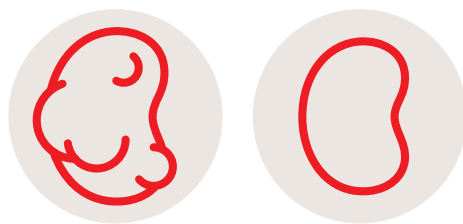


Fact sheet

Kidney Cysts

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Cystic kidney disease causes pockets of clear, watery fluid (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.



Kidney cysts

Normal kidney

Benign cysts are non-cancerous sacs filled with clear, watery fluid. They range from small blisters to large sacs filled with several litres of fluid. Having a few cysts is not unusual, particularly as you become older. These cysts don't usually need treatment and do not mean that you have cystic kidney disease.

Cysts can develop if you have had long-term kidney problems, such as kidney failure and have been on dialysis for a long time. This is called Acquired Cystic Kidney Disease (ACKD). These cysts are not inherited (passed on from your parents) and do not usually need treatment.

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

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

What is polycystic kidney disease (PKD)?

Polycystic Kidney Disease (PKD) is the most common inherited cystic kidney disease. It causes the growth of thousands of cysts (fluid filled sacs) 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 reducing 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 - This is the most common inherited form of PKD. If you have autosomal dominant PKD you have a one in two chance of passing the faulty gene and associated disease to your children. Sometimes, PKD can develop if you have no family history, and it is thought to be caused by a different genetic mutation. If you are planning on starting a family, you can have a blood test and speak to a genetic counsellor to reduce your chance of passing the gene to your child.

Autosomal Recessive PKD - This is a less common form of inherited PKD where both parents have to 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 autosomal recessive PKD may have reduced kidney function any time during childhood and teenage years, which can eventually lead to kidney failure or liver problems.

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

What is medullary cystic kidney disease (MCKD)?

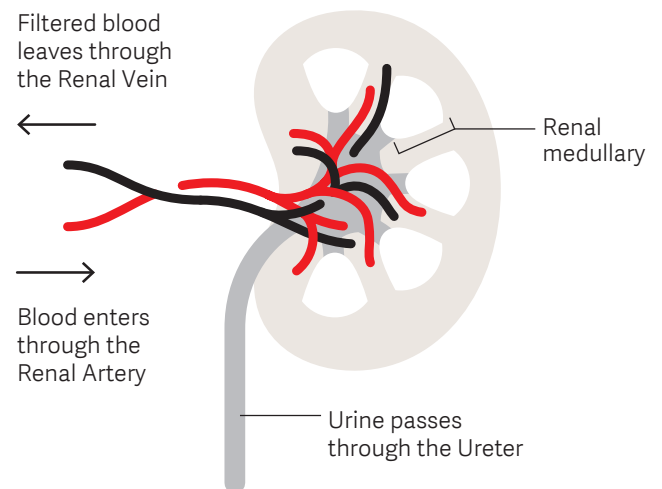
Medullary cystic kidney disease (MCKD) is an inherited kidney disease. If you have MCKD it is likely that other people in your family have it too. In some cases MCKD is not inherited, but is due to a new genetic mutation.

MCKD causes cysts to form in the medulla (centre of your kidneys). Your kidneys gradually lose their ability to work properly, and may eventually lead to kidney failure. Other health problems might include anaemia, kidney bone disease, gout and high blood pressure.

Juvenile nephronophthisis is very similar to MCKD but usually occurs in young children. Juvenile nephronophthisis can also lead to other eye sight problems.

What is medullary sponge kidney?

Medullary sponge kidney is where cysts develop in the kidney's urine collecting ducts and tubules. The cause of medullary sponge kidney is not known. One or both kidneys may be affected. Complications include blood in the urine (haematuria), calcium in the kidneys, kidney stones or infections. Kidney failure is rare but can develop if you have had repeated infections or kidney stones.

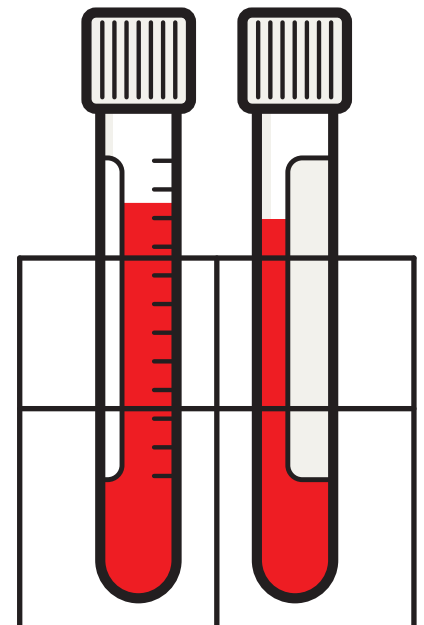


How is cystic kidney disease diagnosed?

The severe symptoms of autosomal recessive PKD usually result in an early diagnosis. 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 urinary tract stones or infections. Sometimes it isn't found until high blood pressure or kidney failure develops.

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

- **Physical checks** - your doctor may detect high blood pressure or enlarged kidneys
- **Blood tests** - to check how your kidneys are working to filter your blood and remove wastes
- **Urine tests** - may detect blood and/or protein in the urine (wee)
- **Ultrasound** - is good at identifying even quite small cysts
- **Computed Tomography (CT) and Magnetic Resonance Imaging (MRI) scans** - can detect very small cysts. They may be required if the results from the ultrasound are not clear or more information is needed
- **Genetic testing** - generally only used if cystic kidney disease runs in your family



How is cystic kidney disease treated?

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



High blood pressure - Effective blood pressure control is very important for maintaining your kidney function. Medications and a healthy lifestyle can help to lower your blood pressure.

Pain - May be due to kidney stones, bleeding or infection. Talk to your doctor if you are getting repeated or severe back and kidney pain, or headaches. Cysts can sometimes be drained to help extreme back and leg pain.

Blood in the urine - May also be due to kidney stones, bleeding or infection. Fluids, medications and bed rest may be required.

Urinary tract infections - Can spread to the cysts in the kidneys. If you feel pain or are needing to urinate more often, speak to your doctor as soon as you can about antibiotic treatment.

Kidney failure - Usually develops very slowly, over many years and may eventually require dialysis or a transplant. Cystic kidney disease does not redevelop in a transplanted kidney.

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.

Non-steroidal anti-inflammatory medications (NSAID's) should not be taken without medical advice as they can worsen kidney function.

Changes to your diet may also help to treat cystic kidney disease. These may include reducing salt, protein, cholesterol (fats) and caffeine. Any changes should be made after talking with your doctor or dietitian.

It is strongly advised that you do not smoke.

New developments

There are several promising developments in preventing cyst growth in PKD. Trials are being done in Australia with medications that may stop the sacs filling up with fluid. Results from worldwide studies have shown promising results for medications which prevent cyst growth and slow the decline of kidney function. These are expensive and have side-effects, and are not yet available in Australia. However, progress is occurring.



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) which is the most common inherited form, medullary cystic kidney disease, and medullary sponge kidney.
- At the moment there is no cure for cystic kidney disease. Early detection and proper treatment may reduce or prevent some of the symptoms and complications.

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.

Computed tomography - An imaging procedure that uses special x-ray equipment to create a series of detailed pictures or scans of areas inside your body.

Cyst - A sack full of fluid.

Dialysis - A treatment for kidney failure that removes waste products and excess fluid from the blood by filtering the blood through a special membrane. There are two types of dialysis; haemodialysis and peritoneal dialysis.

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.

Genetic counsellor - someone trained to help people understand and make decisions around the medical, psychological, family and reproductive effects of your genetic condition. They do not make decisions for you, but will help you reach decisions which are right for you and your family. More information can be found from The Australasian Society of Genetic Counsellors (ASGC) at www.hgsa.org.au/asgc.

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.

Hormone Replacement Therapy (HRT) - can help women with symptoms from menopause.

Kidney bone disease - kidneys play an important role in keeping your bones healthy including levels of calcium, phosphorus and vitamin D. People with kidney disease often develop problems with their bones.

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.

Magnetic Resonance - An imaging procedure that uses a magnetic field and radio waves to take pictures inside the body. It is especially helpful to collect pictures of soft tissue such as organs and muscles that don't show up on x-ray examinations.

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.

Non-steroidal anti-inflammatory drugs (NSAIDs) - Medications are often used to manage pain and inflammation (swelling and redness). They should only be used for short periods of time, so speak to your doctor if the pain does not get better. Some commonly used NSAIDs include aspirin (in brands like Disprin), ibuprofen (such as Nurofen), naproxen (such as Naprosyn), diclofenac (such as Voltaren) and celecoxib (such as Celebrex).

Ultrasound - An imaging procedure where an instrument is moved over the skin, sending and receiving signals to make pictures of your organs, including kidneys and bladder.

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.

For more information about kidney or urinary health, please contact our free call Kidney Health Information Service (KHIS) on 1800 454 363.

Or visit our website kidney.org.au to access free health literature.

This is intended as a general introduction to this topic and is not meant to substitute for your doctor's or health professional's advice. All care is taken to ensure that the information is relevant to the reader and applicable to each state in Australia. It should be noted that Kidney Health Australia recognises that each person's experience is individual and that variations do occur in treatment and management due to personal circumstances, the health professional and the state one lives in. Should you require further information always consult your doctor or health professional.

Kidney Health Australia gratefully acknowledges the valuable contribution of Associate Professor Neil Boudville in the review of this material.



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