



Find Your Voice Toolkit



All about kidney transplants, from learning you have kidney disease to living your best life with a donor kidney.

AST

AMERICAN SOCIETY OF
TRANSPLANTATION®

Table of contents

When to see your doctor about your kidneys.....	3
About transplant evaluation and listing	14
Planning for the kidney transplant process.....	25
What to do while waiting for your transplant	32
What to expect after your transplant.....	37
Glossary of common transplant terms.....	58

1

When to see your doctor about your kidneys



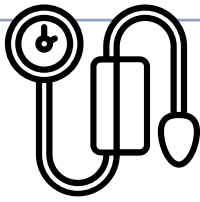
Your kidneys

What do kidneys do?

Kidneys are bean-shaped organs in the back of your body on either side of your spine, protected by your rib cage. Most people have 2 kidneys. They filter and clean your blood to remove waste and extra fluid from your body as urine.

Kidneys also help your body:

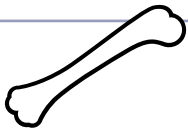
Control your blood pressure



Keep a healthy amount of minerals like sodium and potassium in your blood



Keep your bones strong



Make red blood cells

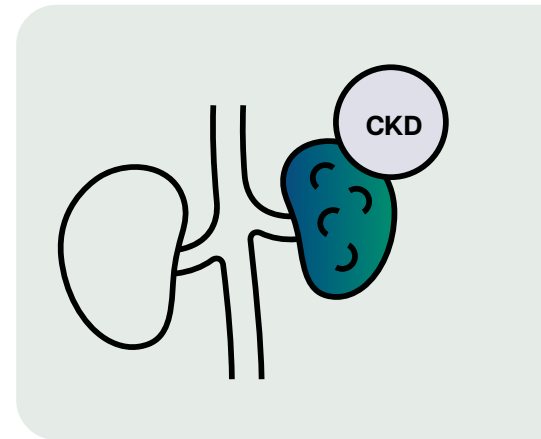


Kidney disease

What is chronic kidney disease?

Chronic kidney disease (CKD) is when your kidneys are damaged, and do not work as well as they should. Diabetes and high blood pressure are common causes of CKD.

As your kidneys get worse over time, you may develop **end-stage kidney disease (ESKD)**, or **kidney failure**. This means that your kidneys no longer work well enough to support your body's daily needs. People with ESKD need dialysis, which is when a machine cleans their blood when their kidneys cannot. They may also get a kidney transplant, which is when doctors replace a damaged kidney with a healthy donor kidney.



Do certain people have a higher chance of kidney disease?

Yes, Black individuals:

- Have a higher chance of CKD compared to other races
- Have a 4 times higher chance of ESKD than white individuals

One reason is that a certain gene (piece of DNA) called APOL1 is more common in the Black population. Having this gene may raise a person's chances of kidney disease that may lead to kidney failure.



There are genetic tests that can tell if a person has the APOL1 gene. However, these tests may cost a lot of money. You can talk with your doctor about getting these genetic tests. In the future, there may be kidney treatments that can help people with the APOL1 gene.



What are signs that my kidneys may not be working as they should?

Early in chronic kidney disease (CKD), you may not have any symptoms. And in many people, kidney disease progresses slowly.

As your kidney function gets worse, your kidneys lose their ability to manage waste and fluid in your blood, and you may have:

- Puffiness or swelling of your face, hands, or feet
- The need to urinate more or less than usual
- High blood pressure that is new or harder to control
- Itchy skin
- Muscle cramps
- Restless legs
- Nausea or throwing up
- Feeling less hungry than usual
- Shortness of breath
- Feeling more tired than usual
- Trouble sleeping
- Dark or foamy urine



Doctors can often tell if you have kidney disease by testing for protein and other substances in your blood and urine.



Talking with your doctor about your kidney health

If you have kidney disease or signs that your kidneys may not be working as they should, **talk with your doctor about your kidney health.**

What should I tell my doctor?

Being prepared can help you get the most out of your clinic visit.



Come to your visit with a list of:

- Your symptoms
- How long you have had your symptoms
- Your current medicines, including how much you take (dose) and how often you take them
- Your recent creatinine and estimated glomerular filtration rate (eGFR) lab test results, if you've had those tests
- Your medical and surgical history
- Your family medical history
- Blood pressure results, if you measure it at home
- Recent weight measurements
- Health insurance information
- Your current doctors and their contact information



What questions can I ask my doctor?

You can bring a list of questions to ask your doctor, such as:



Questions about your kidneys:

- Why am I being referred to a kidney doctor (nephrologist)?
- Why are my kidneys not working properly?
- What stage of kidney disease am I in?
- What does this stage of kidney disease mean for me?
- Could we review my lab tests?



Questions about treatment:

- What are the treatment options for my kidney disease?
- Are there medicines that I shouldn't take?
- Will I eventually need dialysis or a kidney transplant?



Questions about changes you can make:

- How can I slow, delay, or reverse kidney damage?
- Should I change what I eat or drink?
- Can I exercise or make other changes that can help slow kidney damage?



Questions about what to do next:

- What are my next steps?
- Are there other resources to help me better understand my kidney disease?



Asking questions can help you have a good plan for your health

Kidney transplants

What is a kidney transplant?

A kidney transplant is a surgery in which a surgeon places a healthy kidney in your body to do the job that your diseased kidneys can no longer do. A kidney transplant is a treatment for advanced CKD or ESKD.

The surgeon puts the donor kidney into the lower part of your belly and connects the kidney to your bladder.

The kidney can come from someone who has died (called a deceased donor) or someone who is alive (called a living donor) that donates a kidney to you.

A kidney from a living donor can help you avoid the waiting list for a deceased donor kidney. Living donor kidneys are also more likely to work better and for a longer period of time after the transplant than a deceased donor kidney.



Evidence shows that a kidney transplant is the best treatment for ESKD. Compared to staying on dialysis, a kidney transplant can help you live longer and have a better quality of life.

What happens to my own kidneys?

Your own kidneys are usually left where they are unless they are causing you problems, such as pain or infection. If that happens, the surgeon may decide to remove your own kidney or kidneys.

What if I do not want to get a kidney transplant?

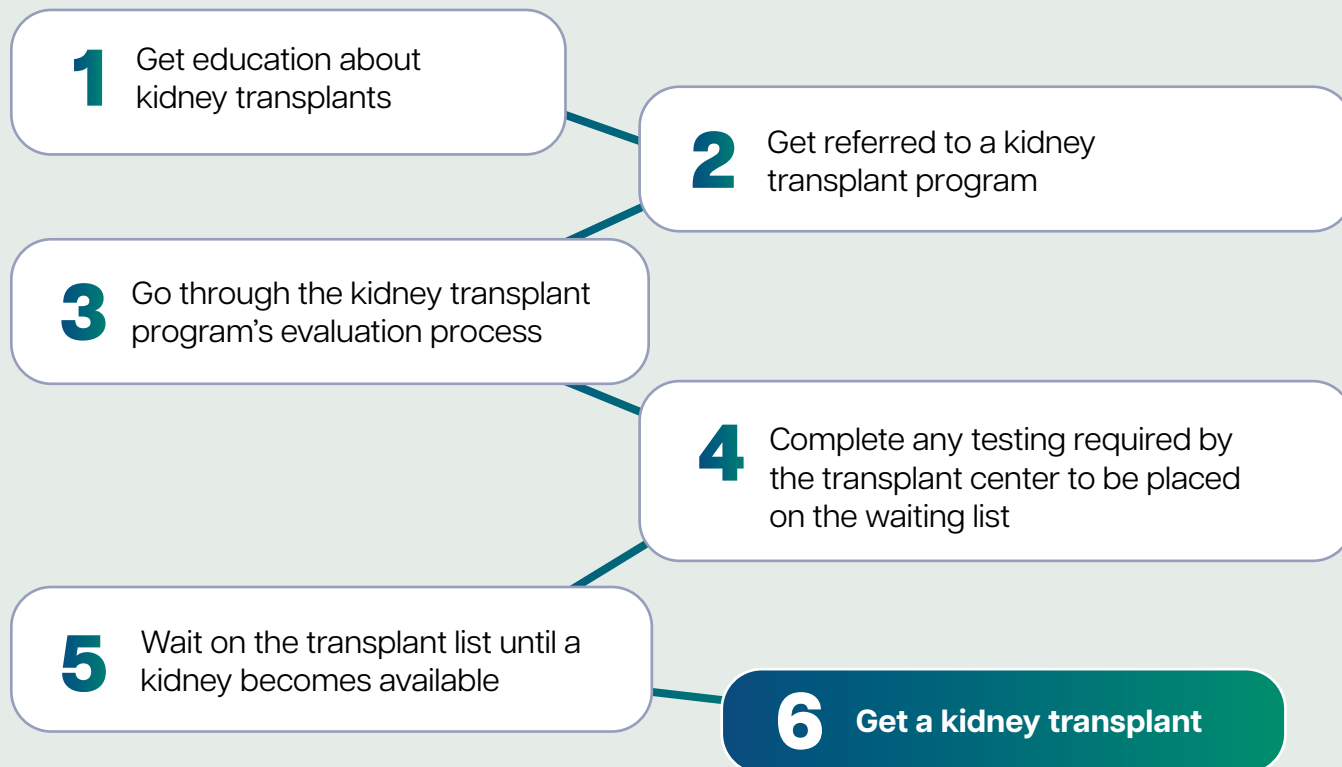
It is okay to not want a kidney transplant. If you do not want a transplant, you will need to continue to get dialysis. However, sometimes people don't want a transplant because they don't know enough about it, such as how it could help them or how the process works.

We encourage you to learn about kidney transplants from your doctor before deciding if a kidney transplant is right for you.



The kidney transplant process

The kidney transplant process has many steps. The main steps are:



How do I get referred to a kidney transplant program?

Your primary care physician, dialysis unit, or kidney doctor (nephrologist) will place the referral. However, you may also contact the transplant center yourself.

When should I get referred?

In general, everyone with advanced kidney disease should be considered for a kidney transplant. A good time to start the transplant process is when your eGFR is between 20-25. eGFR is a measurement of how well your kidneys are working, based on a blood test.

You can get referred and start the transplant process before you are on dialysis, which can:

- Give you more time for the evaluation process
- Give you time to find a living kidney donor, if you choose
- Possibly allow you to get a kidney transplant before you need to go on dialysis

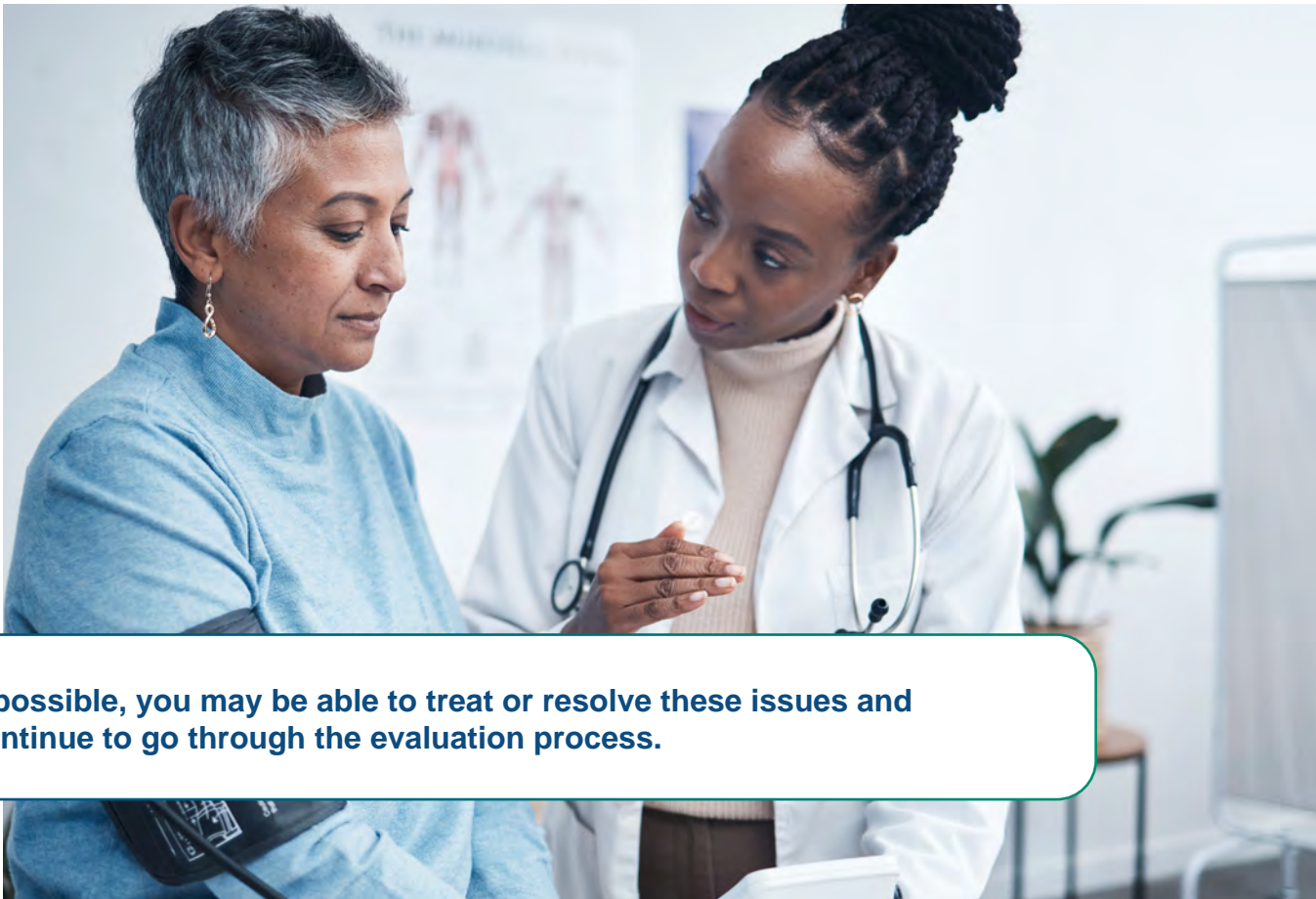
What happens during the evaluation process?

After being referred for a kidney transplant, the next step is the evaluation. During this step, members of the kidney transplant program will talk with you and do many tests. The goal of the evaluation is to make sure you are healthy enough to:

- Survive the kidney transplant surgery
- Benefit from a transplant
- Take good care of your new kidney

It is possible you may not be able to go through the evaluation process due to:

- Having an active infection
- Having cancer
- Actively using street drugs or prescription medicines that are not prescribed to you
- Having serious medical conditions that raise the chance of dying during the transplant surgery
- Not being interested in getting a kidney transplant



If possible, you may be able to treat or resolve these issues and continue to go through the evaluation process.

What will I learn during kidney transplant education?

During your initial education about kidney transplants, you will learn about:

- Why a kidney transplant is preferred over dialysis
- Detailed steps of the evaluation process
- How long the kidney transplant waiting list is in your area
- Things you may need to do to be placed on the waiting list for a kidney transplant, such as lose weight or stop smoking



How will I pay for a kidney transplant?

Before the evaluation process, it is important to review your insurance coverage with a social worker and transplant financial advisor, who your transplant center will provide for you. They may be able to answer questions specific to your situation.

Medicare will cover about 80% of the costs of being evaluated for a kidney transplant, the transplant operation, post-transplant care, and anti-rejection medicines. Medicaid may cover much or all of the remaining costs, if you are disabled. If you have private insurance, they may cover some additional costs as well.

References

- Chronic Kidney Disease Basics | Chronic Kidney Disease Initiative | CDC [Internet]. 2022 [cited 2023 Feb 27]. Available from: <https://www.cdc.gov/kidneydisease/basics.html>
- Bloom RD, Cardella C, Conti D, Danovitch G, First MR, Germain M, et al. Getting A New Kidney: Facts About Kidney Transplants.
- Kidney Transplant [Internet]. National Kidney Foundation. 2017 [cited 2023 Apr 10]. Available from: <https://www.kidney.org/atoz/content/kidney-transplant>

2

About transplant evaluation and listing

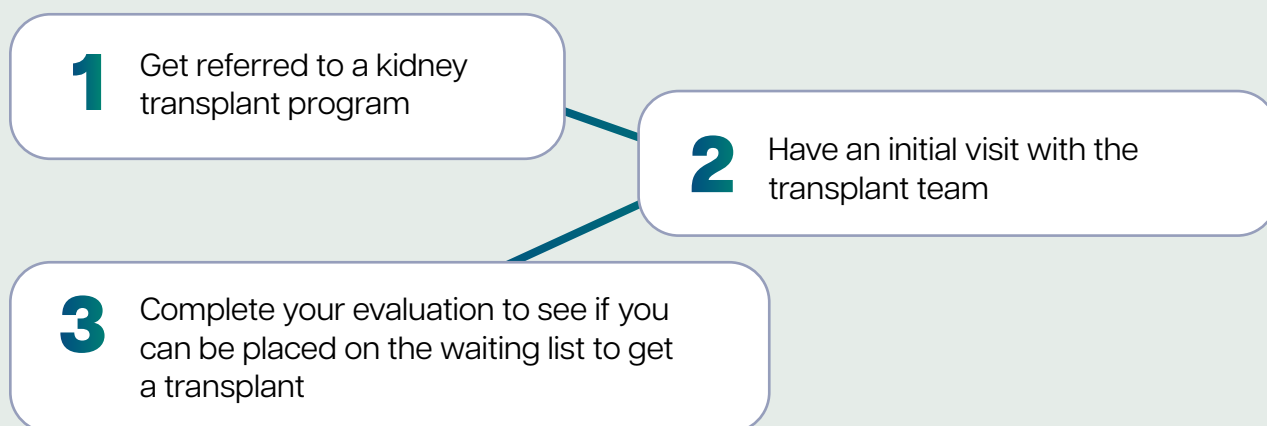


What is transplant evaluation?

Transplant evaluation is a process in which you talk with members of a kidney transplant program and get many tests for a transplant. It can be complex and may take multiple days.

Basic steps of transplant evaluation

Transplant centers across the U.S. may have some differences in their evaluation process, but usually it has 3 main steps:



When should I be referred to a transplant center for evaluation?

Ideally, your nephrologist will refer you when you are in Stage IV Chronic Kidney Disease (CKD), at an eGFR of 20-25 cc/min. This allows you to be listed on the deceased donor list or plan for a living donor transplant when you are still healthy enough for a good recovery from transplant surgery.

If you have kidney disease, ask your primary care doctor and nephrologist questions about:

- Your lab results
- The stage and expected outcome (prognosis) of your kidney disease
- If you should make plans for dialysis or a transplant
- If so, when you should be referred to a transplant center for evaluation

If you are a dialysis patient, ask the dialysis staff if you can be considered for a kidney transplant.

Will I be referred to a transplant center for evaluation?

Not all patients will be referred to a transplant center by their doctors. And some patients are referred very late in their kidney disease (end-stage kidney disease or ESKD). Your doctor may delay your referral for transplant evaluation for reasons such as:

- They want you to become healthier on dialysis before referring you to a transplant center
- You have a medical condition or other issues that make it less likely you will be approved as a transplant candidate, including:
 - Poor strength or endurance
 - Needing to use oxygen
 - A body size not ideal for the transplant surgery
 - Severe heart or vascular disease
 - Having cancer
 - Not able to follow the medical plan after a transplant
 - Actively using illegal drugs
 - Lack of social support
 - Lack of transportation or not able to travel to a transplant center
- Or they do not know you are interested in getting a kidney transplant



To improve your chances of timely referral for transplant evaluation, it is important that you continue to discuss your kidney disease with your nephrologist and other healthcare providers.

How do I get referred to a transplant center for evaluation?

Usually, your kidney doctor (nephrologist), dialysis center, or primary care physician (PCP) will refer you to a transplant program. However, you may also contact the transplant center yourself.

Schedule your evaluation

Once you are referred, the transplant center will:

- Get some information from you by completing a paper packet or giving it by phone or online. They may ask to get some of your medical records **before** they schedule your initial evaluation visit.
- Confirm your insurance coverage
- Schedule you for an initial visit

Complete your transplant evaluation as soon as you can

Once you are referred to a transplant center, **take action**. This shows that you are interested and gets you on the waiting list sooner if you qualify.

1 Schedule your evaluation

2 Complete it as soon as you can



Common things that stand in the way of completing your evaluation may include:

- Challenges communicating with your transplant team
- Cultural or religious beliefs about medical treatments such as transplants
- Negative past experiences with health care
- Financial concerns
- Feeling overwhelmed by the amount of information about the transplant process and what is expected of you
- Not getting all the tests you need

To improve your chances of successfully completing the transplant evaluation in a timely manner, go to all your appointments with the transplant center.

They will give you a list of tests and referrals that you must complete before you can be placed on the transplant waiting list. Delays in getting these tests may lower your chances for a kidney transplant.



If you have questions or concerns about evaluation, please reach out to the transplant center. Good communication with the transplant team can help navigate and complete your evaluation process.

What will happen during my evaluation?

Your initial visit

You will meet with members of the transplant team, including a nephrologist, surgeon, social worker, and dietitian.

The transplant team will talk with you so they can start to evaluate your medical and surgical readiness for a transplant. They will also check on your mental, emotional, and social wellbeing and let you know if more testing is needed.

In your initial visit, it is helpful for you to:

- Show that you are ready to learn about the evaluation process and kidney transplants
- Share all of your medical conditions and medicines
- Bring your list of questions

After your initial visit

After your initial visit, the transplant team will decide if you can continue with evaluation:

- If they think a kidney transplant is appropriate for you, you will continue to the testing part of evaluation
- If they think a transplant would have more risks than possible benefits for you, they will tell you why they do not think you should continue in the transplant process at this time

Tip: If the team decides that a transplant is not appropriate for you, you can seek a second opinion at another transplant center of your choice.

Evaluation testing

If you are approved to continue with transplant evaluation, the team will tell you about the testing you will get before they place your name on the transplant waiting list. You must get some of the tests, while others are recommended but not required.

Evaluation testing may include:



Lab tests, such as blood or urine (pee) tests



Imaging of your abdomen (belly area) and heart, such as with CT scans or MRIs



Stress test of your heart, such as measuring your blood pressure while you walk on a treadmill



Cancer screening based on your age and sex, such as a colonoscopy

Try to complete this testing without delay. If you take too long, the transplant team may think you are not interested in a transplant.

Tip: If you have problems getting any of your tests, such as trouble with transportation, call the transplant center right away. They can help you complete the testing.

After evaluation testing

Once testing is complete, the transplant team will do a full review of your information and test results. They will decide if it is appropriate to place your name on the waiting list for a donor kidney.



If the team decides you are a good candidate for a transplant, they will also ask if you know relatives, friends, or other people in your community who might be willing to donate one of their kidneys to you. Getting a kidney from a living person, called living kidney donation, may shorten the time you have to wait for a transplant.

Being placed on the kidney waiting list

The transplant center will inform you in writing that you have been placed on the waiting list and give the date they are using to start counting your waiting time. This is called your “qualifying date.” The qualifying date will be the first day you started outpatient dialysis, or if you are not on dialysis, the date the transplant center approved you to be placed on the waiting list.

Ways to improve your chances of getting a kidney transplant while on the waiting list

Stay healthy

Stay as healthy as possible while you wait for a donor kidney. This means staying medically, surgically, and mentally a good transplant candidate. To do this:

- Keep a healthy body weight
- Take care of your medical conditions
- Keep up with any medical testing you need
- Keep a positive attitude
- Communicate with your transplant team and update them on any changes in your contact information, health, support, transportation, or insurance

Understand your lab test results

One of the most important ways to take an active part in your care is to learn about and understand the basic transplant lab tests and results, often called “labs.”

The main job of kidneys is to balance the levels of water and key minerals in your body. They do this by sending waste from your blood into your urine so it is removed from your body. That is why many labs use samples of blood or urine that your PCP, nephrologist, and transplant team will collect. The results show how well your kidneys work (kidney function) before and after a transplant.

Labs include a complete blood count, chemistry panel, and (after a transplant) your anti-rejection drug levels. They are usually shown in a chart similar to this example:

---- CHEMISTRY – GENERAL ----						
SERUM	NOV 19 2012	OCT 29 2012	AUG 29 2012	AUG 29 2012	UNITS	REFERENCE RANGES
NA	14:32		141	139	mmol/L	135 – 145
K		4.1	4.1		mmol/L	3.5 – 5
CL			102		mmol/L	100 – 110
CO2			27		mmol/L	20 – 30
BUN			16		mg/dL	7 – 25
CREAT			1.00		mg/dL	.5 – 1.5
eGFR			80		mL/min	
GLUCOSE			105		mg/dL	Ref: < - 199
CA, TOT					mg/dL	8.5 – 10.5
PROTEIN					g/dL	6 – 8.5
ALBUMIN					g/dL	3.2 – 5
PO4					mg/dL	2.5 – 5

Test result chart showing lab results for sodium, potassium, chloride, carbon dioxide, BUN, creatinine, eGFR, glucose, calcium, protein, albumin, and phosphate

Source: U.S. Department of Veterans Affairs [website](#), accessed 11/2/2023

These are the most important lab values to know and are the main way transplant centers check on kidney health before and after a transplant:

- **Serum creatinine (CREAT)** – Healthy kidneys remove creatinine, a waste product from your muscles, so if your creatinine level is above normal, it may mean your kidneys are damaged
- **Estimated glomerular filtration rate (eGFR)** – This is a measure of kidney function based on your creatinine levels and other factors

Other important labs to know about are:

- **Potassium (K)** – High levels of potassium in your blood means your kidneys are not working well enough to remove it from your body
- **Serum bicarbonate (CO2)** – Low amounts of CO2 in your blood mean your kidneys are not removing this waste from your body
- **Glucose** – High amounts of glucose (sugar) in your blood can damage the blood vessels in your kidneys
- **Hemoglobin** – If your kidneys don't work well, they make less of a hormone that triggers a healthy supply of hemoglobin, which is a protein that carries oxygen in your red blood cells
- **Anti-rejection drug levels after a transplant** – Doctors check to see if you have too much or too little of these drugs, which help prevent your body from rejecting the transplanted kidney

Normal value ranges for each lab can be a little different, depending on your lab. The results will often show the normal ranges.

Ask your doctor or someone on your transplant team to show you how to read the results from your labs. If you see a lab result you do not understand, ask for help!

Learn more about lab results for kidney disease:

- www.kidneyfund.org/all-about-kidneys/tests-kidney-disease
- medlineplus.gov/kidneytests.html

Consider getting a living donor kidney

In much of the U.S., the waiting time for a kidney from a deceased donor is longer than 3 years from the qualifying date. Finding a living donor may help you get a kidney transplant sooner.

Living kidney donation is when a person (the donor) donates 1 of their 2 kidneys to someone in need of a kidney transplant (the recipient).

Living donation has some advantages over deceased donation (when a recipient gets a kidney from someone who has died). For example, a living donor kidney:

- Can last 5-10 years longer than a deceased donor kidney
- Begins working sooner after the transplant compared to a deceased donor kidney

Think about people you know who may be able to donate a kidney to you.

People who are in good health, have 2 healthy kidneys, and are emotionally and mentally prepared for the process can be considered as living kidney donors. They can be the same or different age, race, and ethnicity from you.



Living kidney transplants have been done successfully for decades. Nearly 190,000 have been done in the U.S. Transplant teams do full medical evaluations to ensure the donor's safety before going ahead with the surgery.

In most cases, the recipient's insurance covers the donor's medical expenses for evaluation, surgery, and follow-up care. Other financial assistance programs may be available to cover non-medical costs and support the donor during their recovery.

If you would like to learn more about living kidney donation and seek information to share with friends, family, or others who may be considering donating a kidney to you, please visit:

- livingdonortoolkit.com/medical-toolkit to read our Living Kidney Donor Medical Toolkit.
- livingdonortoolkit.com/financial-toolkit to read our Living Donor Financial Toolkit

What is it like to donate a kidney?

The surgery to remove a kidney from a living donor typically takes around 2 - 3 hours. However, the total time involved in the donation process, including the evaluation before surgery and the recovery afterwards, can last several weeks.

Most living kidney donors go on to live normal, healthy lives with 1 kidney. Their remaining kidney typically makes up for the loss of the donated kidney and maintains normal kidney function. However, it is important to maintain a healthy lifestyle and have regular doctor visits to check kidney function.

Donating a kidney does not shorten how long a person can expect to live. On average, living kidney donors tend to live longer due to healthier lifestyle habits such as exercising, eating right, and avoiding poor habits like smoking and drinking too much alcohol.

Each person's recovery time may vary, but most donors can expect to return to their normal activities in 4 - 6 weeks. The donor's transplant team will give them full medical care and support throughout the process. And donors can withdraw at any point in the evaluation process without any explanation.

3

Planning for the kidney transplant process



Can I do virtual care visits for my transplant evaluation visits?

Yes, it is possible for some of your transplant evaluation visits to be virtual. Some transplant centers – but not all – now offer a hybrid model of virtual and in-person transplant evaluation visits.

Ask your transplant provider if your transplant center does virtual visits.

What happens at a virtual visit?

Before your visit, a transplant coordinator may call you to:

- Make sure you have the right equipment (like web camera and microphone)
- Make sure your equipment is working
- Teach you how to use their website platform or app so your visit can go smoothly

During your visit, you and your transplant provider will review your medical information to see if you are a good candidate for a kidney transplant.

You will also learn about:

- The transplant process
- The risks of transplants
- If any conditions you have can affect the outcome of a kidney transplant



After your visit, your transplant provider will tell you what labs and tests you will need. You may be able to do many tests with your local primary care or kidney doctor, rather than having to travel to the transplant center for all of your testing.



What are the benefits of a virtual visit?

Some of the benefits of a virtual transplant evaluation visit are:

- Not having to travel to an in-person visit and pay travel costs (such as gas, parking, or a bus ticket)
- Less time off from work
- Your family members or other support people can be there with you
- It can shorten the time between evaluation and being placed on the transplant waitlist

How do I prepare for a virtual visit?

To prepare for a virtual visit, you can:

- Avoid scheduling things directly after the visit. The first visit is often long, so you want to make sure you are flexible if the visit goes over the scheduled time.
- Test your equipment (like your web camera, microphone, and internet) to make sure it works
- Make sure you can log on and use the platform for the visit
- Have a family member or friend join the visit to help you take notes and remember information, as well as give you moral support
- Have the visit in a well-lit area that feels safe and comfortable to answer private questions
- Have a list of questions you want to ask
- Have a pencil or pen and notepad to write down notes
- Prepare a list of your current medicines and your pharmacy information

How do I get to my in-person visits?

Traveling to in-person evaluation visits can be a challenge.

If you think you may have any trouble getting to your in-person visits, talk to the transplant coordinator or social worker on the transplant team about your travel plans and how you can get help.

When making your travel plans, think about:

- The time of your visit
- How often you will have visits
- How far you will need to travel
- How you will get there. For example, will you drive or have a friend or family member drive you? Or will you take public transportation?

Tips for traveling to your visits:

- Plan to get there before your scheduled appointment time
- If your visit is early in the morning, consider driving the night before and staying in a hotel close to the transplant center
- If your appointment is out of town and you will spend more than 1 night away from home, make arrangements to get dialysis at a place close to the transplant center
- Bring your medicines with you and make sure you have enough for the entire trip

What are my travel options?

If your transplant center is far away or if you can't drive there, here are some options:

- Ask the transplant center if they have a transport assistance program
- Ask your insurance provider if they will reimburse mileage to your visits
- Contact Medicaid transportation for your state to ask if they can help
- There may be other programs in your state that help with transportation
- Take a taxi/cab
- Use a rideshare app, such as Uber or Lyft



Rideshare safety tips:

- Before you get in the car, make sure the car model and license plate number matches what it says on the app. Ask the driver who they are picking up. Do not get in until they say your name.
- Sit in the back of the car
- Share your location or trip status with a family member, friend, or coworker

If you live far and need to fly to the visit, you may be able to get free flights from:



Build your support or care team

You will need at least 1 support person

All transplant centers will require you to have at least 1 adult who will be your main support person during your transplant process. For many, this may be a family member, friend, or even a member of your religious group who will be a caregiver and help with information during the process.

This person may be the one who:

- Comes with you to visits
- Helps you with your medicines
- Helps with other medical conditions, if they happen
- Takes care of you after your transplant – right after the transplant you may need more help as you recover

Some transplant centers may even require you to have a second support to be backup in case your first support person is not available. You can think of them as your personal transplant champions who are rooting for you during your transplant process!

Some people have extended support members as well who can help.

You may have a patient navigator

You may ask your transplant center if they have a **patient navigator**. A patient navigator acts as a bridge between you and the transplant center. They can help you with any issues that keep you from getting the care you need. They may or may not have a healthcare-related background.

A patient navigator is different from a transplant coordinator. A transplant coordinator is a health care professional who coordinates the evaluation and preparation of kidney transplant candidates, treatment, and follow-up care.



You



Navigator



Transplant center

Plan for the costs of a transplant

During the transplant evaluation process, you will meet with a **financial counselor** at your transplant center. You will need to have enough insurance for your transplant. Having insurance will help make sure you have a smooth pre-transplant and post-transplant care process.

Primary insurance

Your primary source of insurance may be through:

- Your workplace
- Medicare – A federal medical insurance program for people age 65 and older, and some people under age 65 with certain disabilities or conditions
- Medicaid – A joint federal and state program that gives health coverage to some people with limited income and resources



If you are on dialysis, you are probably eligible for Medicare. If you have Medicare, you can apply for social security insurance (SSI) or disability benefits to help with costs.

Secondary insurance

You may also need a secondary insurance, such as through Medicare supplement (Medigap) or Medicaid.

Understand your insurance

It is important to understand certain parts of your insurance plan. You need to know if you have a deductible, co-insurance, or any out-of-pocket expenses, as well as prescription drug coverage. Also, your insurance plan may require that you go to a specific transplant center for your transplant evaluation.

When you meet with the financial counselor at your transplant center, talk with them about:

- Your current health insurance coverage, including any limits in coverage that may affect your pre-transplant and post-transplant care
- If you need any supplemental or secondary insurance, and how to apply



Fundraising

Some people hold fundraisers, such as through GoFundMe, to raise money for their transplant. If you want to do this, discuss this with the financial counselor at your transplant center. Money you get through fundraisers are considered income and can cause you to lose your Medicaid benefits.

4

What to do while waiting for your transplant



- **Completing your transplant evaluation and being placed on the waiting list can take a huge amount of time and effort.** The time you spend on the waiting list can also be challenging.

How long will I be on the waiting list?

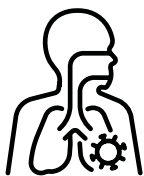
Most people will spend 3 years or more waiting for a kidney transplant. Your waiting time may vary for many reasons, such as:



Your location – If there are a lot of people in your area also waiting for a kidney transplant, you may have to wait longer to get a transplant offer



Your blood type – Your blood type must be compatible with the blood type of your donor



Other medical factors such as an acute illness – This can delay a transplant until you get better



Your antibody levels (also called panel reactive antibodies or PRA) – People who have antibodies against a lot of donors may wait longer to find a compatible donor

What should I do while I'm waiting for my transplant?

While you are on the waiting list, you need to stay healthy. This means staying medically, surgically, and mentally a good transplant candidate.

This can be hard, but there are several things you can do to keep yourself healthy and ready for a transplant, such as:

- Keep a good functional status
- Keep a healthy body weight
- Keep a positive attitude
- Communicate with your transplant center

Having an unacceptable functional status or body weight are 2 of the most common reasons people are put on hold or taken off the waiting list.

Keeping a good functional status

Functional status is your ability to:

- Do normal daily activities to meet your basic needs
- Handle your typical responsibilities
- Stay healthy

Transplant centers often consider things like how far you can walk, if you can go up and down stairs, and if you can shop and cook by yourself.



Be active

The best way to maintain a good functional status is to be as active as possible. This means walking a distance each day that your transplant care team recommends. If you can run, ride a bicycle, or swim, do so as often as you can. You should try to be active for 2 and a half hours a week, or about 30 minutes a day, 5 days a week.

Do strength training

You should also do strength training. When you have end-stage kidney disease (ESKD) and are on dialysis, you may lose muscle and bone mass. You can do resistance exercises, such as squats or push-ups, with your body weight alone or with weights. These exercises can help you keep your muscle mass, which will improve your functional status.

Here are some resources to help you stay healthy:

- Exercises you can do depending on your level of fitness:
 - “Let’s Get Active! Exercise for Kidney Patients” by the National Kidney Federation at: <https://www.kidney.org.uk/lets-get-active-exercise-for-kidney-patients>
- Eating well:
 - “Nutrition Goals Before Transplant” by the University of Michigan at: <https://www.med.umich.edu/pdf/liver-transplant/Diet-and-Nutrition.pdf>
 - “Your Weight Before & After Kidney Transplant” by the National Kidney Foundation at: <https://www.kidney.org/content/your-weight-after-kidney-transplant>
 - “Nutrition before your transplant” by MyHealth.Alberta at: <https://myhealth.alberta.ca/KidneyTransplant/transplant-recipient-information/nutrition-before-and-after-your-transplant/nutrition-before-your-transplant>
 - “Managing kidney disease through lifestyle behaviors” by the American Kidney Fund at: <https://www.kidneyfund.org/living-kidney-disease/healthy-eating-activity>



Keeping a good functional status also helps improve your blood pressure and blood sugar control, and lowers your chance of heart disease.

Keeping a good body weight

Getting and keeping an **acceptable body weight** is important for a successful transplant. Extra weight, especially around your belly, may raise the chance of something going wrong with your transplant surgery.

Keeping a healthy weight can be hard. For many people with ESKD, their disease, income, dialysis, work, and family commitments do not leave a lot of time to focus on their weight.

There are ways to lose or stay the same weight to stay active on the transplant waiting list, such as:

- Regular exercise
- Eating a healthy diet, with a balance of protein, vegetables, and whole grains, which can be done on almost any budget
- Meet with a dietitian from your dialysis unit or transplant center to help you make a meal plan that works for your budget, lifestyle, and tastes

Keeping a positive attitude

It can be very hard to **keep a positive attitude** while waiting for a transplant. It can take a long time to get a transplant, and a lot of things can happen to you medically while you wait. People may have new medical diagnoses, multiple interventions on their dialysis accesses, hospitalizations, and other setbacks.

Here are some ideas to help you:

- Try to keep a strong support network of family and friends who can help you through the process
- Tell your transplant center if you have any feelings of anxiety or depression. These feelings are very common in people with ESKD. Transplant centers have psychologists, psychiatrists, and social workers who can help you and find resources for you.
- Try finding a peer mentor, which are people with ESKD who are also waiting for a transplant or have gotten a transplant. Peer mentors often understand what you are going through even more than your transplant care team. They can give you tips on how to stay positive and engaged while you wait for your transplant. Many transplant centers have a group of peer mentors.

Communicating with your transplant center

Finally, **communication is key**. Keep your transplant center updated on any changes in your contact information, health, support, transportation, or insurance. This will allow your transplant center to help you make a good plan for a successful transplant.

5

What to expect after your transplant



What will I need to do after my transplant?

Help from your support team

All transplant centers will require you to have at least 1 adult who will be your main support person during your transplant process and after your transplant surgery. For many, this may be a family member, friend, or even a member of their religious group that will be a caregiver and help after their transplant.

This person (or people) may:

- Bring you to and from your visits
- Come with you to visits
- Help with your medicines
- Help with other medical conditions, if they happen



As you recover from the transplant surgery and can take care of yourself more, such as driving yourself or managing your medicines, your support person is someone who will still be there to support your physical and emotional wellbeing.

Work with your local kidney doctor

The good news is that there are now more people living longer with successful kidney transplants! Right after your transplant, your transplant center will manage your post-transplant care. Then when you start doing well, your local kidney doctor (nephrologist) will take over your post-transplant care, usually 6 to 12 months after your transplant.

Together, you, your transplant center, and your nephrologist should agree on a detailed follow-up plan. Your plan should include:

- The parts of your care that will be managed by the transplant center, by your local kidney doctor, and by your primary care provider
- Nutrition and physical activity or exercise recommendations
- What medicines you will take, and how to take them correctly
- Your schedule for follow-up medical visits
- Any wellness services you need, such as meeting with a counselor or support group

Take your medicine as prescribed

You will need to take immunosuppression medicine (or immunosuppressants) for a long time after your transplant. These medicines help prevent your body from rejecting your new kidney. You may also need to take medicines to treat other conditions, such as high blood pressure or high cholesterol.

It is very important to take your medicines as prescribed. People who do not take their immunosuppressants are more likely to have problems with their transplanted kidney. For example, people who do not take their medicines are 7 times more likely to have kidney rejection. Rejection can lead to the loss of the kidney, having to do dialysis again, needing another transplant, or even death.

It may be hard for some people to take their medicines as prescribed because of:

- Their personal schedules and routines, which can distract them from taking their medicine. For example, if a person travels often for work, they may forget to bring or take their medicines.
- Their medication schedule. For example, if someone has to take medicines at different times of the day, it may be difficult to keep track of which medicine to take when.
- The side effects of the medicines. Some of the medicines may make people feel sick or have uncomfortable symptoms like diarrhea.
- Not being able to get their medicines, for example, because of the high cost or because they can't get to the pharmacy
- They may take their medicines inconsistently, and continue to do so because they don't notice a difference and think it's OK

If you think you will have any problems taking your medicines as prescribed, talk with your transplant center, kidney doctor, or other healthcare provider as soon as possible. Your healthcare provider can help you make a plan to stick to your medicine routine. For example, if you have problems remembering to take your medicines, they can help you find a pillbox or smartphone app that may help you.

If you have questions about your immunosuppressants or any other medicines you are taking, ask your transplant center for help.

Do you need a medical alert bracelet?

After your transplant, it is recommended that you wear a medical alert bracelet that includes this information:

- That you are a transplant recipient
- That you are immunosuppressed
- If you take prednisone
- If you have diabetes
- That you should not have non-steroidal anti-inflammatory drugs (NSAIDs)

Ask your transplant team if any other information should be on your bracelet.

Plan for post-transplant costs

During the transplant evaluation process, you met with a financial counselor at your transplant center. Having insurance will help make sure you have a smooth post-transplant care process. This includes ongoing care with your transplant center, local kidney doctor, and prescription drug coverage. If you have any changes in your insurance status or are having trouble affording medicines and visits, make sure to let your transplant team know.

Primary insurance

Your primary source of insurance may be through:

- Your workplace
- Medicare – A federal medical insurance program for people age 65 and older, and some people under age 65 with certain disabilities or conditions
- Medicaid – A joint federal and state program that gives health coverage to some people with limited income and resources

Medicare offers coverage for immunosuppressants for eligible kidney transplant recipients. Discuss this with your financial counselor for more details. If you have Medicare, you can apply for social security insurance (SSI) or disability benefits to also help with costs.

Secondary insurance

You may also need a secondary insurance, such as through Medicare supplement (Medigap) or Medicaid.

Understand your insurance

It is important to understand certain parts of your insurance plan. You need to know if you have a deductible, co-insurance, or any out-of-pocket expenses, as well as prescription drug coverage.

When you meet with the financial counselor at your transplant center, talk with them about:

- Your current health insurance coverage. This includes any limits in coverage that may affect your pre-transplant and post-transplant care.
- If you need any supplemental or secondary insurance and how to apply

Fundraising

Some people hold fundraisers, such as through GoFundMe, to raise money for their transplant. If you want to do this, discuss this with the financial counselor at your transplant center. Money you get through fundraisers are considered income and can cause you to lose your Medicaid benefits.

Medicine costs

Your transplant coordinator or pharmacist may know of assistance programs from some pharmaceutical companies that may help with medicine costs.



What are the signs and symptoms of problems after my transplant?

It will be important to pay attention to your body and know the possible post-transplant problems that can happen. If you think you are having any of these problems, tell your transplant coordinator (or local kidney doctor if you are no longer visiting your transplant center).

Rejection

Rejection is when your body tries to attack your new kidney because it recognizes the kidney as someone else's. You will take immunosuppressants to dampen your immune system so that your body does not recognize that your new kidney is from someone else.

Rejection can make your new kidney not work well or stop working. There are no specific symptoms of rejection and typically you will not feel anything. However, these signs and symptoms have been associated with severe rejection:

- Chills
- Body aches
- Nausea
- Cough
- Fever
- Shortness of breath
- Swelling from fluid buildup (when part of your body swells because there is a buildup of fluids there)
- Weight gain
- Increased creatinine level. If your creatinine level goes up after a kidney transplant, your transplant team may do more tests, including a kidney biopsy, to make sure your transplanted kidney is healthy.

Infection

The same medicines that lower the chance of rejection unfortunately also raise your chance of infection. Infection is one of the most common problems after a transplant.

Signs and symptoms of an infection include:

- Fever (100.4 degrees Fahrenheit or above)
- Chills
- Diarrhea
- Fatigue
- Loss of appetite
- Shortness of breath
- Cough
- Coughing up thick mucus
- Difficulty or discomfort with urinating
- Skin rash
- Unexplained pain

Delayed organ function

This is when your new kidney takes a few days to weeks to ‘wake up’ and start working on its own. During this time, you may need to be on dialysis until the new kidney starts working on its own.

Wound infection

Your incision (the cut the surgeon made for the transplant surgery) may not be fully healed when you go home. It is important to follow the instructions for how to care for this wound that you got when leaving the hospital.

Look at your incision daily. Contact your transplant center right away if you notice redness, swelling, more pain, or leaking fluid from the wound. Do not bathe or go swimming until your incision has fully healed because this can introduce bacteria into your incision.

Dehydration

It is important to stay hydrated after your transplant. One of the best ways to stay hydrated is to drink plenty of water. Signs and symptoms of dehydration include:

- Feeling thirsty
- Dry mouth
- Dry skin
- Lightheadedness
- Dizziness
- Urinating less than usual
- Headache
- Weight loss

 **Tell your transplant team as soon as possible if you have these symptoms.**

Diabetes

Some of the medicines that you will be on after your transplant can raise your chance of diabetes. Diabetes is when your body is not making enough insulin to control your blood sugar levels, allowing glucose (a simple sugar that is the body's main source of energy) to build up in your blood.

Signs and symptoms of diabetes include:

- Feeling tired
- Feeling very thirsty
- Weight loss
- Urinating more often than usual
- Blurred vision
- Confusion

 **Tell your transplant team if you have these symptoms.**

High blood pressure

High blood pressure after your transplant can be caused by many things, including:

- Your transplant medicines
- Changes in how your kidney is working
- Having too much salt in your diet

High blood pressure often doesn't cause symptoms, so you should check your blood pressure at least once a week with a home blood pressure monitor. If your home blood pressure readings are consistently high (top number is more than 130 and bottom number is more than 80), make sure to tell your transplant doctors.

Cancer

Transplant recipients have a higher chance of certain types of cancers, such as lymphoma, skin cancer, and cervical cancer. Because of this, you should continue to get age-appropriate cancer screenings, as recommended by the CDC, after your transplant.



To learn what cancer screenings the CDC recommends, visit:

www.cdc.gov/cancer/prevention/screening.html

Lymphoma

Lymphoma is a type of blood cancer. Signs and symptoms of lymphoma include:

- Fatigue
- Unexplained weight loss
- Loss of appetite
- Fevers
- Night sweats
- Swollen lymph nodes



Tell your transplant team if you have these symptoms.

Skin cancer

Signs of a possible skin cancer include:

- New lesions or moles on your skin
- Changes in the size or shape of a mole, or if it is bleeding

➔ **See your dermatologist at least once a year for skin checks.**

Cervical cancer

There are often no symptoms of cervical cancer and it's often found through pap smears. Female transplant recipients should see their gynecologist annually to get screened for cervical cancer.

References

1. Post Transplant Process & Recovery | Heart Transplant. Cleveland Clinic. Accessed October 19, 2023. <https://my.clevelandclinic.org/departments/transplant/programs/heart/recovery>
2. Transplant Complications - Beaumont Hospital. Accessed October 19, 2023. <http://www.beaumont.ie/kidneycentre-forpatients-aguide-complications>

How do I stay healthy after my transplant?

Getting a kidney transplant can feel like getting another chance at life. Just remember, getting a transplant is a treatment, not a cure. So, there are precautions you should take after your transplant to help you stay healthy.

Taking your medicines

Taking your transplant medicines is one of the most important parts of keeping your new organ healthy.

Even missing 1 dose of medicine can cause your body to reject your new kidney.

Make sure you:

- Take your medicines every day as directed by your doctor
- Never stop taking your medicines without talking to your doctor
- Go to all of your doctor's appointments after your transplant
- Eat healthy
- Follow the instructions of your transplant team

Water safety

Follow water safety guidelines to lower your chance of infection from bacteria or parasites in water:

- Treated water in the U.S. is generally safe to drink
- Well water may not be checked frequently for bacteria and parasites. If you have well water, get the water checked to make sure it is safe to drink.
- Using a filter does not necessarily make well water safe to drink
- Pay attention to "boil water" advisories from your local government
- You can drink bottled water instead of boiling water



Food safety

Follow food safety guidelines to lower your chance of infection from bacteria in certain foods:

- Avoid undercooked and raw meats, poultry, and fish
- Avoid drinking unpasteurized milk
- Avoid cheeses made with unpasteurized milk, such as brie, feta, and camembert
- Avoid uncooked seafood, such as oysters, clams, and mussels
- For fresh meat cold cuts that are cut by a meat slicer, only get enough cold cuts for a single serving that you will eat that day. Or get processed deli meat in a package, as it may be safer.





Sports and recreation safety

In general, athletic activities are safe and encouraged for transplant recipients, but pay attention to what is considered safe and what is not safe:

Safer activities include:

- Running
- Basketball
- Swimming (swimming in salt water is safer than swimming in fresh water, such as lakes or rivers)
- Volleyball
- Aerobics
- Skating
- Tennis
- Cycling
- Soccer
- Golf
- Canoeing
- Weightlifting (low weight with high repetition)

Less safe activities have a higher chance of physical injury, such as:

- Football
- Karate and martial arts
- Ice hockey
- Trampolines
- Boxing
- Dodge ball
- Gymnastics
- ATV/snowmobiling
- Downhill skiing or snowboarding
- Sledding
- Power lifting (high weight with low repetition)
- Horseback riding

For activities outside with a lot of sun exposure, it is important to protect your skin, because transplant recipients have a higher chance of skin cancer, such as:

- Wear sunscreen of SPF30 or higher
- Avoid the sun during peak hours from 10am - 4pm
- Avoid tanning beds

Ask your transplant team when it's safe to restart your pre-transplant activities.



Animal contact and pet safety

Having pets is wonderful for our mental health. However, transplant recipients must be careful with pets, because they have a higher chance of getting infections from animals.

Here are some guidelines for certain animals:

- In general, dogs and cats are safe, but they must be up-to-date with their own healthcare, such as their shots
- If you have a cat, avoid changing the kitty litter. If that is not possible, change the litter daily and wear gloves and a mask.
- Avoid certain pets due to the higher chance of infection:
 - Rodents, such as guinea pigs or hamsters
 - Reptiles, such as lizards, snakes, or turtles
 - Amphibians, such as frogs or salamanders
 - Birds, such as parrots, parakeets, or finches

Here are some tips for animal safety:

- Wash your hands carefully after handling pets
- Do not let your pet lick your wounds or chew on your IV tubing
- Avoid handling pets with diarrhea
- Avoid animal bites and scratches and do not pet stray animals
- Ensure your home is free of raccoon latrines. These are areas where raccoons repeatedly go to the bathroom, which may include decks, patios, attics, or garages.

If you work with animals, such as a veterinarian, pet store employee, farmer, or slaughterhouse or laboratory worker, avoid work for 6 months after your transplant.

Gardening safety

Soil has many fungi and molds that can cause infections. You should avoid gardening for the first 6-12 months after your transplant. Ask your doctor when it's safe to work in the soil again.

Here are a few tips to protect yourself when it's safe for you to garden again:

- Wear gloves
- Cover your skin with clothing
- Wear a mask
- Use bug spray (and put it on last, after you're dressed)
- Check yourself for ticks





Travel safety

Discuss your travel plans with your transplant team at least 2 months in advance so they have time to review your plans for safety. You may also want to meet with a travel specialist who works with transplant recipients.

It is generally not recommended for transplant recipients to travel to:

- Developing countries
- Any place that requires vaccine for entrance

If you are traveling to the developing world:

- Water is often not safe to drink, so use only bottled water even for brushing your teeth
- Do not use ice as it likely comes from the local water system
- Follow the rule: “boil it, cook it, peel it, or forget it”
- Never get the yellow fever vaccine because it is a live vaccine. Live vaccines contain a weakened version of the germ it is trying to protect you from. Because of this, there is a small chance the vaccine can cause an infection.

Here are some tips for safe travel:

- Bring an extra supply of your medicine
- Keep all medicine in your carry-on bag
- Bring a note from your doctor explaining what each medicine is for
- Have a plan for leaving in case you get sick or have a medical emergency
- Have a plan in case you get diarrhea, because being dehydrated from diarrhea can affect the levels of your immunosuppressive drugs

Substances

After a kidney transplant:

- Alcohol may be safe in moderation, but talk with your transplant center
- Not much is known about marijuana safety, but keep in mind:
 - It can cause mental impairment, dangerous drug interactions, kidney injury, abnormal heart rhythms, and infections from molds
 - It is safer to eat an edible baked at 300 degrees rather than smoked
 - It may affect your anti-rejection drug levels
- Avoid smoking tobacco because it can lower blood flow to your kidneys and cause your kidneys to not work as well



Keeping a healthy weight

Keeping a healthy weight after your transplant can be hard because some of your medicines, such as steroids, can cause weight gain. Gaining weight can hurt your heart and bone health.

Here are some tips for keeping a healthy weight:

- Eat a healthy diet low in saturated fats and cholesterol, low in trans-fat, and high in fiber
- Limit alcohol. Alcohol has hidden calories and can make you hungry and eat more.
- Drink plenty of water (unless you are on a fluid restriction)
- Follow a low sodium diet
- Avoid dietary supplements as they can cause dangerous drug interactions, liver and kidney damage, and probiotics can cause infections





Safer sex practices

The best way to lower your chance of sexually transmitted infections (STIs) is to have fewer sexual partners or be in a long-term relationship with 1 person (monogamous).

Here are some ways to lower your chance of infection and STIs during sex:

- Always use latex condoms during sexual contact outside of monogamous relationships
- Consider latex condoms in monogamous relationships for the first 6 months after the transplant
- Avoid exposure to feces during sexual activity

Some medicines can affect sexual arousal and performance. Discuss these issues with your transplant team if they happen.



Having children

Many people have had children after a transplant. However, female transplant recipients do have a higher chance of problems during and after pregnancy. Always discuss plans for having children with your transplant team. All females who have a transplant should see a high-risk obstetrician. Doctors recommend:

- Waiting at least 1 year after surgery to become pregnant, until the kidney is stable and without episodes of rejection
- Using contraception early after transplant surgery
- Using long-term contraceptives such as intrauterine device (IUD) and subdermal implants

If you become pregnant, you will need to tell your transplant and obstetrical team right away. Some medicines are not safe for the baby during pregnancy. Your doctors will need to closely monitor your health throughout your pregnancy and after delivery.

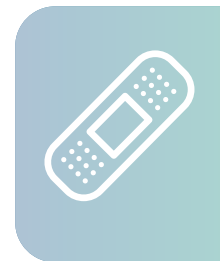
Vaccines

Vaccines are an important way to protect you and your family. Before your transplant, get any vaccines that need to be updated. Your vaccines will work better before your transplant. And make sure everyone in your household is also updated on their vaccines.

Soon after your transplant, you may not be able to get some vaccines, except for your yearly flu shot and pneumococcal vaccines.

Avoid live vaccines, which include MMR, varicella, rotavirus, yellow fever, and the intranasal flu vaccine. Live vaccines can sometimes carry infections. If you learn that someone you have been in close contact with recently got a live vaccine, contact your transplant team.

Whenever you are deciding to get a vaccine, remind your doctor or pharmacist that you are a transplant recipient.



Oral health

Good dental health can help prevent infections, while sore and bleeding gums can cause infections.

Some of your medicines and a poor diet can cause swollen, sore gums and teeth sensitivity.



Here are ways to keep your mouth and teeth healthy:

- Examine your gums and teeth daily
- Brush after each meal with a soft toothbrush and fluorinated toothpaste
- Floss daily
- Make sure any dentures have a proper fit
- Have your teeth cleaned and checked by a dentist every 6 months
- Always tell your dentist that you are a transplant recipient before having any cleanings or procedures done



Vision care

Some of your medicines, such as prednisone, can cause problems such as cataracts or dry eyes. Eye symptoms can be a sign of an infection starting. If you have any eye symptoms, let your transplant team know right away.

See an ophthalmologist (eye doctor) regularly for dilated, cataract, and glaucoma eye exams.



Mental health

Getting a transplant is a major life change and it is normal to have all kinds of feelings after a transplant. While some people may be overjoyed, some people may feel overwhelmed and stressed by the medicines and doctors' visits. Some people may have health problems after their transplant, which can lead to depression. Other people may feel anxiety while trying to keep themselves healthy.

If you ever need emotional support, seek a professional to help you process your feelings and help you cope with your new normal. Your transplant care team may be able to recommend counselors, support groups, and other mental health and wellness resources that can help you.

References:

1. Healthy Living for the Transplant Community.; 2021. Accessed October 19, 2023. <https://www.youtube.com/watch?v=95GOZesNOuY>
2. Avery RK, Michaels MG, AST Infectious Diseases Community of Practice. Strategies for safe living after solid organ transplantation. Am J Transplant. 2013;13 Suppl 4:304-310. doi:10.1111/ajt.12121
3. Deshpande NA, Coscia LA, Gomez-Lobo V, Moritz MJ, Armenti VT. Pregnancy After Solid Organ Transplantation: A Guide for Obstetric Management. Rev Obstet Gynecol. 2013;6(3-4):116-125.
4. Post Transplant Process & Recovery | Heart Transplant. Cleveland Clinic. Accessed October 19, 2023. <https://my.clevelandclinic.org/departments/transplant/programs/heart/recovery>

Glossary of common transplant terms

A

Allograft: Tissue or an organ that is transplanted from one person to another.

Antigen: A molecule, often a protein, that can cause an immune response from your immune system.

AV fistula: When an artery and a vein are connected. This can be done through surgery for hemodialysis.

B

BK virus: A virus that can affect kidney transplant recipients.

Brain death: When a person no longer has any brain function to keep them alive.

C

Chronic kidney disease (CKD): When your kidneys have permanent damage or do not work as well as they should that continues for 3 months or longer.

CMV (Cytomegalovirus): A virus similar to the viruses that cause chicken pox and mononucleosis. Transplant recipients have a higher chance of a CMV infection.

Creatinine: A waste product that your kidneys filter out of your blood. Some creatinine in the blood is normal, but too much can be a sign that there is a problem with your kidneys.

CT scan (Computed Tomography scan): An imaging scan that uses X-rays to take detailed pictures of the inside of your body.

D

DBD Donor (Deceased after brain death donor): A deceased donor who has been declared dead through brain testing.

DCD Donor (Deceased after circulatory death donor): A deceased donor whose heart has stopped beating.

Deceased donor: A person who donates an organ after their death (as opposed to a living donor, who donates an organ while they are alive).

Delayed graft function (DGF): The need for dialysis within 7 days of a kidney transplant.

Dialysis: A type of treatment in which a machine removes extra fluid, electrolytes, and waste products from your blood when your kidneys cannot.

E

End-stage kidney disease (ESKD/ESRD; also called kidney failure): When your kidneys can no longer work well enough to filter your blood due to chronic kidney disease. With ESKD, you need dialysis or a kidney transplant to do the job your kidneys cannot.

EBV (Epstein-Barr Virus): A very common virus that can lead to mononucleosis (a virus).

G

Glomerular filtration rate (GFR): A measure of how well your kidneys are working. The normal range of GFR is 90-120 mL/min/1.73 m². Your doctor may talk to you about percent of kidney function instead, since people are more familiar with percent than GFR. Measuring GFR is inconvenient, so you will usually see an estimated GFR (eGFR) that can be measured from a simple blood test.

Glomerulonephritis (GN): Kidney diseases caused by inflammation that damages the filters of the kidney, called the glomeruli.

Graft survival: How long a kidney transplant lasts.

H

Haplotype: A group of genes inherited (passed down) together from a single parent.

Hematuria: Blood in your urine (pee).

Hemodialysis (HD): A type of dialysis using a machine and a special filter to clean your blood and remove excess fluid. It is often done 3 times a week. People can get this at a dialysis center or in their own home (home hemodialysis).

HLA (Human Leukocyte Antigens): The main proteins that the immune system may react to after a kidney transplant, which may cause it to reject the new kidney. HLAs help your body tell the difference between you and a foreign substance.

Hypertension (or high blood pressure): A blood pressure that is higher than normal. This is usually when the top number is consistently higher than 130.

K

KDPI (Kidney Donor Profile Index): A score that measures the quality of a donor kidney. It ranges from 0 to 100. A lower score means the kidney is expected to work well for a longer time. A higher score means the kidney is expected to work well for a shorter time.

Kidney transplant: A surgery in which a healthy kidney from a living or recently deceased donor is placed into a person who has advanced chronic kidney disease or end-stage kidney disease.

M

Matching: The process of finding out how closely a donor and recipient's HLAs match (Human Leukocyte Antigens, which are proteins). The more similar the HLAs are, the more likely the transplant will succeed.

Microalbumin: Very small amounts of a normal protein called albumin. When it is found in your urine, it may be a very early sign of kidney disease.

MRI scan (Magnetic Resonance Imaging scan): A type of imaging scan that uses strong magnets and radio waves to take detailed pictures of the inside of your body.

N

Nephrectomy: A surgery to remove a kidney or kidney transplant.

O

Organ Procurement Organization (OPO): Not-for-profit organizations responsible for recovering organs from deceased donors for transplants in the U.S.

Organ Procurement Transplantation Network (OPTN): A public-private partnership that links all professionals involved in the U.S. organ donation and transplant system.

P

Panel Reactive Antibody (PRA): A measure of what proportion of the donor population a person with ESKD may have antibodies against. People with a higher PRA may have a harder time finding a donor and a higher chance of rejecting the transplanted kidney.

Peritoneal dialysis (PD): A type of dialysis that uses the lining of your abdomen, called the peritoneum, to filter blood inside your body. This can be done in this hospital or sometimes at home.

Primary Non-Function (PNF): When a kidney transplant never works the way it should.

Proteinuria: A high amount of protein in your urine. It may be a sign of kidney disease.

Pyelonephritis: A kidney infection.

R

Rejection: When a transplant recipient's immune system attacks the transplanted organ or tissue.

S

Stages of CKD: There are 5 stages of kidney disease, which are based on GFR test results. Stage 1 is mild kidney disease and stage 5 is severe chronic kidney disease.

T

Tissue typing: A way to figure out the antigens (proteins) of a specific patient to help match them to a donor kidney.

U

United Network for Organ Sharing (UNOS): A non-profit organization that manages the U.S. Organ Procurement and Transplantation Network (OPTN).

Uremia: A condition in people with advanced CKD where there is a build-up of waste products. Symptoms include fatigue, confusion, nausea, throwing up, and a metallic taste in the mouth.

Urinalysis (UA): A test that looks for abnormal amounts of blood, protein, glucose, and other substances in your urine.

W

Waitlisted/Listed Active: When you are on the kidney transplant waiting list and able to get a kidney transplant.

Waitlisted/Listed Inactive/On Hold: When you are on the kidney transplant waiting list but are not able to get a kidney transplant. This is usually due to an illness or insurance issues.



This content was developed independently by AST
and supported by a healthcare contribution from

