

Polycystic Kidney Disease

What is polycystic kidney disease?

Polycystic kidney disease (PKD) is an inherited disease that affects the kidneys. Sacs of fluid (called *cysts*) grow in the kidneys. If too many cysts grow or if they get too big, the kidneys become damaged. The cysts may also cause pain or may get infected.

PKD is the most common inherited disease in the United States. Children of parents with PKD have a 50% chance of getting the disease.

How will PKD affect me?

Most people with PKD can lead a normal life. In many people, the disease is mild and causes only minor problems. PKD is more severe in some patients and can cause kidney failure. About 60% of patients develop high blood pressure, which can be treated with blood pressure medicine. About 50% of patients with PKD have kidney failure by age 60. *Dialysis* (blood filtration that takes the place of the kidneys) or kidney transplant are both effective treatments for kidney failure. Men, blacks and patients with sickle cell disease generally have worse PKD.

What other organs can be hurt by PKD?

People with PKD may also have cysts in the liver, but these cysts seldom cause problems. Heart valve problems sometimes occur. Other organs that may be affected include the brain, intestines, pancreas, ovaries and spleen. If PKD affects the brain, it can cause an *aneurysm* (a bulging blood vessel that can rupture).

What are the symptoms of PKD?

The most common symptom of PKD is high blood pressure. Other symptoms are:

- Pain in the back and side
- Blood in the urine
- Frequent kidney infections

Symptoms usually begin in middle age. Not all patients will have all of these symptoms.

How is PKD diagnosed?

PKD is often diagnosed when a person begins to have symptoms, such as pain in the abdomen and side, blood in the urine or frequent kidney infections. Symptoms most often occur in middle age. There is also a childhood form of PKD, but this type of disease is less common. It is usually diagnosed shortly after a baby is born. This type of PKD is usually more severe than the type that occurs in adults.

If you have symptoms of PKD or if you are at risk of the disease, your doctor may want you to have an ultrasound exam to look at your kidneys. An ultrasound exam provides a picture of your organs by passing sound waves through the body. An ultrasound exam of your kidneys will detect any cysts in your kidneys. Your doctor may also order an x-ray exam called CT (*computerized tomography*) to look at the inside of your abdomen. If you have PKD, the cysts in the kidney can be seen on CT.

Who should be checked for PKD?

If one of your parents has PKD, you should consider having an ultrasound exam of your kidneys. If you have PKD and you also have a relative who has had a brain aneurysm, you are also at increased risk for a brain aneurysm. Your doctor may suggest that you have a CT or MRI of your brain to check for an aneurysm. With MRI, or *magnetic resonance imaging*, a magnetic field and radio waves are used to produce a picture of your brain. Either a CT or MRI can show an aneurysm. If you are at high risk of an aneurysm, your doctor may suggest that you have CT or MRI of the brain every five years to detect an aneurysm before it causes problems.

Is there treatment for PKD?

No treatment is available for the cysts that occur due to PKD. If the cysts are causing symptoms, these symptoms can be treated so you will be more comfortable.

Can PKD be diagnosed in unborn babies?

Yes. PKD can be diagnosed in unborn babies using procedures called *amniocentesis* (analysis of the amniotic fluid that surrounds the baby) and *chorionic villus sampling* (examination of a small piece of the placenta). The gene for PKD can be detected in the amniotic fluid or placenta. If you have PKD and you're pregnant, talk with your doctor to see if one of these procedures is right for you.

**How can I find
out more
about PKD?**



For more information, write to the Polycystic Kidney Research Foundation, 4901 Main St., Suite 320, Kansas City, MO 64112-2674, or telephone 800-PKD-CURE (753-2873). Information about dialysis and kidney transplantation is available from the National Kidney Foundation, Inc., 30 East 33rd St., New York, NY 10016, or you may telephone 800-622-9010.

This handout provides a general overview on this topic and may not apply to everyone. To find out if this handout applies to you and to get more information on this subject, talk to your family doctor.



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