

## **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. Your OHSU living donor care team is always available to discuss this information and answer any questions you may have.

### **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 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. Each recipient undergoes extensive testing by the transplant team to help decide if getting a transplant is a safe choice for them. 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. HIPPA laws prevent the transplant program from discussing these with potential donors.

### **Why consider a living donor?**

People can get a transplant from a deceased or living donor. Going on the "Waiting List" for a deceased donor transplant is the most common type of transplant; it is a very good option but it can take several years before a kidney becomes available. During that time, the recipient will need to be on dialysis and many patients have a difficult time with the restrictions of chronic dialysis. Getting a transplant from a living donor is much faster—usually a matter of months—and can last longer than a deceased donor transplant. Sometimes a recipient can avoid dialysis all together if they have a living donor. On average, a kidney from a deceased donor lasts about 11 years whereas one from a living donor on average lasts about 18 years. Living donors do not need to be family members or "genetically related"; transplants from friends or "Good Samaritans" do as well as many transplants from family members.

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

National results as well as those for Oregon Health and Science University (OHSU) in particular are available on line at [www.optn.org](http://www.optn.org) ; 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. The sale or purchase of human organs or profiting from donation is a federal crime. 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 reduced after you donate. Most donors have between 60-75% 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. Donating a kidney neither increases nor decreases your risk of developing kidney disease in the future. 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. We recommend an annual blood and urine test 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 it early and minimize the effect it has 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 had you 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. It is difficult to predict the long-term consequences of donation in younger donors as they have not lived long enough to develop their own “medical history”. Developing high blood pressure or becoming obese after donation can increase the workload on your remaining kidney, increasing your risk of problems. Maintaining a healthy lifestyle and regular monitoring are very important after donation. Currently, the United Network of Organ Sharing (UNOS) gives priority on the “Waiting List” to prior living donors who come to 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 or insufficient kidney function
- Have significant transmissible diseases
- Are unable to give informed consent
- Are actively using non-prescribed substances
- Have diabetes or “pre-diabetes”
- Have high blood pressure
- Are significantly overweight (we define that as a “body mass index” over 32)
- Have insufficient financial or social support

- 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 at least 2 days 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 would 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:

- A kidney function test (“Nuclear Medicine GFR”: this involves scanning and blood draws)
- 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

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 is your “point person” in the donor process. Her role is to represent your interests and concerns and make sure that you have the information you need to make a decision that you feel is best for you. Your advocate has no responsibility for your recipient’s care and will support whatever decision you make with respect to donation. Your advocate will assess your understanding of the donor process and be involved with you before, during and after your donation.

There are risks associated with the donor evaluation including but not limited to: allergic reactions to contrast, discovery of reportable infections, discovery of serious medical conditions, discovery of genetic findings unknown to the donor, and discovery of certain conditions that may require additional testing at the donor’s expense. 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. Under most circumstances, OHSU will place your recipient on “hold” on the “Waiting List” for a deceased donor while you are undergoing your medical evaluation. However, if your recipient is “highly sensitized” (difficult to match) we may leave them “active” on the Waiting List. 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 donor’s 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, although at OHSU we have not had a donor report that to us. The ongoing annual monitoring after donation is NOT covered by the recipient’s insurance.

We advise every potential donor to contact their health, life and disability insurance carrier and ask if donation would impact their eligibility or premiums.

Personal expenses of travel, housing in the Portland area, and lost wages related to donation might not be reimbursed by your recipient's insurance. 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, although no donor has reported this to OHSU. 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 or restrict 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).

<b>Surgical Approach</b>	<b>Open</b>	<b>Laparoscopic</b>
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 4 days	3-4 days
Return to desk job	about 3 weeks	about 3 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, infection, nerve damage, or hernias. Every donor experiences 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). 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 bereavement, especially if the donor or recipient experiences medical problems after surgery. These are usually short-term reactions 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?**

Donating a kidney does not affect your life expectancy and it does not increase your risk of kidney problems in the future. 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 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”).

### **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. A recent study did demonstrate a slight increase in the risk to both the mother and the baby in women who became pregnant after donation. As “super healthy” people, the risk to the mom and baby before donation was lower than the risk of the general population. After donation, there is a slight increase in risk both to the mom and the baby such that their risk becomes equal to the general population.

We recommend that woman do not donate for one year after having a baby and wait one year after donation before becoming pregnant.

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

There are very few lifestyle modifications required after donation. Donors can lead a normal, healthy and active lifestyle. We do encourage donors to eat a balanced diet with moderate, not excessive protein intake, 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 do 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. 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.

### **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 advocate. 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 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.