

# Kidney Transplant

Your kidneys are two roughly fist-sized organs that do a lot of work in your body. Their primary functions are to remove waste products and excess fluid, but they also help control several hormones important for bone development and blood pressure regulation. These tiny organs filter around 50 gallons of blood a day and remove approximately two quarts of waste products. If your kidneys start to fail, they can no longer keep up with your body's demand. Eventually your kidney function decreases to the point that they can no longer sustain your body and your options are dialysis, transplant or palliative care (end of life management). Most kidney disease comes from complications associated with diabetes and hypertension. Losing kidney function though doesn't only come about through a slow process and is a disease that impacts children too. Several genetic birth defects, injury, large blood loss, infection, urinary blockages and even some medications can cause your kidneys to fail rapidly. Amazingly, one healthy kidney can sustain your body and do most of the work of two.

A kidney transplant can be an option for you if your kidneys start to fail. Getting a transplant is not a cure for end-stage renal disease (ESRD), but a well matched and taken care of organ/graft should last many years.

A kidney transplant is a surgery that takes a healthy kidney from a donor and replaces a failing kidney in another person. Kidneys can come from a living donor or a deceased organ donor. Family members or others who are a good match may be able to donate one of their kidneys.

The waiting list for a kidney transplant can be several years. To be put on the waiting list, you must talk to your nephrologist. Your nephrologist will send you to a transplant center for evaluation. If testing determines you are a good candidate for a kidney transplant, you will be placed on the list. Then you will be called when a donor is found. Because cadaver kidneys are from people who donate their organs after their death, and there are more people who need kidneys than donate, the waiting list is long.

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## What is a Transplant?

A transplant is a surgical procedure where a healthy kidney from a donor is placed into your body. The new kidney will then perform the work of the two failing organs. Dialysis can

eliminate waste products and provide a healthy lifestyle, but dialysis alone can't replace the 24/7 functioning of your kidneys and won't stimulate hormones as your own organs would.

Organ transplantation is still a pretty recent development in human history. The first attempts went back as far as the early 1900s, but the successes were short lived. Then in 1954 a team led by Joseph E. Murray at Peter Bent Brigham Hospital in Boston performed the first successful kidney transplant between twins[1]. Using twins as paired donors basically eliminated matching issues and since the body recognized the organ as being similar there wasn't a large immune system response. As time went on, improvements were made in donor matching and immunosuppressant medications (drugs that weaken the immune system response and stop the body from fighting the new organ) became available.

Getting a transplant has many advantages over dialysis including:

- Don't need dialysis treatments.
- Much less food and fluid restrictions.
- Improved quality of life and more independence.
- Potentially increased life span.

Even with modern medical advances, getting a transplant is still a big decision and isn't for everyone. First, it is a surgery and no matter how routine a surgery is, there is always a risk for complications. The surgery itself can be expensive and drugs necessary to keep the kidney after the surgery can also be costly. In addition, there are certain qualifications that need to be met to get on the waiting list. Sharing this information isn't meant to discourage anyone from seeking a transplant, we just want to make sure that all of the information is available and of course your healthcare providers and family will help you make your ultimate decision.

These topics will also be covered in more detail later in the class along with information on preemptive transplantation, sources of donor organs, how to care for your new kidney along with resources for additional information.

Major steps in getting a kidney transplant. These are an approximate order and aren't always the exact stepwise process.

1. Work with your health care team to determine if a transplant is correct for you.
2. If transplant is a good option for you, you will need a referral by your physician to a transplant center (please note some centers don't require a physician referral).
3. At the center, you will learn about the process of getting a transplant, have your physical and mental health evaluated and you will work with a financial expert to determine if you are a good candidate for transplantation. If so you will be put on the national transplant list.
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.
6. Have the surgery and recover.
7. Keep your new organ healthy.

[1] Kidney Transplantation: Past Present and Future. Stanford University. Retrieved from <http://www.stanford.edu/dept/HPS/transplant/html/history.html> [1].

# Meet your Transplant Care Team

**1. Work with your healthcare team to determine if a transplant is correct for you.**

**2. If transplant is a good option for you, you will need a referral by your physician to a transplant center (please note some centers don't require a physician referral).**

To work through steps one and two you will first need to understand who the members of your team are and how they will guide you through the process.

The players involved.

The most important individual is YOU! You are the ultimate decider. It is your responsibility (with help from others covered below) to understand all of your options, prepare for surgery and care for your new organ.

Friends/Family ? These individuals are your support team and will help fill in any gaps in your care. They are also your best option for a living donor. We will cover the process of asking later in the class, but do remember that even if they say no that it doesn't mean they love you any less or are a bad friend. It is a difficult situation and everyone deals with it in their own way.

## **Renal (kidney) healthcare team**

Doctors ? Your team of doctors will consist of primary care physician who will look after your general medical care and specialists such as your nephrologist that have responsibility for the overall care for your kidney disease. Your nephrologist in many cases will refer you to the transplant evaluation center, but others on your care team can also play a role in your referral and some places allow patients to refer themselves.

Nurses ? Your nurses normally serve as your first point of contact for any questions about your care. They either know the answers to your questions or they can point you in the right direction. They can also be instrumental in helping you get a referral for a transplant evaluation.

Social worker ? Your social worker is another player that can wear many hats. They can help provide you with information about a transplant, help find financial support and also help remove emotional stresses and burdens.

Dietician/Nutritionist ? These are the people that can help you get your diet on track to prepare for a transplant and help you stay healthy after your surgery. They are specialists that can help make a renal friendly diet that still takes your favorite foods into account.

Transplant Doctor/Surgeon ? Once accepted into a transplant program, your transplant doctor will handle your medical care before and after your transplant. The transplant surgeon will determine if a transplant is best for you, handle the surgery itself and will also serve as an expert to help you understand the risks and benefits and care for your new organ.

Transplant Coordinator/Staff ? These staff serve as a strong linkage between your pre-transplant care team and your new transplant team. As their name suggests they coordinate all of the activities surrounding your transplant. They are responsible for providing education, organizing your care, helping you schedule appointments, answer questions about the transplant and just help you through the entire process.

Pharmacist(s) ? Your pharmacist is another valuable resource in your care team. Not only do they dispense your prescriptions, but they can also help you understand side effects, any possible interactions and can work with your doctors to fine tune your medications.

Psychologist/Psychiatrist ? These experts will help with the mental health side of your total body health. Mental health is often underrated and having a good outlook can dramatically improve your physical health. Not every facility will have an individual on staff nor will every patient need this resource. However, your transplant center will at least be able to refer you to a mental health specialist.

Financial Advisor ? This is the individual that will help you cover the money side of getting a transplant. They will work closely with other support staff such as social workers to figure out if getting a transplant is a good option for you and how to best pay for that option.

## Evaluation Process

**1. At the center, you will learn about the process of getting a transplant, have your physical and mental health evaluated and you will work with a financial expert to determine if you are a good candidate for transplantation. If so you will be put on the national transplant list.**

Even though this is an opportunity for you to be evaluated, it is also a great chance to learn more about the process. And remember it is perfectly fine to decide that getting a transplant isn't for you. Every transplant center will be slightly different so use this as a guide of what to expect. In many centers the first step is an orientation process to learn more about their center and about the procedure itself.<sup>[1][2]</sup> This initial meeting will give you and in many cases

your family or close friend a chance to meet a few of the staff, learn about the steps before and after the surgery, tour the facility and get your questions answered.

After the initial meeting you will begin your physical and mental evaluation. These tests tend to include:

- Blood draws for testing blood type and as a screen for diseases
- Human Leukocyte Antigens (HLA, commonly referred to as ?tissue typing?) for matching purposes.
- Disease screening for diseases such as hepatitis and human immunodeficiency virus (HIV)
- Basic physical examination to look for items such as acceptable weight, cardiovascular health and overall health
- Chest x-ray to look for abnormal lung function or the status of tuberculosis
- Dental exam to look for cavities and infections
- Electrocardiogram (EKG) to look for abnormal heart function
- Mental health or psycho-social evaluation that helps determine how you will cope with the process and if you are motivated to care for your new organ

There are a few items that could immediately rule you out for a kidney transplant at least temporarily and these include:

- Obesity
- Smoking status
- History of cancer
- History of heart attacks
- Having a drug or alcohol addiction
- Having an active infection
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[1] The Kidney Transplant Evaluation Process. Emory Kidney Transplant Program. Retrieved from <http://www.emoryhealthcare.org/transplant-kidney/become-patient/evaluation-process.html> [2].

[2] The Evaluation Process, UC Davis Transplant Center. Retrieved from [http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn\\_eval\\_process.html](http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn_eval_process.html) [3].

## Cost

Paying for a transplant can be a little tricky and it all depends on what type of insurance coverage that you have. The good news is that your social worker, transplant center and financial counselor will be able to guide you through the process.

Private insurance typically will cover most of the cost of the transplant itself and many plans will also help cover the cost of medications. Additionally, if you have both private insurance and Medicare, they can be used in combination to cover more of your medical needs. It is important to talk with your insurance company to see what is and isn't covered and shares this information with your healthcare team. Thanks to Medicare Secondary Payer (MSP), if you are diagnosed with kidney failure you are able to keep your private insurance coverage 30 months before enrollment in Medicare. MSP helps those with private insurance because many Medicare benefits don't start until after three months.

Medicare is another option and you qualify if

You need dialysis

Or

You have had a previous Medicare-covered kidney transplant

And

You paid into Social Security yourself

Or

You are the child or spouse of someone who has worked under the Railroad Retirement Board or as government employee or the child or spouse of someone who has worked for the government

OR

You are already receiving Social Security.[1]

Medicare Part A covers 100% of approved costs associated with the hospital and Part B covers 80% of medical expenses such as dialysis and requires a monthly premium fee, which was \$99 dollars for the standard rate in 2012.[2] There are services that can help pay this premium such as Medicaid or other patient assistance organizations.

The following chart was taken from the Medicare Coverage of Dialysis and Kidney Transplant Services Handout.

Service or supply	Medicare Part A	Medicare Part B
<b>Inpatient services in an approved hospital</b>	?	
<b>Kidney registry fee</b>	?	
<b>Laboratory and other tests needed to evaluate your medical condition*</b>	?	
<b>Laboratory and other tests needed to evaluate the medical condition of potential kidney donors*</b>	?	
<b>The costs of finding the proper kidney for your transplant surgery (if there's no kidney donor)</b>	?	

<b>The full cost of care for your kidney donor</b> (including care before surgery, the actual surgery, and care after surgery)	?	
<b>Any additional inpatient hospital care for your donor in case of problems due to the surgery</b>		?
<b>Doctors? services for kidney transplant surgery</b> (including care before surgery, the actual surgery, and care after surgery)		?
<b>Doctors? services for your kidney donor during their hospital stay</b>		?
<b>Immunosuppressive drugs</b> (for a limited time after you leave the hospital following a transplant).		?

<b>Blood</b> (whole or units of packed red blood cells, blood components, and the cost of processing and giving you blood).	?	?
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Medicaid is also a possibility payment options as primary or secondary insurance. This is another government sponsored program meant for lower income patients. The programs themselves are managed at the state level and differ from state to state. It is important for you to work closely with your team to learn if this is an option and how your state handles coverage.

After you figure out how you will pay for the surgery, it is important to figure out how you will pay for the medication. We will go into legislation surrounding this later, but all transplant patients will need immunosuppressants so that their body won't reject the new organ.

[1] National Kidney and Urologic Diseases Information Clearinghouse. Financial Help for Treatment of Kidney Failure. Retrieved from <http://kidney.niddk.nih.gov/kudiseases/pubs/financialhelp/> [4].

[2] Centers for Medicare and Medicaid Services. Medicare Coverage of Kidney Dialysis & Kidney Transplant Services. Retrieved from <http://www.medicare.gov/pubs/pdf/10128.pdf> [5].

## 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](#) [6].
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> [7].

[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> [8].

## 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](http://www.ustransplant.org/annual_reports/current/113_surv-new_dh.htm) [9].

[2] The Waiting List. Kidneylink Your Kidney Transplant Navigator. Retrieved from <http://www.kidneylink.org/TheWaitingList.aspx> [10].

# 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](#) <sup>[11]</sup> 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.<sup>[1]</sup> 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](http://kidneyregistry.org/living_donors.php#why_nkr) [12].

## 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/> [13]

[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> [14].

## 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](#) <sup>[15]</sup>. 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.<sup>[1]</sup> 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](https://www.unos.org/wp-content/uploads/unos/Multiple_Listing.pdf) <sup>[15]</sup>.

## Getting Closer to the Big Day

### 6. Prepare for transplant, have the surgery and recover.

After you have been approved for a transplant you now have to wait for the big day. As we shared earlier your wait time could be a few months or several years. One of the best ways to prepare for a transplant is to try to get yourself in the best health possible. This seems pretty obvious, but this will help remove issues with the surgery, help you recover faster and help your organ last longer.

It is important for you to:

- Eat healthy and exercise regularly

- Take all of your medications
- Make all of your doctor's visits and other appointments
- Stop smoking at least a month in advance

It is important to keep in close contact with your transplant team and alert them if anything major changes with your health. This includes updating emergency contact numbers and letting them know of out of state travel or other events that could stop you from being ready right when an organ becomes available.

As you get closer to your surgery date it will be important to have your hospital bag and transportation secured. A few days before your surgery, the transplant center and/or hospital team will work with you to do pre-admission testing and give specific instructions for the night before surgery. These instructions normally include items such as not eating or drinking after midnight on the eve of surgery, removing jewelry and any last minute paperwork or verification.

The day of the surgery, you will have the chance to go over any last questions, sign paperwork and start anesthesia. The surgery itself normally takes 2-4 hours and the surgery is called heterotopic, which means that your new kidney will be put in a slightly different part of your body than your original kidneys.[1] This is because your kidneys will normally remain in your body unless they are causing major issues for your body.

If you are receiving a donation from a living donor, you will be in two close operating rooms and surgeons will use a laparoscopic surgery technique to remove the donor organ. This technique uses small incisions and a tiny camera to remove the donor kidney. The donor kidney is then removed through an approximately 3-4 inch incision in the abdomen. The donor organ is then inserted you're your body artery that carries blood to your kidney and the vein that takes the blood away are connected and the ureter (connecting tube) of the donor organ is connected to your bladder to remove waste in the form of urine. Unless there are medical setbacks, recovery for the donor is pretty quick with 1-2 days of hospitalization, a couple weeks of recovery before heading back to work and follow up appointments at strategic dates in the future such as 6 months, 1 year and then annually.[2]

In the case of a deceased organ you will not have as much time to plan and you will need an additional test to ensure the donor organ is a match. Here they will do a cross match test to see if your body will react to the new organ. If your body doesn't have a reaction, then you will be taken into surgery. Just like the process of the living donor, your surgeons will connect the blood supply to your new kidney and make the connection to your bladder for waste removal. You will then be stitched back up and taken to recovery.

Your recovery as the kidney recipient will be a bit longer than the donors. After the effects of the anesthesia wears off, many patients say that they immediately feel better and some begin to urinate right away. The typical recovery in the hospital is right around a week. During recovery, your doctors will be looking for signs of infection and making sure that your new kidney is working properly. No matter how good the match is your body will still see the new kidney as something that doesn't belong and immunosuppressive drugs are needed to stop the body's natural reaction. Once your doctors determine that you are healing correctly and you are let go from the hospital, the real caring process begins.

[1] University of California San Francisco. Phases of Transplant. Retrieved from <http://transplant.surgery.ucsf.edu/conditions--procedures/kidney-transplantation.aspx>

[16].

[2] University of Maryland Medical Center. Living Donor Kidney Frequently Asked Questions. Retrieved from <http://www.umm.edu/transplant/kidney/qanda.htm#9> [17].

## Caring for your Organ

One of the biggest benefits of having a healthy kidney is the freedom and increased quality of life that you will have. In the early stages of recovery, it is important to remember that you still had major surgery and it is going to take your body some time to get used to your new organ. Moderation is important especially for activities that are physically taxing. In your early stages of recovery, you will meet with many staff. Their job is to teach you how to take care of your kidney. After you are released you are the main person in charge of monitoring your health and alerting others if changes in your health occur.

## Medications

As we have talked about, your body will need medications to help recover and to maintain your kidney. It is important to take all of your medications as prescribed and your pharmacist will be a great resource for questions. Due to the nature of some of your medications, it is important that you talk with your doctors and pharmacist if you take anything over the counter such as cold and flu or headache medicine since this can also interact with your other drugs.

The main medications that you will need to maintain your kidney are immunosuppressants. Common immunosuppressant drugs include Prograf, Rapamune, Cyclosporin and Prednisone. [1] If you don't take these drugs, your body will reject the organ. Since these drugs suppress (weaken) your immune system you will be at additional risk to develop infections. Like any drug, there are side effects and they range from minor headaches, hand tremors, nausea to more severe issues such as increased blood sugar and high blood pressure. Your doctors and pharmacist will work together to minimize symptoms and make sure that you don't have any serious issues.

In addition to immunosuppressants you will also be prescribed other pain and infection control medications. Since immunosuppressants weaken your immune system you are more prone to infections. It is important that you take extra precautionary steps like hand washing, getting flu vaccinations, avoiding environments where others are sick and not eating raw foods.

A natural way to help speed your recovery is exercise. Your healthcare team will help you determine what is best for you, but starting off with walking is a good first step, literally. The better you take care of your body overall the better it will take care of your new kidney.

Exercise will not only help control factors such as hypertension and obesity that contribute to kidney disease, but also exercise can help reduce some of the negative side effects of immunosuppressants such as osteoporosis and weight gain.[2]

[1] Duke University. After Kidney Transplantation. Retrieved from <http://www.dukehealth.org/repository/dukehealth/2010/02/04/12/08/29/9659/Kidney-TransplantationAfter.pdf> [18].

[2] Gordon Elisa J., Phohaska Thomas, Siminoff Laura A., Needed: Tailored Exercise Regimens for Kidney Transplant Recipients. *American Journal of Kidney Disease*. 45(4): 769-774. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1242115/> [19].

## Signs of rejection

Rejection can happen to anyone and doesn't mean that there was a mistake or that you did something wrong. Rejection can be reversed if it is found early and recognizing the signs of early rejection could help keep your kidney. You should always worry about fevers because they are signs of infection, but these become even more important right after surgery.

You should also look for:

- Extreme soreness where your new kidney is
- Decreases in the amount of urine you produce
- Swollen feet or ankles
- Weakness
- Nausea

All of these things can point to your body fighting an infection and/or your kidney. Each clinic will treat rejection differently, but you might need to increase or add another immunosuppressant drug or spend some time back in the hospital.

Rejection is identified by using routine tests of kidney function much the way they were done before you had a transplant. Your medical staff will normally draw some routine blood samples and they are looking for signs of infection. Other potential tests include:[1]

- Renal flow scan that looks for blood flow through the kidney Even if your body fully rejects your kidney, there are still options available. Most patients can join the transplant list again and have the option to get another kidney.
- Ultrasound that enables your doctors to look for physical issues

- Biopsy is a surgical procedure where a small piece of tissue is collected and tested

Even if your body fully rejects your kidney, there are still options available. Most patients can join the transplant list again and have the option to get another kidney.

[1] Cleveland Clinic. Transplant Program ? What you need to know about kidney transplant rejection. Retrieved from [http://my.clevelandclinic.org/transplant/services/kidney/what\\_you\\_need\\_to\\_know.aspx](http://my.clevelandclinic.org/transplant/services/kidney/what_you_need_to_know.aspx) [20].

## Diet

After you receive a transplant, it is possible that many of the diet restrictions you had during dialysis will disappear. This however, doesn't mean that proper nutrition is any less important. Also, if you have other conditions like hypertension and diabetes, you will need to continue following those diet restrictions.

Diet and proper nutrition become even more important because some of the immunosuppressants can also increase blood sugar levels leading to an increased risk of diabetes and increase your appetite.

Also, even though many of your dialysis related restrictions go away, there are still things that you should keep doing. These are items that should continue to be limited in your diet.

- Processed foods
- Sodium
- Excess fat
- High sugar foods
- Alcohol
- Raw sushi
- Limit buffets and salad bars
- Grapefruit and star fruit or grapefruit juice (interacts with medications)
- Uncooked cookie dough
- Bean sprouts
- Undercooked meats
- Cold deli meats

These items can also either conflict with your medications or put you at a higher risk for an infection.

Maintaining an ideal bodyweight and eating properly will lower your risk for heart disease, high

blood pressure, diabetes and help reduce complications from surgery. Being underweight or undernourished can be just as bad as being overweight. Your body needs fuel to work and it needs vitamins and nutrients to heal and be healthy. Your nutrition will be an excellent resource to help you with your diet.

To learn more about nutrition, stop by our DPC nutrition management [page](#). [21]

## Mental Health

Mental health is just as important as physical health and the two go hand in hand. This shift of considering individual health as a whole mind body experience is refreshing, but the idea still needs to spread and build from a definition into a cultural mindset. Patients with chronic kidney disease (CKD) and end-stage renal disease (ESRD) know that the numbers on the machine or lab printout don't tell the entire story. Research has shown that the death rate from chronic disease such as heart disease and diabetes is two to three times greater for people living with mental illnesses.[1] As you can see having a chronic condition can greatly impact your mental state and your mindset and emotions can also worsen the symptoms of your disease.

Mental health is defined as "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community." [2] Therefore, if you do not have a healthy mental state it will be hard for you to live your life the way you normally would. Poor mental health can affect many aspects of a person's life, but it can be treated effectively so that you can function normally in your everyday life.

Getting a transplant can be stressful for both you and your family and feelings can increase if a friend or family member has decided to be a living donor. Everyone handles stress differently and kidney disease, treatments, medications and waiting can all add to this stress.

Many facilities will have a social worker and a psychiatrist available for consultation. These experts can help you rehabilitate, handle financial concerns, discuss family issues and can even just be another person to talk about life with.

You shouldn't feel embarrassed to seek help and that is exactly what the experts are for. Not getting help can not only impact the transplant itself, but also your life in general.

- **Trouble complying with your medication regimen** - Non-compliance to treatment is recognized as a problem for people with a mental illness, estimates of poor adherence range from 40%-80% [3]. If you do not take your medication properly your transplant will not be as effective.
- **Difficulty engaging in physical activity** - One of the symptoms of mental illness is

fatigue. If you are suffering from this symptom it will make it hard to participate in healthy, physical activity.

- **Eating healthily** - When your mental status is comprised you are less likely to make healthy food choices that could have the potential to lead to poor nutritional status.
- **May alter your immune system function** - If you are stressed, your body's hormonal response alters your immune system function influencing your susceptibility to becoming ill. This can lead to an increased illness and death in ESRD patients.[4]
- **Can lead to longer illness duration** - Because your mental state is comprised your medical regime may not be consistent and your immune system could be negatively affected. If this happens it will make it difficult for you to improve your outcome.

Additional information on mental health can be found here (link to other class). This class provides a background on mental health and can point you towards additional resources. Remember you are not alone and sometimes just a conversation can make all the difference in your wait or your recovery.

[1] Marc De Hert., Christoph U. Correll, Julio Bobes, Marcelo Cetkovich, Et. Al. Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care. *Official Journal of the World Psychiatric Association*. 2011 February; 10(1): 52-77. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3048500/> [22]

[2] World Health Organization. Mental Health. Retrieved from [http://www.who.int/topics/mental\\_health/en/](http://www.who.int/topics/mental_health/en/) [23].

[3] Coombs Tim., Deane Frank, Lambert, Gordon, Griffiths, Rhonda., What Influences Patients? Medication Adherence?. *International Journal of Mental Health Nursing*. Volume 12(2) June 2003p 148-152. Retrieved from <http://www.nursing2007criticalcare.com/pt/re/merck/fulltext.00134462-200306000-00009.htm;jsessionid=R1TbCkLswZjpQ2bJ4yflkKyVT2VxM2DBQRyv0wDSw8hZsYWKB1Tf!1786591821?nav=reference> [24]

[4] Kimmel PL, Philips TM, Simmens SJ, et al., Immunologic function and survival in hemodialysis patients, *Kidney Int*, 1998;54:236-44. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9648084> [25]

# Legislation

Recently, two bills relating to kidney and organ transplants have been introduced in Congress.

The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2013 (S. 323) in the Senate and a companion bill (H.R. 1325) in the House.

If passed, these bills will extend Medicare immunosuppressive drug coverage for kidney transplant patients under 65 years old for the life of the graft. Under current law, Medicare beneficiaries who are under 65, and therefore only eligible for Medicare due to their ESRD diagnosis, lose Medicare coverage 3 years after their transplant. Without the immunosuppressive drugs, the body will reject the transplant and a patient must go back on dialysis. Currently, these drugs cost about \$24,000 a year while dialysis costs almost \$86,000. This means it costs Medicare an additional \$62,000 per year per patient that loses drug coverage.

Additionally in February 2012, the HIV Organ Policy Equity (HOPE) Act was introduced in both the House of Representatives and Senate. The HOPE Act allows for the study of the safety and effectiveness of organ transplants from HIV-positive deceased donors to HIV-positive recipients. The act doesn't make this type of donation possible, but allows researchers to determine if this is safe and effective. If studies find these transplants safe and effective, this procedure has the potential to lower waiting time on organ transplant lists for all patients, as experts estimate that an additional 500 organs each year could be available for transplantation.

These bills have the potential to increase access to transplants for all kidney patients on the waiting lists. Our sister organization, [Dialysis Patient Citizens](#) <sup>[26]</sup>, and the kidney community at-large will be working hard to garner as much support for these bills as possible and to get them passed into law.

# Additional Resources

American Organ Transplant Association [27] ? is a resource that can help provided transportation help.

The American Association of Kidney Patients [28] ? is a good resource for information on transplants and can link to organizations that provide support.

The American Kidney Fund [29] ? is a non-profit organization dedicated to providing financial assistance to kidney and dialysis patients.

The American Society of Transplantation [30] ? is an organization of health professionals that can provide education and opportunities to advocate for transplant issues.

Children's Organ Transplant Association [31] ? is an organization that works with patients 21 and under and their families with the purpose of helping them raise money to fund transplants.

Coalition on Donation [32] ? is a non-profit organization that is committed to increasing organ and tissue donation. They are a good resource to share general information about transplants.

Kidney Transplant Dialysis Association [33] ? is a volunteer patient led organization that can help provide education and financial assistance to patients.

Kidney Link [34] ? is a good resource for information on all types of donation and education.

Medicare Payment Information [5] ? is a brochure on the Medicare and Medicaid payment procedures for 2012.

National Foundation for Transplants ? is another non-profit dedicated to providing patient financial assistance for transplants. [35]

National Kidney Foundation [36] ? is a non-profit organization that has a lot of resources dedicated to transplant awareness and education.

National Kidney Registry [37] ? is a non-profit organization that helps create living donor chains.

National Transplant Assistance Fund [38] ? is a source for information on raising money to cover uninsured medical expenses.

Organ Procurement and Transplantation Network [39] ? is a government site that manages the national patient waiting list.

Organ Donor US Government [40] ? is a government site that is dedicated to sharing information about organ transplantation.

Scientific Registry of Transplant Recipients [41] ? is a national database of transplant statistics.

Transplant Recipients International Organization [42] ? is a non-profit organization with the goal

of improving the quality of life of transplant patients.

United Network for Organ Sharing (UNOS) [43] ? is the private organization that manages the US national organ transplant system.

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**Source URL:** <http://www.dpcedcenter.org/classroom/kidney-transplant>

### Links

- [1] <http://www.stanford.edu/dept/HPS/transplant/html/history.html>
- [2] <http://www.emoryhealthcare.org/transplant-kidney/become-patient/evaluation-process.html>
- [3] [http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn\\_eval\\_process.html](http://www.ucdmc.ucdavis.edu/transplant/learnabout/learn_eval_process.html)
- [4] <http://kidney.niddk.nih.gov/kudiseases/pubs/financialhelp/>
- [5] <http://www.medicare.gov/pubs/pdf/10128.pdf>
- [6] <http://organdonor.gov/becomingdonor/stateregistries.html>
- [7] <http://optn.transplant.hrsa.gov/latestData/rptData.asp>
- [8] <http://www.organdonor.gov/about/organmatching.html>
- [9] [http://www.ustransplant.org/annual\\_reports/current/113\\_surv-new\\_dh.htm](http://www.ustransplant.org/annual_reports/current/113_surv-new_dh.htm)
- [10] <http://www.kidneylink.org/TheWaitingList.aspx>
- [11] <https://www.kidneyregistry.org>
- [12] [http://kidneyregistry.org/living\\_donors.php#why\\_nkr](http://kidneyregistry.org/living_donors.php#why_nkr)
- [13] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4989865/>
- [14] <https://www.ncbi.nlm.nih.gov/pubmed/20827196>
- [15] [https://www.unos.org/wp-content/uploads/unos/Multiple\\_Listing.pdf](https://www.unos.org/wp-content/uploads/unos/Multiple_Listing.pdf)
- [16] <http://transplant.surgery.ucsf.edu/conditions--procedures/kidney-transplantation.aspx>
- [17] <http://www.umm.edu/transplant/kidney/qanda.htm#9>
- [18] <http://www.dukehealth.org/repository/dukehealth/2010/02/04/12/08/29/9659/Kidney-TransplantationAfter.pdf>
- [19] <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1242115/>
- [20] [http://my.clevelandclinic.org/transplant/services/kidney/what\\_you\\_need\\_to\\_know.aspx](http://my.clevelandclinic.org/transplant/services/kidney/what_you_need_to_know.aspx)
- [21] <http://dpcedcenter.org/classroom/nutrition-management-kidney-disease-patients/following-diet-transplant-patient>
- [22] <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3048500/>
- [23] [http://www.who.int/topics/mental\\_health/en/](http://www.who.int/topics/mental_health/en/)
- [24] <http://www.nursing2007criticalcare.com/pt/re/merck/fulltext.00134462-200306000-00009.htm;jsessionid=R1TbCkLswZjpQ2bJ4yflkKyVT2VxM2DBQRyv0wDSw8hZsYWKb1Tf!1786591821!18119562>

1?nav=reference

[25] <http://www.ncbi.nlm.nih.gov/pubmed/9648084>

[26] <http://www.dialysispatients.org>

[27] <http://www.a-o-t-a.org/>

[28] <http://www.aakp.org/>

[29] <http://www.kidneyfund.org/>

[30] <http://www.myast.org/>

[31] <http://www.cota.org/>

[32] <http://www.donatelife.net/>

[33] <http://www.ktda.org/>

[34] <http://www.kidneylink.org/>

[35] <http://www.transplants.org/>

[36] <http://www.kidney.org/>

[37] <http://kidneyregistry.org/?cookie=1>

[38] <http://www.transplantfund.org/>

[39] <http://optn.transplant.hrsa.gov/>

[40] <http://organdonor.gov/materialsresources/materialsopolist.html>

[41] <http://www.srtr.org/>

[42] <http://www.trioweb.org/>

[43] <http://www.unos.org/>