

Discussing Living Kidney Donation with Family and Friends

Asking someone to be a living kidney donor involves careful consideration and may create a variety of emotions. For many people, the shift in thinking from "I need to ask someone to donate an organ" to "I need to let people know about my situation and educate them about organ donation" can have a significant impact on their state of mind and willingness to talk to family members and friends.

Common Concerns

There are lots of reasons why you might be hesitant to start a conversation about living donation. Some concerns and questions may include:

- Why should I rely on others to help me with my illness?
- What are the medical risks involved?
- How will I feel if a potential donor doesn't follow-through with the screening process?
- Am I prepared to deal with the possible rejection of the organ?
- How could I possibly thank someone for being my living donor?
- Will donation have an impact on my relationship with donor?

Ultimately, living donation is a gift that you need to feel comfortable accepting as well as a gift that your donor feels comfortable offering.

Educate yourself

Once you have the motivation to talk to other people, it is important to educate yourself about living donation. Having the knowledge about organ donation will give you the confidence to talk about your situation and answer any questions raised by others. OHSU's living donor advocates are available to answer any questions as well and can be reached at 503-494-8500. In addition, OHSU's living donor education materials are on our website: <http://www.ohsu.edu/transplant>. Choose "living donation" from the menu on the left and then click on the links to learn what is involved with living kidney donation, including:

- the donor evaluation process
- donor eligibility criteria
- potential risks of donation
- the advantages of living donation
- financing living donation
- long-term medical and psychological considerations
- lifestyle after living kidney donation

These are important questions that deserve careful consideration. Talk to your transplant team to be sure you have a complete and accurate understanding of how potential living donors are evaluated and selected.

You or your potential donors may also benefit from speaking with someone who has already donated. OHSU can put you in touch with donors who are willing to do this.

Educate others

These options may be helpful when planning how to discuss your need for a living donor:

- Be prepared with information and resources that you can provide to family and friends. The OHSU website is a great starting point. The UNOS and Transplant Living websites are also excellent.

Other transplant candidates have found these suggestions to be helpful:

- Bring family members and friends together to discuss your health problems. Tell them about why your doctors are recommending transplantation, especially a living donor transplant.
- Let your family and friends know that they can learn about kidney donation by going to the OHSU website.
- Write an e-mail or letter and send it to family members and friends letting them know that you are considering (or have been accepted for) a transplant and that you would benefit from a living donor.
- Recruit an advocate who can talk to people about being a living donor. Often times, this advocate is a family member, friend, pastor or other important person in your life.
- Consider bringing someone close to you to your transplant evaluation and re-evaluation appointments. This person can share information with potential donors.

Careful consideration takes time

- Don't expect potential donors to respond right away after you discuss donation with them. Some people make their decision immediately while others need time to consider process the details involved with living donation.
- If anyone expresses interest in living donation, thank them and tell them how to contact the OHSU donor team. You need to call your transplant coordinator and let them know that your donor will be calling as well. Be sure to let your donors know that they can confidentially discuss their questions or concerns with the donor team.
- Keep your options open. Someone may offer to donate when you least expect it.

Using Social Media to Find a Living Donor

Social networking sites enable people to communicate with others around the world using forums, interest groups, blogs, chat rooms, e-mail, etc. Although the media is filled with stories about people who have found a living donor online, it is essential that you protect yourself by taking some common-sense precautions:

- First, discuss your idea of creating public notice with your transplant coordinator who can review the pros and cons of using social media and help you develop a plan.
- Do not include your coordinator's name or phone number in any posting! Anyone who is interested should go the OHSU website to learn more about donation and then communicate with you directly. You need to decide if you feel comfortable with each particular donor before you have them call the donor team at OHSU.
- Use appropriate caution when sharing sensitive health-related information. Don't disclose anything about yourself that you wouldn't want to be made public.
- Understand how various social networking sites work and what privacy choices you may have. There are no guarantees of privacy-- anything can be cut, pasted and re-sent.
- Remember that once information appears on a Web site, it can never be completely erased. Even if it's modified or deleted, older versions may exist on others' computers.
- Be cautious about meeting cyber contacts in person. It's hard to judge people by photos or information they post online about themselves. Some people are truly motivated by their desire to help but some may have other motives or expectations of a relationship afterwards.

Discussing living donation can be uncomfortable; we hope that this information helps you approach these conversations with more confidence. Remember, your OHSU transplant coordinator and the donor team are here to support you and your donors through this process.

Adapted from Transplant Living 2014