

A caregiver's guide to finding the cause of kidney disease



As a caregiver you may feel that you are not always taken seriously or heard at doctors' appointments, but you play an important role in your loved one's journey, from helping them to better understand the cause of their kidney disease to providing support day to day. This guide will help you navigate doctors' appointments, conversations with the healthcare team and be a successful caregiver to someone who has kidney disease.



Why is it important to know the cause of kidney disease?

As a caregiver, understanding the cause and helping your care recipient navigate the process, can make a big difference. Knowing the cause of kidney disease can help in many ways including:

- Helping slow disease progression and choosing the best treatment options including medicines and surgery
- Navigating future health decisions and family planning if the disease has a genetic cause
- Accessing clinical trials
- Protecting overall health and helping to slow or avoid other health complications
- Bringing peace of mind to you and your care recipient



Navigating doctors' appointments

As a caregiver you may feel like your concerns or questions aren't always taken seriously, but you are an important part of the care team. Speak up, ask questions, and help your care recipient or loved one feel empowered. Your voice is important. Here are four steps to help with effective communication during appointments:

1 INTRODUCE YOURSELF:

At the start of any appointment, be sure to introduce yourself. This helps to clarify your role, establish trust and ensure open communication.

– “Hi, I’m [your name], and I am [patient’s name]’s caregiver.”

– “I’m here to help ask questions, take notes, and keep track of next steps.”



Quick tip! Bring a notebook or use your phone to take notes during the appointment.

2

ASK QUESTIONS DURING THE VISIT:

Speak up and don't be afraid to ask questions during appointments. This will allow you to be an advocate and ensure that your care recipient or loved one is getting the best possible care.

- *"Do you know what's causing their kidney disease?"*
- *"Are there other tests we should consider?"*
- *"Can you explain what [name of test] test results mean in simple terms?"*
- *"Is there anything I should watch out for at home?"*
- *"Where can we access the test results later? Will other members of our healthcare team be able to view these results too?"*
- *"What are the possible side effects of the medicine they've been prescribed or recommended?"*



Quick tip! Talk to your care recipient before the appointment and write down any questions you think of. This way you won't forget during the appointment.

3

ASK FOR CLARIFICATION:

Doctors' appointments can feel overwhelming, and it's normal to need something repeated or explained in a different way. If you don't understand something, don't be afraid to ask again. You play an important role in the health of the person you are caring for, asking for clarification can help to ensure effective and clear communication.

- *"Just to be sure, can you explain that part again?"*
- *"Would you mind repeating that? I want to make sure I understand everything clearly."*
- *"I don't understand that, can you explain in another way?"*

4

DISCUSS NEXT STEPS:

This can help you prepare for future appointments and help strengthen your relationship with the care team.

- *"What should we expect next?"*
- *"What follow-up appointments or tests are needed?"*
- *"Is there anything we need to do before the next visit?"*
- *"Can you go over those next steps one more time, just to make sure I've got it right?"*
- *"Do you have a summary or notes we can take home to help us remember everything?"*



Testing and Kidney disease

Knowing the different types of tests and what they can tell you about kidney disease is an important part of being a caregiver. You can better communicate with the care team, make informed decisions, and navigate appointments with confidence. Here are some common types of tests that doctors may order to learn more about kidney disease and its cause:



BLOOD TESTS:

- [eGFR \(estimated glomerular filtration rate\)](#) is a blood test that shows how well the kidneys are working by measuring the waste and toxins in the blood.
- [Serum creatinine level](#) is based on a blood test that measures the amount of creatinine in the blood to show how well kidneys are working.
- Your [blood urea nitrogen \(BUN\)](#) level is based on a blood test that measures the amount of urea nitrogen in the blood, which can tell doctors how well the kidneys are filtering blood.



URINE TESTS:

- [uACR \(albumin-to-creatinine ratio\)](#) is a urine test that measures how much albumin (protein) and creatinine (waste product from muscles) is present in the urine and can indicate how well kidneys are functioning.
- 24-hour urine test measures protein in the urine and looks for other substances like sodium or potassium which might indicate a specific kind of kidney disease.



KIDNEY BIOPSY:

Kidney biopsy is a procedure where a doctor will remove a small piece of kidney tissue and then examine it under a microscope for damage.



IMAGE TESTS:

Image tests look for physical changes (abnormal shape, injuries, cysts) in the kidneys that might be a cause of kidney disease.

- Kidney ultrasound
- CT or CAT Scan
- MRI
- Xray



GENETIC TESTING:

[Genetic testing and counseling](#) can be done when there is a family history of kidney disease or if other tests have not found a cause.

- Genetic testing uses blood or saliva (spit) to look at DNA and see if there are mutations that may cause kidney disease.
- **NOTE:** It may be helpful to meet with a genetic counselor (care professionals with special training in genetics) before and/or after genetic testing. This can help you better understand available genetic testing options and genetic test results for your loved one. Talk to your care recipient's healthcare team to get more information.

As a caregiver you play an important role in helping your care recipient or loved one to better understand the cause of their kidney disease and to help in their overall care and wellbeing.

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