

# Polycystic Kidney Disease: Information For Patients

## What Is Polycystic Kidney Disease?

Healthy kidneys filter wastes and control fluids in the body. In people with polycystic kidney disease (PKD), sacs filled with fluid called cysts form throughout the kidney. These cysts cause damage, making it harder for the kidneys to work. Cysts sometimes form in other places in the body, such as the liver and pancreas. Although PKD begins at birth and progresses throughout life, many people continue to have healthy kidney function for decades.

## What Causes PKD?

PKD is an inherited disease caused by a genetic mutation. The disease usually becomes apparent in people in their 30s. When one parent carries the genetic defect, each child has a 50% chance of inheriting PKD.

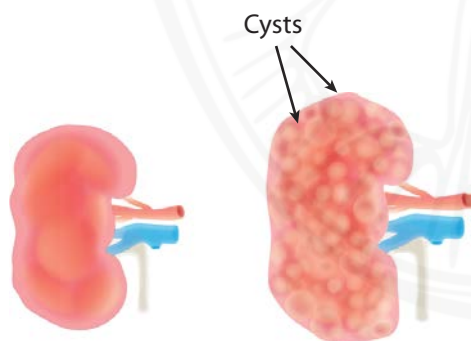
## What Are Common PKD Symptoms?

For many people, PKD may cause only minor problems or no symptoms at all until adulthood. The most common symptoms of PKD are low to middle back pain caused by the increasing size of the kidneys, headache, urinary tract infections, blood in the urine, high blood pressure, increased urination at night, and kidney stones. Severe headaches may be the sign of an uncommon but very serious brain condition called aneurysm that requires urgent attention.

## How Is PKD Diagnosed?

The first indication that someone might have PKD is a family history of kidney disease or one of the symptoms above. Studies that allow doctors to create an image of your kidneys can be used to identify cysts. The most common test is ultrasound, a painless procedure that uses sound waves to obtain an internal image. Rarely, a CT or MR scan is done. In unusual cases, a blood test can determine the genetic defect that causes PKD. When PKD runs in someone's family, this test can help predict the risk of passing the genetic condition on to children before cysts are visible. A specialist called a genetic counselor can help patients consider all the factors involved in deciding whether to get a genetic test.

In polycystic kidney disease, fluid-filled sacs called cysts develop throughout the kidney. The cysts eventually replace most of the healthy tissue of the kidneys causing them to stop working. After many years the kidneys may fail.



Normal Kidney

Cystic Kidney

## Is PKD Treatable?

There is no treatment that can stop PKD, although medications are being tested to find a way to slow cyst development and kidney damage. Currently, treatment focuses on managing the symptoms and addressing medical problems that arise as a result of PKD.

High blood pressure should be identified and controlled early. Medications to lower blood pressure can help to slow damage to the kidneys. Lifestyle changes such as diet and exercise can help with high blood pressure, as well as improve kidney health and functioning.

Over-the-counter medications can help to control back pain and headaches. Cysts sometimes get infected, which requires treatment including antibiotics. Surgery is sometimes used to reduce cyst size, and this can decrease pain.

Eventually, the kidneys are unable to function and about half of patients with PKD will have kidney failure by age 55. When kidneys fail, dialysis or transplantation are necessary. Dialysis can be used to remove wastes that would have been filtered out by the kidney. With hemodialysis, a machine circulates blood through an external filter and back into the body. With peritoneal dialysis, a solution is put into the abdomen (belly) and drained out after several hours. Transplanting a healthy kidney from a donor to the patient with PKD can allow a patient to live without dialysis and the new kidney will not develop cysts.

## What Should I Do Now?

- Write down your questions and concerns before you talk to your doctor.
- You may need to see one or more specialists. Having a team to help manage your PKD can provide you with a wide range of expertise.
- Keep a journal, writing down important changes in your health and lifestyle. Note the frequency and severity of your symptoms.

Always tell your doctor if you:

- Have blood in your urine
- Pass less or more urine than usual
- Feel burning or pain when urinating
- Feel increased need to urinate at night
- Feel lower back or abdominal pain
- Cannot control your blood pressure
- If you have a severe or unusual headache, it may be a medical emergency

## Where Can I Get More Information?

Polycystic Kidney Disease Foundation  
(800) 753-2873  
[www.pkdcure.org](http://www.pkdcure.org)

National Kidney Foundation  
(800) 622-9010  
[www.kidney.org](http://www.kidney.org)

**Authors:** Arlene B. Chapman, MD  
Jared J. Grantham, MD, FACP



Otsuka

Otsuka America Pharmaceutical, Inc.

Supported by an educational grant from  
Otsuka America Pharmaceutical, Inc.

©2013 CMEology