

# Renal agenesis

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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Most people are born with two kidneys. Renal agenesis (or kidney agenesis) means one or both kidneys do not develop while a baby is growing in the womb.

Renal agenesis may be picked up before birth on the 20 week antenatal ultrasound scan, or soon after birth. It may also be picked up in an older child who has certain symptoms.

- If one kidney has not developed, this is called unilateral renal agenesis. Many children and adults live with one kidney with no serious problems. They may need to go to follow-up appointments to check for any possible long-term effects.
- If both kidneys have not developed, this is called bilateral renal agenesis. If this is suspected on your antenatal scan, you will need to go back to the hospital for more scans to confirm the problem. Sadly, babies with no 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.

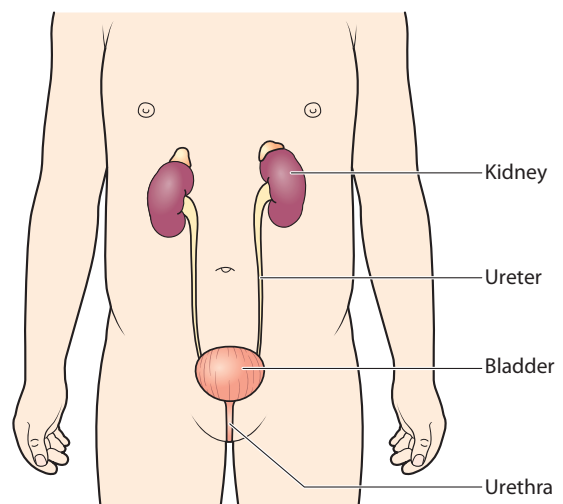
The **kidneys** are bean-shaped organs. They filter blood to remove extra water, salt and waste in urine (wee). Most of us have two kidneys. They are at the back on either side of our spine (backbone), near the bottom edge of our ribs.

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 tummy area.

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

Renal agenesis happens in the womb when one or both kidneys do not develop. It is estimated that one baby in a thousand is born with only one kidney. However, it is very rare that both kidneys do not develop.

It is not always possible to know why renal agenesis 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 renal agenesis or other problems with the kidneys.

Occasionally a specific cause is found.

» [More about causes](#)

## Tests and diagnosis

### During pregnancy

The 20 week antenatal **ultrasound scan** looks at your baby growing in the womb. Renal agenesis may be suspected if one or both kidneys cannot be seen on this scan. You may need to go back to the hospital for more scans or other tests to check whether this is affecting your baby.

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.

After your baby is born, he or she may need an **ultrasound scan** or other tests to confirm whether there is renal agenesis.

## Unilateral renal agenesis

In **unilateral renal agenesis**, one kidney has not developed. ('Unilateral' means one side.) Many children with only one kidney have no symptoms or complications and do not need treatment. Sometimes the other kidney grows larger than normal to make up for the missing kidney. However, children may be at risk of **urinary tract infections (UTIs)** and/or hypertension (high blood pressure) later in life.

Your child may need to visit your family doctor for **urine tests** and **blood pressure measurements**.

» [More about unilateral renal agenesis](#)

## Bilateral renal agenesis

In **bilateral renal agenesis**, both kidneys have not developed. ('Bilateral' means two sides.) If this is suspected, you will need to go back to the hospital for more scans to confirm the problem. Sadly, babies with no kidneys are unable to survive.

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.

» [More about bilateral renal agenesis](#)

# Causes

Doctors understand that there are some possible causes of renal agenesis, 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

Renal agenesis can be broken down:

- renal: to do with one or both kidneys
- agenesis: part of the body does not develop.

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.

## How common is it?

Unilateral renal agenesis is relatively common – it is estimated that one baby in a thousand is born with only one kidney. Bilateral renal agenesis is much rarer.

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

## Genetic mutations (inherited)

Most cases of renal agenesis are *not* inherited from the baby's mother or father. However, some 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 renal agenesis is part of a **syndrome**, which is a collection of symptoms and signs. These children also have other problems, such as with the digestive system, nervous system, heart and blood vessels, muscles and skeleton, or other parts of the urinary system. These may be caused by genetic mutations.

## Medicines and other drugs

A few cases of renal agenesis 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 ACE inhibitors (angiotensin-converting enzyme inhibitors) and angiotensin receptor blockers (ARBs)). Speak with your doctor about the medicines that you are taking during pregnancy.

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

## Will it affect other family members?

Unless you have been told that your baby's renal agenesis was caused by a genetic mutation, it is unlikely that a future pregnancy will result in renal agenesis, or other problems with the kidneys. If one of your children has this renal agenesis, it is unlikely that another of your children or family members will get it. Your doctor or healthcare professional will be able to give you more information.

# Unilateral renal agenesis (One kidney)

In unilateral renal agenesis, one kidney does not develop while a baby is growing in the womb. ('Unilateral' means one side.) The other kidney usually looks and works as normal. Most people have no long-term problems with unilateral renal agenesis, and some do not even know that they have only one kidney.

## Tests and diagnosis in pregnancy

### During pregnancy

The 20 week antenatal ultrasound scan looks at your baby growing in the womb. Unilateral renal agenesis may be suspected if one of the kidneys cannot be seen.

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. 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.

If there is not enough amniotic fluid (oligohydramnios), this may mean that one or both kidneys are not working properly, and the baby may have problems breathing after birth.

### What the ultrasound can tell us

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 the remainder of your pregnancy.

### Referral

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

### Antenatal hydronephrosis

Sometimes, unilateral renal agenesis can be seen with another condition that happens in the womb, called **antenatal hydronephrosis**. The other kidney does not drain urine properly. The affected kidney becomes 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, unilateral renal agenesis 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.

## Tests after birth

After your baby is born, he or she may need some imaging tests (scans). These use special equipment to get images of the inside of the body. They are used to confirm that your child has only one kidney and look for any complications.

- **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** – 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. This can check that the single kidney is normal.

Occasionally other imaging tests are needed. Your doctor will discuss this with you.

## 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

People with only one kidney have a slightly higher risk of hypertension, blood pressure that is too high.

If your child has hypertension, he or she will need to reduce their 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). Babies and children with UTIs may become irritable, have a fever, have pain on weeing, feel sick or be sick.

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.

## Chronic kidney disease

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

Sometimes children with unilateral renal agenesis have an abnormality in the other kidney. This 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

Many children will not have long-term problems. The other kidney usually grows larger to help do the work of two kidneys.

A small number may be at higher risk of problems later in life.

Your child should be able to do all the things 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 may 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.

## 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 renal agenesis. 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 renal agenesis (Both kidneys)

In bilateral renal agenesis, neither kidney develops in the womb. ('Bilateral' means two sides.) Babies with this condition have no working kidneys.

## Tests and diagnosis in pregnancy

The 20 week antenatal **ultrasound scan** looks at your baby growing in the womb. If the person doing the ultrasound cannot see kidneys, or can only see a small amount of tissue where the kidneys should be, bilateral renal agenesis will be suspected.

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. 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. If there is very little or no fluid, this is another sign of a serious problem with the kidneys, such as bilateral renal agenesis.

## Referral

If bilateral renal agenesis 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.

## Further tests

You may need more ultrasound scans during the pregnancy to help find out whether it is bilateral renal agenesis.

## What happens

Sadly, babies with bilateral renal agenesis are unable to survive. Some die during the pregnancy or within days after they are born.

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.

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 renal agenesis. It is sometimes caused by a **genetic mutation**, which means that it may be inherited from the mother or father.

However, it is not usually likely that a future pregnancy will result in renal agenesis, or other problems with the kidneys. Your doctor or healthcare professional will be able to give you 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 renal agenesis. 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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