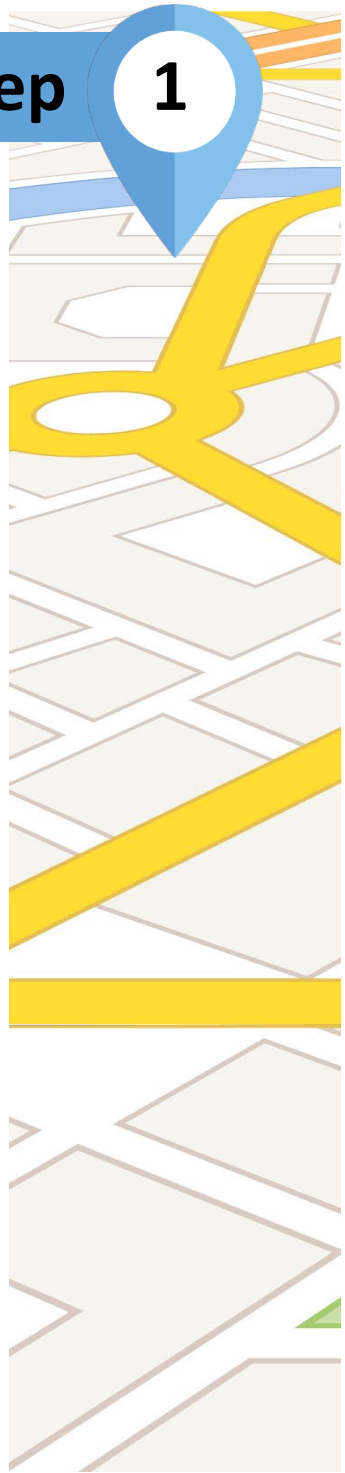
The Roadmap to Success:

Navigating Your Kidney Transplant Journey

HSAG HEALTH SERVICES ADVISORY GROUP

ESRD Networks 7, 13, 15, 17, 18

Am I a Candidate for a Kidney Transplant?—Step 1



Let's Get Started!

A kidney transplant is often the best treatment for kidney failure. However, the road to kidney transplant can take time and involves many steps. As your partners in care, your doctor and healthcare team can help decide if a transplant is right for you and help connect you with a transplant center. You may want to keep a binder to store your notes, important papers, and questions in one place. The checklist and resources below will help get you started on your kidney transplant journey.

	Strategies to Implement	Tools and Resources
☐	Talk to your healthcare team and ask about your transplant options based on your current kidney function, overall health, and transplant programs in your community.	From the NIDDK: • Education Program From the NKF: • How to Keep Your Kidneys Healthy in 2024 • Evaluation for Kidney Transplant From the AST: • When to Start: When to See Your Doctor About Your Kidneys From the UNOS Transplant Living: • Treatment Options • What Is a Kidney Transplant? • Kidney Transplant Learning Center From the HSAG ESRD Networks: • Transplant Patient Education Resources
☐	Take steps to protect your kidneys and prevent the progression of CKD. Examples include controlling your blood pressure, eating a kidney-friendly diet, exercising, taking medications, following all treatments (including dialysis) as prescribed, and getting regular lab tests to monitor your overall health and kidney function.	
☐	Involve your family and loved ones in your care decisions. Their support is important before and after your transplant. Many transplant facilities will require you to include at least one person in your care.	
☐	Join a support group to connect with others who have had a kidney transplant. Hearing about someone else's transplant journey may ease your concerns and start you on the best path. It can also help you understand what to expect during the transplant process and how to take care of yourself after.	

CKD = chronic kidney disease; NIDDK = National Institute of Diabetes and Digestive and Kidney Diseases; NKF = National Kidney Foundation; AST = American Society of Transplantation; UNOS = United Network of Organ Sharing; HSAG = Health Services Advisory Group; ESRD = End Stage Renal Disease

Selecting a Transplant Center—Step 2

Getting a referral for a kidney transplant is just the first step of the journey. Each transplant center has different criteria for who they will accept. If one center is unable to meet your transplant needs another might, so you may need to apply to more than one transplant center. Being declined by a transplant center can feel frustrating, but don't give up. Keep exploring your options until you find the right transplant center for you. The resources below can help make your search easier.

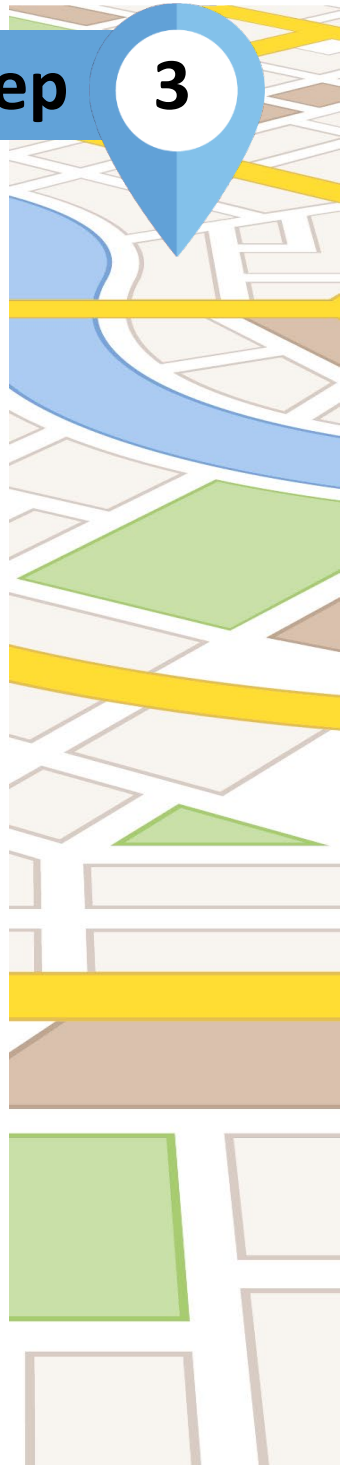
	Strategies to Implement	Tools and Resources
☐	Compare transplant centers in your area. Look at factors such as insurance coverage, surgeon experience (how many kidney transplants have they done and how often do they perform them?), location, and how far you will need to travel for checkups, surgery, and follow-up visits. You may also want to check if there are hotels nearby and if they offer discounts for transplant patients and their loved ones.	From the AST: • Selecting a Transplant Center From the HRSA: • Organ Donation Statistics From the NKF: • The Kidney Transplant Waitlist • Evaluation for Kidney Transplant From the UNOS: • Frequently Asked Questions about Kidney Transplant Evaluation and Listing From the OPTN: • Kidney From the HSAG ESRD Networks: • Turning Negatives Into Positives—Why Transplant Is a Good Idea for Me! From the SRTR: • Find and Compare Transplant Programs • Website Overview: Getting Started • Kidney Transplant Decision Aid
☐	Research transplant center quality outcomes. Each center is unique, and public data is available for all transplant centers so you can compare their success rates.	
☐	Create a list of questions to ask your transplant team, such as: • How many people are on the transplant waitlist? • How long is the average wait for a kidney? • What is the one-year transplant survival rate? • Who will manage my care after the transplant and for how long?	

HRSA = Health Resources and Services Administration; OPTN = Organ Procurement and Transplantation Network; SRTR = Scientific Registry of Transplant Recipients

Finding the Right Kidney for Me—Step 3

There are multiple types of donor kidneys and being open to all available options may help get you a transplant sooner. Kidneys can come from living or deceased donors, and factors like the Kidney Donor Profile Index (KDPI) help determine how long a kidney may last. It's vital to talk with your healthcare team and loved ones about your transplant options early in the process so expectations are clear, and you don't miss a chance for a transplant. The resources below will help you navigate this complex process, ask the right questions, and share important information with your loved ones.

	Strategies to Implement	Tools and Resources
☐	**Living Donor:** Living donation involves matching you with a donor who is biologically similar enough to you that you likely won't reject the transplant. Many individuals prefer living donation because it can shorten wait times, but finding a matching donor can be difficult. Factors like blood type, donor health, and medical risks may be a limiting factor.	From the SRTR: • Living vs. Deceased Donor: Kidney Transplant Decision Aid • Questions For Your Doctor: Kidney Transplant Decision Aid From the NKF: • Kidney Transplant • High KDPI • The Kidney Transplant Waitlist and High KDPI Kidneys From the OPTN: • Questions and Answers for Transplant Candidates About the Kidney Allocation System From the NKR: • Finding the Best Kidney Transplant Match From the AKF: • Consider Getting a Kidney from an Expanded Criteria Donor From the ESRD NCC: • Understanding High-KDPI and Increased Risk Kidneys Video
☐	**Deceased Donor:** Accepting an organ from a deceased donor is becoming more common as the need for transplant is increasing and there aren't enough living donors. If you choose this option, a deceased donor kidney is matched through an online registry based on criteria you select with your transplant team to find the best kidney for you.	
☐	**KDPI:** If a deceased donor kidney is the right option for you, understanding the KDPI is important because it helps estimate how long a kidney transplant may last. Factors such as your age, overall health, and how quickly you want a transplant all play a role in selecting the right KDPI range for you.	

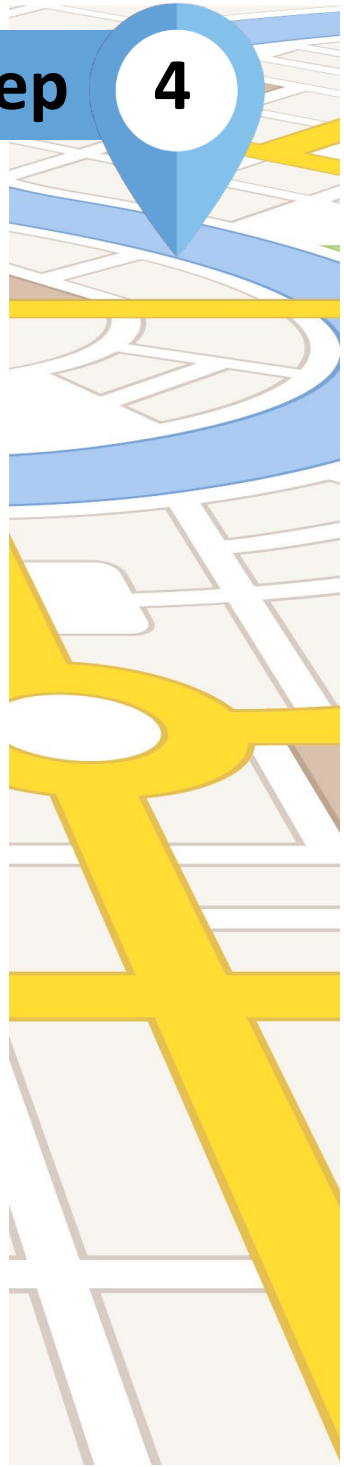


NKR = National Kidney Registry; AKF = American Kidney Fund; ESRD NCC = End Stage Renal Disease National Coordinating Center

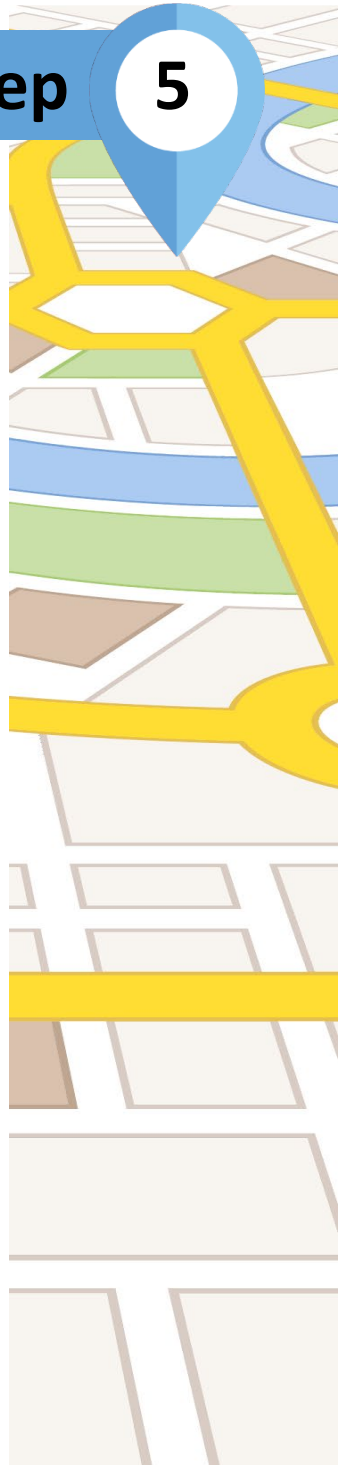
Understanding the Transplant Waitlist—Step 4

After selecting a transplant center, if you decide on a kidney transplant from a deceased donor, you will be placed on the national organ transplant waitlist. This list includes everyone waiting for an organ transplant in the United States. Your transplant center and your dialysis center will help manage your active status on the waitlist. The resources below will help you remain ready for transplant.

	Strategies to Implement	Tools and Resources
☐	Keeping an active status on the waitlist is crucial. If your lab tests are out-of-date, your contact information changes, or you miss a required test, ***you could be placed on inactive status and you will not receive a kidney offer***. If you're receiving dialysis, your provider can check your waitlist status and provide you with monthly updates regarding any actions that need to be taken.	From the AKF: • Transplant Waiting List From the UNOS: • Transplant Living's Getting on the List • Transplant Living's How Organs Are Matched • Transplant Living's The Kidney Transplant Waitlist From the OPTN: • Questions and Answers for Transplant Candidates About the Kidney Allocation System • Transplant Process From the NKF: • The Kidney Transplant Waitlist • Multiple Listing for Kidney Transplant From the HSAG ESRD Networks: • How Might I Shorten My Time on the Waitlist?
☐	Communicate frequently with your transplant team. You will be required to follow up at least annually to stay eligible for a transplant. Staying as healthy as possible will help you to be ready when you receive the call for a transplant. This means keeping up with your vaccines, having your yearly health checkup, staying up to date with tests and lab work, getting a dental checkup each year, taking your medications as prescribed, going to all your dialysis treatments if you need them, and following your healthcare team's advice to make sure you are healthy enough for a kidney transplant.	



Remaining Transplant Ready—Step 5



The average wait time for a kidney transplant in the United States is 3–5 years, but some centers have wait times as long as 10 years. Staying ready for transplant can be difficult, but it is essential. The call could come at any time—at night, on weekends, or even on a holiday—so it's important to have a plan for different situations. The resources below will help you, your loved ones, and your transplant team be prepared when it's time to receive your kidney transplant.

	Strategies to Implement	Tools and Resources
☐	Ask your transplant center about overall wait times, how long they estimate you will wait, and when kidney transplants are most frequently performed at their center.	From the HSAG ESRD Networks: • 10 Steps to Remain Active on the Waitlist From the UNOS: • Transplant Living's Waiting for Your transplant • Transplant Living's Receiving "The Call" From the ATF: • Free Patient Checklists for Transplant Recipients and Living Donors From the Kidney Transplant Connectors: • Education & Resources From the NKF: • Getting a Kidney Transplant From the LifeSource: • How Does the Organ Transplant Wait List Work?
☐	Save the transplant center's contact information in your phone and be sure to answer all incoming calls, even if you do not recognize the number.	
☐	The hospital will let you know when you are close to receiving your transplant. Pack a bag with everything you need for an extended hospital stay (e.g., toiletries, comfort items, medical documents). It's also a good idea for your loved one to pack a bag, as they may stay with you during your hospital stay.	
☐	Practice your plan a few times a year to make sure you're ready and can get to the transplant center on time, especially if it's far from home. You can do a "drill" by driving to the transplant center or planning your ride to see how long it takes and if there are any problems.	
☐	Call the transplant center periodically to check in with your healthcare team, and to stay updated on any changes that may impact you. Being up to date will ensure you're always transplant ready.	

ATF = American Transplant Foundation

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