diabetes, high blood pressure or becoming obese after donation can increase the workload on your remaining kidney, increasing your risk of health problems up to and including a shorter life expectancy. Maintaining a healthy lifestyle and regular monitoring are very important after donation. Currently, the United Network for Organ Sharing (UNOS) gives priority on the “Waiting List” to prior living donors who need a kidney transplant.

### **Who is NOT a good donor candidate?**

OHSU does not consider donors who:

- Are under the age of 21 (it is very difficult to determine the long-term risks of donation in young donors)
- Have significant underlying medical issues that increase their risk with surgery

- Have significant underlying medical issues that increase their risk with life-long reduced kidney function after donation
- Have kidney disease, including but not limited to recent kidney stones or insufficient kidney function
- Have significant transmissible diseases, including but not limited to HIV
- Are mentally incapable of making an informed decision
- Are actively using non-prescribed substances
- Have diabetes or “pre-diabetes”
- Have high blood pressure with or without the use of blood pressure medication(s)
- Have active or incompletely treated malignancy (cancer)
- Are significantly overweight (we define that as a “body mass index” over 32)
- Have insufficient financial or social support
- Have active, significant mental health issues
- Are inmates of correctional facilities
- Are not comfortable with proceeding

Donors over the age of 70 are rarely considered to be appropriate.

### **What will my testing involve?**

You will have a very thorough evaluation to determine if donation is safe for you. We can begin that evaluation locally but every donor will need to come to OHSU for one full day to complete their testing. If you live more than a few hours from Portland, you should plan on staying in the Portland area for approximately 2 ½ weeks at the time of your surgery before you can return home.

Your medical testing will involve:

Tests that can be done “locally”

- Blood tests to determine if you and your recipient are “compatible”. This involves determining your blood type (you don’t necessarily need to have the same blood type as your recipient), your “tissue type” (not to worry, we do this with blood, not actual tissue), and a “crossmatch” to see if your recipient can accept your kidney. The crossmatch will be repeated within a week of your actual donation to make sure that you and your recipient are still compatible.
- General medical testing: blood and urine tests to look at your kidney function, liver function, whether you are anemic. We also check for “pre-diabetes” and significant contagious diseases.
- Depending on your personal and family medical history, we may get some other tests or consultations before you travel to OHSU.

All your routine health maintenance per the American Cancer Society guidelines needs to be current and acceptable. You need to do these tests through your own health care provider.

Tests that will be done at OHSU:

- More blood and urine tests
- Chest X-ray
- ECG
- A CAT scan of your abdomen to check for any abnormalities and “map” the blood vessels that feed your kidneys. This test requires the use of IV contrast; some donors have an allergic reaction to that contrast which requires treatment at the time of the test.

Additional tests or consultations may be required based on your medical history or the results of the above tests.

Consultations at OHSU: you will meet with your donor care team:

- A donor surgeon will perform a history and physical exam to assess your risks with surgery; he will discuss those risks as well as the operative procedure and recovery with you.

- An independent nephrologist (a kidney specialist who has no responsibility for the care of your recipient) will also perform a history and physical exam, assess your long-term medical risks after donation and discuss those with you.
- A pharmacist will assess your past and current medication use and educate you regarding medications to avoid after donation.
- A nutritionist will assess your diet and nutrition and educate you regarding dietary health after donation.
- A social worker will assess your ability to make an informed decision, your social and financial support, and your plans for your recovery. She will also discuss possible emotional responses to donation, as well as financial considerations related to donation. A psychiatric evaluation may also be required.
- An independent living donor advocate will again assess your understanding of the donor process including the medical and psychosocial evaluation, surgery, recovery and lifestyle modifications after donation. S/he will also assess your comfort with donation and willingness to continue in the process.

There are risks associated with the donor evaluation including but not limited to: allergic reactions to contrast, discovery of infections that must be reported to local, state or federal public health authorities, discovery of serious medical conditions, discovery of adverse genetic findings unknown to the donor, and discovery of certain conditions that may require additional testing at the donor's expense or create the need for unexpected decisions on the part of the transplant team. After your evaluation, the donor team will review all the information and determine if donation is a safe choice for you. There is no "universal" selection criteria for living donors; each transplant center makes a decision to accept or decline a donor based on its best medical judgment. The transplant center has a responsibility to explain their decision to the donor, but their decision is final. A different program might accept a donor that we do not feel is appropriate; the reverse might also be the case. A recipient and donor may request a referral to a different program if they disagree with the team's decision. If the team decides that donation is not a safe choice for you, your recipient can go on the Waiting List for a deceased donor transplant or can have another potential living donor call us to be evaluated.

### **How long does all this take?**

On average, it can take 2-3 months to complete your donor testing and another few weeks before your surgery is scheduled. The donor process can take longer than that if either you or your recipient has issues that need to be resolved before scheduling surgery. We cannot schedule your surgery until both you and your recipient have completed all of your testing and are accepted by the team. Your recipient will remain "active" on the deceased donor waiting list until you successfully complete your initial testing. At that time, they will be placed on "hold" on the waiting list unless they are "highly sensitized" or difficult to match. It is possible, although unlikely, that a compatible deceased donor might be found for your recipient before you complete your evaluation.

### **What are the financial issues around donation?**

Your medical testing, the surgery and hospital stay and your post-op check-up are covered by your recipient's insurance. However, if your donor testing reveals a condition that would need further evaluation or treatment independent of donation (i.e. it is needed for your own health whether you were going to donate or not), it will be billed to your own insurance. While we don't require that donors have health insurance, we strongly encourage them to have insurance in place before evaluation. Donor testing might reveal a medical condition that would make it more difficult or costly to obtain health, life or disability insurance. Future health problems related to donation may not be covered by the recipient's insurance. Nationally, some donors have reported that their own insurance has denied coverage for complications after donation. While OHSU will pay for routine post-donation

blood and urine tests at 6, 12 and 24 months after donation, ongoing annual monitoring after two years is NOT covered by the recipient's insurance or by OHSU.

Nationally, some donors have reported problems obtaining, maintaining or affording health, life and/or disability insurance. We advise every potential donor to contact their own health, life and disability insurance carriers and ask if donation would impact their eligibility or premiums and whether they would cover any complications of donation.

Personal expenses of travel, housing in the Portland area, and lost wages related to donation might not be reimbursed. There are some funds available for donors who qualify for financial assistance; please refer to the "National Living Donor Assistance Center" handout in your packet for more details. Other out-of-pocket expenses such as child care costs might not be covered. Some donors have reported a change in their employment status and even the loss of their job after donation. Donation may make it more difficult to obtain future employment. It is essential that you discuss donation with your Human Resources Department at your work or with your immediate supervisor if you do not have a Human Resources Department to determine ahead of time what benefits are available to you and whether your job will be secure after donation. You can engage in most occupations after donation, however, the military, police or fire departments might disqualify you or restrict your duties after donation.

### **What types of donor surgery are done at OHSU?**

OHSU does both "open" (traditional) and "modified laparoscopic" donor surgery. Your surgeon will decide which procedure you will have based on your preference as well as the findings of your CAT scan (the anatomy of your kidneys).

#### **Surgical Approach**

#### **Open**

#### **Laparoscopic**

Time in the OR	about 4 hours	about 4-6 hours
Incisions/scars	one; about 8 inches	one about 4 inches plus two about 1 inch
Hospital stay	about 3-4 days	2-4 days
Return to desk job	about 3-4 weeks	about 3-4 weeks
Return to manual job	about 12 weeks	about 6 weeks

### **What will surgery involve?**

Donating a kidney is major surgery and requires general anesthesia. Donors assume all the risks of surgery without any direct medical benefit to themselves. You will have an IV for 2-3 days until you are able to drink and eat; you will have a catheter to drain urine for the first day or so. You will be encouraged to get out of bed and start moving soon after your surgery to speed your recovery. In addition to your surgeon and the in-patient nurses, the pharmacist, nutritionist, social worker and donor advocate will assess and educate you before you are discharged from the hospital.

### **What are the risks with surgery?**

A donor nephrectomy involves the same risk to you as any major surgery would. The risk of dying with donor surgery is reported as 3 in 10,000. It is reported that 2-6% of donors develop complications following surgery. Possible complications include: bleeding, blood clots, pneumonia, wound or other infections, nerve damage, or incisional hernias. Every donor experiences scars, pain and fatigue after surgery and it can take a while for your "gut" to get back to normal because of the anesthesia and pain medicines. You may experience bloating or nausea and in rare cases a "bowel obstruction" (blockage). Surgical complications may be temporary or permanent. Again, a donor's risk of health or complications can be affected by their pre-existing conditions, such as obesity, high blood pressure or smoking. Alternating exercise (walking) and rest is important after any surgery to regain your stamina. Most donors are feeling 80-90% by a few weeks after surgery, but it can take several months to feel

fully recovered. Some donors do experience emotional problems after surgery including body image problems, depression or anxiety, emotional distress or grief. This is more common if the donor or recipient experience medical problems such as recurrent kidney disease or death after surgery. Emotional reactions are usually short-term and the donor team is available to help work through these issues. Please see the handout in your packet entitled “Take Home Instructions for the Kidney Donor” for more detailed information about recovery.

### **Are there any long term risks after donating a kidney?**

A recent study by John’s Hopkins found that kidney donors had an increased but still small risk of kidney failure compared to people with a similar medical characteristics who didn’t donate a kidney. There was no increased risk of kidney failure in donors compared to the general population with the same demographic profile (for example: age, gender, race). Donation does not affect your life expectancy unless you develop other medical problems after donation. There can be a slight increase in blood pressure after donation, so we recommend that you keep an eye on your blood pressure a few times a year after donating and let your doctor know if it is getting higher. Several transplant programs have done long-term studies (up to 20 years) on donors and those results are very encouraging but widespread research in this area is still lacking. To start to address this, UNOS now requires that transplant programs monitor donors at 6, 12 and 24 months after donation to learn more about how donation affects their health. We do know that you can lead a very healthy, normal lifestyle with one kidney. After recovery you can participate in most sports (although we do advise against “extreme sports”). We recommend donors in the military, police or fire departments speak with their supervisor early in the donor process regarding any impact donation may have on their career.

### **What is known about pregnancy after donation?**

There is no evidence that donating a kidney has any effect on the donor’s ability to have children. Recent studies have shown an increased risk of preeclampsia and gestational hypertension (pregnancy-associated high blood pressure) in women after donation. The risk of this can be twice what it was before donation. We recommend that woman do not donate for one year after having a baby and wait one year after donation before becoming pregnant. We also recommend that donors discuss pregnancy with their own physician before becoming pregnant and, of course, get early and regular pre-natal care.

### **What lifestyle modifications will I need to make after donation?**

Donors can lead a normal, healthy and active lifestyle, but we do recommend a lifestyle that is “friendly” to your remaining kidney. We encourage donors to eat a balanced diet with moderate, not excessive protein intake (see the “Healthy Eating after Kidney Donation” handout included with this packet for more details), stay well hydrated (drink at least 2 quarts/day) and watch their added salt as well as maintain a healthy weight and exercise regularly. In addition, we strongly advise donors to avoid excessive use of non-steroidal anti-inflammatory medicines (NSAIDs) after donation such as Motrin, ibuprofen, Advil, Aleve, aspirin, etc. We advise that donors limit these to a maximum of 20 over-the-counter strength tablets per month. Little is known about the effect of many herbal supplements on kidney function; unless your doctor can tell you they are safe, we recommend that you avoid them and encourage you to call the transplant program for advice regarding supplements as well. We also recommend that you do not take vitamins or minerals in excess of the recommended daily allowance (RDA)—high doses of vitamin C in particular can be harmful to your remaining kidney. Regular monitoring of kidney function is key with a blood test (chemistry) and urine test (UA) yearly after donation as well as checking blood pressure a few times a year. Donors should let all their health

care providers know that they have donated as it might affect the medicine they prescribe for you or the dye they might use in an x-ray study. While a few donors find these changes challenging, most donors are able to adjust.

### **What can I do if I disagree with my transplant program?**

Every transplant program makes decisions in accordance with its best judgment. If you disagree with your team's decision, you should discuss your concerns directly with your independent living donor advocate. OHSU also has a Patient Advocate that you can contact. If you still do not feel that your voice was heard, UNOS provides a patient services line for you to discuss your concerns. This number is 888-894-6361.

### **What if I'm having a hard time deciding?**

Some people make a decision to donate quickly, on an emotional level with few worries or concerns while others really struggle with their decision. We encourage donors to take their time, think things over, be honest with themselves about their feelings and ask lots of questions. Sometimes discussing donation with your friends, family or physician may be helpful; of course, the donor team is always available as well. If you would like, we can arrange for you to speak with a previous donor to get the personal perspective of someone who has lived through donation. Remember, you are never "locked into" this decision—if your circumstances or feelings change, just let us know that you are no longer comfortable donating. Your recipient will be told that you are not an acceptable donor. The only "right" decision regarding donation is one that you are comfortable with. It is important to accept that a donated kidney is a gift. What happens to the kidney is out of your control after surgery. Your gratification will come from knowing that you gave your recipient the best opportunity for a longer and healthier life.

### **Final Thoughts**

Obviously, there's a lot to consider in deciding if donation is a good choice for you. We encourage you to learn as much as you can and are always available for your questions. Our goal is to prepare donors for this truly unique and often very rewarding experience.

You can reach the transplant office at 503-494-8500 or 1-800-452-1369 ext. 48500.