CONDITION

Polycystic kidney disease

Polycystic kidney disease is an inherited condition that causes fluid-filled cysts to grow in the kidneys.

WHAT IT IS
Inherited condition causing multiple fluid-filled kidney cysts

BODY SYSTEM
Kidneys and urinary system

MAIN SYMPTOMS
High blood pressure, side pain, blood in urine, infections

WHAT CAUSES IT
Inherited gene changes

HOW IT IS DIAGNOSED
Kidney imaging, family history, and sometimes genetic testing

MAIN TREATMENT
Kidney protection, blood pressure control, and complication treatment

CAN IT BE CURED?
No - care can slow damage and treat complications

IS IT AN EMERGENCY?
Sometimes - especially with a sudden severe headache

LONG-TERM OUTLOOK
Often gradual kidney decline, with wide differences between people

Overview

Polycystic kidney disease, or PKD, is an inherited condition in which many fluid-filled sacs called cysts develop in the kidneys. These are different from the small, simple kidney cysts that many people develop with age.

As PKD cysts grow, the kidneys may become larger and work less well. Kidney function can remain stable for many years, but some people eventually develop kidney failure. PKD can also affect blood pressure and other parts of the body.

The main forms are:

ADPKD may also cause cysts in the liver. Less commonly, it is linked with weak areas in brain arteries, called intracranial aneurysms, and certain heart valve or blood vessel problems.

ARPKD can affect both the kidneys and liver. Children with this form need specialist kidney and liver care.

PKD is not related to polycystic ovary syndrome, despite the similar name.

- Autosomal dominant polycystic kidney disease (ADPKD): the most common form, usually diagnosed in adults
- Autosomal recessive polycystic kidney disease (ARPKD): a less common form that often becomes apparent before birth or during childhood

Symptoms

ADPKD may cause no symptoms for years. Some people learn they have it after imaging for another reason, during family screening, or when high blood pressure is found.

Possible symptoms include:

Pain may come from enlarged kidneys, bleeding into a cyst, infection, or a kidney stone. Sudden pain does not always mean the condition has worsened permanently, but it should be assessed if it is severe, persistent, or accompanied by fever or visible blood in the urine.

ARPKD can cause enlarged kidneys, high blood pressure, reduced kidney function, or breathing problems in newborns. Liver scarring may lead to increased pressure in the blood vessels around the liver, an enlarged spleen, or bleeding in the digestive tract.

Symptoms do not show exactly how well the kidneys are working. Blood and urine tests are needed to measure kidney function and look for kidney damage.

- High blood pressure
- Pain in the side, back, or abdomen
- Blood in the urine
- Repeated urinary tract or kidney infections
- Kidney stones
- A feeling of fullness in the abdomen
- Headaches, sometimes related to high blood pressure
- Tiredness as kidney function declines

Causes and risk factors

PKD is caused by changes in genes involved in the structure and function of kidney cells.

Most ADPKD is linked to changes in the PKD1 or PKD2 gene. A person with ADPKD usually has one altered copy of the gene. Each biological child then has a 1 in 2 chance of inheriting that change.

Some people have ADPKD without a known family history. This may happen because the gene change began in them, because affected relatives were never diagnosed, or because the condition was mild in earlier generations.

ARPKD is usually caused by changes in the PKHD1 gene. A child develops it after inheriting an altered copy from both biological parents. When both parents carry the same recessive condition, each pregnancy has a 1 in 4 chance of resulting in an affected child.

The speed of kidney decline differs greatly between people. The specific gene change, kidney size, early high blood pressure, and previous kidney complications can help specialists estimate risk. Lifestyle does not cause PKD, although smoking, uncontrolled blood pressure, and other health conditions can add to kidney and blood vessel damage.

Diagnosis

PKD is usually confirmed with kidney imaging. An ultrasound uses sound waves to show the kidneys and cysts. The number of cysts needed to support an ADPKD diagnosis differs by age and family history because simple cysts become more common with age.

Magnetic resonance imaging, or MRI, can show smaller cysts and measure kidney size in more detail. A computed tomography, or CT, scan may also show cysts, stones, bleeding, or other causes of pain. CT scans use radiation; some also require contrast dye.

Assessment commonly includes:

Creatinine is a waste product filtered by the kidneys. The eGFR uses the creatinine result and other information to estimate how well the kidneys are filtering blood.

Genetic testing is not needed for everyone. It may be considered when imaging is uncertain, there is no clear family history, a relative is being assessed as a possible kidney donor, or someone wants information for family planning. Testing does not always find a definite gene change or predict the exact course.

- Blood pressure measurement
- Blood tests for creatinine and estimated glomerular filtration rate, or eGFR
- Urine tests for blood, protein, and infection

- Review of family history
- Imaging of the kidneys and sometimes the liver

Treatment and management

There is no treatment that removes all PKD cysts or repairs the underlying gene change. Care aims to protect kidney function, control symptoms, and treat complications.

Good blood pressure control is central to care. Medicines that block the renin-angiotensin system, such as ACE inhibitors or angiotensin receptor blockers, are often used. The choice and target blood pressure are based on age, kidney function, pregnancy status, and other health factors.

Tolvaptan may be offered to selected adults with ADPKD who are at risk of rapid kidney decline. It can slow loss of kidney function, but it does not cure PKD. It causes increased urination and thirst and can affect the liver, so regular blood tests and specialist monitoring are required.

Other management may include:

Non-steroidal anti-inflammatory drugs like ibuprofen or naproxen , or NSAIDs, include ibuprofen and naproxen. Frequent or prolonged use can harm kidney function in some people. A clinician or pharmacist can advise whether a pain medicine is suitable.

Dialysis filters waste and extra fluid from the blood when the kidneys can no longer do enough. A transplant replaces kidney function with a donated kidney. The inherited cyst-forming process does not develop in the transplanted kidney.

Children with ARPKD may need treatment for breathing problems, high blood pressure, kidney failure, or complications of liver scarring. Their care usually involves paediatric kidney and liver specialists.

- Antibiotics like amoxicillin or doxycycline for bacterial urinary or kidney infections
- Pain treatment suited to the person's kidney function
- Treatment for kidney stones
- Procedures for selected large, painful, infected, or bleeding cysts
- Treatment of high cholesterol, diabetes, or other cardiovascular risks
- Dialysis or a kidney transplant if kidney failure develops

Complications

High blood pressure is common and may develop before kidney function falls. Over time, it can increase the risk of heart and blood vessel problems and can speed kidney damage.

Other possible complications include:

An intracranial aneurysm is a weakened, bulging area in an artery in the brain. Most people with ADPKD do not have a ruptured aneurysm. Routine screening is not required for everyone, but it may be discussed when there is a personal or family history of aneurysm or brain bleeding, certain high-risk circumstances, or significant concern after informed discussion.

A ruptured aneurysm can cause a sudden, extremely severe headache and is an emergency.

- Chronic kidney disease and kidney failure
- Bleeding into a cyst
- Kidney or urinary tract infections
- Kidney stones
- Persistent pain
- Liver cysts, especially in ADPKD
- Pregnancy complications related to high blood pressure or reduced kidney function
- Intracranial aneurysms in some people with ADPKD

Prevention

Inherited PKD cannot usually be prevented through diet, exercise, or other lifestyle choices. Nothing a parent did during pregnancy causes the usual genetic forms.

Genetic counselling can explain inheritance, testing, and reproductive options. It can be useful before pregnancy, but decisions about testing or family planning are personal.

Although the condition itself cannot be prevented, you may be able to reduce added stress on the kidneys. This can include keeping blood pressure controlled, not smoking, staying physically active, maintaining a suitable weight, and limiting excess salt.

There is no proven special diet that clears kidney cysts. Fluid, protein, potassium, and salt needs may change as kidney function changes, so dietary advice should match your test results and treatment. People taking tolvaptan need specific guidance about fluids and avoiding dehydration.

Living with it and what to expect

ADPKD often changes slowly over many years. Some people keep useful kidney function throughout life, while others develop kidney failure in middle or later adulthood. The timing cannot be predicted from symptoms alone.

Follow-up usually includes blood pressure checks, kidney blood tests, urine tests, and review of symptoms. Imaging may be repeated when it would change treatment or help estimate the risk of progression. Routine visits are also a chance to review medicines, pregnancy plans, pain, infections, and emotional wellbeing.

Kidneys may continue to enlarge even while blood test results look stable. Later, eGFR may begin to fall. This is why ongoing monitoring matters even when you feel well.

Most people can work, exercise, travel, and have relationships and families. Contact sports or activities with a high risk of a blow to enlarged kidneys may need individual discussion. Pregnancy is possible for many people with ADPKD, but kidney function and blood pressure should be reviewed because pregnancy can carry added risks.

ARPKD has a broader range of courses. Some babies are seriously affected at birth. Others reach childhood or adulthood while managing kidney disease, high blood pressure, and liver-related complications. Long-term needs may change as kidney or liver problems become more prominent.

When to get medical help

Arrange routine follow-up if you have PKD, even when you have no symptoms. Seek a medical review sooner for new or worsening side pain, repeated urinary symptoms, rising home blood pressure readings, increasing swelling, or changes in urination.

Seek urgent medical assessment for:

Call emergency services for a sudden, extremely severe headache, particularly with vomiting, neck stiffness, fainting, confusion, weakness, difficulty speaking, or a seizure. These symptoms can occur with bleeding around the brain and need immediate assessment.

Severe shortness of breath, chest pain, collapse, or stroke-like symptoms also require emergency care.

- Fever with side or back pain, which may indicate kidney infection
- Visible blood in the urine, especially if it persists or contains clots

- Severe or persistent abdominal, side, or back pain
- Vomiting that prevents you from keeping fluids down
- Very little urine or an inability to pass urine
- New severe headache during pregnancy, especially with vision changes or high blood pressure

Common questions

Is polycystic kidney disease cancer?

No. PKD cysts are not cancer. They form because of inherited changes in how kidney cells grow and handle fluid. A new solid mass or an unusual imaging finding may still need separate assessment.

Will everyone with PKD need dialysis?

No. Some people never reach kidney failure. Others eventually need dialysis or a transplant. Gene type, kidney size, blood pressure, age, and changes in eGFR help estimate risk, but they cannot predict an exact date.

Can kidney cysts shrink or go away?

PKD cysts usually do not disappear on their own. Tolvaptan may slow kidney enlargement in selected adults, but it does not remove existing cysts. A procedure may drain or treat a particular cyst when it is causing significant symptoms.

Can I pass PKD to my children?

A person with ADPKD usually has a 1 in 2 chance of passing the altered gene to each biological child. ARPKD follows a different pattern and usually requires both parents to carry an altered gene. Genetic counselling can explain the pattern in a particular family.

Can I get pregnant if I have PKD?

Many people with ADPKD have successful pregnancies. Risks are higher when there is reduced kidney function, high blood pressure, or previous pregnancy complications. Some blood pressure medicines and tolvaptan are not suitable during pregnancy, so a medication and kidney review is important before trying to conceive.

Does drinking more water stop the cysts growing?

There is not enough evidence that simply drinking large amounts of water prevents PKD progression. Too much fluid can also be unsafe in some circumstances. Follow advice based on your kidney function, medicines, heart health, and risk of dehydration.

Sources

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- GeneReviews: Autosomal Recessive Polycystic Kidney Disease-PKHD1
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- US Food and Drug Administration: Jynarque prescribing information