

1

# When to see your doctor about your kidneys



**Find Your  
Voice Toolkit**

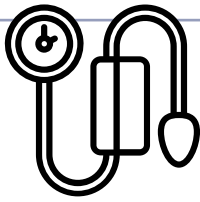
# Your kidneys

## 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:

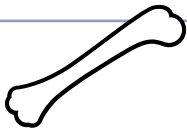
**Control your blood pressure**



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



**Keep your bones strong**



**Make red blood cells**

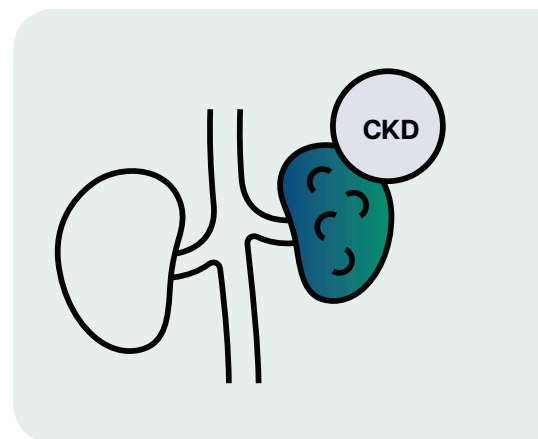


# Kidney disease

## 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.

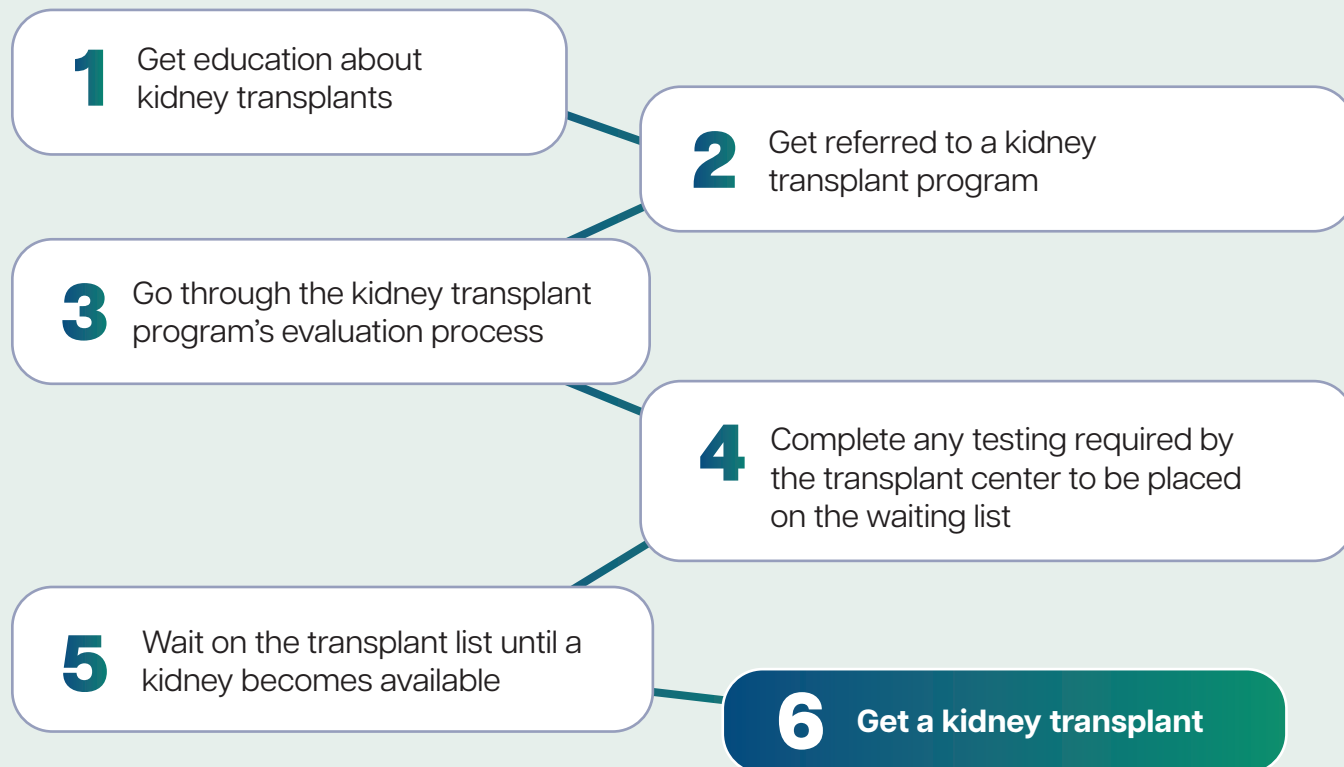
**We encourage you to learn about kidney transplants from your doctor before deciding if a kidney transplant is right for you.**





# 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 nephrologist (kidney doctor) 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



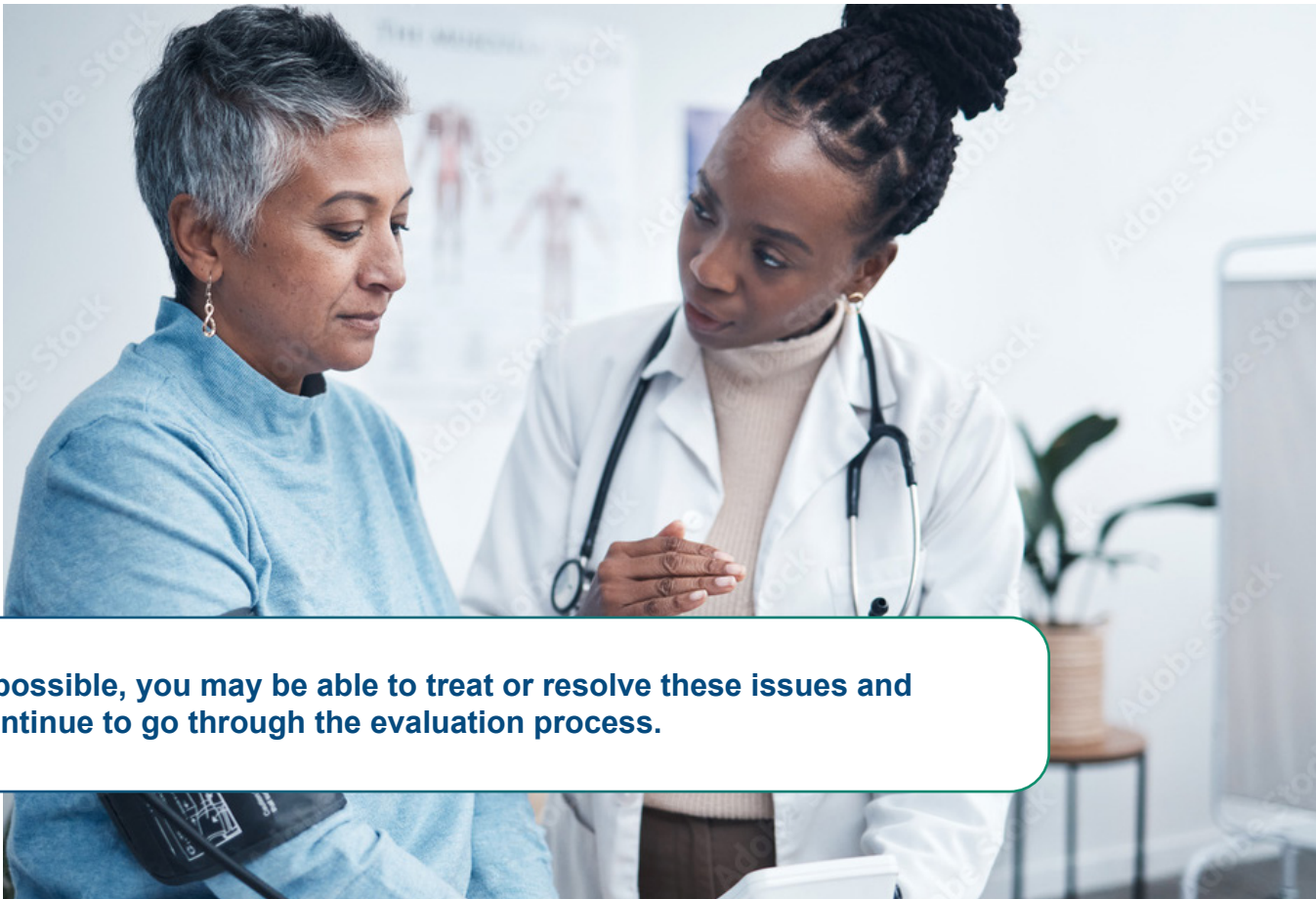
## What happens during the evaluation process?

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>

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

**sanofi**

