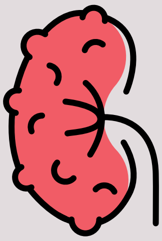
Kidney Health Australia

Multicystic dysplastic kidney

Multicystic dysplastic kidney (MCDK) is a condition that happens when one of the kidneys does not form correctly in the womb before birth.



- **Multicystic** means many fluid filled sacs (cysts).
- **Dysplastic** means the tissues in the kidney do not grow in a normal way.

The kidneys begin to develop at around the 5th or 6th week of pregnancy. If something goes wrong during this time, it is possible to end up with one or both kidneys that do not work as well.

In MCDK, the ureters (which connect the kidney to your bladder) or nephrons (filtering units) do not form well or become blocked. This causes the urine (wee) to build up in the baby's kidney and causes cysts and scars.

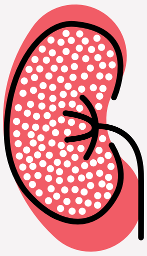
After birth, the **affected kidney shrinks** and may disappear over time. If only one kidney is affected, the remaining kidney grows larger and heavier. This single kidney provides up to 75 per cent of normal kidney function rather than the 50 per cent you might expect.

MCDK can rarely affect both kidneys. This is called **bilateral MCDK**. If babies are born with this condition, it can be life threatening, and they may need dialysis from birth.

MCDK should not be confused with polycystic kidney disease, which is a condition affecting both kidneys that gradually gets worse over time.

Most people born with MCDK in only one kidney have normal lifespans.

What causes MCDK?



MCDK is caused by a random problem when your kidneys are forming in the womb. Building your kidneys is complicated, with hundreds of thousands of steps that must occur correctly. A problem in even one step can lead to an abnormal kidney.

Usually, the cause of MCDK is not known. There are rare cases when MCDK runs in families because of a hereditary condition, meaning that it's passed down from your parents' genes. However, most of the time MCDK happens with no family history.

MCDK is thought to affect between 1 and every 1,000 to 4,300 births. That number may actually be higher because some people who have it are never diagnosed. It occurs more frequently in boys than in girls, and is most common in people of Caucasian background.

Can it be prevented?

Because the cause of MCDK is not known, there is no way to prevent MCDK.

In some babies, it is likely that there was a blockage to the kidney that ended up causing the damage.

If you are **pregnant or planning to become pregnant**, be sure to talk to your doctor about any medicines that you take.

A few cases of MCDK have been linked to taking certain drugs during pregnancy. Your doctor will tell you which medicines are safe during pregnancy.

How is it diagnosed?

Most cases of MCDK are discovered before birth. This is because it can be noticed on a routine pregnancy ultrasound.

An **ultrasound** is an imaging test that uses sound waves to show the kidneys of your baby inside your womb. The doctor may see cysts and scarring on one or both of your baby's kidneys.

Sometimes, your doctor orders extra scans, like a **nuclear scan**, to check the baby's kidneys and confirm what is happening.

Your doctor may recommend **genetic testing** to identify other possible health problems for your baby. Genetic testing involves taking a sample of the amniotic fluid (the fluid surrounding your baby) or taking a blood test.

What are the problems with MCDK?

MCDK does not usually cause any symptoms. Many people may have only one working kidney and not even know it. Some were born with MCDK, and the damaged kidney slowly shrank before anyone noticed.

Most people with MCDK live a normal life and do not have long-term effects from the disease. The normal kidney usually works well and easily does the work of two kidneys.

It is recommended that your child sees a **nephrologist** (kidney specialist) at least once to make sure the remaining kidney is healthy. In some cases, there may be other problems with the structure of the remaining kidney.

Some babies may develop **urinary reflux**, where the urine (wee) flows back up towards the bladder and kidneys. The doctor may order a test called a **voiding cystourethrogram** to check for this condition. This test uses an X-ray to take an image of your child's bladder when urinating. Luckily, this condition is treatable.

Most children with MCDK can play sport, go to school, and live a normal life with one kidney. To learn more, see our factsheet Life with a single kidney

What is the treatment?

Most cases of MCDK require no special treatment. Over time, the abnormal kidney usually shrinks and just goes away. In rare cases, the doctor will remove the affected kidney in a surgery called a nephrectomy.

Most people with MCDK have one working kidney for the rest of their life. There is no reason to adjust medicine doses or to have a special diet, unless advised by your doctor. If you know your baby has MCDK, regular follow-up with the doctor is important to monitor the health of your baby's kidneys.

The doctor will order regular ultrasounds to ensure that the cystic kidney does shrink and the remaining kidney grows. People with MCDK should also have regular Kidney Health Checks, which include:

A blood pressure check + **A urine test** + **A blood test**

What can I do to cope?

Learning about your baby's diagnosis of MCDK can be frightening and you may feel upset, angry, or hopeless. These feelings are normal and okay.

To help yourself feel better, ask questions if things aren't clear, and take small steps each day to care for yourself.

Help is available. Talking to a trusted family member or asking for a referral to a social worker can help relieve stress. Social workers and psychologists are trained to help you process your thoughts and cope with your emotions.

Things to remember:

- ✓ Multicystic dysplastic kidney is when one or both kidney does not develop properly before birth and is **full of cysts and scar tissue**.
- ✓ The cause of MCDK is not known, and usually **happens by chance**. Babies with MCDK can have normal lifespans.
- ✓ Your doctor will **monitor the health of your kidneys** with regular ultrasounds and Kidney Health Checks.

What does that word mean?

Dysplastic – Abnormal development or growth of tissues, organs, or cells.

Hereditary – Characteristics that are passed from parents to their children.

Cyst – A sack full of fluid.

Nephrectomy – Surgical removal of one or both kidneys.

Nephrologist – A medical doctor who specialises in kidney function.

Nephron – The tiny parts of the kidney that filter blood to make urine. There are over one million filters in each kidney.

Nuclear scan – An imaging procedure that uses radioactive substances to show structures and functions inside your body.

Polycystic kidney disease (PKD) – An inherited kidney disease where many fluid filled sacs (cysts) grow on the kidneys.

Ultrasound – An imaging procedure that uses sounds waves to show structures and functions inside your body. This is a diagnostic test, often used to measure the size of the kidneys.

Ureter – The tube that connects the kidneys to the bladder.

Kidney Health® Australia

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kidney.org.au

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Have them connect you to the Free Kidney Helpline - 1800 454 363

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