

Do you or a family member have kidney disease?

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 type 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 (runs in families) disease that is passed down from a parent with ADPKD to their child. You only need to have one parent with ADPKD to be born with it.



The earlier you know if you have ADPKD, the sooner you can take action and make a plan for the future.

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

Before your visit:

- Write down your symptoms and a list of questions to bring with you on the other side of this guide
- 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 on the other side of this guide



Symptoms that I'll tell my doctor about

My doctor wants to learn about my symptoms to give me the right care and information.

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: _____



Questions to ask my doctor

Questions about testing for ADPKD

- 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 tell you if I have ADPKD, and what happens in those tests?

Imaging tests: _____ Blood tests: _____

- When will I find out the results of my tests? _____

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? _____

Other questions I want to ask my doctor

- _____
- _____