



TALK TO YOUR DOCTOR ABOUT AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE (ADPKD)



Use this guide to talk with your doctor about:

- Tests to learn if you have ADPKD
- Ways to slow down kidney damage if you have ADPKD

ADPKD runs in families

ADPKD is the most common form of polycystic kidney disease (PKD). ADPKD causes cysts (fluid-filled sacs) to grow in the kidneys. These cysts damage the kidneys over time. Symptoms of ADPKD usually start when you're between 30 and 50 years old.

ADPKD is a genetic disease that is passed down from a parent with ADPKD to their child. If a parent has ADPKD, there is a 50% chance that they will pass the mutated gene on to their children.



Follow these tips to talk with your nephrologist (kidney doctor) about ADPKD, and how to find out if you have it.

Before your visit:

- Use the second page of this guide to write down your symptoms and plan questions to bring with you
- Ask a family member or friend to go with you to help remember what the doctor says

During your visit:

- Describe your symptoms to the doctor – this helps them give you the right care and information
- When you ask questions, start with those that are most important to you
- To make sure you clearly understand what your doctor explained, repeat the information back to them in your own words
- Write down your doctor's answers next to the questions

Symptoms that I'll tell my doctor about

My symptoms (check all that apply):

- | | | |
|--|--|--|
| ☐ Pain in my back and sides | ☐ Headaches | ☐ Blood in my pee |
| ☐ High blood pressure | ☐ Urinary tract infections (UTIs) | ☐ Kidney stones |

- My symptoms started when I was: _____ years old
 - Another family member also has kidney disease: ☐ Yes ☐ No Who: _____
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Questions to ask my doctor

- Is there anything in my medical history that raises my chance of having ADPKD? ☐ Yes ☐ No
If so, what? _____
 - Should I get tested for ADPKD? ☐ Yes ☐ No
 - What tests will you do to tell if I have ADPKD?

 - When will I find out the results of my tests? _____
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Questions about caring for ADPKD

- How do I take care of myself if I have ADPKD?

- What can I do to keep my kidneys working as long as possible?

- What are the chances my kidneys will stop working?

- What should I do to prepare if my kidneys stop working?

- What medications would help slow damage to my kidneys?

LEARN MORE



To learn more about ADPKD, scan the QR code
or visit KidneyFund.org/ADPKD