

KNOW

Your Cause

**YOUR GUIDE TO GETTING A
COMPLETE KIDNEY DISEASE DIAGNOSIS**



ABOUT *This Guide*

WHY SHOULD I FIND OUT THE CAUSE OF MY KIDNEY DISEASE?

It's important to know the cause of your kidney disease because it may affect the type of treatment you receive from your care team. This guide will walk you through the steps for getting a complete diagnosis for your kidney disease.

As many as
15%
of people do not
know the cause of
their kidney disease!

HOW TO USE THIS GUIDE

This guide can help you in the following ways:

1

Learn what
questions
to ask

2

Learn about
different tests
that are available

3

Have places
to take notes as
you work through
the guide

4

Bring it with
you to doctor
visits

AKF'S ROLE IN SUPPORTING YOU

The American Kidney Fund (AKF) is the only organization that takes a full approach to ending kidney disease. From helping people prevent kidney disease through life after a transplant, our work is powered by a caring community of people like you.

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WHY GET A *Complete Diagnosis?*

There are many reasons to find out the cause of your kidney disease. Some of these reasons include:



SLOW THE DAMAGE FROM KIDNEY DISEASE

If your care team knows what is causing your kidney disease, they can work to slow it down and treat the cause. For example, if your doctor finds out your kidney disease is due to diabetes, your doctor may prescribe certain medicines or ask you to follow a specific eating plan.



FAMILY PLANNING

Many kidney diseases are passed down through families (genetic). Knowing if your kidney disease has a genetic cause can inform your decisions about family planning and seeking health care for future children.



ACCESS TO CLINICAL TRIALS

Clinical trials are research studies that study how well new treatments work and how safe they are. Clinical trials are key to learning more about treating chronic kidney disease and other types of kidney diseases.

Often, researchers decide who qualifies to be in a clinical trial based on:

- Age
- Gender
- Having the disease or health condition being studied (patient volunteers)
- Not having the disease or health condition being studied (healthy volunteers)

Getting a complete diagnosis could help you qualify to take part in a clinical trial. To learn more about trials, visit [kidneyfund.org/kidney-health-for-all/clinical-trials](https://www.kidneyfund.org/kidney-health-for-all/clinical-trials).



PROTECTING THE TRANSPLANT

Knowing the cause of your kidney disease can help your doctors know which treatments may or may not help you. This includes helping to protect your kidney transplant, if you ever have one.



MANAGING OTHER HEALTH ISSUES

Your kidneys help your whole body work. When your kidneys do not work as well as they should, you have a higher chance of having other health problems. Knowing the cause of your kidney disease could help you manage your other health issues as well. For example, people with kidney disease may also have:

- Diabetes
 - High blood pressure
 - Gout (a type of arthritis)
 - Anemia (low red blood cells)
 - Heart disease
 - Bone disease
-



PEACE OF MIND FROM KNOWING

When your doctor tells you that you have kidney disease, you may be shocked and surprised. You may feel some sense of relief from finding out what is causing your kidney disease.

HOW DO YOU KNOW IF YOUR *Diagnosis is Complete?*

Doctors are experts on medicine, but you are the expert on your body and how you feel. Tell your doctor if you still have questions or unexplained symptoms.

HAVE YOU HAD THE BASIC TESTS?

Having the basic tests that check for kidney disease can help your doctor learn more about your diagnosis. Doctors can usually find kidney problems through:

- Blood tests
- Urine tests

DOES THE DIAGNOSIS MAKE SENSE TO YOU?

Trust your gut! Have you researched kidney disease on your own and found another explanation that your doctor has not mentioned? If so, be sure to print out any information and bring this up at your next visit.

SHARE ALL OF YOUR SYMPTOMS WITH YOUR DOCTOR.

Rare kidney diseases sometimes have symptoms that you might not connect to kidney disease. Here are just a few examples, but it is important to share any symptoms you are having that can't be explained.

- Hearing loss
 - Not sweating
 - Getting kidney stones often
 - Pain, tingling, or burning in your hands or feet
 - _____
- _____
 - _____
 - _____
 - _____
 - _____

HAVE YOU GOTTEN ADVANCED TESTING?

Your doctor might suggest more advanced testing if your tests show:

- Blood in your urine
 - A large amount of protein in your urine
 - Nephrotic syndrome (a group of symptoms that, when they happen together, can show that your kidneys are not working as well as they should)
 - No clear cause for your kidney disease
 - Kidney disease that has worsened quickly
-

More advanced testing might include:

- Imaging such as an x-ray or CT scan
- Kidney ultrasound
- Kidney biopsy
- Genetic testing

You can ask for more advanced testing if you have had basic tests (such as urine and blood tests) but still don't have a complete diagnosis.



WHAT TESTS ARE *Available?*

NAME OF TEST	WHAT THE TEST IS	WHAT DISEASES THE TEST COULD HELP FIND
eGFR (estimated glomerular filtration rate)	eGFR is a measure of how well your kidneys are working. Your eGFR is an estimated number based on a blood test and your age, sex, body type and race.	Examples: <ul style="list-style-type: none"> • Chronic kidney disease (CKD) • End-stage kidney disease (ESKD)
uACR (urine albumin-creatinine ratio)	A urine (pee) test that shows if you have albumin in your urine. Albumin is a type of protein that's normally found in the blood.	Examples: <ul style="list-style-type: none"> • CKD • ESKD • Nephrotic syndrome
Kidney ultrasound	A safe and painless test that uses sound waves to make images of your kidneys.	Examples: <ul style="list-style-type: none"> • Polycystic kidney disease (PKD), which includes both autosomal dominant and autosomal recessive, which are also called ADPKD and ARPKD • Acute kidney injury • Kidney stones
Kidney biopsy	A small surgery where doctors take a small piece of tissue from your kidneys to look at under a microscope.	Examples: <ul style="list-style-type: none"> • IgA nephropathy • Lupus nephritis • Glomerulonephritis • Interstitial nephritis • Amyloidosis
Genetic testing	Testing of a sample of blood or tissue to find changes in a person's genes.	Examples: <ul style="list-style-type: none"> • APOL1 (Apolipoprotein L1) – mediated kidney disease • Cystinosis • Autosomal dominant polycystic kidney disease (ADPKD) • Fabry Disease • aHUS (atypical hemolytic uremic syndrome) • Thrombotic thrombocytopenic purpura (TTP)

DO YOU KNOW YOUR *Family Health History?*

You are more likely to get kidney disease if you have a **family history of it.**



Learning about your family health history could help you and your health care team discover the cause of your kidney disease. And if you know you have a risk (higher chance) of kidney disease based on your family history, you can take the right steps to slow or stop it from getting worse.

If you want to talk with your family about kidney disease but don't know how to start, follow these tips:

HELPFUL STARTING POINTS

- Ask permission first! For example: "Can we talk about something important to me? I want to talk about kidney disease."
- Consider printing off resources to share from kidneyfund.org. This may give you an easy place to start or a way to guide the conversation.
- Don't force a discussion if someone is not comfortable.

QUESTIONS TO ASK YOUR FAMILY MEMBERS

- Has anyone in our family had kidney disease or kidney failure?
- Have you been tested for kidney disease?
- What other health conditions run in our family?
 - Diabetes
 - Heart disease or hypertension (high blood pressure)
 - Autoimmune diseases (the immune system mistakenly attacks healthy cells) such as lupus nephritis

GENETIC *Testing*

WHAT IS GENETIC TESTING?

Genes and mutations (changes in genes) are passed down from parents to children. You have two copies of each gene: one from each of your parents. Some people have a mutation in one or both copies of certain genes.

Kidney doctors and other experts think that more than 1 in 10 kidney disease cases (10%) in the United States may be genetic.

Genetic testing is done by testing of a sample of blood, saliva (spit) or tissue to find changes in a person's genes.



WHO CAN GET TESTED?

You and your doctor may consider genetic testing if you have kidney disease and do not know the cause. You may also consider genetic testing if you know a family member carries certain gene mutations such as APOL1 (a gene mutation that causes kidney disease). A carrier may not have symptoms of a disease, but can pass the gene to their children.

HOW TO GET GENETIC TESTING

Your doctor can order the genetic test or send you to a genetic counselor (a health care professional with specific training in genetics and counseling). The best way to find a genetic counselor is to ask your doctor for a referral.

OTHER RESOURCES

If your doctor doesn't want to do genetic testing, you can get a second opinion.

- Search for a clinic near you through the American College of Medical Genetics and Genomics: [clinics.acmg.net](https://www.clinics.acmg.net)
- Find a genetic counselor through the National Society of Genetic Counselors: [findageneticcounselor.nsgc.org](https://www.findageneticcounselor.nsgc.org)

WHO IS ON YOUR *Care Team?*

Good health care is a team effort! Care teams want to understand your needs and support your health. There are many people who can be part of your care team, and it includes you, too!

CONTACT INFORMATION:

Primary care doctor

Nephrologist (kidney doctor)

Renal (kidney) dietitian

Social worker

Mental health support, such as a therapist

Genetic counselor

Nurse

QUESTIONS TO ASK *Your Doctors*

Share This With
Your Doctor



QUESTIONS FOR YOUR *PRIMARY CARE DOCTOR*

Do you know what caused my kidney disease?

When should I see a nephrologist (kidney doctor)?

Can I still see you for other health problems?

Who should I call with new health problems or questions?

How often should I see you?

Should I make a follow-up visit with you if I get more information about my kidney disease?

QUESTIONS FOR YOUR *NEPHROLOGIST* (KIDNEY DOCTOR)

Do you know what caused my kidney disease?

What tests do you recommend for me?

Are there other specialists I should see?

Is there a specific eating plan I should follow?

Could my kidney problems be genetic? If so, what testing is available?

Will I need dialysis or a kidney transplant in the future?

Are there any new treatments for my condition?

Are there any clinical trials that I might be eligible for?

QUESTIONS TO ASK YOUR HEALTH INSURER

Is there a list of nephrologists who are in-network with my health insurance plan?

Will my plan cover the costs of getting a second opinion?

If my doctor thinks I need additional testing, what types of tests are covered?

What are my yearly deductible and maximum out of pocket I will spend?

Are my medicines covered by my plan?

MORE RESOURCES

Check out these additional helpful resources from AKF:

- **AKF website:** [kidneyfund.org](https://www.kidneyfund.org)
- **Kidney Kitchen:** kitchen.kidneyfund.org
- **AKF page for professionals:** [kidneyfund.org/professionals-and-research](https://www.kidneyfund.org/professionals-and-research)
- **Community Resources:** [kidneyfund.org/community-resource-finder](https://www.kidneyfund.org/community-resource-finder)

TRACK YOUR *Kidney Test Results*

USE THE EMPTY ROWS TO ENTER ANY ADDITIONAL TESTING YOU'VE HAD DONE

TEST	DATE	RESULTS	NOTES
eGFR			
uACR			

WHERE MY TESTS WILL TAKE PLACE

TEST	ADDRESS	PHONE NUMBER	WEBSITE
Kidney Ultrasound			
Kidney Biopsy			
Genetic Testing			

TRACK ALL OF YOUR *Numbers*

TEST	DATE	RESULTS	NOTES
Potassium			
BUN (Blood Urea Nitrogen)			
Serum Creatinine			
Cystatin-C			

NOTES FROM *Medical Visits*

Date of Visit: _____

Doctor Name: _____ Doctor Specialty: _____

Contact Information: _____

Notes: _____

Date of Visit: _____

Doctor Name: _____ Doctor Specialty: _____

Contact Information: _____

Notes: _____

CARE TEAM

Contact and Locations

	NAME	OFFICE LOCATION & CONTACT INFO
Primary care doctor		
Nephrologist		
Dietitian		
Social worker		
Nurse		
Mental health counselor		
Genetic counselor		
Health insurance benefits number		



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