

# Polycystic kidney disease (ADPKD)

## *Autosomal dominant polycystic kidney disease*

An inherited condition in which fluid-filled cysts grow in both kidneys. How fast it progresses varies a lot, and treatment can help protect your kidneys.

### What is it?

Many fluid-filled sacs (cysts) slowly grow in both kidneys. Over years, the kidneys get larger and can lose their ability to filter. Cysts can also grow in the liver. ADPKD is the most common inherited kidney disease, affecting about 1 in 1,000 people.

### How is it inherited?

It's caused by a change in a gene, most often *PKD1* or *PKD2*. One changed copy is enough to cause it, so each child of a parent with ADPKD has a 1 in 2 (50%) chance of having it. Some people have no family history.

### What you might notice

Symptoms usually start in adulthood, often between 30 and 50: high blood pressure (often the first sign), back or side pain, blood in the urine, kidney stones, urinary infections, or a full feeling in the belly.

### How it's found

- kidney ultrasound, usually the first test
- MRI to measure kidney size, which helps predict how fast it may progress
- genetic testing in some cases

### How it's treated

- **Blood pressure control**, to a target your team sets with you.
- For some people at risk of faster progression, a medicine that slows cyst growth. It needs regular blood tests. Your team will tell you if it's right for you.
- Treatment for pain, stones and infections.
- Planning for dialysis or a transplant if kidney function falls a lot.

### What you can do

- Drink plenty of water through the day, unless your team tells you otherwise.
- Eat less salt, aim for a healthy weight and don't smoke.
- Avoid anti-inflammatory pain relievers (NSAIDs) unless your doctor says they're okay. Your pharmacist can tell you which products contain them.
- **Talk with your family.** Relatives may want to ask their doctor or a genetic counsellor about testing.
- Tell your doctor if a close relative has had a brain aneurysm or bleeding in the brain. You may be offered screening.

### Get help right away

- **Call 911** for a sudden, severe headache, the worst of your life. It can be a sign of bleeding in the brain.
- Go to emergency for fever with back or side pain.

**Learn more:** PKD Foundation of Canada, [endpkd.ca](http://endpkd.ca). Kidney Foundation of Canada, [kidney.ca](http://kidney.ca).

General information only. This sheet doesn't replace advice from your own health care team. In an emergency, call 911 or go to the nearest emergency department.

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