

Types of Donation

4. Determine if you will get a kidney from a living or deceased donor.

5. Wait for your surgery date in the case of a living organ donation or wait for an organ to become available and prepare for transplant.

Now that you have completed your evaluation, you will need to determine what type of transplant is best for you.

There are two broad sources where organs come from and they are from living and deceased donors and there are subcategories of each that will be covered in a later chapter. Live donations come from close relatives like a mother/father or sister/brother; however they can also come from spouses, friends, coworkers or anyone else that is interested in helping another person. Of course there are qualifications to become a living donor, including:

- Need to be within the ages of 18-65
- Must be a compatible blood type and have a good cross match (so your body will accept the organ)
- Can't have any severe medical or psychiatric illness
- Can't be pregnant
- Must be in good physical condition and able to handle the surgery and meet transplant center requirements such as non-smoking and weight requirements.

More generally, living donors need to be able to handle the surgery and not have a diminished quality of life afterward as a result of the surgery.

Live donors are less common and last year (2012) made up 5,619 out of 16,487 transplants or 34% of transplants. The rest (10,868) came from deceased donors.[1] Those organs come from individuals that signed up to be organ donors and their wishes were carried out by their families. Donors are normally between the ages of 18-65, were in good physical health and passed away from a condition that didn't impact their kidneys. The kidneys and other organs/tissues are collected and can last up to 72 hours but commonly last 36-48 hours outside of the body.[2]

There are many steps before a potential deceased donor organ becomes available for transplant:

1. The individual chooses to register in their state's donor registry, which often happens when they go to apply for a driver's license or come in to renew it. A listing of the state

registries can be found [here](#) [1].

2. This individual is either ill and already in the hospital or comes in due to an accident or trauma. The hospital does their best to save the individual, and if the individual can't be saved doctors perform multiple tests to check for brain activity.
3. If no brain activity is found, the hospital contacts the local organ procurement branch and the first step in the matching process occurs. The individual's information is checked again to ensure they are a qualified donor and a representative comes to the hospital. If a person isn't listed on a registry, there is opportunity for the organ procurement agent to speak with the next of kin to get family consent. No one pressures the family and any family wish is upheld.
4. After receiving consent, the individual undergoes an evaluation and if successful, this information is given to the national Organ Procurement and Transplantation Network (OPTN) and they use their database of wait listed candidates to search for a match. Matches are determined using characteristics such as wait list time, illness type, location to the potential donor and physical characteristics such as blood and tissue type, height and weight.
5. From this, a list is generated and the organ is offered to the patient at the top of the list. Medical experts can determine that this particular organ is better for another patient because the person at the top of the list is currently too sick to be transplanted or won't make it to surgery in time. Most organs stay local, but sometimes they are given to other regions.
6. The donor's body is maintained to keep the organ alive while the hospital and OPTN representatives work to coordinate the surgeries to remove and implant the new organ.

This is just a brief overview of the steps involved, but we shared it with you to show that it is a multi-step process and a lot of thought and effort goes into matching donors with recipients. Recently, there have been several proposals to update the matching process and make sure that organs go to those that need them the most.

There are several advantages of getting a kidney as outlined in the introduction, but there is also a difference between getting an organ from a living donor as compared to a deceased donor.

Type of Donor Organ	Pro	Cons
Living	Can qualify for a preemptive transplant	Not only you but a family member or friend needs surgery
	Shorter waiting time	Takes time to test and evaluate potential candidates

	Better match means less chance of rejection	Especially if from the same family, there aren't many resources to cover lost time at work or expenses for travel
	Kidney usually works from the start	
Deceased Donor	Doesn't require a family member or friend to get surgery too	Substantial wait times are likely
	Potential to be less costly on a single family	Kidney might not work right away
		Higher rejection rate
		Still have individual costs for the surgery and medication

Even though there are advantages to getting a live donation, this is not an option for everyone and receiving an organ from a deceased donor still has a great track record and is a good treatment option.

[1] United States Department of Health and Human Services. Organ Procurement and Transplantation Network. Transplants in the U.S. by Recipient Age. Accessed 4-16-13. Retrieved from <http://optn.transplant.hrsa.gov/latestData/rptData.asp> [2].

[2] United States Department of Health & Human Services. Donate the Gift of Life: About Donation and Transplantation. Retrieved from <http://www.organdonor.gov/about/organmatching.html> [3].

A closer look at the numbers

According to data from the US government OPTN annual report, the average graft from a deceased donor has a 69% chance of lasting five years and 43% chance of lasting ten. Additionally, on average a living donor kidney has an 81% chance of survival after five years and a 59% chance of lasting ten years. As you can see there are differences that come from receiving an organ donated from a deceased individual (cadaver) versus getting an organ from a living donor.

Kidney and Patient Survival Averages for 3 years, 5 years and 10 Years[1]

	3 Years	5 Years	10 Years
Deceased Donor kidney Survival	80.1%	69.3%	43.3%
Living Donor kidney Survival	89.6%	81.4%	59.3%
Deceased Donor Patient Survival	89.1%	81.9%	61.2%
Living Donor Patient Survival	95.3%	91.0%	77.1%

So what are some of the factors that help living donor organs have better survival rates?

You don't need to wait on the deceased donor waiting list. Dialysis is a wonderful life saving treatment, but it can't replace all of the functions of the kidney. Even daily treatments need to squeeze the activity that your kidneys do constantly into a shortened time frame. The average time on the waiting list at most transplant centers is anywhere from three to five years depending on your blood type.[2] Any time that you don't have to wait on the list can increase your chances of survival.

In addition to decreased waiting time, you can also schedule the surgery when it is best for

you and your donor. You don't have to stay on immediate alert and this can significantly reduce stress, minimize time missed from work, plan childcare and other planning. A side benefit of being able to schedule the surgery is that the organ won't have to travel. The less time spent out of the body, the longer the organ can survive.

If the donor is an immediate family member, then the kidney would likely be a better genetic match. What this does is convince your body that the new kidney is not a foreign object. Your body recognizes the kidney as its own. Unless it is a perfect match (extremely rare) there will still be a need for immunosuppressant drugs. A better match does lead to longer organ and patient survival.

Having an organ that starts working immediately also helps with survival time since there is immediate feedback that the organ is working and less risk of an immediate rejection.

[1] United States Department of Health and Human Services. Organ Procurement and Transplantation Network Annual Report. 2009. Retrieved from http://www.ustransplant.org/annual_reports/current/113_surv-new_dh.htm [4].

[2] The Waiting List. Kidneylink Your Kidney Transplant Navigator. Retrieved from <http://www.kidneylink.org/TheWaitingList.aspx> [5].

How to ask for a living donor

Asking someone to give you a kidney is not an easy thing to do. Although it is scary, the worst case scenario is that your friends and family won't be able to be a donor. Some of you will have no problem asking and the process will be very smooth. Others might be nervous and we are here to provide some advice. The first step is remembering that this is a big decision and everyone handles situations differently.

A few tips are:

- Educate friends and family members about your disease and how a transplant works
- Think about providing information and the opportunity to connect more than just asking
- Don't pressure anyone and allow your potential donors to volunteer or decline
- Provide additional details to those that are interested
- Be prepared to hear a no or a delayed response
- Remember these people support you and care about you so share what this means to you
- Sometimes you can even get a relative to be your champion and do the heavy lifting of asking for you

Even if you can't find a living donor, there are still plenty of options available to you. It is quite normal for there to be concerns or fears. Talking over the concerns and sharing as

much information as possible can help remove the fear. Also, make sure that you are presenting all of the information to your potential donor, not just the positives, but the potential negatives as well. Your medical team will help you explain all of this, too. Leaving out crucial details could put serious strain on your relationship or even cause your potential donor to not qualify or decide to not be your donor. Remember these people care about you deeply and would treat you the same way!

There are several possible outcomes from having a live donor.

- Your relationship is strengthened further because of the process or your relationship is strained due to the stress
- The organ survives for many years without complications or the organ can be rejected quickly
- You or the donor live long happy health lives or unfortunately one or both of you could face complications.

Risks are rare and many donors live normal lives with only one kidney. Normally donors spend a few weeks recovering from the surgery and can continue with the activities they did before the donation. The main symptoms after the surgery for donors are tenderness, pain and itching as it heals. Some people are born with only one kidney and live normal healthy lives regardless.

Living donors also need to be aware of costs involved. Normally the kidney recipient's insurance covers the cost of the surgery. Travel to and from the center as well as time missed from work are normally not directly covered. There are organizations such as the National Living Donor Assistance Center that can help with some of these costs. Also, some employers may cover employees under the Family Medical Leave Act. Some states have programs that will let a living donor deduct an amount from their income taxes to help offset some of the costs.

Forms of pairing

Finding out that you need a new kidney can be devastating news. After the initial shock wears off, friends and family members graciously get screened and sometimes there is a good match, but sometimes there isn't. It might seem like awful news, but focus back on the positives. You are still eligible to get a transplant and can still get an organ from a deceased donor. Oh wait there are still some new and exciting options available!

Recently, pairing networks have been set up that give you even more options. The idea for

creating these networks came from looking at the long wait list times and thinking that there must be a better way to lower the wait. The concept is simple. You need a kidney and you are able to find one or more people that are willing to donate, but none of them are a good enough match. Now networks such as the National Kidney Registry [6] help pair you with another person in a similar situation. The easiest is a direct pair. Here your donor would give to another recipient, and that recipient's donor would donate to you.

It can get a little more complicated though. A good samaritan can decide to donate to a complete stranger, and this sets off a chain of events. Having an essentially surplus organ can help connect a pair of donor/recipient teams and then one of their potential donors could match a new pair and the chain continues. This type of linkage has been able to facilitate six transplants and even up to twenty.[1] Regardless of the process, organizations that help facilitate paired donations are decreasing the number on wait lists and helping to save lives.

[1] National Kidney Registry: Facilitating Living Donor Transplants. Living Donors. Retrieved from http://kidneyregistry.org/living_donors.php#why_nkr [7].

Preemptive transplantation



This is where you get a transplant before going on dialysis or, in some cases, shortly after. Generally, you won't be a candidate until your kidney disease has at least progressed to stage 3. Then, you and your donor would go through a quickened evaluation process and set a date for surgery before your kidneys completely fail or shortly after. Preemptive transplantation takes place in 17% of all transplants.[1] The surgery is not for everyone, and some potential barriers include:

- Some patients believe that dialysis is necessary before transplant
- Learning about transplant after dialysis has started
- Not knowing that a living donor is an option
- Discomfort in asking a loved one to be a donor
- Medicare coverage as a primary payer for those who are under 65
- Late referral to a nephrologist
- Variability in transplant center selection criteria across the country

Broad access to a preemptive transplant seems to depend heavily upon education, financial resources and access to a living donor. Benefits of preemptive transplant are mixed, however, data seems to be trending towards an overall benefit in organ and patient survival. Studies have shown up to a 52% reduction in the first-year rate of transplant failure and increased survival of the organ with a half-life of 16.9 years compared to 8 years.[2] Opponents of such findings say that these numbers are artificially improved because of advances in transplant survival rates overall and that other factors such as health status of those that are now getting preemptive transplants are making the numbers look better compared to a broader population. No matter if researchers disagree with increases in organ and patient survival, they still agree that avoiding time on dialysis has benefits. To learn more about this as an option, speak with your healthcare team, and they will be able to share additional details.

[1] Jay, Colleen L., Dean, Patrick G., Helmick, Ryan A. Reassessing Preemptive Kidney Transplantation in the United States: Are We Making progress? *The New England Journal of Medicine*. 100:1120-1127. 2016. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4989865/> [8]

[2] Davis, Connie L. Preemptive transplantation and the transplant first initiative. *Current Opinion in Nephrology and Hypertension*.19:592-597. 2010. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/20827196> [9].

Multiple waiting list

There are still ways to help decrease your wait time even if you don't have a living donor. Another option is being listed on multiple transplant waiting lists at two or more centers. The United Network for Organ Sharing (UNOS) has a really in depth resource available

[here](#) [10]. Being listed in multiple places helps by giving you access to more kidneys than are available to just your transplant center. Each transplant center gives first priority to those closest to their center, but being on the list could get you a transplant sooner if local candidates with the same amount of wait time aren't good candidates for a donor organ. It is up to the individual center, if you are able to be added to their listing and some centers won't accept patients who are listed elsewhere.[1] Please also note that some insurance options will not cover the expenses of additional evaluations at new transplant centers.

Your primary wait time will still remain as the longest that you have waited at any clinic, however each additional new center will start the day you are listed there. For example if you have already waited a year at your center and decide that you want to get listed at a new center you would have one year of primary wait time and your new center would start at day one. You do have the option to switch your wait times if you want your new center to have the year of wait time credited and your old center to start at day one. Also, you can just transfer your wait time to a new center. The one thing you can't do is add your wait times together. Being listed at multiple clinics is not a guarantee that you will get a kidney sooner. This option does give you a chance to reduce your time though.

While you are waiting it is important to keep your center up to date and let them know of any major medical changes. You will work with your current medical team to keep your testing up to date and you will have at least annual appointments with your transplant center.

[1] United Network for Organ Sharing. Questions and Answers for Transplant Candidates about Multiple Listing and Waiting Time Transfer. Retrieved from https://www.unos.org/wp-content/uploads/unos/Multiple_Listing.pdf [10].

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Links

[1] <http://organdonor.gov/becomingdonor/stateregistries.html>.

[2] <http://optn.transplant.hrsa.gov/latestData/rptData.asp>

[3] <http://www.organdonor.gov/about/organmatching.html>

[4] http://www.ustransplant.org/annual_reports/current/113_surv-new_dh.htm

[5] <http://www.kidneylink.org/TheWaitingList.aspx>

[6] <https://www.kidneyregistry.org>

[7] http://kidneyregistry.org/living_donors.php#why_nkr

[8] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4989865/>

[9] <https://www.ncbi.nlm.nih.gov/pubmed/20827196>

[10] https://www.unos.org/wp-content/uploads/unos/Multiple_Listing.pdf