REFLUX NEPHROPATHY

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Reflux nephropathy

What is Reflux Nephropathy?

Reflux means that something goes back the way it has come, instead of travelling onwards. In reflux nephropathy, this means that urine passes back up from the bladder towards the kidneys, instead of coming out of the body (see below picture of the bladder, kidneys and drainage tubes). Nephropathy is a medical term for kidney disease.

Reflux nephropathy is sometimes also called just ‘reflux’, and an older name for the same condition is ‘chronic pyelonephritis’, or ‘chronic pyelonephritis with reflux’. It is sometimes also called ‘vesico-ureteric reflux’. ‘Vesico-ureteric’ means from the bladder to the ureter (the tube from bladder to kidney).

What causes reflux nephropathy?

Nearly all cases of reflux are caused by an abnormality that develops before birth. One or both of the drainage tube from the kidneys to the bladder (called ureters) enter the bladder at the wrong angle. When the bladder contracts to pass urine outwards, the ureter is not ‘pinched off’, and instead of all the urine being passed out of the body, some goes back up the ureters towards the kidneys.
Sometimes, reflux can be secondary to other problems that have developed during life, such as bladder disease or radiation to the ureters. Reflux can also occur after kidney transplantation.

Reflux of urine from the bladder up towards the kidneys is common, occurring in more than 1 in 100 new born babies. As the baby grows, reflux usually disappears. This is because the section of the drainage tube from the kidney that lies within the muscular wall of the bladder lengthens during growth. This means that as the bladder squeezes to eliminate urine from the body, it becomes more likely to ‘pinch off’ the ureter and stop any urine refluxing.

Reflux nephropathy is generally only a problem if there have been infections very early in life that have caused some damage (scarring) to the kidney, or if the reflux does not go away as the baby grows. Only about 1 in 10 babies born with reflux develop such problems. The majority grow up normally, often without anyone knowing that there had been reflux at any time in their lives.

Kidney damage occurs in some people with reflux. The exact cause of the damage is not always clear. Sometimes it seems that a severe infection has damaged a section of a kidney so much that it turns into scar tissue and cannot function normally. The reflux itself may put back pressure on the tissue of the kidney when the bladder is emptying, which might also cause damage. Lastly, some people develop kidney failure from reflux nephropathy in the absence of obvious infections, and also in the absence of ongoing reflux of urine back towards the kidneys. The exact explanation for this is not clear, and it is an area where a lot of research is being carried out.

Reflux caused by other medical conditions

Reflux of urine from the bladder can occur because other medical conditions have affected the junction of the bladder and ureter (tube coming down from the kidney). There are many conditions reported as causing this, but they are not common in the United Kingdom. Irradiation (X-ray therapy) to the bladder, surgery to the bladder or ureter, kidney transplantation, and bladder problems secondary to spina bifida or multiple sclerosis are some of the causes.

The treatment of reflux in these circumstances is similar to that of reflux nephropathy generally. However, the chances of developing severe problems such as kidney failure vary from case to case, and advice should be sought from the medical specialist.
I have had several urinary infections – might I have reflux?

There are many causes of infection in the urine. Most people with urine infections do not have reflux nephropathy. Any abnormality in the drainage system from the kidneys, or abnormality in the bladder, can lead to urine infections. Although urine has no germs in it when it leaves the kidneys, if it does not leave the body right away, germs can grow very fast as urine is an extremely ‘fertile’ breeding ground.

However, urine infections in babies and young children are an important sign of possible reflux nephropathy. Tests should be performed to make sure reflux is not present, especially if urine infections in babies are repeated.

For further information regarding Urine Infections please see NKF leaflet entitled “Urine Infections” or call the Helpline on 0845 601 02 09

I’m worried my child could have reflux nephropathy. What are the symptoms?

Reflux nephropathy can show itself in a number of ways. It can occasionally be detected before birth, using an ultrasound scan of the baby in the womb. The scan may show evidence of back pressure from the bladder on developing kidneys. Most often, reflux is detected because a child has urine infections. Occasionally, urine infection does not cause typical pain, but can cause bedwetting. Most children with bedwetting do not have reflux nephropathy, but a simple urine test should detect whether urine infection is present.

Does reflux nephropathy cause pain?

Not usually, but it can occur. Infection usually causes pain, which may be in the groin. A burning feeling while passing urine is the most common, but there may also be smelly urine and itching. If infection affects the kidney, there may be pain in the loin. The back pressure caused by the reflux of urine does not often cause pain, though this can happen. In adults, pain of this type is very occasionally helped by surgery (see below Surgery for Reflux Nephropathy).

Is reflux nephropathy common, and can it go away on its own?

Reflux of urine is common, occurring in 1 in 100 children. In many cases this causes no problems. The majority of reflux then disappears during childhood, in about 9 out of 10 cases. However, some kidney damage can also occur at an early age, and children with reflux require careful treatment.
How is reflux nephropathy diagnosed?

Reflux nephropathy requires tests to be performed before a firm diagnosis can be made. The simplest is an ultrasound (sound wave) scan of the bladder and kidneys. To prove a diagnosis of reflux, a test called a micturating cystogram might be performed. This requires a catheter (small tube) to be inserted into the bladder, and X-ray dye to be injected into the bladder.

Even if a doctor might suspect reflux nephropathy very strongly, for example if someone has multiple urine infections and there are a number of proven cases in the family, tests must be performed before the diagnosis can be proven.

The tests that might be performed are listed. Not all of these are needed, and someone’s own specialist will need to decide what is necessary.

Urine tests

Urine tests will be performed to look for infection in the urine, and also to test for blood or protein in the urine. In some cases, a 24 hour collection of urine may be performed to measure the exact amount of protein in the urine (see available leaflet on Proteinuria).

Blood tests

Blood tests will be performed to measure the level of kidney function, and to look for other possible causes of kidney disease if the diagnosis is not certain.

Ultrasound scan

This is a scan using sound waves (the sound waves are too high pitched for us to hear). A probe is pressed gently on the skin, with some jelly on the skin to make a good contact. Ultrasound is painless and harmless, and can easily be performed on babies as well as older people. An ultrasound can show the size and shape of the kidneys, and sometimes can show enlarged ureters (tubes from kidney to bladder). It can also show whether the bladder empties fully. Unfortunately, though, it cannot prove whether reflux is actually occurring. Therefore further tests may be necessary.

‘IVU’ or ‘IVP’

Pictures of the kidneys and ureters can be obtained by a series of X-ray pictures after an injection of an X-ray dye into the arm. This is called an ‘IVU’ or ‘IVP’. It is not, however, 100% reliable at showing reflux.
Micturating cystogram

‘Micturating’ is a medical term which means passing urine. Cystogram means picture of the bladder. A catheter is passed into the bladder and X-ray contrast injected into the bladder. Pictures are taken while urine is being passed. This gives the best pictures of reflux and can assess the need for surgery, but is not pleasant, and carries a small risk of causing urine infection.

In children a micturating cystogram may need to be carried out using a short anaesthetic to put your child to sleep.

Other tests

A number of other tests are sometimes advised. Surgeons may inspect the inside of the bladder using a tube called a cystoscope. This examination may be performed while you are awake, using a local anaesthetic, or sometimes while someone is asleep (for example in children). Using the cystoscope, a doctor may be able to see abnormal ureters, or take X-ray pictures in the operating theatre which show reflux. A ‘micturating radio-isotope scan’ is a type of scan performed by putting slightly radio-active fluid fluid into the bladder though a tube. When urine is being passed, pictures are taken to measure any reflux of urine. This is a specialist technique, but is very successful in some hospitals. The radio-isotope is radioactive, but the exposure of the subject to radiation is equal to, or less than, a micturating cystogram.

Tests in babies

Performing medical tests in children and young babies is not always easy. Unfortunately, simple urine tests and ultrasound are not always enough to diagnose reflux nephropathy (and other conditions of the kidneys) with certainty. The specialist may then advise other tests, which are less pleasant. Sometimes it is possible for these to be performed under an anaesthetic, although of course there are slight risks associated with a general anaesthetic. If a slightly unpleasant test reduces the chances of a baby developing kidney failure in adult life, it may be worth having, even if it causes some worry to the parents. The details of each case need to be discussed with a specialist.

I have reflux and want to get pregnant. Will there be problems?

Women with reflux nephropathy normally have successful pregnancies. However, there is an increased risk of urine infection during pregnancy. If there is protein in the urine or scarring on the kidneys, there is an increased
risk of high blood pressure, and this requires careful management. If someone with severely damaged kidneys from reflux nephropathy wants to get pregnant, the risks depend upon the exact level of kidney function. Some larger hospitals have clinics run by a kidney specialist and an obstetrician working together to provide extra care for pregnant women with kidney diseases. Ask your GP or obstetrician about any such service in your area.

By the time they are old enough to have children, most women who had reflux as a baby will have grown out of it and will have a normal pregnancy. However, there is a risk of problems. These are urine infection; high blood pressure; and kidney failure.

**Urine infection**

Urine infection is common for any woman during pregnancy. The womb presses on the bladder and on the ureters (drainage tubes from kidneys to bladder). Urine does not flow so easily out of the body, and disturbance to the normal flow of urine makes infections more likely. In some cases, it may be best to take antibiotics on a long term, low dose basis through pregnancy. Doctors do not advise medication in pregnancy lightly, but sometimes the risks to the baby may be greater from repeated infections in the mother than from a once daily antibiotic.

**High blood pressure**

High blood pressure towards the end of pregnancy is important, because if it is not treated, serious problems can occur in mother and baby. If someone with reflux nephropathy has a scarred kidney, high blood pressure is much more likely to develop. The warning sign for this is protein in the urine. Therefore a woman known to have reflux nephropathy who has protein in the urine early in pregnancy should be watched very closely for high blood pressure later in pregnancy.

**Kidney failure**

Kidney failure is very unusual unless the kidneys are already not working properly at the start of pregnancy.

Some larger hospitals have clinics run by kidney specialist and an obstetrician working together to provide extra care for pregnant women with kidney disease. Ask your GP or obstetrician about any such service in your area.
What is the treatment for reflux nephropathy?

There is much someone with reflux nephropathy can do for themselves to reduce the risk of infections and other problems. Treatment and prevention of urine infections is the most important treatment for reflux, and sometimes this requires long term antibiotic treatment. It is possible for a surgeon to perform an operation that is designed to reduce the reflux of urine. Research has shown that this surgery is necessary in only a very few people with reflux. These are children with very severe reflux, and adults with painful reflux.

What you can do yourself

No treatment guarantees that reflux will not cause problems, but you can help yourself enormously. If recurrent infections are a problem, it is best to take a high fluid intake, and avoid alcohol during an infection. It is best to empty your bladder fully when you go to the toilet, and empty your bladder after sex (for more details on Urinary Infections see available leaflet).

If you have high blood pressure or kidney damage from reflux nephropathy, make sure you have a good understanding of the condition, and work with your doctors and other staff to develop effective treatment strategies. Some medication, especially high blood pressure treatment, can cause side effects. Discuss these honestly with the doctor or pharmacist, and do not just stop taking medication without telling anyone.

Treatment of urine infections

As well as the self-help measures identified above, antibiotics are often needed to treat urine infections. In a few cases, people can eliminate an infection by raising fluid intake, but antibiotics need to be prescribed most of the time. Remember to tell the doctor if you have any allergies, and take the full course even if you feel better after the first day or two.

Some people get repeated infections. There are several strategies that can be used to deal with these, and the one which suits each person best should be discussed with the specialist. Do remember, though, that the doctor wants not only to treat any unpleasant symptoms you get from an infection, but also to prevent damage to the kidneys and reduce the chances of getting kidney failure in the long term. The four strategies most often used are:-

1. Take a single course of antibiotic, ideally after a sample of urine has been sent to the laboratory to test for germs.
2. Some people get ill quickly from infections, and keep some antibiotics at home to start themselves at the first sign of infection, so avoiding delay. Ideally, they should also collect a sample of urine for culture before starting the antibiotic.

3. Some people get a series of infections one after the other, coming back as soon as antibiotics are stopped. A three month course of antibiotics, at a daily low dose, may then be tried. In many cases this is effective, and antibiotics can then be stopped. Long term antibiotics are usually well tolerated, but can cause problems with sickness or diarrhoea or thrush (itchy infection in the genital area). If an infection ‘breaks through’ preventative antibiotics, it may be resistant to the antibiotic, but this is not usually a problem as there are many different types of antibiotic available, and a different type of antibiotic will generally work quickly.

4. Rarely, even a three month course of preventative antibiotics fails, and it may be necessary to take a daily antibiotic for longer, even years in some cases. In some people a single type of antibiotic seems to work, in others it is best to ‘rotate’, that is, to take a different antibiotic each month. This is thought to reduce the rate of breakthrough infection and antibiotic resistance. Most doctors rotating antibiotics would use three different types.

**Surgery for reflux nephropathy**

A surgeon can operate on a ureter with reflux. The most commonly performed operation ‘tunnels’ the ureter under the surface of the bladder, trying to get it to the position it should have been in at birth. Although an operation may look technically successful, research over the last 30 years has shown that it does not necessarily make people better. The indications for surgery have therefore been defined more clearly, and surgery for reflux is carried out far less often than 30 years ago.

It is still not proven exactly which people should have surgery, and not all surgeons agree. The general consensus is that once scarring or kidney failure have started, surgery does not protect a kidney against further damage. Surgery carried out before the age of 3 years in children with severe reflux may prevent kidney damage later in life. Some adults with loin pain when the bladder is full may benefit from surgery.

A kidney which has been very badly damaged by reflux may be removed completely, to prevent further infections or to help with blood pressure control. Obviously this is a last resort, in a kidney which has virtually no function left.
**What are the complications of reflux nephropathy?**

Some of the complications of reflux nephropathy have already been discussed, such as urine infection, protein in the urine, high blood pressure and kidney failure. Less than 1 in 10 of the people with reflux will develop high blood pressure and kidney failure.

There are other less common complications of reflux nephropathy.

**Kidney stones**

If there is longstanding infection in a kidney, a stone may form. This occurs because calcium and phosphate in the urine come out of solution and cause chalky lumps. One of the reasons for treating urine infections carefully is to reduce the chances that stones will develop. Stones may be small and cause pain in the loin, or may lead to blood in the urine. A small stone could fall out of the kidney and block the tube leading down to the bladder, with back pressure on the kidney; This can cause severe pain. In some cases, the stone in the kidney can grow to a large size, filling the space in the kidney where the urine collects. This space has several ‘branches’ coming off it, so this type of stone is a called a ‘stag horn’, because it looks at little like the horns of a large deer.

Doctors generally try hard to get rid of kidney stones. The techniques available include shock wave treatment (lithotripsy), and surgery, using either a keyhole approach or surgery through a 10cm cut in the side. The specialist can advise which type of approach in best in a particular case. Surgery carries a risk of damage to the kidney, and although lithotripsy can be carried out several times without problems, surgeons are usually unwilling to operate on a kidney more than once.

If someone has high blood pressure, and especially if there is any sign of kidney scarring or reduced kidney function, vigorous treatment of high blood pressure is essential to reduce any ongoing damage to the kidneys, and to help protect the heart and circulation.

**Can someone with reflux nephropathy have dialysis or a kidney transplant?**

If someone with reflux nephropathy develops complete kidney failure, dialysis and transplantation can usually be given in the same way as for anyone else. Some people with recurrent infections may need to have their own kidneys removed to make kidney transplantation safer.
Should the family be tested for reflux nephropathy?

Reflex nephropathy can run in families, and scarring to the kidneys can develop at an early age. Therefore family screening is recommended.

There is at present no genetic test that can be done to see if someone has reflux nephropathy. Therefore screening consists of tests on the kidneys and bladder to look for evidence of reflux.

There is no general agreement amongst doctors about who should have screening for reflux nephropathy if one person in the family is known to have the condition. Many doctors say that all the brothers, sisters and children of someone with reflux should be tested. Other doctors say that if reflux has not caused severe kidney damage, it is not necessary to screen adults who are fit and well. However, if a close adult relative of someone with reflux nephropathy has urine infections or high blood pressure or protein in the urine, they should be tested for the condition. It is generally agreed that babies with either a mother or father with reflux should be tested at an early age, since kidney damage starts at an early age and can be prevented in many cases with careful treatment.

Because reflux of urine is common and usually gets better on its own, most cases are not detected and family screening does not occur. This may not matter. However, if a family member has had reflux nephropathy with kidney failure or severe damage to a kidney, family screening would be sensible. In older children and adults, a urine test for protein and an ultrasound scan of the kidneys would detect any serious damage. If someone has had a series of urine infections, further tests may be necessary, but a specialist should be consulted. Occasionally, a scan of a baby’s kidneys while it is still in the mother’s womb will show some signs of reflux. This does not necessarily mean that the baby will have badly damaged kidneys, but specialist care should be given.

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