

Guide to Transplantation and Living Donation



PKD FOUNDATION
Polycystic Kidney Disease



About transplantation

With more than 100,000 people waiting for a kidney in the United States, it is important to educate yourself and your family about transplantation as early as possible so that you are prepared. There are many questions when it comes to transplantation. When is the right time – before dialysis or after? What is the process? Do I get listed at one center or several? Read on to learn about the transplant process and how you can be an advocate for your own health.

Timing

When your GFR nears 20, you can start considering a transplant. Making the decision to be evaluated for a kidney transplant should be discussed with your doctor and/or nephrologist and your closest family and friends. Because of the way kidneys are allocated (read more on this on page 6) combined with the progressive nature of PKD, it is important to consider being listed early – before dialysis is required. Although you can be listed earlier, you cannot start accumulating waiting time until your GFR is at 20 or below, so it is important to gather information early. You may have to start the conversation with your physician; don't wait for him or her to bring it up!

Transplant Process Steps

Once you have decided to be evaluated for the transplant list, there are many steps to take.

- 1. You are evaluated for a transplant by the medical team at your transplant center.**
- 2. If accepted as a transplant candidate, you are registered on the national organ transplant waiting list. A living donor may also be identified and evaluated for living donation (more information about living kidney donation on the next page). This is also the time to decide if you want to register at more than one transplant center (more on page 8).**
- 3. Organize your support system.**
- 4. Develop your financial strategy.**
- 5. The waiting period begins.**
- 6. Your transplant takes place.**
- 7. Your medical team manages your post-transplant care.**

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The Evaluation

When you and your doctor agree it is time for you to be evaluated for a transplant, you will undergo a series of tests to assess your options. You'll be evaluated for potential issues like heart disease, obesity and diabetes. A social worker or transplant coordinator will discuss the logistics with you as well. Things like transportation, housing, financial and family support will all be considered.

Steps to get on the national waiting list:

1. Get a referral from your physician or nephrologist.
2. Contact a transplant hospital. Learn as much as possible about the 200+ transplant hospitals in the United States and choose one based on your needs, including insurance, location, average wait time, finances and support group availability.
3. Schedule an appointment for an evaluation to find out if you are a good candidate for transplant.
4. During the evaluation, ask questions to learn as much as possible about the hospital and its transplant team.
5. If the hospital's transplant team determines that you are a good transplant candidate, they will add you to the national waiting list and schedule you for monthly blood tests.
6. United Network for Organ Sharing (UNOS) will not notify you when you have been added to the list. Your transplant hospital will notify you within 10 days to inform you about your date of listing. If you have questions about your status on the list, ask the team at your transplant hospital.

Screening tests:

There are several screening tests to determine your blood and tissue type. This information is needed to match you to a donor kidney (living or deceased). In addition to the tests below, other tests may be required depending on your age, medical history, etc.

- ▶ Blood typing will tell you which of the four blood types – A, B, AB, or O, you are.
- ▶ Compatible blood types:
 - If your blood type is A, donor blood type must be A or O
 - If your blood type is B, donor blood type must be B or O
 - If your blood type is AB (universal recipient), donor blood type must be A, B, AB or O
 - If your blood type is O (universal donor), donor blood type must be O

The Rh type (+ or -) is not a factor in donor matching.

- ▶ Human leukocyte antigens (HLA) determination, also called tissue typing. The HLA are found on most blood cells; they are markers that let your immune system know which cells belong to your body and which do not.
- ▶ Crossmatch testing tells you what antibodies you have in your body. Antibodies are produced by your immune system when it attacks foreign substances. You make antibodies when you have an infection, are pregnant, have a blood transfusion or undergo a kidney transplant. If you have antibodies to the donor kidney, your body will fight that kidney and could destroy it.

Once the results from the tests are back, your transplant team will meet to discuss your results. They will discuss your medical and social history (history of drug or alcohol abuse, level of family and financial support, etc.) and make a decision. If they decide you are a good candidate to be listed for a transplant you'll be placed on the UNOS waiting list.

Finding a kidney

There are two ways to get a kidney transplant – through a living donation or through a deceased donation.

Living donation

Living donation is when a living person decides to donate a kidney (or other organ) to someone who needs a transplant. 6,000 organ transplants a year are made possible by living donors. The kidney is the most commonly transplanted organ from a living donor.

Positive aspects of living donation:

- ▶ A living donation makes it possible to schedule the transplant surgery at a time that is optimal for both you and your donor.
- ▶ Better genetic matches between you and your donor decrease the risk of organ rejection.
- ▶ Kidneys from living donors usually work immediately, as the kidney is removed from a healthy donor and transplanted right away.
- ▶ A living donor transplant may reduce or eliminate your time on dialysis and/or years of waiting for a deceased donor organ.

Who can be a living donor?

Potential living donors must be in good overall health, both physically and psychologically. Gender and race are not factors. All centers carefully evaluate living donors to ensure their safety.

Types of living donor transplants

Directed donation

Directed donation is the most common type of living donation. In a directed donation, the donor names the specific person to receive the transplant.

The donor may be:

- Related: your biological relative, such as a parent, brother, sister, or adult child
- Non-related: a biologically unrelated person who has a personal or social connection with you, such as a spouse or significant other, a friend or a coworker

Non-directed/altruistic donation

In a non-directed or altruistic donation, the donor does not name a specific person to get their organ. The match is arranged based on medical compatibility with a patient in need. Some non-directed donors choose never to meet their recipient. In other cases, the donor and recipient may meet at some time, if they both agree, and if the transplant center policy permits it.

Paired donation or paired exchange

Paired donation involves two or more pairs of living kidney donors and transplant candidates who do not have matching blood types. The candidates “trade” donors so that each candidate receives a kidney from a donor with a compatible blood type. For example, in figure 8, Joan wants to donate to her sister Betty, but they do not have matching blood types. Jim wants to donate to his wife Donna, but they are also not compatible. By “swapping” donors so that Jim matches Betty and Joan matches Donna, two transplants are made possible. This type of exchange often involves multiple living kidney donor/transplant candidate pairs and can join incompatible pairs from different centers or even different parts of the country!



Other considerations for living donation

Costs

Most medical costs associated with living donation are covered by your (the recipient) insurance. The government requires all certified transplant centers to charge your insurance an “acquisition fee” when you receive a transplant. The medical costs related to your donor’s medical evaluation, transplant procedure and postoperative care, called the “donor protocol” are covered by this fee. Anything that falls outside of this protocol is not covered. These non-covered and, thus, out-of-pocket costs could include annual physicals, travel, lodging, lost-wages, dependent care and other non-medical expenses. Your donor must agree to pay these expenses and must prove that they have the financial capacity to do so.

Disability pay

If your job provides disability insurance coverage, then you will most likely be entitled to disability pay. Check with your employer for details.

Scheduling the transplant surgery

This decision is made jointly by the transplant team, by you, and by your donor. The transplant team, particularly the doctors involved directly in your care, will determine as accurately as possible the best time to do the transplant, based on your medical condition.

A number of events could happen that may change the date of the transplant. For example, your condition might deteriorate to the point that you are too sick to undergo surgery. Or, you or your donor might develop an infection or some other condition that would need to be treated before the transplant could be done. Additionally, your donor has the right to change their mind at any point. This is why it is so important to encourage your donor to take the time and give the consideration necessary to explore the process and fully understand all the benefits and risks before agreeing to donate.

Deceased donation

In the United States, most kidney transplants come from deceased kidney donors. Deceased donors are most often individuals who die from accidents or sudden death and have previously indicated their wish to be an organ donor or their next of kin consent to organ donation. Donor organs are matched to waiting recipients by a national registry called the Organ Procurement and Transplantation Network (OPTN). This registry is operated by the United Network for Organ Sharing (UNOS).

Kidney Allocation System (KAS)

The current kidney allocation system, implemented in December 2014, aims to provide recipients with longer function with their transplanted kidney by matching the donated kidney that has the longest potential life with the recipient who has the longest potential life with that kidney.

Once you are listed for a transplant, you will be assigned an estimated post-transplant survival score (EPTS) – a percentile score that ranges from zero to 100. The score is based on how long you will need a functioning kidney as compared to all other transplant candidates on the list. If you have an EPTS of 20, it means that you will need a kidney longer than 80 percent of all other candidates. Your EPTS will be electronically updated daily. To determine your EPTS, four factor values are entered into a mathematical formula:

- 1) Whether or not you are diabetic
- 2) Your current age
- 3) If you are on dialysis and, if so, for how long
- 4) Previous transplantation of any organ(s)

Each available deceased kidney is assigned a kidney donor profile index (KDPI) score – a percentile score ranging from zero to 100. The KDPI is associated with how long the kidney is likely to function as compared to other kidneys, based on information about the donor. A KDPI score of 60 means that the kidney is likely to function longer than 40 percent of other available kidneys.

The KDPI is calculated based on factors including:

- Age
- Height
- Weight
- Ethnicity
- Cause of death
 - Loss of heart function
 - Loss of brain function
 - Stroke
- History of high blood pressure
- History of diabetes
- Exposure to Hepatitis C
- Serum creatinine (renal function)

The EPTS and KDPI allocate kidneys

When a kidney becomes available and is given a KDPI score, the EPTS scores of all recipients are considered. The 20 percent of kidneys expected to last the longest (those with a KDPI score of 20 or less) will first be offered to patients likely to need a transplant the longest (those with an EPTS of 20 or less). If a kidney with a KDPI of 20 or less is not accepted for any of these patients, it will then be offered to any other person who would match, regardless of their EPTS score. Kidneys with high KDPI scores are expected to function for a shorter amount of time than others. They may be best used to help candidates who are less able to stay on dialysis for a long time, thus needing a kidney very quickly.

The KAS and PKD patients

A common concern is that as a PKD patient, you receive fewer transplant opportunities because you would not be accumulating time on dialysis, as your kidney function declines more slowly (early in the disease). However, the remedy for this is to be evaluated and listed as early as possible.

In this case, based on the natural rate of progression of PKD, most patients should have at least several years of waiting time before being faced with dialysis, and so “preemptive” (before dialysis begins) transplantation should still be a common option. A second concern is that “all the young donors’ kidneys will be given to other groups.” This is a valid concern because PKD patients are often older on average when you reach stage 4-5 CKD. However, two points must be considered:

- 1) Even people into their 60s can have an EPTS under 20
- 2) The majority of kidneys are allocated without regard to the EPTS or KDPI (all kidneys from 20-85 KDPI)

Previous listing

If you were on the transplant list prior to the KAS changes being made (December 2014), you do not need to be reevaluated or relisted. You may be contacted by your transplant program for information, but only to ensure everything is accurate in the system. You will not lose credit for any time you have already spent waiting and if you began dialysis before you were listed, your transplant waiting time will be backdated to your first dialysis date.

Nephrectomy

Removal of your native polycystic kidney(s), a process called nephrectomy, before a kidney transplant, is generally not performed unless you have a history of:

- ▶ Kidney cyst infections
- ▶ Severe bleeding from the cystic kidney
- ▶ Cancer of the cystic kidney
- ▶ Kidneys so large there is no room for a new kidney to be transplanted
- ▶ Kidneys that are very uncomfortable or cause a lot of pain due to their size.

If one or both of your kidneys are removed, the timing will depend on your individual case as well as the center where you are having your transplant. They can remove one or both kidneys before, during (rare), or after transplant.



Transplant Centers

The distance between you and your transplant center(s) is very important. Once you have been notified that a kidney is available, you will have a limited amount of time to get to the center. The less time the organ must be held outside the donor's body will mean a better chance that the kidney will function when transplanted. There are three geographic levels to consider:

- 1. Local:** this is your local area and is served by the local organ procurement organization (OPO). There are 58 OPOs in the U.S.; they are typically state-wide but can be smaller or larger. Your transplant center will tell you what your local area and OPO is. An available organ will be offered within the OPO first.
- 2. Region or zone:** if the local OPO does not find a suitable match for an organ, they can be offered to patients at centers in a wider area. Kidneys are first offered within one of 11 regions of the U.S.
- 3. Nationwide:** if there are no local or regional matches, kidneys can be offered to anyone in the U.S. who is a potential match.

Multiple listing

Most candidates are listed at a single transplant center, but some people choose to register at two or more transplant centers, called multiple listing, to potentially increase their chances of receiving a kidney. Unfortunately, there is no guarantee that multiple listing will shorten waiting time. Of the many factors affecting how long you will wait, location is only one. Multi-listing may offer more benefit to some patients than others and this should be discussed with your nephrologist or local transplant team.

Restrictions and considerations

The Organ Procurement and Transplantation Network (OPTN) has a policy to allow for multiple listing. That said, it is up to each individual transplant center to decide if they will accept you as a transplant candidate. Multiple listing in the same local area will probably not be of much benefit, even if you are listed at multiple hospitals. Some centers may have policy against accepting multiple-listed patients.

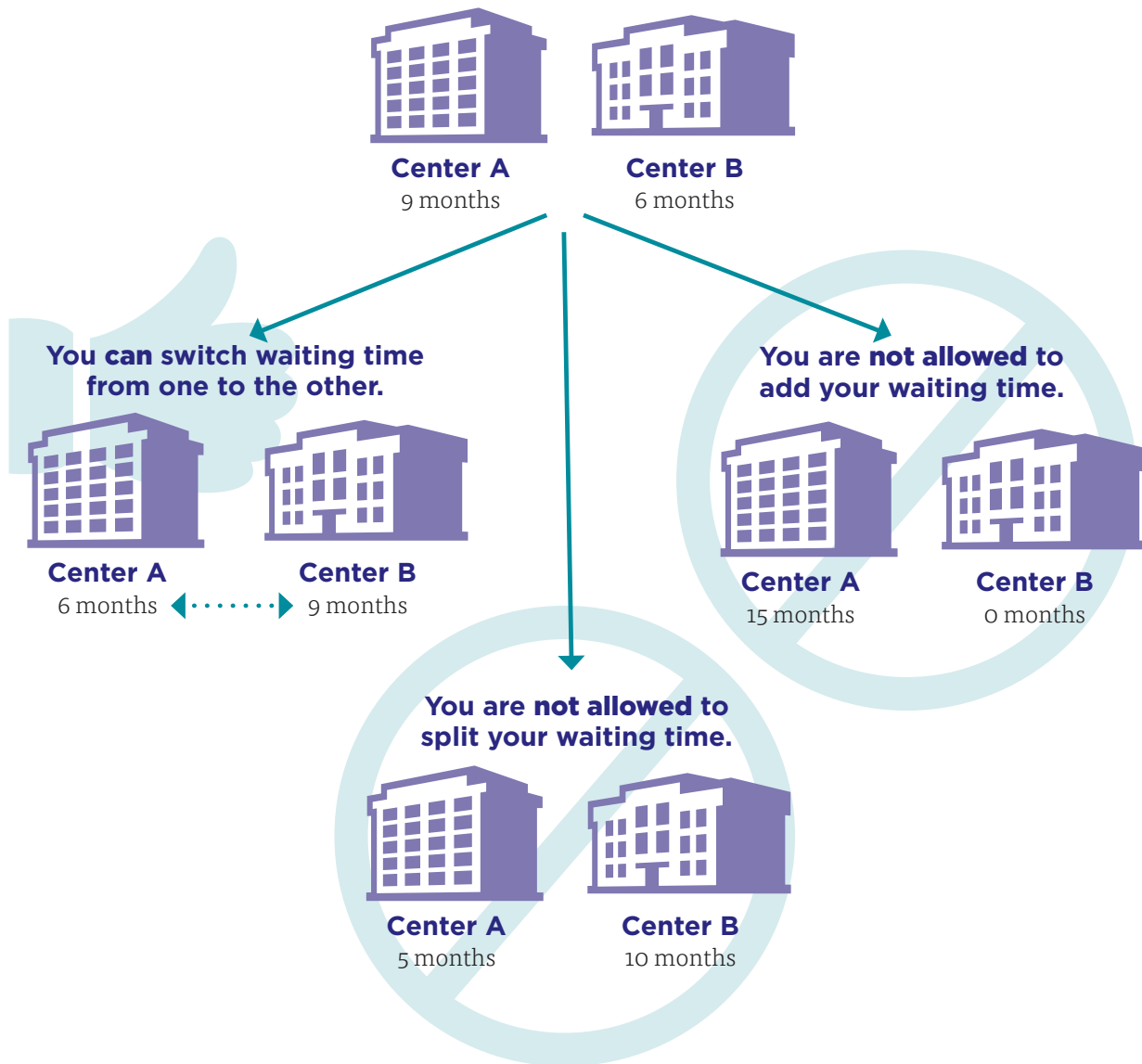


Process

You must be considered and accepted as a transplant candidate at each center you want to be listed. This could include completing the full medical evaluation and agreeing to conditions set by the center. You will need to check with your insurance provider to understand how the cost of additional evaluations will be covered (they may only cover the cost of one evaluation). You'll need to maintain current lab results and contact information for each center.

Waiting time is an important factor when waiting for a kidney transplant. The longest amount of time you have waited at any center is called your primary waiting time. If you are listed at multiple centers, your waiting time will start from the date each individual center listed you (unless you started dialysis before your first listing in which case they all date back to the dialysis start date). You can transfer your primary waiting time to another center (where you are listed) or switch time waited at different programs.

Multiple Center Listings



All requests to transfer or switch waiting time must be approved by all involved center(s).

Transfer of Care

You may want to end your listing at one center and transfer it to another. You can do this as long as you coordinate with both programs. The new center will generally ask you to put your request in writing. It is very important to note that if you end your listing at one center before your new center formally accepts you, *you may not be able to continue to accumulate waiting time.*

Before Transplantation Surgery

Once you are approved and on the list for a transplant, the waiting begins. The hope is that eventually a kidney will become available for you either through a living donor or a deceased donor. During this waiting period, you will have periodic blood tests and will want to stay in close contact with your transplant center. Be sure to notify your transplant coordinator of any significant medical changes.

It is also important to stay as healthy as possible so that you are in optimal condition when the time comes for surgery. If you are overweight, work toward eating healthy and exercising (only after discussion and approval from your nephrologist) and don't use tobacco products. Now is the time to adopt a healthy lifestyle as even after your transplant you'll want to continue this to preserve your new kidney.

You'll also need to stay close to the transplant center so you can get there as quickly as possible when you're notified that a donor kidney is available. If you must travel, notify your transplant coordinator to work out a plan and ensure you can get to the transplant center in time.

The Surgery

Transplant surgery is a major operation and comes with risks for complications just like any other. During the surgery, you will receive general anesthesia and possibly other forms of pain-blocking anesthetic as well. Your transplant surgeon will make an incision in your lower abdomen to insert the new kidney and connect it to your blood vessels and bladder. Your own kidneys are not removed at this time (see section on nephrectomy on page 7). Often your new kidney will begin to function immediately, although sometimes it can take several days for it to "wake up" and start working. In some cases, dialysis is needed for a short time (one to three weeks) after surgery to help your new kidney until it is fully functional.

Post Surgery

After your transplant, you'll remain in the hospital anywhere from two to seven days, depending on your recovery progress and the protocol in place. Your transplant surgeon and nephrologist will monitor your recovery until you are released.

Once you are discharged, you'll still require follow up care, provided by the hospital and your primary care physician (internist or nephrologist). You'll need regular blood draws to monitor kidney function, your immunosuppressive medication levels, and watch for signs of infection or rejection. You will communicate regularly with your transplant nurse coordinator and your doctors for up to a year to check your progress and ensure your health.

Your activity will be restricted for several weeks. No driving or lifting and a general "take it easy" approach will be necessary. Return to work will occur only after your doctor and insurance have both signed off. It could take up to two months before you're ready to go back. It is absolutely necessary to follow your doctor's orders; do not rush physical activity until you've discussed and received approval. Becoming active too quickly could put your transplant, and your health, in jeopardy.

Medications

You'll be required to take immunosuppressive medications for the rest of your life to keep your body from rejecting your kidney. Your drug regimen can vary and is determined by your transplant team and doctor. Be sure to ask questions so you can fully understand each medication you are taking, what its function is and possible interactions with other drugs, food, etc. Understanding and taking your medicine exactly as prescribed is one of the most important factors in keeping your new kidney healthy. Failing to do so could result in losing the kidney to rejection.

Immunosuppressive medications will lower your body's immune system, leaving it open to infections. You must take special care to avoid exposure as even a common cold could result in serious health issues for you. You must report anything out of the ordinary to your doctor. A wound that doesn't heal quickly,

pain during urination, cloudy or foul-smelling urine, and symptoms of illness (tired, cough, nasal congestion, fever, etc.) all need to be reported immediately. This is important because you may not feel as sick as you really are.

Be sure to get vaccinated only as your doctor advises as some vaccines can be dangerous to your new organ (they can cause the disease they are supposed to prevent). Wash your hands frequently. You also should carry antimicrobial gel and use often, especially during cold and flu season.

Tips to avoid infection:

- ▶ Frequent hand washing, especially after shaking hands, using the bathroom, touching a door handle, using public transportation, being in a crowd, touching pets and before eating or touching your face or nose
- ▶ Avoid contact with people who have contagious illness
- ▶ Avoid contact with anyone who has recently had live vaccinations, including the nasal flu vaccine
- ▶ Know and practice safe food handling: proper food storage, minimum cooking temperatures, and clean up practices are all important

Although this advice may seem overwhelming at first, transplant patients can and do enjoy an active life including travel, sports, and most other normal activities.

Cost of transplantation

In general, Medicare covers a significant amount of the cost of dialysis and transplantation. To be eligible, a person must have earned Social Security benefits or be the spouse or dependent of someone who has. About 93 percent of those with ESRD are eligible for this benefit. Medicare covers immunosuppressive drugs for 36 months (three years) after the month of transplant. Medicare will continue to pay for your immunosuppressive drugs with no time limit if:

- ▶ You were already entitled to Medicare because of age or disability before you got ESRD
- ▶ You became entitled to Medicare because of age or disability after getting a transplant that was paid for by Medicare or paid for by private insurance that paid primary to your Medicare Hospital Insurance coverage.

For more detailed information regarding Medicare and payment of costs associated with dialysis and transplant, call your local Social Security Medicare office or visit the website of the U.S. Department of Health and Human Services. Medicaid may cover those who do not qualify for Medicare. A social worker or financial counselor in the dialysis unit or transplant program at your hospital will help you work through the financial issues.

Our Mission: Promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for polycystic kidney disease and improve the lives of all it affects.

Our Vision: One day, no one will suffer the full effects of polycystic kidney disease.



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pkdcure.org
1.800.PKD.CURE