

# 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 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 each of their children.



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?  
\_\_\_\_\_
- What medications would help slow damage to my kidneys?  
\_\_\_\_\_

### Other questions I want to ask my doctor

\_\_\_\_\_