Vesicoureteral reflux and reflux nephropathy



This infoKID topic is for parents and carers about children's kidney conditions. Visit 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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Vesicoureteral reflux (VUR) – also called vesicoureteric reflux – is quite a common condition, especially in babies and young children. When children with VUR go for a wee, some urine refluxes, or passes back up the wrong way, towards one or both kidneys.

Many children with VUR do not have any symptoms or need treatment. They may be at greater risk of urinary tract infections (UTIs) in their bladder or kidneys, and may need to take medicines to prevent or treat infection.

VUR is diagnosed (identified) in a test called an MCUG, which finds out how much urine refluxes and whether it is held in the kidney. There are five grades.

• Grades 1 and 2 are mild. Children will visit the clinic or hospital to check for any problems, and may need to take medicines to prevent infection.



• Grades 3, 4 and 5 are more severe. Urine refluxes all the way to one or both kidneys, causing swelling. The bladder may not fully empty. Children may need further treatment, such as medicines that protect their kidneys. Very occasionally, surgery is needed. This higher grade often gets better over time, but may take longer.

Reflux nephropathy means there is VUR and scars or abnormal development in one or both kidneys, which may be mild or more severe. Occasionally, this means that one or both kidneys work less well.

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 and waste in urine (wee). Most of us have two kidneys. They are on either side of our spine (backbone), near the bottom edge of our ribs at the back.

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. 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





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Symptoms and complications

These conditions do not usually hurt and may not cause symptoms. Some children have complications – health problems caused by or worsened by VUR or reflux nephropathy.

- Urinary tract infection (UTI) when bacteria (germs) get into the urine and cause an infection, usually in the bladder. Babies and children with a UTI may become irritable, have a fever, have pain on weeing, feel sick or be sick.
- Kidney infection (pyelonephritis) sometimes bacteria that cause UTI travel all the way up to the kidneys, where they cause a more serious infection and illness. This is more likely in severe VUR, when urine goes back up in the kidneys.
- Bladder problems in severe cases, the bladder does not empty properly, and this may cause more UTIs and further kidney damage.

Reflux nephropathy may cause the following:

- high blood pressure (hypertension) especially when a child is older or reaches adulthood
- protein in the urine (proteinuria) this may be found if the kidney damage gets worse over time. You cannot usually see the protein, but it can be found on a simple urine test.

» More about symptoms and complications

Causes

It is not always clear why these conditions happen. They are not caused by anything that the mother does during her pregnancy.

VUR

VUR sometimes runs in families. If one of your children has it, your doctor may recommend that his or her brothers and sisters are also tested, especially if they have any complications such as frequent UTIs.

VUR is caused by a problem with the way one or both ureters connect with the bladder. In some cases, it is caused by problems with the bladder itself.

VUR may affect one side (unilateral VUR) or both sides (bilateral VUR).

Reflux nephropathy

Reflux nephropathy is kidney scars or abnormal kidney development that is seen with VUR. We understand that it develops in children with VUR who get kidney infections (pyelonephritis).

There may be scars on one kidney only (**unilateral reflux nephropathy**), or on both kidneys (**bilateral reflux nephropathy**).

It is not always known whether the kidney damage in reflux nephropathy is present at birth or starts later in life.

» More about causes

Test and diagnosis

Before birth

The 20 week antenatal ultrasound scan looks at your baby growing in the womb. In some pregnancies, one or both of the baby's kidneys hold on to urine, and become stretched and swollen – this is called **antenatal hydronephrosis**.

Often, the hydronephrosis goes away during pregnancy. If it continues, you may need more tests. Sometimes it is caused by severe VUR.

Diagnosis

Some babies with antenatal hydronephrosis or other problems in pregnancy are tested for VUR after birth. Older children may be tested for VUR if they have symptoms, such as one or more UTIs.

The first test is normally an **ultrasound scan**, which is similar to the scan mothers have in pregnancy. VUR can be diagnosed (identified) in a baby or older child with other scans – this is normally a test called an **MCUG**, but sometimes another test called a **MAG3 scan with indirect cystogram** is used.

Some children are referred to a **paediatrician**, a children's doctor, and/or a **paediatric urologist**, a surgeon who treats children with problems of the urinary system. He or she will talk with you about whether your child needs further tests to help find out whether he or she needs treatment.

Your child may also need to go back to the clinic or hospital for follow-up tests.

» More about tests and diagnosis

Treatment

After your child's tests, your doctor will speak with you about whether your child needs treatment.

Because VUR and reflux nephropathy may increase the risk of **urinary tract infections (UTIs)**, especially infections that keep coming back and that may affect the kidney, some babies and children need to take a small dose of **antibiotic medicine** each day for some time. This medicine kills the bacteria that cause UTIs and helps to prevent these infections. If your child does get a UTI, he or she will need to take a course of antibiotics to fight the infection.

Some children need further treatment to protect their kidneys. This includes controlling blood pressure by eating a healthy diet with no added salt and, sometimes, taking medicines. Occasionally, other treatment or surgery to correct the VUR is needed.

The scarring in reflux nephropathy cannot be treated.

» More about treatment



About the future

All children with VUR need to go back to the clinic or hospital for more tests and to see the doctor. Children with reflux nephropathy need long-term follow-up.

Your child will be able to do all of the things that other children their age do. Your child should be able to go to nursery and school, play with other children and stay active. As they grow, most children have no symptoms from VUR or reflux nephropathy, especially after 5 years of age.

A very small number of children, especially those with more severe VUR and/or reflux nephropathy, develop long-term problems with their kidneys and will need specialist treatment.

» More information about the future

Symptoms and complications

VUR

VUR does not usually hurt or cause symptoms. Some children with VUR are at higher risk of urinary tract infections (UTIs), including kidney infections, or bladder problems.

Urinary tract infections

Urine is normally sterile (free of germs), but sometimes bacteria (germs) get into the urine and travel into the urinary system. This causes a **urinary tract infection (UTI)**. This is usually in the bladder (also called **cystitis**).

- Babies and young children with a UTI may have fever (temperature over 38°C), be sick (vomit), feel tired or irritable and not feed well.
- Older children with a UTI may have pain or a stinging/ burning feeling when passing urine (**dysuria**), may need to go to the toilet more often than usual (frequency) or hold on because it is painful to go, or may wet themselves more often than usual.
- ➔ If you think that your child may have a UTI, contact your doctor. If you cannot reach your doctor straight away, contact 111 or NHS Direct or your local out-of-hours GP service.

Kidney infections

In more severe VUR, urine passes backs into the kidneys. This makes it possible for bacteria to get into the kidney, causing an infection – this type of UTI is called **pyelonephritis**.

Pyelonephritis is more difficult to treat than cystitis. It may lead to lead to more serious illness, with fever, nausea (feeling sick), vomiting or pain. It may resolve (get better) completely, or may lead to kidney scarring.

» More about UTIs, including kidney infections

Bladder problems

Some children have bladder problems, especially if they have severe VUR. If the bladder does not completely empty, this may cause more UTIs.

Reflux nephropathy

The scars found in reflux nephropathy do not hurt. However, some children with reflux nephropathy may have **complications**.

High blood pressure

Reflux nephropathy may lead to blood pressure that is too high (hypertension). In some children, this causes headaches, vomiting or blurred (fuzzy) vision. Hypertension that lasts a long time can also increase the risk of getting heart disease and stroke in adulthood.

Proteinuria

In reflux nephropathy, some of the tiny kidney filters are damaged. This means that the rest of the kidney filters have to filter more blood than usual – this is called **hyperfiltration**.

Over time, these working kidney filters may get damaged and may leak **protein** into the urine – this is called proteinuria. You cannot usually see the protein but it can be found on a **urine test**. If your child is found to have **proteinuria**, he or she will need regular urine tests.

Kidney problems

If there is reflux nephropathy in both kidneys (**bilateral reflux nephropathy**), this may lead to long-term kidney problems. Your child will have regular **blood tests** to check how well his or her kidneys are working.



Causes

VUR – how it happens

How we pass urine

Urine is made in each kidney and then passes through its ureter to the bladder. The bladder fills up with urine, like a balloon. When it is full, it sends signals to the brain that 'tell' the bladder muscles to push urine out through the urethra. This is how we pass urine (wee).

As most people urinate (wee), the end of each ureter that goes into the bladder squeezes tight. It acts like a one-way valve – urine can go into the bladder, but cannot leave the bladder back up the ureter.

How VUR happens

In VUR there is a problem with the way one or both ureters enter the bladder. The 'valve' does not work. This is usually present at birth.

As children with VUR urinate, some urine **refluxes** (goes back up) one or both ureters, and may reach the kidney.

After urinating, this urine settles back into the bladder. In severe VUR, this means the bladder is never completely empty.

The name means:

- vesico to do with the bladder
- ureteral (or ureteric) to do with the ureter
- reflux a backward flow.

Grades

VUR has 5 grades. These depend how far urine refluxes up the ureter, and whether it is held up in the kidney. Grades 1 and 2 are mild, and Grades 3, 4 and 5 are more severe.

- Grade 1 urine refluxes into the ureter only.
- Grade 2 urine refluxes into the kidney (this is in the renal pelvis, the area of the kidney nearest the ureters, which normally collects urine after it is made in the kidneys).



- **Grade 3** urine refluxes into the kidney, and the renal calyces, the areas of the kidney that collect urine after it is made, start to dilate (get larger).
- Grade 4 urine refluxes into the ureter, and the renal calyces are more dilated.
- Grade 5 urine refluxes into the ureter, and the renal pelvis is severely dilated the entire kidney looks larger.

Some children stay at the same grade for a long time, and a few get worse (go to a higher grade). The VUR gets better in more than half of children in the first few years of life.

One or both sides

- Urine may go back up one ureter and towards one kidney only – this is called unilateral VUR ('unilateral' means one side).
- Or, urine may go back up both ureters and towards both kidneys – this is called **bilateral VUR** ('bilateral' means two sides). If VUR is bilateral and high grade, it is more likely that the bladder is never completely empty.

VUR - causes

VUR is not caused by anything that the mother does during her pregnancy. It sometimes runs in families. If one of your children has VUR, your doctor may recommend that his or her brothers and sisters are also tested, especially if they have any complications such as frequent **urinary tract infections (UTIs)**.

No known cause

VUR may happen on its own, though it is not always known why this happens. This is called **primary VUR**.

Known causes

VUR may be caused by, or happen with, another problem in the urinary system that makes it difficult to pass urine. This is called secondary VUR. Most of these problems are present at birth.

- Posterior urethral valves (PUV) a blockage in part of the urethra (nearest the bladder) that happens in some boys.
- Neuropathic bladder (or neurogenic bladder) a problem with the nervous system (including the brain), which affects how the bladder works. These children are unable to control how their bladder works, and may dribble urine or have bladder spasms.
- Ureterocele the ureter dilates (swells) where it enters the bladder because the opening is very small. This is often found where a kidney and ureter develop in two parts (duplex kidney) – in these cases, sometimes one of the ureters has a ureterocele and one has reflux.

Other problems

VUR may also happen with other kidney problems that develop while the baby is growing in the womb. These include **renal dysplasia** or **renal hypoplasia**, when one or both kidneys do not fully develop and are often smaller than usual.

Children may also be at risk of UTIs in the affected kidney, which may cause further damage.



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Reflux nephropathy – causes

Reflux nephropathy is kidney scarring (damage) that is seen with VUR. This develops rarely in children with VUR who get kidney infections (pyelonephritis), which may cause scars on the kidneys.

One or both sides

- There may be scars on one kidney only this is called **unilateral reflux nephropathy**.
- Or, there may be scars on both kidneys this is called **bilateral reflux nephropathy**.

Tests and diagnosis

Before birth

The 20 week antenatal **ultrasound scan** looks at the baby growing in the womb. In some pregnancies, one or both of the baby's kidneys hold on to urine, and become stretched and swollen – this is called **antenatal hydronephrosis**. This is due to the large amount of urine the fetus makes towards the end of the pregnancy, and it usually resolves (gets better) on its own. Sometimes, the swelling continues throughout pregnancy, and this may be caused by a number of conditions, including severe VUR.

After birth

Some babies with antenatal hydronephrosis are tested for VUR and other kidney conditions after birth.

In older children, VUR is normally found when looking for other problems, such as a **urinary tract infection** (UTI). Your doctor will speak with you and your child about the symptoms and do a physical examination of your child. Your child's **blood pressure** will also be measured.

Imaging tests

Your child may need one or more imaging tests (scans). These use special equipment to create pictures of the inside of his or her body.

Ultrasound scan

Your baby or child will probably first have an **ultrasound scan** to look at the kidneys and urinary system. A small handheld device is moved around your child's skin and uses sound waves to create an image on a screen.

Diagnosing VUR

Your child may have an **MCUG** (sometimes called a VCUG). A thin flexible tube called a catheter is passed through your child's urethra and a dye is put through to reach the bladder. This does not hurt your child. A special X-ray machine takes images (pictures) of your child's bladder while he or she is passing urine.

Another test that may be used instead for older children (who are potty trained) is an MAG3 scan with indirect cystogram. A chemical called MAG3 that gives out a small amount of radiation (energy) is injected into one of your child's blood vessels – a special gel or cream can be used to stop your child feeling any pain. A special camera takes images of your child's urinary system as the chemical passes through it.

Diagnosing reflux nephropathy

Your child may need other scans to check for any scarring on the kidneys (reflux nephropathy).

In a **DMSA scan**, a chemical called DMSA is injected into a blood vessel. The chemical is taken up by healthy parts of the kidney. A large camera takes images.

Sometimes an **MR urogram** is used instead. A special dye is injected into a blood vessel. Your child lies on a bed that passes into the MRI scanner, a large machine with a tunnel. This uses powerful magnets to build up a picture of your child's urinary system.

Urine tests

A urine test can diagnose a **urinary tract infection (UTI)** or find protein in the urine **(proteinuria)**.

You, or a nurse may need to 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 depending on what substances are in the urine. The sample may also be sent to a laboratory for more accurate tests.

Blood tests

Your child may need a blood test. A blood test can find out about your child's **kidney function** (how well his or her kidneys are working) by **measuring the glomerular filtration rate (GFR)**. A small amount of blood may be taken from a vein, with a needle and syringe. A special gel or cream can be used to help your child stop feeling any pain.

» More about measuring GFR in Blood tests



The treatment depends on the grade of VUR (how severe it is). Many children grow out of VUR, and treatment may only be needed for their early years before they go to school.

Where will my child be treated?

If your baby or child has VUR, he or she may be referred to a **paediatrician**, a doctor who treats babies, children and young people.

Some babies and children with high-grade (severe) VUR or reflux nephropathy are referred to a **paediatric urologist**, a surgeon who treats children with problems of the urinary system. The urologist will assess your child and consider whether treatment is needed.

Occasionally, children are referred to a **paediatric nephrologist**, a doctor who treats children with kidney problems.

Preventing and treating urinary tract infections

Children with VUR and reflux nephropathy are at higher risk of **urinary tract infections (UTIs)**, which may keep coming back (**recurrent**). In serious cases, these may affect their kidneys.

It is important to treat UTIs quickly when they do happen.

Preventing UTIs

Children with high-grade VUR may benefit from taking a small dose of **antibiotic medicine** once a day – this is called a **prophylactic antibiotic**. Antibiotics kill bacteria (germs) that cause UTIs, and so help prevent these infections.

Treating UTIs

Sometimes UTIs can happen even when your child is taking these antibiotics. It is important that UTIs are diagnosed and treated quickly to try to prevent them causing kidney damage. If you think your child has a UTI, contact your doctor or local NHS services.

- ➔ It is important to follow your doctor's instructions about when and how much to give. Continue to give the antibiotics to your baby as your doctor has told you.
- » More about UTIs

Controlling blood pressure

It is important that your child's **blood pressure** is in a healthy range, to help keep his or her kidneys healthy. If your child has high blood pressure (**hypertension**), he or she may need to change what he or she eats and drinks. Some children need to take medicines.

» More about hypertension and how to control blood pressure

Reducing protein loss in urine

If your child's urine tests show **proteinuria** (more protein in the urine than normal), he or she will need more tests. If the proteinuria persists or gets worse, your child may need medicines. These will try to reduce the amount of protein lost in their urine and so protect the kidneys.

» More about proteinuria

Surgery – injecting a gel (Deflux®)

Surgery is rarely needed. However, if your child has highgrade (severe) VUR and recurrent UTIs (that keep coming back), your paediatric urologist may recommend surgery to correct the VUR. This aims to protect the kidneys from infections.

The first surgical procedure that is usually recommended is to inject a gel into the end of the ureter within the bladder. This narrows the space, preventing urine refluxing out of the bladder, without blocking urine flowing into the bladder. The gel used is usually one called Deflux[®], though other gels may be used.

This is a quick procedure, and may be used for babies and children of any age. Your child can usually go home the same day.

Risks and complications

Serious complications are very rare. However, no procedure is completely safe, and it is important you understand the risks. Your urologist will speak with you about the possible problems before you consent (agree) to the procedure.

- Although rare, the gel can partially block urine flowing out of the kidney. This will be checked with an **ultrasound scan** a few weeks after the procedure.
- Occasionally, children get a **urinary tract infection** after the procedure, and will need to take antibiotics to treat the infection. Your child may be given a small dose of antibiotics to help prevent infection during the procedure, and for a short time afterwards.
- Some children have visible blood in their urine (haematuria) for a short time after the operation. This resolves (gets better) on its own.
- Although this procedure works in most children, there is a risk that the reflux may come back. It is possible to repeat the procedure a second or third time if necessary. If these repeat procedures also fail, the paediatric urologist may then recommend **open surgery**.



What happens

- A general anaesthetic is used to make your child go to sleep so he or she does not feel pain anywhere in his or her body. General anaesthetic may be given as a gas that your child will breathe in or it may be injected into a blood vessel. You will see an anaesthetist (a specialist doctor who is trained in giving these medicines) before the procedure.
- A **cystoscope** (like a tiny telescope) is covered with a special gel, and gently passed through your child's urethra and into the bladder.
- Sterile (completely clean) water is pumped through the cystoscope, so that the urologist can see inside the bladder using the camera and then inject the gel.

After treatment

 Your baby or child will stay in hospital until they are feeding or eating well and passing urine normally. He or she can normally go home the same or next day. Your baby or child may need to take antibiotic medicines to prevent or treat any infection caused by the cystoscopy.

Ureteric reimplantation

Very occasionally, another operation called **ureteric reimplantation** is recommended. This procedure retunnels the ureter into the bladder to create an anti-reflux mechanism – as should normally happen.

The urologist makes a cut at the bottom of your child's abdomen (tummy), and tunnels the ureter through the bladder wall. A thin flexible tube called a **catheter** is placed through the urethra to drain urine from the bladder. It is left in place for a few days until your child can pass urine on his or her own.

This surgery is also done under **general anaesthesia**, so your child can sleep through the procedure and not feel any pain.

About the future

Follow-up

All children with VUR and reflux nephropathy need to go back to the clinic or hospital for more tests and to see the doctor. It is important that you go to these appointments even if your child seems well. They will check whether your child is getting better, or whether there is any damage to his or her kidneys.

After a while, your child will only have more tests if he or she has problems with **urinary tract infections** (UTIs) that keep coming back.

Preventing UTIs

Children with VUR and reflux nephropathy are at higher risk of UTIs. If your child is taking antibiotics once a day to prevent UTIs, it is important that you continue giving the medicines until your doctor tells you to stop. Speak with your doctor if you have any concerns.

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

Reflux nephropathy on one kidney

If your child has scars on one kidney (**unilateral reflux nephropathy**), he or she has a higher risk of developing high blood pressure (**hypertension**) over time.

Your child will need long-term follow-up. This may include **blood pressure measurements** once a year.

Reflux nephropathy on both kidneys

If your child has scars on both kidneys (**bilateral reflux nephropathy**), he or she will need long-term follow up. This includes:

- blood pressure measurements
- urine tests to check for protein and other substances in his or her urine – if there is more protein than usual in the

urine (proteinuria), this may be a sign of hyperfiltration, when there are fewer kidney filters working

• **blood tests** – to measure his or her **kidney function** (how well his or her kidneys are working).

Long-term effects

In many children, VUR will disappear as they grow. It is not known how many children continue to have VUR as they grow older, because most do not need regular tests.

Kidney problems

A very small number of children, especially those with high-grade (severe) VUR and/or bilateral reflux nephropathy, can progress to later stages of **chronic kidney disease (CKD)**. Their kidneys gradually stop working properly – this usually happens slowly over many years. Many children with CKD do not have any problems until they reach puberty (teenage years), when they grow quickly.

If your child has CKD, you and your child will learn more on how to help manage the condition, and what to expect.

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 VUR and reflux nephropathy. If you would like to read more about other kidney conditions, tests and diagnosis, treatment or supporting information, you can find a list of topics covered on the infoKID website at www.infoKID.org.uk.



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<u>Your notes and contact information</u>

www.infoKID.org.uk





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