



MedStar Health

MedStar Georgetown
Transplant Institute



**Frequently asked questions
for waitlisted patients.**

**It's how we
treat people.**

Questions about my follow-up on the waitlist

Q: How long will I have to wait for a new kidney?

A: Wait time for a donor organ is dependent upon several factors. These include your blood type, tissue matching, presence of preformed antibodies, and the time from which you began dialysis.

Your wait time will be calculated from the day you started dialysis, not the date you completed your evaluation.

For patients listed before they started dialysis, your time will still be calculated from your date of listing.

Living donation offers significantly decreased wait times for transplant. Anyone interested in becoming a living donor should begin the process by logging on to **MedStarGeorgetown.org/KidneyRecipient**.

Q: How often should I expect to be in touch with the transplant center?

A: We like to see patients once a year while on the waitlist so that we can keep updated on medical issues that might affect getting a transplant.

For patients with more significant medical history, we may see you as frequently as every 6 months.

While we may only be in touch with you every 6 to 12 months, you should always contact us at **202-444-3700** with any new medical or contact information.

Q: What sort of events do I need to let the transplant center know about?

A: We would like to hear about any and all changes to your medical condition, contact information, and insurance. Please contact us immediately:

- If you have surgery or receive blood. If you are having elective surgery of any kind, you should let us know before the surgery happens.
- If you have a major medical event or significant new medical problem, such as a stroke or cancer diagnosis.
- If you require an overnight hospital stay.
- If abnormal screening tests are ordered by your primary care provider.
- If you move or change your phone number. If we do not have your correct phone number then we may not be able to contact you if we have an organ offer.
- If your dialysis center changes.
- You change your nephrologist or primary care doctor.
- Your insurance information changes.

When in doubt—call us or send a message to your provider via the patient portal!

On the cover: A living donor helped Ken get a kidney transplant much more quickly.

The cover photo was selected prior to the COVID-19 pandemic. All patients and providers are expected to follow the current MedStar Health guidelines for safety, including proper masking and physical distancing where appropriate. Learn more at **MedStarHealth.org/Safe**.

Q: What testing is needed while I am on the waitlist?

A: Monthly blood testing (1 red top tube)

- We need a sample of blood sent to our lab every month you are on the list. We use this blood to test compatibility with the donor kidneys. If we do not have blood from you, we cannot test the kidneys, and you will not be offered a transplant.
 - If you are on dialysis, your dialysis unit should be taking care of this. **Be sure to check with your dialysis center that this is being done.** If you are not yet on dialysis, you should receive the required supplies in the mail so that you can have the blood drawn locally.
 - If you are on home dialysis, you can take your PRA kit in with you to your monthly dialysis visit and have your blood drawn at your dialysis center.

Annual testing for hepatitis and other viruses

- We will do this for you at your annual visits to the transplant center.

Annual chest X-ray and electrocardiogram (EKG)

- Repeat heart testing (a stress test and an echocardiogram—ECHO) every 2 years

You must keep current with age-appropriate cancer screenings, including (as appropriate): Pap smears, mammograms, colonoscopy, and prostate specific antigen testing.

Q: What can I do to make my transplant easier or safer?

A: Stop using all tobacco products (cigarettes, cigars, pipes, dip).

The use of tobacco products affects your immune system. It makes you more likely to get an infection, but also makes the immune system more likely to attack the kidney. Some studies have found that people who smoke are **eight times more likely to lose their transplanted kidney** than people who do not smoke. Speak to your doctor about programs and medications to help you quit smoking.

If you are diabetic, it is very important to have good control of your blood sugars prior to your transplant. Immediately following your transplant, you will likely need adjustment to your insulin, and this is easier to accomplish if your sugars were in good control prior to the transplant.

Keep your weight well controlled. Surgical complications increase for patients who are more overweight. We look at the body mass index (BMI), which adjusts for how tall you are.

BMI Guidelines for MedStar Transplant

Patients with a BMI above 40 might not be offered a kidney.

Patients with a BMI above 35 are still at higher risk for complications.

Ideally, patients will have a BMI at or below 30 at the time of their transplant.

You can calculate your own BMI by using a site like Https://www.nhlbi.nih.gov/Health/Educational/Lose_wt/BMI/bmicalc.htm.

Q: What should I know about the current Kidney Allocation System?

A: Your time on the list starts from your first day of dialysis.

- Even if you were listed after many years of dialysis, those years will be added to your waiting time.
- For patients listed before they are on dialysis, waiting time will start at listing, so there is still an advantage to being listed before starting dialysis.

It is possible to be listed at multiple centers, but it is more important to choose the center that gives you the best chance of being transplanted.

Q: Will Medicare cover my transplant?

A: If you are a U.S. citizen or a legal permanent resident who has lived in the country for 5 years, you are eligible for Medicare once you are on dialysis.

- If you never applied for Medicare while on dialysis and receive a transplant, you can still qualify for Medicare coverage.
- Regardless of when you applied for Medicare, if you are not 65 years old or on disability, **your Medicare coverage will end 3 years after you receive your transplant.**
 - Patients on Medicare should consider what insurance options will be available to them once this 3-year deadline arrives.

If you have Medicare, make sure you have Medicare Part A, B, and D (Pharmacy coverage).

- Part B covers your physician fees and your anti-rejection medications.
- Even with full Medicare coverage, Medicare will only pay for 80% of your doctor's fees and medication costs. Without additional (secondary) coverage, you will be responsible for 20% of these costs post-transplant.
- **These costs can be hundreds or even thousands of dollars a year. We strongly advise you to find secondary insurance in addition to Medicare.**

The Immuno Bill is likely to go into effect in January of 2023, and would help cover the cost of immunosuppression medications after three years. Watch for updates.

Q: How can I ensure I have adequate health care coverage post-transplant?

A: Know what your current insurance coverage is and who is paying for it.

- **Medication costs alone can run \$3,000 to 6,000 per month after transplant.**

If any of your insurance premiums are paid by the American Kidney Fund, you should know that the American Kidney Fund will not pay for your premiums post-transplant. You will be responsible for these premiums post-transplant.

MedStar Georgetown Transplant Institute has financial coordinators who are experts in transplantation and insurance coverage. If you are concerned about your coverage, please call us. Our coordinators will be happy to advise and assist you in getting the best possible coverage for your transplant needs.

If you are concerned about adequate health care coverage, we encourage you to apply for secondary insurance through your state's Healthcare Exchange Plan.

If you are in significant financial trouble or have concerns, we have financial coordinators and social workers who are here to help. Please call **202-444-3700**.

More information about this can be found at **HealthCare.gov**.

Questions about the kind of kidneys you might receive

Q: What are my options for transplantation?

A: Patients can receive a kidney from a living donor (living donor kidney: LDK) or a deceased donor (deceased donor kidney: DDK). An LDK is superior to a DDK in several ways.

	Living Donor Kidneys (LDK)	Deceased Donor Kidneys (DDK)
Time to Transplant	Months	2 to 8 years on waitlist
Function	90%+ function immediately	70%
Kidney Lifespan	Average 15 to 20 years	Average 10 to 12 years
Scheduling	When convenient for patient and donor	Whenever organ is available

Q: What is the Kidney Donor Profile Index (KDPI)?

A: KDPI is a way of describing which organs will tend to do better over time. Each organ is given a score between 0 and 100. **The lower the number, the better the kidney is expected to function.** The score is based upon 10 factors (e.g., age, diabetes or hypertension) measured in the donor.

KDPI is used *only* for deceased donors.

Kidneys with a KDPI of 0 to 20 will *only* go to recipients who are estimated to have the best expected post-transplant survival (EPTS). These recipients will tend to be those who:

- Do not have diabetes
- Have not had a prior transplant
- Are younger
- Have had a shorter time on dialysis

Questions about living donor kidneys

Q: Who can donate a kidney to me?

A: Donors can be anyone who is healthy enough to donate.

- They do not have to be related to you.
- They do not have to be of the same age, race, or sex as you.
- They do not need to be the same blood type as you.

Even if you know you have a donor who is incompatible, they can still help you get a transplant through a paired kidney exchange.

Even if you looked for a potential living donor in the past, it's important to always think of new possibilities.

Q: What is 'Paired Kidney Exchange'?

Patients may have a living donor who is not able to donate directly to them because of a different blood group, or because of antibodies in the recipient's blood. These donors can still donate their kidneys via **Paired Kidney Exchange (PKE).**

In a PKE, your donor will donate their kidney to another patient (with whom they are compatible) and you will receive a kidney from that person's living donor.

- Through PKE, you will always receive a living donor kidney.
- The transplants are usually done within a day of each other, however the donor you provide does not necessarily need to donate on that day.

Paired Kidney Exchange offers the best option for patients who are highly sensitized.

Even if you are compatible with your donor, paired kidney exchange may be able to give you a better quality kidney than your original donor. You should ask your coordinator about compatible paired kidney exchange if you are interested.

Q: I have a person who is interested in donating. How do I start this process?

A: Potential donors should visit MedStarGeorgetown.org/LivingKidneyDonor and complete the online questionnaire. A member of the MedStar Georgetown Transplant Institute team will contact the donor directly.

- Potential donors can also contact the transplant institute at **202-444-3714**. Donors will be directed to the website to see if they are healthy enough to donate.
- After completing the questionnaire, the next step is blood tests to see if they are compatible.
- Potential donors will then need to come to one of the Transplant Institute's locations to complete their evaluation.



Become a Living Donor

Key Points

- Keep your testing and labs up-to-date.
- Actively look for a living donor!
- Stop smoking!
- Be transparent! Let your coordinator know what is going on and if anything medical related has changed or if you have decided you are no longer interested in transplant.
- Please be reachable and respond to MedStar Georgetown Transplant Institute in a timely manner. Provide an **accurate** and **working** telephone number for the team to call you for appointments, and more importantly, a **transplant!**

Helpful resources

The following websites are sources for information regarding the organ transplant wait list, waiting times, and organ donation.

UNOS.org
optn.transplant.hrsa.gov
TransplantLiving.org

You're never far from the MedStar Georgetown Transplant Institute.

The MedStar Georgetown Transplant Institute is making it more convenient for you to be evaluated for transplantation. We're everywhere you are. Our convenient locations throughout the Washington, D.C., region make it easy to access our experienced multidisciplinary team. We are now evaluating kidney and pancreas transplant candidates at seven convenient locations. To make an appointment, please call **202-444-3700**.

A. MedStar Georgetown University Hospital

3800 Reservoir Rd., NW
Washington, DC 20007

B. MedStar Washington Hospital Center

110 Irving St., NW
Washington, DC 20010

C. MedStar Georgetown Transplant Institute in Fairfax

3020 Hamaker Ct., Ste.501
Fairfax, VA 22031

D. MedStar Southern Maryland Hospital Center

7503 Surratts Rd.
Clinton, MD 20735

E. MedStar Georgetown Transplant Institute in Frederick

163 Thomas Johnson Dr.
Ste. E
Frederick, MD 21702

F. MedStar Georgetown Transplant Institute in Annapolis

Annapolis Tech Park
2629 Riva Rd., Ste. 110
Annapolis, MD 21401



G. MedStar Franklin Square Medical Center

9000 Franklin Square Dr.
Baltimore, MD 21237

H. MedStar Georgetown Transplant Institute in Ellicott City

9501 Old Annapolis Rd.
Ste. 220
Ellicott City, MD 21042

MedStarGeorgetown.org/Transplant

3800 Reservoir Rd., NW
Washington, DC 20007
202-444-3700