Kidney Health® Australia

Kidney cysts

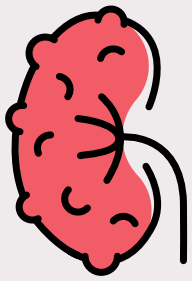
Cystic kidney disease causes pockets of clear, watery fluid sacs (cysts) to form in the kidneys. The cysts slowly replace healthy kidney tissue causing the kidneys to become larger. This makes it harder for your kidneys to work properly.

Benign or simple cysts are sacs filled with clear, watery fluid. They range from small blisters to large sacs filled with several litres of fluid.

This fact sheet covers the common types of cystic kidney disease:

- **Polycystic kidney disease**
- **Medullary cystic kidney disease**
- **Medullary sponge kidney**

Some people get simple cysts as they age. These are usually harmless. Cystic kidney disease is different, where many cysts can cause harm to the kidney.



What is polycystic kidney disease?

Polycystic kidney disease (PKD) is the most common inherited cystic kidney disease. It causes the growth of thousands of cysts in your kidneys.

Both kidneys are affected, but one kidney may develop the cysts earlier than the other. The cysts gradually grow, making your kidneys larger and replace healthy kidney tissue.

You may develop high blood pressure and kidney failure as a result of PKD. PKD affects males and females in equal numbers and the cysts can appear at any age.

There are two main types of PKD.

- **Autosomal Dominant PKD (ADPKD):** This is the most common inherited form of PKD. If you have ADPKD you have a one in two chance of passing the faulty gene to your children.
- **Autosomal Recessive PKD (ARPKD):** This is a less common form of inherited PKD where both parents carry this gene. In this case there is a one in four chance of passing the faulty gene to your child. Cysts can develop in the early months of life or even before birth. Children with ARPKD can have poorly working kidneys which can lead to kidney failure.

For more information about PKD see the **Polycystic Kidney Disease** fact sheet.

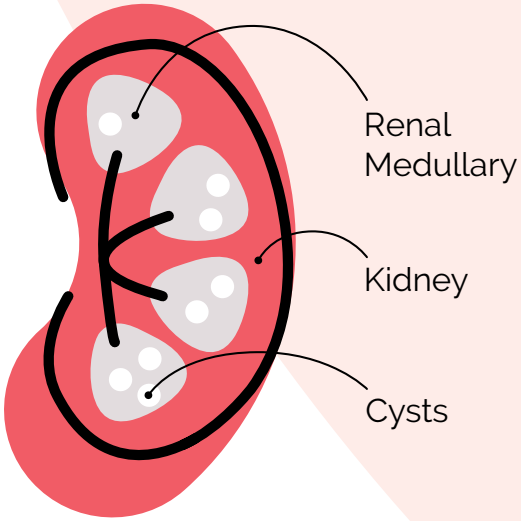
What is medullary cystic kidney disease (MCKD)?

Medullary cystic kidney disease (MCKD) is an inherited kidney disease. If you have MCKD, it is likely that other people in your family have it too.

In rare cases, MCKD is not inherited, but is due to a mistake in your genes.

MCKD can cause cysts to form in the medulla (centre of your kidneys). These cysts can cause scarring of the kidney tissue.

Your kidneys gradually lose their ability to work properly, eventually leading to kidney failure. Some people with MCKD have trouble filtering out a waste called uric acid. This can build up in MCKD and lead to gout, a painful condition affecting your joints. Other signs include having to wee more often or at night and salt cravings.



A picture of a kidney stone

What is medullary sponge kidney?

Medullary sponge kidney is where small cysts develop in the small tubes inside your kidneys. The cause of medullary sponge kidney is not known, with only less than 5% of cases linked to genetics. One or both kidneys may be affected.

Most people do not have any symptoms.

Medullary sponge kidney can cause other problems, like:

- **kidney stones**
- **pain in the abdomen (stomach pains)**
- **urinary tract infections**
- **blood in the urine (haematuria)**
- **calcium in the kidneys.**

Kidney failure is rare but can develop if you have had repeated infections or kidney stones.

How is cystic kidney disease diagnosed?

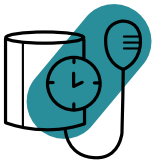
Autosomal recessive PKD is usually found soon after birth. However, in most other cases of cystic kidney disease, you may not notice health symptoms for many years.

Physical check-ups, blood and urine tests, or even ultrasound scans may not pick it up in the early stages.

It is often found when you visit your doctor for other health problems, such as kidney stones or urinary tract infections. Sometimes, cystic kidney disease is not discovered until high blood pressure or kidney failure develops.

Cystic kidney disease is often picked up when your doctor tests for other health problems.

Diagnosing cystic kidney disease can involve a number of tests including:



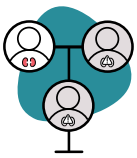
Blood pressure checks and physical exams - your doctor may detect high blood pressure or enlarged kidneys.

Blood tests - to check how well your kidneys are working to filter your blood and remove wastes.

Urine tests - may detect blood and/or protein in the urine (wee).

Ultrasound - uses soundwaves to show an image of the smalls cysts in the kidney.

Computed tomography (CT) and magnetic resonance imaging (MRI) scans - imaging tests to detect very small cysts. They may be required if the results from the ultrasound are not clear or more information is needed.



Genetic testing - involves a medical test that identifies changes in chromosomes, genes, and proteins. Your doctor may recommend genetic testing if cystic kidney disease runs in your family.

How is cystic kidney disease treated?

There is not a cure for cystic kidney disease. Finding it early and getting the right care can help to slow down kidney damage and prevent problems.

- **High blood pressure:** Keeping your blood pressure under control helps to protect your kidney function. Medicines, such as ACE-inhibitors (medicines ending in -PRIL) or angiotensin receptor blockers (medicines ending in -SARTAN) are used to lower your blood pressure and protect your kidneys.
- **Pain:** Sometimes cystic kidney disease can cause pain, especially if you have kidney stones, bleeding, or an infection.
- **Blood in the urine:** Bleeding can occur if you have kidney stones or infection. Your doctor may suggest fluids, medicine, and/or bed rest.
- **Urinary tract infections (UTIs):** Germs can spread to the cysts in the kidneys. If you feel pain or are needing to urinate (wee) more often, speak to your doctor as soon as you can. Your doctor will prescribe antibiotic medicines to treat UTIs.
- **Kidney stones:** These are more common in medullary sponge kidney and PKD. Some kidney stones will pass on their own. Others may require medicines or surgery to be removed.
- **Kidney failure:** Treatments for kidney failure include dialysis or kidney transplant. Cystic kidney disease does not redevelop in a transplanted kidney.

There is no cure for cystic kidney disease. However, early detection and proper treatment can reduce complications or slow the worsening of kidney function.

For ADPKD, there is a new medicine available to help slow the formation of cysts and delay kidney failure. Ask your nephrologist if this medicine is right for you.

Healthy habits to support your kidneys

In addition to following up with your doctor and taking any prescribed medicines, you can follow these healthy lifestyle choices to manage your kidney disease:

Eat a healthy diet.

Eat 5 serves of vegetables and 2 serves of fruit per day, along with lean proteins and wholegrains. Avoid ultra-processed foods.

Limit alcohol.

The less you drink alcohol, the better. Drink no more than four standard drinks per day or ten per week.

Drink water instead.

Avoid sugar-sweetened drinks like cola, fruit juices, and energy drinks. You may be advised to drink up to two litres a day if you have recurrent kidney stones due to your cystic kidney disease.

Exercise regularly.

Aim for 2.5 - 5 hours of moderate intensity exercise per week.

Stop smoking or vaping.

If you need tips to help you quit, call the Quitline on 13 7848 or speak to your doctor.

Maintain a healthy weight.

Exercise and a healthy diet can help.

Reduce salt in your diet.

Do not add extra salt at the dinner table.

If cystic kidney disease means your kidneys are very enlarged, you may need to avoid contact sports, as a strong knock to your stomach area can cause damage.

Things to remember:

- ✓ **Cystic kidney disease causes pockets of clear, watery fluid (cysts) to form in the kidneys, making it harder for your kidneys to work properly.**
- ✓ **Cystic kidney diseases include: polycystic kidney disease (PKD), medullary cystic kidney disease, and medullary sponge kidney.**
- ✓ **Treating other health problems, like high blood pressure, kidney stones, and UTIs, can help protect your kidneys.**
- ✓ **A new medicine is available to reduce cysts in ADPKD. Ask your doctor if this medicine is right for you.**

What does that word mean?

Anaemia – When there are only a small number of red blood cells in the blood or the blood cells are not working properly. Red blood cells carry oxygen, so if you have anaemia you can feel weak, tired and short of breath.

Blood pressure – The pressure of the blood in the arteries as it is pumped around the body by the heart.

Dialysis – A treatment for kidney failure that removes waste products and excess fluid from the blood by filtering the blood through a special membrane.

Gene – Each cell in the human body contains about 25,000 to 35,000 genes. Genes carry the information that determines your traits, which are features or characteristics that are passed on to you - or inherited - from your parents.

Gout – is a type of arthritis which causes pain in your joints. Your doctor will advise on a treatment plan which will include following a healthy lifestyle.

Kidney stones – Kidney stones happen when salts in the urine form a solid crystal. These stones can block the flow of urine and cause infection, kidney damage or even kidney failure.

Mutation – A gene that is faulty and does not work like it should. This can be inherited or caused by environmental factors including diet and chemicals.

Urinary tract infection (UTI) – causes symptoms like needing to urinate frequently or pain when urinating. It is caused by bacteria and may need to be treated with antibiotics.

Kidney Health® Australia

Free Kidney Helpline 1800 454 363
kidney.org.au

If you have a hearing or speech impairment, contact the National Relay Service on 1800 555 677 or relayservice.com.au
Have them connect you to the Free Kidney Helpline - 1800 454 363

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