

# Multicystic dysplastic kidney (MCDK)

This infoKID topic is for parents and carers about children's kidney conditions. Visit [www.infoKID.org.uk](http://www.infoKID.org.uk) to find more topics about conditions, tests & diagnosis, treatments and supporting information.

Each topic starts with an overview followed by several sections with more information.

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A multicystic dysplastic kidney (MCDK or MDK) is a kidney that has not developed normally in the womb. Instead of a working kidney, there is a bundle of cysts, which are like sacs filled with liquid. The cysts may be very large at first, though over time they get smaller and the kidney gradually shrinks.

MCDK may be picked up before birth on the 20 week antenatal ultrasound scan, or soon after birth. Occasionally, it is not picked up until a child is older.

- MCDK usually affects one kidney only – this is called **unilateral MCDK**. This does not usually cause any problems, and the affected kidney may shrink and disappear by the time a child is five years old. The other kidney does the work of two kidneys, and usually gets larger. Children usually need monitoring throughout their childhood for possible long-term effects.
- Very rarely, MCDK affects both kidneys – this is called **bilateral MCDK**. Or, one kidney may be affected by MCDK and the other kidney may have another problem – this is another form of bilateral kidney disease. If this is suspected, you will need to go back to the hospital for more scans to confirm the problem. Sadly, babies with no working kidneys are unable to survive.



## Overview

### About the urinary system

The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

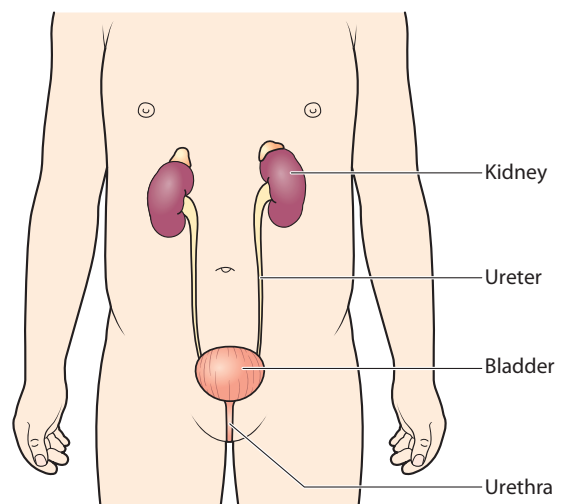
The **kidneys** are bean-shaped organs. They filter blood to remove extra water, salt and waste in urine (wee). Most of us have two kidneys. They are at the back on either side of our spine (backbone), near the bottom edge of our ribs.

The two **ureters** are long tubes that carry urine from the kidneys to the bladder.

The **bladder** is a bag that stores urine until we are ready to urinate (have a wee). It sits low down in the pelvis.

The **urethra** is a tube that carries urine from the bladder to the outside of the body.

» [More about the urinary system and kidneys](#)



## Causes

It is estimated that 1 in 4300 babies is born with unilateral MCDK. Bilateral MCDK is much rarer.

It is not always possible to know why MCDK happens. In the majority of cases, it is not caused by anything that the mother does during her pregnancy, and it is unlikely that a future pregnancy will result in MCDK or other problems with the kidneys.

Occasionally a specific cause is found.

» [More about causes](#)

## Tests and diagnosis

### Tests in pregnancy

The 20 week antenatal **ultrasound scan** looks at your baby growing in the womb. The scan also measures the amount of **amniotic fluid** (or liquor), the fluid that your baby floats in. The baby's kidneys start making urine and pass this out into the amniotic fluid.

MCDK may be suspected if one or both of the kidneys look different from usual. If there is too little amniotic fluid, this may mean that the kidneys are not working properly.

### What the ultrasound can tell us

The antenatal ultrasound scan *cannot* always **diagnose** (identify) the problem. Other problems that look like MCDK on the antenatal ultrasound scan include:

- **renal dysplasia** – the affected kidney has not developed properly; it may have some cysts and is usually smaller than usual
- **renal hypoplasia** – the affected kidney is smaller than usual, but otherwise works normally.

Although your doctor will not always know how your baby will be affected at birth, he or she is less likely to have significant problems if:

- he or she is growing well in the womb
- no other problems have been found, and
- there is a normal amount of amniotic fluid.

You may need to go back to the hospital for more ultrasound scans during pregnancy.

### Referral

Your obstetrician may refer you to a paediatrician, a doctor who treats babies, children and young people, or a **paediatric nephrologist**, a doctor who treats babies, children and young people with kidney problems.

## Antenatal hydronephrosis

Sometimes, MCDK can be seen with another condition that happens in the womb, called **antenatal hydronephrosis**. The kidney does not drain urine properly. The affected kidney can become stretched and swollen. Antenatal hydronephrosis often gets better at a later stage in the pregnancy, but your doctor will check how your baby is affected.

### Diagnosis later in childhood

Sometimes, MCDK is only picked up after birth or when a child is older. It is usually found during a scan that a child is having for another reason, such as a **urinary tract infection (UTI)** or after an accident.

## Unilateral MCDK

In unilateral MCDK, one kidney does not develop properly in the womb. ('Unilateral' means one side.) Unilateral MCDK rarely causes any problems during the pregnancy or in childbirth.

Many children with only one working kidney have no complications and do not need special treatment. Sometimes the other kidney grows larger than normal to make up for the missing kidney. However, they may be at risk of **urinary tract infections (UTIs)** and/or **hypertension** (high blood pressure) later in life.

Occasionally, babies have MCDK on one side, and some degree of **renal dysplasia** or **hypoplasia** on the other side – this is another form of bilateral kidney disease. Overall kidney function will depend on how well the kidney with dysplasia or hypoplasia is working. Your doctor will discuss this with you.

» [More about unilateral MCDK](#)

## Bilateral MCDK

In **bilateral MCDK**, both kidneys do not develop properly. ('Bilateral' means two sides.) Babies with bilateral MCDK have no working kidneys. This is very rare. Sadly, babies with no working kidneys are unable to survive.

» [More about bilateral MCDK](#)

# Causes

Doctors understand that there are some possible causes of MCDK, though it may not always be possible to identify the cause in your baby. It is not usually caused by anything that the mother does during her pregnancy.

## About the name

Multicystic means that the kidney has many (multiple) cysts. Dysplastic means that it has not developed properly.

It is one type of congenital anomaly of the kidneys and urinary tract. 'Congenital' means that the problem is present at birth and 'anomaly' means different than normal.

MCDK is a severe form of **renal dysplasia**, in which one or both of the baby's kidneys do not develop properly.

## How common is it?

It is estimated that 1 in 4300 babies is born with unilateral MCDK. Bilateral MCDK is much rarer.

## How does it happen?

MCDK happens when part of the kidney does not develop properly in the womb.

Although there are a few known causes of MCDK most of the time we cannot identify a specific cause.

## Genetic mutations (inherited)

Most cases of MCDK are *not* inherited from the baby's mother or father. However, some rare cases are caused by **genetic mutations**. These are problems in the genes (which are in each of our body's living cells), which are passed on by the parents.

If your doctor thinks your baby has a problem that is caused by genetic mutations, you may be referred for **genetic testing** and counselling. Genetic testing usually involves getting a sample of blood or body tissue, which can be checked for a specific gene. **Genetic counselling** is a service that can give you information and guidance about conditions caused by genetic mutations.

Occasionally, the MCDK is part of a **syndrome**, which are a collection of symptoms and signs. These children also have other problems, such as with their digestive system, nervous system, heart and blood vessels, muscles and skeleton, or other parts of their urinary system. These may be caused by genetic mutations.

## Medicines and other drugs

A few cases of MCDK are caused by some medicines taken by the pregnant woman – including medicines for seizures (also called convulsions or fits) or high blood pressure (such as angiotensin-converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs). Speak with your doctor about the medicines that you are taking during your pregnancy.

It may also be caused by some illicit drugs, such as cocaine.

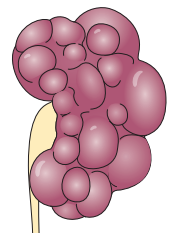
## Will it affect other family members?

Unless you have been told that your baby's MCDK was caused by a genetic mutation, it is unlikely that a future pregnancy will result in MCDK, or other problems with the kidneys. If one of your children has MCDK, it is unlikely that another of your children or family members will get it. Speak with your doctor for more information.

### Causes: Read more about how MCDK happens

The kidneys form while a baby is growing in the womb. Normally, two tubes, which become the ureters, grow from the bladder into tissue, which becomes the kidneys. These tubes form the renal pelvis, the part of the kidney that collects urine. These tubes also form long tubes that link to the nephrons, the many tiny parts that filter blood and make urine.

In MCDK, the tubes fail to completely branch out, so that the kidney does not grow normally. The whole of what should be the kidney is a mass of cysts, which are like sacs filled with fluid (liquid).



An illustration of a kidney with cysts

# Unilateral MCDK (One kidney)

In unilateral multicystic dysplastic kidney (MCDK), one kidney does not develop properly while a baby is growing in the womb. Instead of a working kidney, there is a bundle of many cysts, which are like sacs filled with liquid.

## Tests and diagnosis in pregnancy

The 20 week **antenatal ultrasound scan** looks at your baby growing in the womb. Unilateral MCDK may be suspected if one of the kidneys looks different from usual.

The scan also measures the amount of **amniotic fluid** (or liquor), the fluid that your baby floats in. This fluid protects your baby from getting hurt from the outside and helps his or her lungs mature so he or she is ready to breathe after birth. The baby's kidneys start making urine and pass this out into the amniotic fluid.

The baby's kidneys start making urine and pass this out into the amniotic fluid.

If there is not enough amniotic fluid (**oligohydramnios**), this may be a sign that the kidneys are not working well, and the baby may have problems breathing after birth.

## Tests after birth

After your baby is born, he or she will need some tests to confirm the diagnosis. These tests will also check whether the other kidney is normal or needs treatment.

### Blood tests

Your baby may need one or more **blood tests**. These measure the **kidney function** (how well his or her kidneys are working).

### Imaging tests

Your baby may need **imaging tests** (scans) to confirm the condition and look for any complications. These use special equipment to get images (pictures) of the inside of his or her body.

- **Ultrasound scan** – looks at the shape and size of your baby's kidneys and other parts of the urinary system. A small handheld device is moved around your child's skin and uses sound waves to create an image on a screen.
- **DMSA scan** – checks for any damage on the kidney(s). A chemical that gives out a small amount of radiation is injected into one of your child's blood vessels. This chemical is taken up by healthy parts of the kidney and a special camera takes pictures.

Occasionally other imaging tests are needed.

- **MAG3 scan** – for babies who also have **antenatal hydronephrosis**, this shows how much blood is going into and out of their kidneys, and whether they are passing urine normally. As in the DMSA test, a chemical that gives out a small amount of radiation is injected into a blood vessel, and a special camera takes pictures.

- **Cystourethrogram** or **MCUG** (sometimes called a VCUG) – usually for babies and children who are suspected of having **vesicoureteral reflux (VUR)**. In this condition, some urine refluxes (goes back up) the wrong way up the ureters, towards, and sometimes into, the kidneys. This test can check how your baby is passing urine. A special X-ray machine takes a series of images of your baby's bladder while he or she is passing urine.

## Complications and treatment

In most cases babies do not need treatment. A small number of children have symptoms or complications, which may not happen until later in life. These may need follow up or treatment, such as medicines.

### High blood pressure

Some children develop **hypertension**, blood pressure that is too high.

If your child has hypertension, he or she will need to reduce his or her blood pressure so it is in the healthy range. Your child will probably need to eat a no-added salt diet, and may need to take medicines, to control his or her blood pressure. It is also recommended that all children, especially those with hypertension, keep to a healthy body weight and exercise regularly.

### Urinary tract infections

Some children get **urinary tract infections (UTIs)**, when germs get into the urine and travel up the urinary tract (or system) and cause an infection, usually in the bladder. Babies and children with UTIs may become irritable, have a fever, have pain on weeing, feel sick or be sick.

UTIs that keep coming back are more likely in children who also have **vesicoureteral reflux (VUR)**, when some urine refluxes (goes back up) towards, and sometimes into, the kidneys.

If your child has a UTI, he or she will need to take **antibiotics**, medicines that kill the germs.

→ If you think your child has a UTI, seek medical advice.

### Operating to remove the kidney with MCDK

Normally, an operation is not required to remove the affected kidney. This is because in most children it does not cause any problems, and the affected kidney usually shrinks and disappears by the time the child is five years old.

Some children with unilateral MCDK who develop **hypertension** (blood pressure that is too high) continue to have a high blood pressure despite being treated with medicines. They may need an operation to remove the



affected kidney as this can reduce the blood pressure in about two out of every three children.

In the past, children had operations to remove the kidney with MCDK because of concerns that **cancer** may develop in this kidney. More recent research, however, has shown that the risk of developing a kidney cancer is not increased in kidneys with MCDK, so an operation is no longer recommended.

## Chronic kidney disease

In most people with unilateral MCDK the other kidney works normally. The normal kidney can work harder to compensate and do the work of two kidneys.

Sometimes children with MCDK have an abnormality in the other kidney. These may include **renal hypoplasia** or **renal dysplasia**. Part or all of the kidney does not develop properly and is smaller than usual. The kidney can usually clean blood and make urine, but may not work as well as a kidney with no abnormality.

If the other kidney does not work normally, your child may have reduced kidney function. He or she may be at greater risk of progressing to later stages of **chronic kidney disease (CKD)**, and will need more monitoring.

» [Read more about chronic kidney disease](#)

## About the future

Most people live normal lives with just one working kidney. The other kidney usually works normally, and may grow larger to help do the work of two kidneys. The kidney with MCDK may shrink and even disappear by the time a child becomes an adult.

Your child should be able to do all the things that other children their age do. He or she can go to nursery and school, play with other children and stay active.

## Follow up

In the first few years of his or her life, your child may need to go back to the hospital for some tests. Later, he or she will need to see your family doctor about once a year. It is important to go to these appointments even if your child seems well. You will also have the opportunity to ask any questions. At these appointments your child will have:

- his or her **blood pressure** measured, to check for **hypertension**

- **urine tests** – to check for protein in his or her urine (proteinuria), which may be a sign of problems in the kidney. You or a nurse will collect some of your child's urine in a small, clean container. A **dipstick** will be dipped into the urine – this is a strip with chemical pads that change colour if there is protein in the urine
- **blood tests** – to measure his or her kidney function
- his or her height and weight checked in childhood, to measure how much he or she is growing
- **ultrasound scans** – to look at the kidney with MCDK to see whether it has shrunk or disappeared.

## Living healthily

Your child can help protect his or her kidneys, and reduce the risk of hypertension later in life, by leading a healthy lifestyle through their child and adult years. This includes:

- eating a healthy diet – with at least five servings of fruit and vegetables a day, taking care not to eat too much salt, sugar and fats (especially saturated fats)
- getting plenty of exercise
- not smoking.

## Further support

This can be a difficult and stressful experience for you and your family.

→ [If you have any concerns or need additional support, speak with your doctor or nurse.](#)

## Further information

This is the end of the information about unilateral MCDK. If you would like to read more about tests and diagnosis, treatment or supporting information, you can find a list of topics covered on the infoKID website at [www.infoKID.org.uk](http://www.infoKID.org.uk).

# Bilateral MCDK (Both kidneys)

In bilateral multicystic dysplastic kidney (MCDK), both kidneys do not develop properly while a baby is growing in the womb. Instead of working kidneys, there are bundles of many cysts, which are like sacs filled with liquid. ('Bilateral' means two sides.) Babies with this condition have no working kidneys.

Sadly, these babies are unable to survive. Some die during the pregnancy or within days after they are born.

## Tests and diagnosis in pregnancy

Bilateral MCDK may be suspected on the 20 week **antenatal ultrasound scan**, which looks at your baby growing in the womb. MCDK may be suspected if one or both of the kidneys look different from usual.

The scan also measures the amount of **amniotic fluid** (or liquor), the fluid that your baby floats in. This fluid protects your baby from getting hurt from the outside and helps his or her lungs mature so he or she is ready to breathe after birth. The baby's kidneys start making urine and pass this out into the amniotic fluid.

If there is not enough amniotic fluid (**oligohydramnios**), this may be a sign that the kidneys are not working well, and the baby may have problems breathing after birth.

## What happens

If bilateral MCDK is suspected, you will be referred to specialist healthcare professionals as early as possible in the pregnancy. They may include a:

- **foetal medicine specialist** – a doctor who specialises in the health of unborn babies (foetuses)
- **obstetrician** – a doctor who specialises in pregnancy, delivering babies and the care of women after childbirth
- **paediatrician** – a doctor who treats babies, children and young people
- **paediatric nephrologist** – a doctor who treats babies, children and young people with kidney problems
- **neonatologist** – a doctor who specialises in newborn babies.

You may need more ultrasound scans during the pregnancy to help find out whether your baby has bilateral MCDK.

In such situations, some people decide to **terminate** (stop) a pregnancy. This is a very personal decision. A healthcare professional will speak with you and support whatever decision you make.

## Why does this happen?

Normal kidneys remove waste products from the body, and make sure the body has the right balance of water and salts. They also control blood pressure, help keep bones and teeth strong and healthy, and control the production of red blood cells. If there are no kidneys, the body cannot do this work.

While a baby is growing in the **uterus** (womb), he or she floats in amniotic fluid. This protects the baby from getting hurt from the outside and helps the lungs mature so that he or she is ready to breathe after birth. The baby swallows or 'breathes in' the amniotic fluid, helping the lungs grow and develop.

Normally, the kidneys develop and start making urine. The baby passes the urine out, adding to the amount of amniotic fluid. If the baby does not have kidneys, he or she cannot produce urine, and this leads to not enough amniotic fluid – this is called **oligohydramnios**. This can stop the lungs fully developing.

## Will it happen in future pregnancies?

Doctors are trying to understand what causes bilateral MCDK. It is sometimes caused by a **genetic mutation**, which means that it may be inherited from the mother or father.

However, it is very rare for a future pregnancy to result in MCDK, or other problems with the kidneys. Speak with your doctor for more information.

## Further support

This can be a difficult and stressful experience for you and your family.

→ If you have any concerns or need additional support, speak with your doctor or nurse.

## Further information

This is the end of the information about bilateral MCDK. If you would like to read more about tests and diagnosis, treatment or supporting information, you can find a list of topics covered on the infoKID website at [www.infoKID.org.uk](http://www.infoKID.org.uk).

## Your notes and contact information

[www.infoKID.org.uk](http://www.infoKID.org.uk)



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