Information for Patients



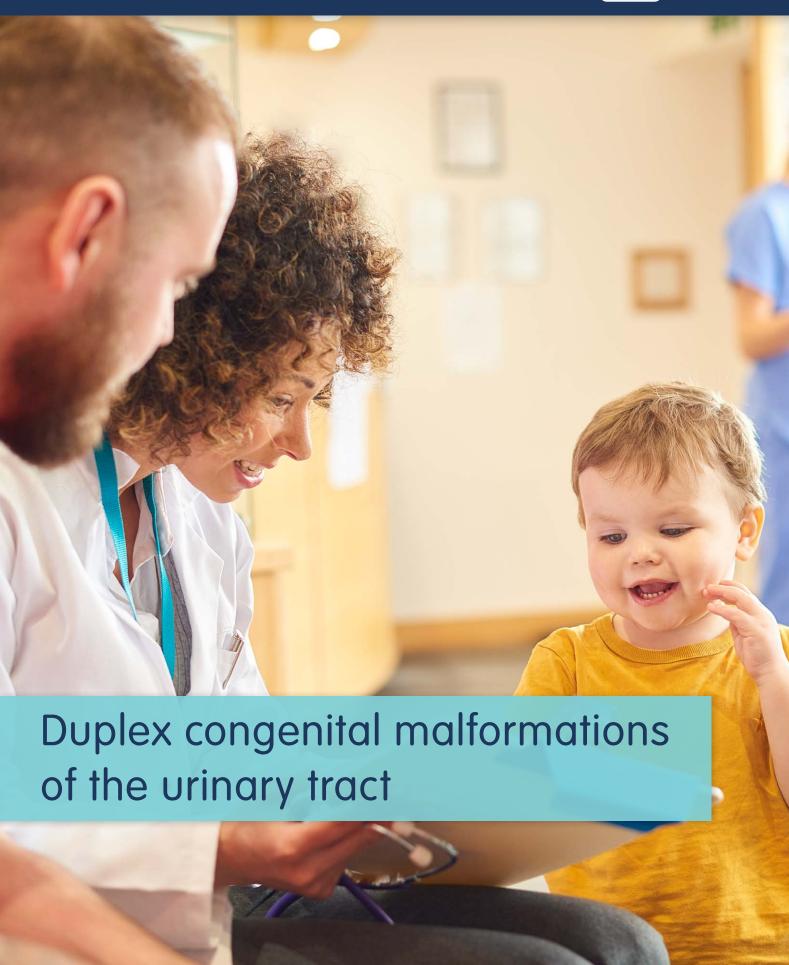




Table of contents

Duplex kidney (ureteral duplication)3
What is duplex kidney?4
How common is duplex kidney?4
What are the symptoms of duplex kidney?4
What treatments are available for duplex kidney?5
Ureterocele7
What is a ureterocele? 7
How common are ureteroceles?7
What are the symptoms of a ureterocele? 8
What treatments are available for ureteroceles?9
Ectopic ureter
What are ectopic ureters?11
How common are ectopic ureters?11
What are the symptoms of ectopic ureters?12
What treatments are available for ectopic ureter?12
Vesicoureteral reflux (VUR)
What is vesicoureteral reflux?13
How common is vesicoureteral reflux?13
What are the symptoms of vesicoureteral reflux?13
How problematic is vesicoureteral reflux?15
What treatments are available for vesicoureteral reflux?15

My notes and questions ______17

This information was produced by the European Association of Urology (EAU), in collaboration with ERN eUROGEN, October 2023.

This chapter contains general information about duplex congenital malformations of the urinary tract. If you have any specific questions about your child's individual medical situation you should consult your doctor or other professional healthcare provider. No website or leaflet can replace a personal conversation with your doctor.

Contributors:

Dr. Bernhard Haid, Linz (AT), EAU Working Group on Paediatric Urology

Prof. Dr. M.S. Silay, Istanbul (TR), EAU Paediatric Urology Guidelines Panel

This information has been reviewed by a lay panel.



eUROGEN Urogenital Diseases







Duplex congenital malformations of the urinary tract

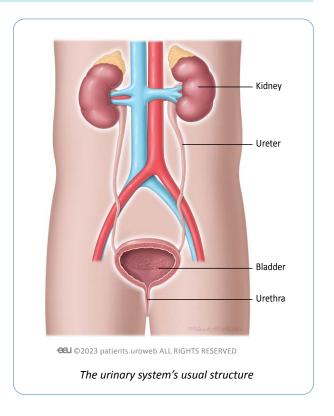
What are congenital malformations of the urinary tract ("urinary tract differences")?

Benign prostate enlargement, or BPE, is a non-cancerous condition in which the prostate gland, located below the A small number of babies, while growing in the womb, may develop some differences in their urinary system (the organs in the body that produce and carry away urine). These differences are known as "congenital malformations of the urinary tract".

Broken down, this medical term means:

- Congenital a condition that develops during development in the womb
- Malformation where an organ develops differently than usual
- Urinary tract consisting of the kidneys, the ureters (the tubes that connect the kidneys to the bladder), the bladder, and the urethra (the wee tube that carries urine from the bladder and out of the body)

Throughout this website, we refer to congenital malformations of the urinary tract as "urinary tract differences".



Although urinary tract differences are rare, the most common ones are:

Hydronephrosis (pronounced 'hi-dron-eff-roe-sis')

This condition is where one or both kidneys swell up due to the build up of urine. This happens if urine is unable to flow from the kidney (or both kidneys) to the bladder and is sometimes caused by a blockage or a urinary infection.

Ureteral duplication (pronounced 'yur-eet-eral dew-plik-ay-shun'), also called duplex kidney

This is where one or both kidneys have an extra ureter tube connecting down to the bladder, rather than one ureter connecting the kidney to the bladder.

Ureterocele (pronounced 'yur-reet-ero-seel')

This is where the lower part of the ureter becomes enlarged and forms a balloon-like structure inside the bladder.

Ectopic ureter (pronounced 'ek-top-ik yur-eet-er')

This describes a condition where the upper part of the ureter attaches incorrectly elsewhere in the urinary tract or bladder.

Vesicoureteral reflux (pronounced 'vessy-co-yur-eet-er-ral ree-flux'), also called VUR

VUR happens when urine flows backward from the bladder, back up into one or both ureters, and sometimes even into the kidney.





These urinary tract differences may be found during one of the ultrasound scans that are carried out throughout your pregnancy. Being told your unborn child or, if the condition is diagnosed after birth, your newborn, has any kind of medical problem can be a worrying time, but it's important for you to know that most children born with urinary tract differences don't experience any symptoms or urinary problems at all.

Urinary tract differences can occur due to unexplained changes in genes that happen while a baby is developing in the womb. In rare cases, they can be inherited (passed down) from the parents.

Sometimes, urinary tract differences can occur alongside <u>congenital</u> malformations (differences) in other parts of the body. For instance, there are over 500 medical conditions that are linked to urinary tract differences.

Medical tests, such as regular ultrasounds carried out during pregnancy, can identify these potential differences early on so that they can be monitored and treated, if necessary. If your child is found to have a difference in the structure of their urinary tract, a team of specialist healthcare professionals will support you and your family to ensure your child receives the best possible care and treatment for their individual needs.

On this patient website, we aim to provide you with detailed information on urinary tract differences, treatment options and any long-term care considerations, to help you feel informed. You may wish to write down some questions you would like to ask your child's medical team at your next appointment.

Duplex kidney (ureteral duplication)

What is duplex kidney?

Duplex kidney is another term for ureteral duplication. This is where a child has 2 <u>ureters</u> (instead of one) connected to a single kidney. The extra ureter may be completely separate (this is called complete duplication), or start separately but combine with the original ureter before it attaches to the bladder (this is called incomplete duplication).

You can watch our video about duplex kidney here.

How common is duplex kidney?

Urinary tract differences are rare, but the most common type is duplex kidney, which affects around 0.8% of the population. The majority of children with this condition have no symptoms and do not experience any related problems, so both the child and parents are very often unaware of the condition.

What are the symptoms of duplex kidney?

While many children with duplex kidney may not have any symptoms at all, some may experience urinary tract infections (UTIs) or urinary incontinence.

Genes

Genes are like instructions that tell our cells how to grow and develop, including how to form our organs. They are made of a substance called DNA.

Inherited

Genes are like instructions that tell our cells how to grow and develop, including how to form our organs. They are made of a substance called DNA. The instructions are passed down from our parents, so we inherit some of their traits because we get some of their genes.

Congenital

Congenital means developed in the womb and present from birth.

Ureteral duplication

Pronounced 'yur-eet-eral dew-plik-ay-shun'

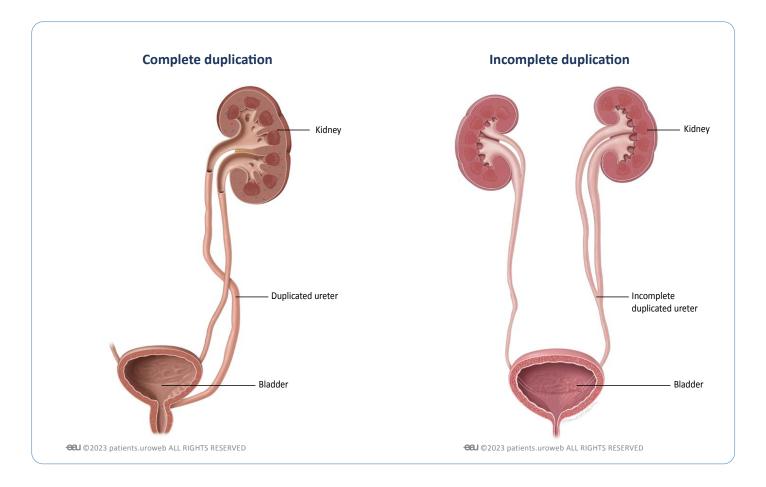
Hrotors

Ureters are the tubes that run down from each kidney to the bladder.









Urinary Tract Infections (UTIs)

In cases of duplicated ureters, up to 20% of children may experience vesicoureteral reflux (VUR), which is where urine flows from the bladder, back up the ureter to the kidney. This results in a higher risk of UTIs because VUR slows the flow of urine and causes bacteria to be carried back up the urinary tract, instead of being passed out of the body in the urine via the urethra (wee tube). This can cause bladder or kidney infections.

Symptoms of a UTI include a burning sensation while weeing, having to go to the bathroom to wee a lot (UTIs can make you feel as though you need to wee all the time), cloudy or foul-smelling wee, and pain in the abdomen.

However, in young children and infants, identifying a UTI can be more challenging as they may not be able to describe their symptoms. Often, the main symptom is a sudden high fever without any accompanying problems. Alternatively, you may notice your child is more irritable or doesn't want to eat as much as usual.

Detecting a UTI early is very important as it allows for the infection to be treated quickly, usually with antibiotics. Treatment greatly reduces the risk of kidney problems. UTIs can become serious if left untreated.

Urinary Incontinence

Urinary incontinence means having difficulty holding urine in the bladder. This can lead to your child leaking urine or having an 'accident' if they don't make it to the toilet in time. For children with duplex kidney, urinary incontinence

can be a lifelong problem, but this depends on the way in which the ureters (the tubes that connect the kidneys to the bladder) have separated and reattached themselves. Your child's medical team will be able to explain more about your child's individual circumstances.

Vesicoureteral reflux

Pronounced: 'vessy-co-yur-eet-er-ral

ree-flux'





What treatments are available for duplex kidney?

In most cases, no treatment is needed. However, treatment may be considered depending on specific circumstances, such as:

- your child's age
- your child's symptoms
- how their urine flows
- their kidney function and their medical history.

Wait and See

In over 90% of cases, diagnosis of duplex kidney does not require any treatment. For instance, if it causes no symptoms and does not pose any significant risks. In this situation, your doctor may suggest a "wait and see" approach. This means keeping an eye on things, with regular check-ups so any urinary issues that may arise in the future can be investigated quickly.

Antibiotics

If your child keeps getting UTIs because of duplex kidney, your doctor may prescribe antibiotics to kill the bacteria causing the infection. Curing the infection also addresses any discomfort your child may be feeling from the UTI.

It is important to tell your doctor quickly if your child has symptoms of a UTI to prevent kidney damage or other related problems from occurring.

Surgery

Whether or not surgery is needed depends on your child's individual circumstances and what their medical team recommends. The treatment options offered to you might be different depending on where in Europe you live, as healthcare practices differ between countries. Your doctor will discuss your child's medical condition with you and will present you with the available and recommended treatment options, so you can make an

informed decision.

If surgery is a recommended option, your doctor may discuss some, or all, of the following procedures with you:

- Ureteral re-implantation
- Nephrectomy
- Ureteroureterostomy

These types of surgery are carried out under general anaesthesia. This is where your child is given medication to send them to sleep. Once they are asleep, they do not feel anything, nor will they remember the operation.

After the procedure, your child will be taken to the recovery area and closely monitored. Your healthcare team will provide instructions on wound care, pain management and any potential dietary or activity restrictions. It's important to follow these instructions so that your child has a good recovery.



Kidney function means how well your kidneys are working in their job to clear waste products from the body. Kidney function is assessed with urine or blood tests.

Medical history

Your medical history is the record that is kept of all of your vaccinations, past illnesses, family health history, your visits to your doctor and any medicines that have been prescribed to you.

Nephrectomy

Pronounced: 'neff-rec-tomee'

Ureteroureterostomy

Pronounced: 'yur-reet-ero-yur-reet-erost-omee'







Ureteral re-implantation

Ureteral re-implantation surgery involves moving the ureter (or both ureters) from its incorrect position and reconnecting it in the right place so that urine can flow freely through the urinary tract and in the right direction. This procedure is used to treat blockages as well as vesicoureteral reflux.

Nephrectomy (pronounced 'neff-rec-tomee')

Nephrectomy involves the removal of a kidney, or in cases of duplex kidneys, a part of a kidney (partial nephrectomy). However, it is not commonly carried out in cases of duplex kidney.

Nephrectomy may be considered in cases where one kidney is non-functioning and if not removed, could harm your child's overall health. A partial nephrectomy may be considered if a problem is found in a particular section of a kidney. In this situation, the goal would be to fix the problem while saving as much healthy kidney tissue as possible.

Ureteroureterostomy (pronounced:'yur-reet-ero-yur-reet-er-ost-omee')

Ureteroureterostomy is a reconstructive surgical procedure where the duplicated (additional) ureters running down from the kidney or kidneys are connected to each other. It is usually performed in specific cases where there is a need to redirect the flow of urine.

Ureterocele

What is a ureterocele?

Ureterocele is a condition where a part of the ureter, the tube that connects the kidney to the bladder, forms a bulge or balloon-like structure inside the bladder. There are 2 types of Q

ureterocele:

- Orthotopic ureterocele, where the bulge is located completely inside the bladder.
- Ectopic ureterocele, where the bulge extends into the bladder opening or the urethra.

Ureteroceles can cause urine to collect in the balloon-like structure, which can trigger problematic symptoms.

Not all children with ureterocele experience symptoms and in some cases, the condition is only found when a child is undergoing medical scans or urinary tests later in life.

How common are ureteroceles?

Ureteroceles are quite rare, affecting around one in every 4,000 children. It's more commonly seen in girls than in boys, with girls being 4 to 7 times more likely to have the condition. About 80% of ureteroceles in children are linked to duplex kidneys, especially those affecting the upper part of the ureter.

Ureters

Ureters are the tubes that run down from each kidney to the bladder.

Vesicoureteral reflux

Pronounced: 'vessy-co-yur-eet-er-ral ree-flux'

Vesicoureteral reflux, often shortened to VUR, is where urine is able to flow back up from the bladder, through the ureter and up into the kidney.

Ureterocele

Pronounced: 'yur-reet-ero-seel'

Urethra

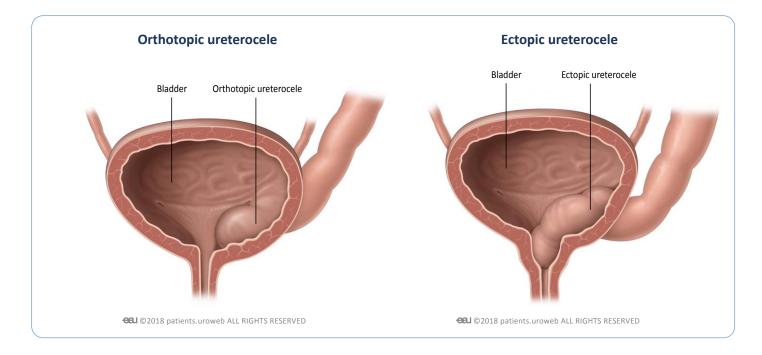
The urethra is the wee tube that runs down from the bladder and carries urine out of the body.

Duplex kidney

Duplex kidney is another term for ureteral duplication. This is where a child has 2 ureters (instead of one) connected to a single kidney.







While ureterocele are not often detected before birth, the condition can cause an enlargement (swelling) of your baby's urinary tract, which can be seen on an ultrasound scan. This swelling of the urinary tract could be due to a blockage in the flow of urine or be a sign of other urinary tract conditions.

Your medical team will keep a watchful eye on any swelling of your unborn baby's urinary tract during your pregnancy. This way, if they detect potential problems, they will be on hand to provide specialist healthcare support to ensure your baby receives the best possible care and treatment.

What are the symptoms of a ureterocele?

Usually smaller and non-obstructed ureteroceles don't cause any symptoms. The symptoms of a ureterocele can vary, but they often include:

Urinary Tract Infections (UTIs)

When a ureterocele creates a bulge where urine can collect, it can result in stagnant or stale urine which can be a perfect place for bacteria to grow. This can lead to a UTI. The main symptom young children with a UTI experience is a high fever. Young infants and toddlers may not show specific UTI symptoms such as pain when weeing, and instead may be irritable or have trouble feeding. Children over the age of 6 years may need to wee a lot, have cloudy or foul-smelling urine, or abdominal discomfort. They are more likely to be able to describe their symptoms.

If your child does have a UTI, it is important to see your doctor quickly, so that they can prescribe antibiotics, if needed. UTIs can become serious if left untreated.

Urinary Frequency and Urgency / Bladder Emptying Problems

When a ureterocele blocks the normal flow of urine, it can lead to a backup of urine in the kidney, causing irritation and inflammation. This makes the bladder contract (squeeze) more often. That's why children with a ureterocele might feel like they have to wee often and urgently. They may try to empty their bladder more often in an attempt to relieve the pressure and discomfort they are feeling.





Haematuria (pronounced 'hee-mat-yur-ee-ya')

Haematuria is the medical term for blood in the urine. This symptom is extremely rare in childhood.

In children with a ureterocele, the bulge blocks the normal flow of urine through the ureter, causing urine to get stuck in the <u>ureter</u> or kidney. This can cause swelling, inflammation (irritation), and bleeding. The increased pressure in the urinary system can make the blood vessels break, which can be another cause of the blood in the urine.

What treatments are available for ureteroceles?

The treatment of a ureterocele depends on how severe your child's symptoms are and how it affects their kidneys. Regular follow-up appointments with a specialist medical professional are important to manage and monitor the condition.

Wait and See

In mild cases where the symptoms of a ureterocele are not causing complications, close monitoring by a doctor with regular check-ups may be recommended. This is called a 'wait and see' approach. However, if ureterocele is causing your child to keep getting UTIs or suffer kidney-related issues, appropriate treatment options will be discussed with you.

Antibiotics

If your child has regular UTIs, your doctor may prescribe antibiotics. These medicines treat the current infection and prevent future ones. Antibiotics kill the bacteria causing the infection and help to make your child feel better.

It's important to inform your doctor about any symptoms of a UTI, as this can help reduce the chances of kidney damage or other complications.

Surgery

Your child's doctor may recommend surgery to treat the ureterocele. The treatment options offered to you will depend on your child's individual circumstances and where in Europe you live, as healthcare practices differ between countries. Your doctor will discuss all treatment options available, the potential outcomes and any risks with you. Any recommendation they make will be based on careful assessment of your child's individual medical circumstances.

In the majority of cases, surgery is carried out under general anaesthesia. This is where your child is given medication to send them to sleep. Once they are asleep, they do not feel anything, nor will they remember the operation.

After the procedure, your child will be taken to the recovery area and closely monitored. Your healthcare team will provide instructions on wound care, pain management and any potential dietary or activity restrictions. It's important to follow these instructions so that your child has a good recovery.

Endoscopic decompression

This operation involves having a thin tube with a camera on the end, called an endoscope, passed through the urethra (wee tube) to reach the ureterocele.

The doctor uses the endoscope to see the ureterocele and they can also use it to make a small cut in the ureterocele with a medical laser. The openings created with the laser allow the trapped urine to flow correctly into the bladder, relieving the blockage and preventing further urine from building up.



Ureters

Ureters are the tubes that run down from each kidney to the bladder.



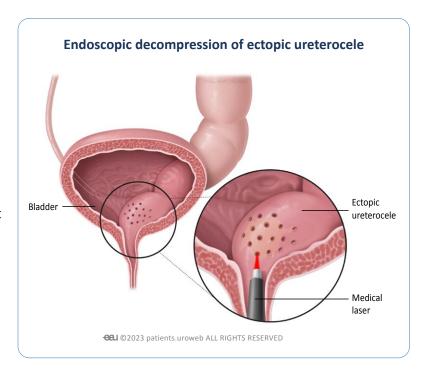


Endoscopic decompression procedures involve a risk of developing a condition called vesicoureteral reflux (where urine flows backwards from the bladder and back up into the ureters or kidneys). This can happen if a puncture or cut is made in the urinary system during the procedure. If reflux becomes a problem, additional surgery may be necessary.

A less likely scenario, if there is a puncture, is that urine may flow back through the puncture site. Similarly, if there is a cut during the procedure (which happens 40% of the time) urine may flow backward through the cut.

Ureteral re-implantation

This surgery is carried out if a ureterocele causes severe urinary blockages or frequent UTIs.



The surgeon makes a small cut in the lower abdomen to reach the bladder, then carefully disconnects the affected ureter from the bladder and repositions it to help improve the flow of urine from the kidneys to the bladder and prevent any blockages or reflux of urine.

During the surgery, the surgeon will also remove the ureterocele.

Complete primary reconstruction

Complete primary reconstruction is a major surgery which involves removing the ureterocele while reconstructing the ureter and the bladder to ensure urine can flow correctly. This procedure is typically recommended for very large and ectopic ureterocele which are causing problems with bladder emptying, or if other treatment methods have been unsuccessful.

The procedure involves a surgeon making a small cut in the lower abdomen and pelvic area to access the ureter and bladder. The ureterocele is then removed and the ureter and bladder are reconstructed to help improve urine flow and prevent future blockages or reflux.

(Partial) nephroureterectomy (pronounced:'neff-rur-yur-reet-er-rec -tomee')

This surgery is used when a kidney (or a part of it) is causing problems such as high blood pressure, severe UTIs, kidney stones, poor functioning, or if there is an issue that is too large to treat with other methods. The surgery involves removing the kidney, the entire ureter connecting it to the bladder, and a small piece of bladder where the ureter and bladder connect, including the ureterocele.

This procedure can be done in a minimally-invasive way such as with laparoscopy/robotic surgery, where small cuts are made and surgical instruments are threaded through, rather than with open surgery (which would involve a large cut being made in the abdomen).

Vesicoureteral reflux

Pronounced: 'vessy-co-yur-eet-er-ral ree-flux'





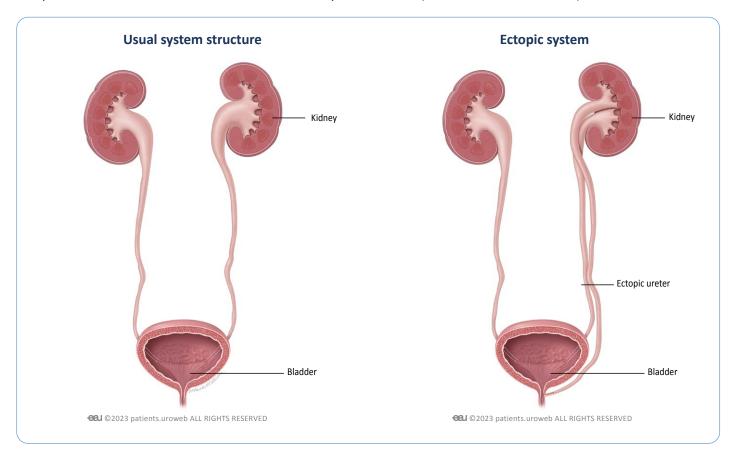
Partial nephroureterectomy is considered a major surgery and the recovery period can vary from person to person. During the recovery period, you may be advised to limit your child's physical activities to help the healing process. The development of new technology means this procedure can now be performed in a minimallyinvasive way such as with laparoscopy or robotic surgeries in hospitals that have these facilities. Such methods enable a shorter recovery time and less discomfort after surgery.

Ectopic ureter

What are ectopic ureters?

An ectopic ureter is when the ureter doesn't connect to the bladder in the usual place. Instead, it can connect into different places, such as the vagina or the urethra (the wee tube that runs from the bladder and out of the body). This often causes urine to build up as it cannot drain like it should. This can lead to problems such as ureteral enlargement, where the ureter swells up.

Ectopic ureters can increase the risk of UTIs or urinary incontinence (uncontrolled loss of urine).



How common are ectopic ureters?

Ectopic ureter is a rare condition that affects around 10 out of 19,000 children. It is more commonly diagnosed in girls, because it tends to have a larger impact on their health and wellbeing. For instance, in girls, the ectopic ureter can connect to an unusual location, such as the vagina and can result in urinary incontinence.



Pronounced: Pronounced 'ek-top-ik yur-eet-er'

Ureterocele

Ureters are the tubes that run down from each kidney to the bladder.







An ectopic ureter is also more frequently seen in children who have duplex kidney. In some cases, children with an ectopic ureter may not experience any symptoms at all, making it challenging to determine the actual number of children with the condition.

Duplex kidney occurs when a child has 2 ureters connected to a single kidney, instead of one ureter. The extra ureter may be completely separate (called complete duplication), or start separately but combine to create a single tube that attaches to the bladder (called incomplete duplication).

What are the symptoms of ectopic ureters?

Many children with ectopic ureters don't experience any symptoms at all, but for those children who do, the following are known symptoms of the condition:

Urinary Tract Infections (UTIs)

Ectopic ureters can result in a slower flow of urine which can increase the risk of bacteria reaching the kidneys or bladder and therefore a higher chance of developing UTIs. It's important to be familiar with the signs of a UTI, as prompt medical treatment is necessary to avoid damage to the kidneys.

In children over the age of 6 years, symptoms can include a burning sensation while weeing, a frequent need to wee, cloudy or foul-smelling urine and discomfort in their abdomen.

It can be very difficult to identify a UTI in younger children and babies as they may not appear to have these symptoms or they may only have a high temperature. However, you may notice your child is more unsettled or they have gone off their food. If you suspect your child has a UTI, it is important to take them to see their doctor to receive a diagnosis and so that antibiotics can be prescribed, if needed.

Urinary Incontinence

In girls, an ectopic ureter can attach to the vagina or the <u>urethra</u> and may not connect near the muscle that controls urine flow. This can cause urinary incontinence, which means that your child may have difficulty holding their urine and may leak it by accident.

Although boys can experience urinary incontinence, it is unlikely to be caused by an ectopic ureter.

What treatments are available for ectopic ureter?

The type of treatments that are offered depend on the specific condition, your child's age, overall symptoms, urine flow, kidney function and medical history.

Antibiotics

If your child keeps getting UTIs, your doctor may prescribe antibiotics. Antibiotics work to kill the bacteria causing the infection and help reduce any discomfort.

It is important to tell your doctor about any symptoms of UTI your child is experiencing to reduce the risk of kidney damage or other complications.



Urethra

The urethra is the 'wee tube' that runs down from the bladder and carries urine out of the body.

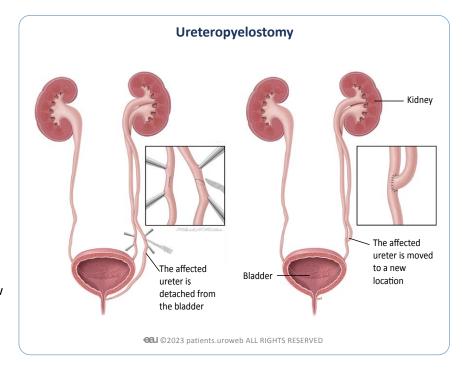




Surgery

Surgery for ectopic ureter is carried out under general anaesthesia. This is where your child is given medication to send them to sleep. Once they are asleep, they do not feel anything, nor will they remember the operation.

After the procedure, your child will be taken to the recovery area and closely monitored. Your healthcare team will provide instructions on wound care, pain management and any potential dietary or activity restrictions. It's important to follow these instructions so that your child has a good recovery.



Ureteropyelostomy

(pronounced:'yur-reet-ero-pie-los -tomee')

If ectopic ureters are causing blockages or other urinary issues, your doctor may recommend a ureteropyelostomy.

The aim of this surgery is to create a direct connection between the ectopic ureter and a specific part of the kidney called the renal pelvis, to help urine to flow properly from the kidney to the bladder. It's an option in cases with duplex ureters or where a person has specific issues with the lower portion of their ureter.

Ureteral re-implantation

complications.

This surgery is performed when ectopic ureters are causing significant complications.

The surgeon makes a small cut in the lower abdomen to access the bladder and carefully detaches the affected ureter from the bladder and moves it to a new location to improve the flow of urine from the kidneys to the bladder and prevent any blockages or urine reflux.

Heminephro-ureterectomy (pronounced:'hem-ee-neff-roe your-reet-er-rec-tomee') (only in duplex kidney)

A heminephro-ureterectomy is an operation to remove part of the kidney and one of the ureters, ifthe kidney and ureter are not functioning properly. The aim of surgery is to improve how the kidney works and prevent any further

During the procedure, the surgeon makes a small cut in the abdomen or side of the body to access the kidney. They identify and remove the part of the kidney that is causing problems, as well as the ureter connected to it.

Ureteroureterostomy (pronounced:'yur-reet-ero-yur-reet-er-ost-omee') (only in duplex kidney)

If an ectopic ureter is causing problems by draining urine into the urethra, reproductive organs, or other areas, your doctor may recommend a ureteroureterostomy. This procedure involves the surgeon connecting the 2 ends of the same ureter to the correct places, allowing urine to flow properly from the kidney down to the bladder.

This surgery aims to improve urine drainage, prevent complications and protect the kidney.





Vesicoureteral reflux (VUR)

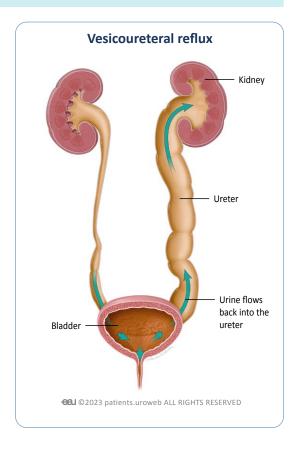
What is vesicoureteral reflux?

Vesicoureteral reflux, often shortened to VUR, is a condition where urine travels back up from the bladder, into one or both ureters and in severe cases, all the way back up to the kidneys. It happens when the valve that usually prevents urine from flowing backwards from the bladder is weakened or isn't working properly.

Urine is a waste product and it is not supposed to flow back up through the urinary system. Urine passing back through the urinary tract can cause problems such as infection and damage to the kidneys.

VUR is graded from grade 1 to grade 5, with grade 1 being the mildest form, where urine flows from the bladder back only to the ureters, and grade 5 being the most severe, where the urine flows all the way up to the kidneys and causes significant stretching of the ureters and kidneys. More than 80% of VUR cases are graded as 2 or higher, which means that in most cases, the condition is moderate to severe.

Doctors use this grading system to help them propose the best treatment options.



How common is vesicoureteral reflux?

VUR is present in about 2% of all newborn babies. Only a few children have noticeable symptoms. As children grow older and the bladder matures, diagnosis of this condition becomes less common.

VUR is sometimes found during a medical test such as a scan being carried out for other symptoms or another medical condition. It is more commonly seen in children who have congenital differences in their kidneys or other part of their urinary system, such as those with duplex kidney, ureterocele and ectopic ureters.

VUR is found to be the cause in 30-50% of children who have medical tests carried out for recurrent UTIs.

If your child is diagnosed with VUR, their doctor will advise you if any treatment or further investigation is needed.

What are the symptoms of vesicoureteral reflux?

Usually, vesicoureteral reflux doesn't cause any noticeable symptoms, but the most common is a UTI. In young children and babies, a UTI can be challenging to identify. The most common sign is a high fever. Alternatively, they may seem irritable or off their food.

In older children, signs of a UTI are easier to spot and include a burning sensation while peeing, having to pee a lot, cloudy or foul-smelling urine, and abdominal discomfort. An older child will also be able to better communicate with you about their symptoms.

Duplex kidney

Ureteral duplication, also called duplex kidney is where one or both kidneys have an extra ureter.

Ureterocele

Ureterocele is where the lower part of the ureter becomes enlarged, forming a balloon-like structure inside the bladder.

Ectopic ureters

An ectopic ureter is where the ureter attaches elsewhere in the urinary tract or bladder.





If your child does have a UTI, your doctor will prescribe antibiotics. If you suspect your child has a UTI, it is important to see a doctor promptly for treatment. Untreated infections can spread up to the kidney and cause serious infections.

How problematic is vesicoureteral reflux?

Children with VUR may experience repeat urinary infections, which require treatment and investigation as repeat infection can cause kidney damage. Your child's doctor will be able to advise you about how severe their VUR is and how to manage the condition.

To grade your child's VUR, doctors use a range of medical tests, to assess their renal (kidney or urinary) function in further detail. These tests include scans such as dimercaptosuccinic acid renal scanning (DMSA) which is a type of scan that involves a safe tracer dye being injected into your child's arm. This dye works its way through the bloodstream and into the kidneys and it causes any scarred areas to glow up on a scan, so that doctors can check to see whether VUR has caused any damage to your child's kidneys.

The results of tests such as this are used by doctors to diagnose and grade VUR and to work out how best to treat it. Further testing may be needed if initial tests and scans are unable to provide all the information needed for the doctor to make a diagnosis. This includes tests to rule out other medical conditions.

Your child's doctor will discuss any testing that is necessary to make a diagnosis, at each stage, with you so that you understand what tests are being proposed, why and what they entail, as well as if there are any risks involved.

What treatments are available for vesicoureteral reflux? Antibiotics

Your doctor may prescribe antibiotics to treat or to prevent infections caused by VUR. Antibiotics work to kill the bacteria causing the infection and help to reduce the discomfort associated with UTIs.

It is important to tell your doctor about any symptoms of UTI your child is experiencing to reduce the risk of kidney damage or other complications.

Bladder Re-training

If a child is toilet trained, bladder re-training and treatment for any bladder issues can help to lower pressure in the bladder and effectively treat VUR.

Surgery

Surgery for VUR is usually based on correcting the underlying urinary differences. Procedures may involve repairing or making changes to the ureters to correct the urine flow and prevent VUR. The specific surgery offered will depend on factors such as the severity of the condition and the risk of further kidney damage.

Surgery for VUR is carried out under general anaesthesia. This is where your child is given medication to send them to sleep. Once they are asleep, they do not feel anything, nor will they remember the operation.

After the procedure, your child will be taken to the recovery area and closely monitored. Your healthcare team will provide instructions on wound care, pain management and any potential dietary or activity restrictions. It's important to follow these instructions so that your child has a good recovery.





Endoscopic treatment of VUR

This procedure involves threading a synthetic (manufactured) implant up through the urethra (wee tube) using an endoscope (a long narrow surgical tool that has a camera at the end). This treatment is minimally-invasive (requires no cuts to be made to the skin) as it uses the existing opening of the urethra.

Endoscopic treatment with an implant can be an effective way of restoring the bladder's valve mechanism without the need for open surgery (where a surgeon would cut open the skin).

It involves only a short hospital stay and a low risk of complications as there are no cuts to the skin, so there are no scars following surgery.

Your child's doctor will assess their specific needs and provide you with the necessary information and guidance to make a decision about this treatment option if it is offered.

Ureteral re-implantation

This surgery is typically performed when severe VUR is causing significant complications like frequent UTIs, or it is still causing problems even after endoscopic treatment.

With this type of surgery, the surgeon makes a small cut in the lower abdomen to reach the bladder, then carefully cuts away the ureter that isn't working properly and repositions it, attaching it to another location in the bladder and in the process, restoring the valve mechanism so that the flow of urine is correctly controlled.

This surgery can be done in a minimally-invasive manner such as via laparoscopy or robotic surgery (where only small cuts to the skin are required rather than open surgery which would involve opening of the skin) in hospitals with these facilities.





My notes and questions



European Association of Urology

PO Box 30016 NL-6803 AA ARNHEM The Netherlands

e-Mail: info.patientinformation@uroweb.org

Website: patients.uroweb.org

