

Nephrotic syndrome

Steroid-sensitive



infoKID

Information for parents and carers
about children's kidney conditions

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.

[Links to sections](#) in topic | [Other topics](#) available on website

In nephrotic syndrome, the kidneys leak too much protein into urine, leading to a drop in the levels of protein in the blood. This causes swelling in the body, especially in the face, legs and feet.

Children usually need to stay in hospital for monitoring and treatment the first time this happens.

About nine in ten children with nephrotic syndrome have a type that can be treated with a steroid medicine. This is steroid-sensitive nephrotic syndrome (SSNS), because it is "sensitive" to steroids. It is sometimes called minimal change nephrotic syndrome (MCNS).

In a few children, the nephrotic syndrome does not get better with steroids, or keeps coming back (relapsing). If your doctor has told you that your child has a different type of nephrotic syndrome, please go to the topic:

- [Nephrotic syndrome – frequently relapsing](#)
- [Focal segmental glomerulosclerosis and IgM nephropathy.](#)



Overview

About the urinary system

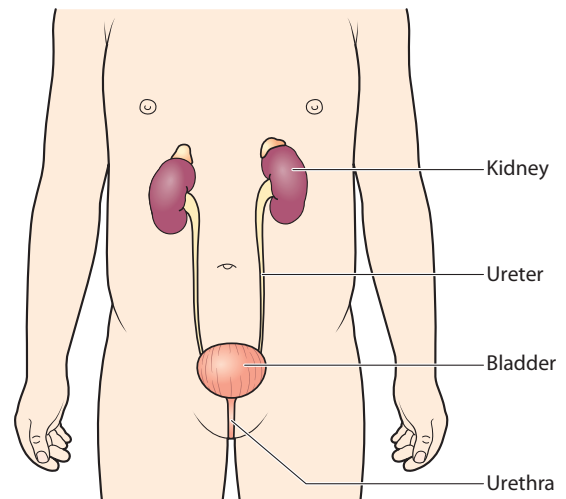
The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

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

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

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

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



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

Symptoms and complications

The main symptom of nephrotic syndrome is swelling in the body - this is called **oedema**. In children, the swelling is mainly around the eyes and in the legs and feet.

The swelling happens because the kidneys leak a lot of protein in the urine (which is called **proteinuria**). You cannot usually see the protein, though it can be found on a simple urine test.

A small number of children have other symptoms such as a very swollen tummy (**ascites**) or breathlessness. Complications, or further problems, are extremely rare.



A girl with a swollen tummy

» [More about symptoms and complications](#)

Causes

Nephrotic syndrome is rare – about 1 in 50,000 children get nephrotic syndrome each year. It affects more boys than girls. It can happen in people of all ages, though often starts when a child is between 2 and 5 years old.

Many cases are linked to the **immune system**, which normally protects the body against disease and infection.

There are different types of nephrotic syndrome. These depend on whether steroid medicine will treat the symptoms or the cause.

It is often not possible to find out which type your child has until after he or she has taken a course of steroids.

» [More about causes](#)

Tests and diagnosis

Your doctor can **diagnose** (identify) nephrotic syndrome by doing a physical examination, asking about the symptoms and doing a **urine test** to look for protein. Your child may need other tests, such as **blood tests**.

» [More about tests and diagnosis](#)

Treatment

Your child will probably need to be admitted to hospital for a few days or longer.

He or she will need to take a **steroid** medicine called **prednisolone**. Most children start to get better after taking steroids for 1 to 2 weeks. In about 9 in 10 children, the nephrotic syndrome will have responded to the steroids within 4 weeks.

Some children need to take other medicines to help prevent or treat infections or to reduce the oedema (swelling).

» [More about treatment](#)

Monitoring

You will need to test your child's urine for protein every morning at home – while your child is on steroids, and then for at least 6 months.

Your nurse will show you how to do this.

- If there is no or very little protein in the urine and the swelling goes down, the nephrotic syndrome has gone into **remission**.
- If there is protein in the urine again, this is a **relapse**. You will need to contact your doctor, and your child may need another course of steroid medicines.

» [More about monitoring treatment](#)

About the future

Relapses

About half of children with SSNS will have at least one relapse, and many have two or three relapses. In most children, the SSNS tends to relapse less often as they grow into their teenage years.

It is rare that SSNS continues to relapse in adulthood.

If your child's nephrotic syndrome keeps coming back, this is called **frequently relapsing nephrotic syndrome**. Your doctor will consider the best treatment for your child.

Follow up

All children with nephrotic syndrome need to go back to the hospital or clinic for follow-up appointments to check for any health problems. Remember to bring the results from your urine testing.

Kidney problems

A very small number of children with nephrotic syndrome have more serious problems with their kidneys. Your doctor will refer your child to a **paediatric nephrologist**, a children's kidney doctor, for more specialist treatment.

» [More about the future](#)

Symptoms and complications

Swelling in the body

Children with nephrotic syndrome have swelling or puffiness in different parts of their body – this is called **oedema**.

The oedema is normally around the eyes in the morning, and in the legs and feet later in the day. After a while there may be swelling throughout the day.

Boys may also have oedema in the scrotum.

It is **pitting oedema** - when the affected area is gently pushed, there is a small dent for a few moments.

→ If your child has swelling in the body, seek medical advice as soon as possible.



An example of pitting oedema

Why the oedema happens

The oedema happens because there is too much fluid in the body's soft tissues.

This happens because the kidneys leak a lot of protein, which is normally in blood, into urine. When there is more protein in the urine than normal, this is called **proteinuria**.

If there is enough protein in the urine to cause nephrotic syndrome, this is called **nephrotic-range proteinuria**.

You cannot usually see the protein, but the urine may look frothy. Proteinuria can be found on a urine test.

There are different types of protein in the blood. The most common type that is leaked is a type called **albumin**. Albumin helps keep fluid in the blood. Fluid moves between the blood and the body's soft tissues. When there is not enough albumin in the blood, fluid stays in the soft tissues.

Rare symptoms and signs

Swelling in the tummy and breathlessness

- A few children get a large swelling in their abdomen (tummy area). This is called **ascites**. It happens when fluid builds up in the area around the organs in the abdomen – the **peritoneal cavity**.
- A very small number of children feel breathless. This happens when fluid builds up in the area around their lungs.

→ If your child has nephrotic syndrome and a very swollen tummy or feels breathless, contact your doctor as soon as possible.

Other rare symptoms

A few children with nephrotic syndrome may also:

- feel tired, have low energy or have difficulty concentrating
- have a decreased appetite (not want to eat)
- have nausea (feel sick) or vomit (be sick), or have diarrhoea
- have pain in their abdomen (tummy).

Complications

Some children have **complications** – health problems that happen because of the nephrotic syndrome or its treatment. These are more likely to happen if the nephrotic syndrome lasts a long time – but even then, complications are very rare.

Risk of infections

Nephrotic syndrome is treated with steroid medicines, which make the immune system less active. This means it is more likely for children to get infections.

→ If your child is unwell and you are worried about an infection, contact your doctor straight away.

Acute kidney injury

Rarely, the kidneys stop working as well as they should – this is called **acute kidney injury (AKI)**. In nephrotic syndrome, this may happen when the body has a lower volume of blood than normal – this is called hypovolaemia.

Some children with AKI get better after a few weeks, and some need to take medicines or have more intensive treatment.

Other complications

If your child has any of the below, seek medical advice:

- severe pain in the tummy or a fever (temperature above 38°C) – if your child sweats more than usual or is shivery – this may be a sign of an infection called **peritonitis**
- swollen, red or painful leg – this may be a sign of a **blood clot**, when blood clumps together
- feeling more tired than usual, having sleep disturbances such as difficulty getting to sleep, becoming more forgetful or gaining weight – this may be a sign of low levels of **thyroid hormone**, a chemical in the body

» Read more about complications on the next page

Peritonitis is a bacterial infection in the **peritoneum**. This is a thin layer that lines the inside of the abdomen (tummy). It surrounds and supports organs such as the stomach and liver. Tell your doctor if your child has:

- severe pain in the tummy
- fever (temperature above 38°C) – if your child sweats more than usual and/or is shivery.

Thrombosis (blood clots)

Blood may be more likely to form clumps, or clots, in the veins. This may cause a condition called **thrombosis**, especially in the veins of the leg. This may cause the leg to look more swollen and there may be pain and redness.

Blood is more likely to clot as it is thicker than normal as some of the liquid normally in the veins has leaked out and has caused the oedema.

High levels of fat in blood

Some children have a high level of cholesterol, especially if their nephrotic syndrome is chronic, or lasts a long time. A high level of cholesterol is **hypercholesterolaemia** (“hyper” means too much).

If the nephrotic syndrome goes away, the levels of cholesterol return back to normal. If it doesn't and the cholesterol level remains high, this can be treated with special medicines that lower the cholesterol level.

Eating a healthy diet and being active usually helps keep these fats at a healthy level.

Low levels of thyroid hormone

The **thyroid** is a gland in the neck which makes thyroid hormone. This **hormone** (a chemical that sends messages to other parts of the body) controls how the body uses energy.

Some children have low levels of thyroid hormone in their body, especially if their nephrotic syndrome is chronic. This is called **hypothyroidism** (“hypo” means low or not enough), and causes many of the body's functions to slow down.

Some children with hypothyroidism may:

- be more tired than usual or have sleep disturbances such as difficulty getting to sleep
- become more forgetful
- gain weight
- have dry hair, skin and nails
- have changes in the mood (more sad than normal)
- be constipated
- feel breathless
- feel sensitive to cold
- get cramps in their muscles, or feel weak.

Causes

The immune system

Studies show that different types of nephrotic syndrome are linked to the **immune system**, which normally protects the body against disease and infection.

Many germs – including bacteria and viruses – can make us sick if they get into the body. The immune system can kill these germs. However, if the immune system is not working properly, it can start to cause problems. In nephrotic syndrome, the immune system can interfere with the tiny filters in the kidneys, the glomeruli.

Will it affect other family members?

It is very rare for nephrotic syndrome to run in families. If one of your children has nephrotic syndrome, it is not likely that another of your children or another family member will get it. However, a few types may run in families.

Types of nephrotic syndrome

There are different types of nephrotic syndrome, which depend on whether they can be treated by steroids. It is often not possible to find out which type your child has until after they have taken a course of steroids.

Some causes of nephrotic syndrome can only be **diagnosed** (identified) in a **kidney biopsy** in which a tiny piece of one kidney is removed from the body with a needle and examined under special microscopes.

- About 9 in 10 children with nephrotic syndrome will have a type that can be treated with steroids – this is called **steroid-sensitive nephrotic syndrome (SSNS)** or **minimal change nephrotic syndrome (MCNS)**.
- In some children the nephrotic syndrome keeps coming back, even after successful treatment with steroids – this is called **frequently relapsing nephrotic syndrome**.

- A few children (about 1 in 10) have a type that cannot be treated by steroids alone – this is called steroid-resistant nephrotic syndrome (SRNS) because it is “resistant” (does not respond) to steroid treatment. Focal segmental glomerulosclerosis (FSGS) and IgM nephropathy are causes of steroid-resistant nephrotic syndrome.
- A small number of children have nephrotic syndrome because of another condition or infection that affects the kidneys.
- Occasionally, babies are born with congenital nephrotic syndrome. These babies may have serious damage to their kidneys and will usually need intensive treatment.

» [Read more about types of nephrotic syndrome on the next page](#)

Causes: Read more about how the kidney works & why nephrotic syndrome happens

About its name

The name nephrotic syndrome can be broken down:

- nephrotic – to do with the kidney
- syndrome – a set of symptoms and signs.

How the kidney works

Inside each kidney, there are about one million **nephrons**. Each nephron is made up of a **glomerulus** (when we talk about more than one glomerulus, we say glomeruli), and a **renal tubule**.

- Each glomerulus acts like a sieve, helping to remove extra water and waste from the body, and holding on to blood cells and protein, which the body needs.
- Blood flows into the kidneys and to each glomerulus.
- Most of the water and some other substances in the blood pass through the glomeruli.
- This liquid flows into the renal tubule. Most of this liquid moves back into the bloodstream. The rest of it becomes urine.
- The urine leaves the kidney by the ureters and goes into the bladder, where it is stored until we are ready to go to the toilet.

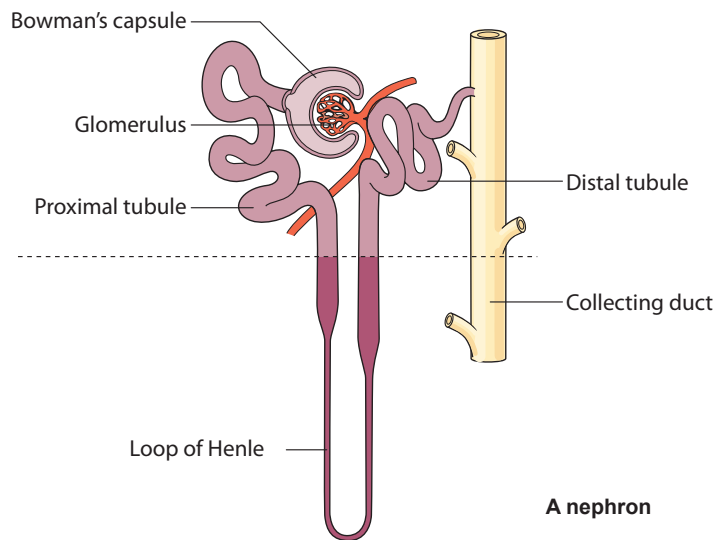
» [More about what the kidney does](#)

Protein leak

It is important that we have the right amounts of protein in our body to stay healthy. Protein is an important part of our diet and is in most foods. When we eat protein, it is digested (broken down) in the stomach and intestines and taken into the blood.

Normally, most protein stays in the blood and does *not* get removed by the kidneys into the urine. This is mostly because they are too big to pass through the glomeruli.

In nephrotic syndrome, there is a change in the glomeruli. They become more leaky, and so some proteins pass through, leaving the body in urine. The main protein that leaks out is albumin which is quite a small protein and more likely to leak through the glomeruli. Albumin helps keep fluid in the blood and oedema (swelling) occurs as a result of albumin leaking into the urine.



Steroid-sensitive (minimal change)

About 9 in 10 children with nephrotic syndrome will have a type that can be treated with steroids – this is called **steroid-sensitive nephrotic syndrome (SSNS)** because it is “sensitive” to steroids.

Your doctor may also use the term **minimal change nephrotic syndrome (MCNS)** or **minimal change disease (MCD)**. It is called this because there is minimal (very little) change to the way the kidney looks compared to a kidney that is working normally.

MCNS can only be diagnosed in a child who has a kidney biopsy. However, doctors assume the nephrotic syndrome is MCNS if the child responds to steroids and has no other risk factors.

Other names are:

- **idiopathic nephrotic syndrome** (idiopathic means that the condition has no known cause)
- **childhood nephrotic syndrome** (because it usually affects children).

Steroid-resistant

A few children have a type of nephrotic syndrome that cannot be treated by steroids alone. This is called **steroid-resistant nephrotic syndrome (SRNS)** because it is resistant to (does not respond to) steroid treatment. Children may be more likely to have SRNS if they:

- are very young, usually under 1 year old
- are older teenagers
- have a rash or pain in their joints
- have high blood pressure (**hypertension**)
- have blood in their urine that can be seen (**macroscopic haematuria**)
- have reduced kidney function (their kidneys are not working properly)
- have abnormal results in tests related to their immune system.

If your child has SRNS, it may be due to a rarer type of nephrotic syndrome that is caused by different conditions such as focal segmental glomerulosclerosis and IgM nephropathy:

- **focal segmental glomerulosclerosis (FSGS)** – some of the glomeruli have scars

- **IgM nephropathy** – a protein called immunoglobulin M or IgM gets trapped in the glomeruli and they cannot filter blood properly

» **Read more about focal segmental glomerulosclerosis and IgM nephropathy on www.infoKID.org.uk**

Other causes

Other cases of nephrotic syndrome are very rare in children:

- **Glomerulonephritis:** A group of conditions that cause inflammation (swelling) in the glomeruli, the tiny filters in the kidneys. Children have both protein and blood cells in their urine. There are different types of glomerulonephritis.
- **Systemic lupus erythematosus (SLE or lupus):** The immune system does not work properly and can start to damage blood vessels in many parts of the body, sometimes including the kidney.
- **Henoch-Schönlein purpura (HSP):** Blood vessels in the body, including in the kidney, become inflamed (swollen), causing symptoms such as a skin rash, pain in the tummy, and pain in the arms and legs.
- **Alport syndrome:** A very rare condition that runs in families, which may also be called hereditary nephritis. Children have an abnormality of the walls of the blood vessels that make up their glomeruli. They may have problems with hearing or seeing. The complications are usually more serious in boys than in girls.
- **Diabetes:** Children who have diabetes are not able to control the level of sugar in their blood. If there is too much sugar in their blood, it may damage their glomeruli.
- **Infections:** Some infections, including hepatitis B and malaria, can, rarely, cause nephrotic syndrome.
- **Drugs and poisons:** Rarely, poisons such as the metals lead and mercury can cause nephrotic syndrome. A small number of children are affected by the medicine penicillamine, which is sometimes used to treat disease in children.

The **immune system** protects the body against germs such as **bacteria** and **viruses** that can cause illness. These germs can enter the body in lots of ways, such as through the nose and throat or the urinary system. If we get a cold or flu, this means that a virus germ has got into the body and started to infect some of our body's cells.

Germs have special 'markers' that are different from the markers on our own body's cells. This means that the immune system can recognise that they are germs and kill them. We often feel sick for a few days or a few weeks while this is happening.

Parts of the immune system

The immune system has many different ways to protect the body against disease.

- **White blood cells** are living cells in the blood. Often, the number of white blood cells found in a **blood test** can give information about someone's immune system. The two main types of white blood cells in the immune system are neutrophils and lymphocytes.
- **Antibodies** or immunoglobulins recognise the germs that have come into the body, and can bind (stick) to them. There are five types: immunoglobulin A (IgA), immunoglobulin D (IgD), immunoglobulin E (IgE), immunoglobulin G (IgG) and immunoglobulin M (IgM).
- The **complement system** is made up of other proteins that float in the blood. These proteins work with (complement) other parts of the immune system to help kill germs or cells infected by germs. Normally, the body controls when complement is activated, so it does not attack the body itself.

When the immune system does not work properly

Sometimes the immune system does not work as expected and can cause problems. For example, sometimes the immune system cannot recognise the body's own cells and may attack them as if they were invaders like germs.

Tests and diagnosis

Your doctor can diagnose nephrotic syndrome by doing a physical examination and asking about the symptoms. Your child will need one or more urine tests, and may need other tests, such as blood tests or imaging tests.

Urine tests

You or a nurse will collect some of your child's urine in a small, clean container for a **urine test**.

A **dipstick**, a strip with chemical pads that can change colour, is dipped into the urine. It can test for protein. Some dipsticks can also test for other substances, such as blood and sugar.

The urine sample may also be sent to a laboratory for more testing.

Some children will need more than one urine test.

Blood tests

A small amount of blood will be taken from a vein with a needle and syringe for a **blood test**. The blood test results can give the doctor more information, including:

- the level of protein in the blood
- information about the immune system
- how well the kidneys are working – this is called the **kidney function**
- the number of types of blood cells.

Imaging tests

Some children need **imaging tests** (scans). These use

special equipment to get images (pictures) of the inside of their body.

- **Ultrasound scan** – looks at the shape and size of 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
- **Chest x-ray** – for children with breathing problems, this test checks for any fluid (liquid) around the lungs. Your child sits or lies still for a few seconds while a machine takes x-ray images.

Occasionally, other imaging tests are needed.

Kidney biopsy

A **kidney biopsy** is not usually needed, but your doctor may recommend one to find out if there is damage in the kidney. This is especially important if your child has relapses, as some medicines that are used to treat the nephrotic syndrome may harm the kidneys.

A tiny sample of a kidney is removed from the body with a needle – special medicines are used so your child will not feel any pain or can sleep through the procedure. The sample is sent to laboratory where it is looked at under microscopes.

Urine tests - Protein

The dipstick urine test shows whether there is any protein in the urine, but does not give an accurate measurement. This can be calculated in the laboratory. The amount of protein is compared to the amount of **creatinine**, a waste product made in the body, which is normally removed by the kidneys into urine.

- The urine protein:creatinine ratio (PCR) compares the amounts of protein and creatinine in the urine.
- The albumin:creatinine ratio (ACR) compares the amounts of albumin, one type of protein that is most likely to be leaked in nephrotic syndrome, and creatinine in the urine.

Urine tests - Sodium and osmolality

Your child's urine may be checked for the amount of **sodium** (salt) and how concentrated it is – this is called the **osmolality**. These help find out if a child is at risk of **hypovolaemia** (not enough blood in the blood vessels).

Blood tests

- The amount of protein in the blood, including a type called **albumin**, can be measured. Because albumin is small, it is more likely to leak through the glomeruli, which means there may be less albumin in the blood.
- **Antibodies** can be identified. These are special proteins made by the immune system to identify and kill specific germs.
- The amount of **urea** and **creatinine** can be measured. These are waste products made in the body, which are normally removed by the kidneys into urine. They may build up in nephrotic syndrome if there is **hypovolaemia** (not enough blood in the blood vessels).
- The kidney function can be **measured by the glomerular filtration rate (GFR)**. The GFR is the amount of fluid the kidneys filter each minute. It can be estimated by measuring the amount of creatinine in the blood.
- The amounts of different types of blood cells can be measured in a **full blood count**.

Treatment

When your child first develops nephrotic syndrome, he or she probably needs to stay in hospital for a few days to be carefully monitored.

Your child will probably be in a paediatric unit, a special area of your hospital for children. He or she will be looked after by a paediatrician, a children's doctor.

A team of healthcare professionals will monitor your child to:

- check the kidney function (how well the kidneys are working)
- measure how much your child is drinking and how much urine he or she is passing
- test the urine with a dipstick
- check the blood pressure
- weigh him or her.

Steroids

The first treatment for nephrotic syndrome is a steroid medicine called **prednisolone**.

Steroids are made in the body, but can also be made as medicines. They suppress the immune system, or make it less active.

Giving medicine

Your doctor will let you know how often and for how long to give prednisolone. He or she will work out the amount of medicine (dose) that is right for your child – this will be shown on the medicine label.

Prednisolone is available as tablets and solution. Children who are unable to take medicines by mouth may be given a similar medicine called methylprednisolone, which is injected using a needle.

→ It is important that you follow your doctor's instructions about when and how much to give. Continue to give the medicine to your child as your doctor has told you, even if he or she is getting better. *Do not stop the medicine suddenly.*

Vaccines

It is important that your child has the **vaccines** (immunisations) that he or she needs to reduce the risk

of some diseases. Speak with your doctor about these – some vaccines are not safe to give while a child is taking steroids or immunosuppressants.

It is important that your child has the flu vaccine each year. The live attenuated influenza vaccine (Fluenz Tetra®) should not be given to children who are receiving corticosteroids

Infections

Children taking steroids are more likely to get infections. Speak with your doctor or nurse, and your child's teacher or daycare manager, about how you can help prevent infection.

Seek medical advice straight away if your child:

- has been in contact with someone who has chicken pox (if they have not had this illness before) or measles (if they have not had the MMR vaccine, which protects against measles, mumps and rubella);
- or, is unwell and you are worried about an infection.

If your child does get an infection, he or she may need to take an **antibiotic medicine**, which kills the germs that cause infection. Your child must take the medicine for the number of days that the doctor has told you, or until all of the medicine has been taken.

Side-effects

We use medicines to help children get better, but sometimes they have side-effects.

Seek medical advice straight away if your child:

- has fever (temperature above 38°C), with a sore throat or a cough
- has a rash, unusual bleeding that is difficult to stop, or severe bruising
- has bad stomach pain or repeated vomiting (being sick)

Other side-effects

Other side-effects that affect some children are below – speak with your doctor or nurse if you are concerned or need more support:

- irritation to the lining of the stomach – your doctor may give your child some medicine to treat this
- behavioural problems – you may find that your child is more likely to have tantrums, be moody, feel depressed, have difficulty sleeping or have nightmares
- weight gain and larger appetite – you can help by making sure your child has lots of physical activity and eats fruits, vegetables and low-calorie food, rather than food that is high in calories (such as cakes, biscuits, sweets and crisps) and by reducing the portion size
- high blood pressure (**hypertension**) – if this happens, your child's blood pressure will need to be controlled so it is in a healthy range.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor.

No-added salt diet

Eating too much salt can make the oedema worse and increase the risk of developing **hypertension** (high blood pressure), especially while on steroids.

Your child should avoid eating or drinking lots of salted nuts, crisps, crackers, soft drinks, fast food meals, takeaways and processed foods (meals that are pre-prepared, including soups) – these often have more salt than we think.

Do not add extra salt to meals that you cook or at the dining table.

→ **A paediatric dietitian at the hospital may be able to give you support.**

Treatment: Read more the side-effects of long-term use or high doses of steroids

- Steroids can slow growth and affect puberty. They can also cause growth of body hair and irregular periods in girls. Your doctor will check your child's growth and development. If you have any concerns, talk to your doctor.
- All steroid medicines, including prednisolone, may affect the adrenal glands so that they produce less of a hormone called cortisol when the body is stressed (e.g. during illness or injury). This means that your child may have more difficulty fighting off an infection, or may recover less quickly from injury or after surgery. If your child is unwell and you are worried about an infection, contact your doctor straight away.
- Your child's skin may become thinner, and heal more slowly than usual. Acne (spots) may become worse, or your child may develop mouth ulcers or thrush (candidiasis). If you are concerned, contact your doctor.
- Your child may develop problems with their hip bones, or their bones may become weaker (osteoporosis). The muscles around their hips and shoulders may also become weaker. If your child has any difficulty walking or moving around, contact your doctor.
- Occasionally, steroids cause diabetes. If your child seems more thirsty than normal, needs to pass urine (wee) often, or starts wetting the bed at night, contact your doctor.

Reducing swelling in the body – diuretics

Very occasionally, children need to take **diuretics**, medicines that help reduce oedema. Diuretics work on the kidneys to increase the amount of water and salt they remove from the body in urine. Your doctor will examine your child for oedema and measure your child's weight while they are taking diuretics, to check how well the medicine is working.

Common diuretics are: furosemide, spironolactone and metolazone. Other diuretics that may be used are: amiloride, bendroflumethiazide and chlorothiazide.

Your child will need to eat less salt at the same time as taking these medicines.

Questions to ask the doctor or nurse

- What treatment will my child need?
- How will this help my child?
- How can I help my child prepare for procedures and treatments?
- What happens next if the first treatment does not work for my child?
- How will I know if we need to go back to the hospital or see the doctor?
- Will the nephrotic syndrome come back? How will I know?

Treatment: Read more about preventing or treating infections - antibiotics

Children being treated for nephrotic syndrome are more likely to get infections. Steroid medicines make the immune system less effective.

One important infection is **peritonitis**, which affects the peritoneum, the area around the organs in the abdomen (tummy area).

Your child may need to take antibiotics to prevent or treat infection – this is often the medicine **penicillin**.

- To prevent infections, you may need to give a small amount of antibiotic twice a day while your child has oedema. This is known as a **prophylactic** (preventative) dose.
- If your child gets an infection, you may need to give a full course of this or another antibiotic to treat it.

→ It is important that you follow your doctor's instructions about when and how much to give.

» [Medicines for Children website | Penicillin V for prevention of pneumococcal infection](#)

» [Medicines for Children website | Penicillin V for bacterial infection](#)

Monitoring treatment

Most children with nephrotic syndrome will start to get better after taking steroids for 1 to 2 weeks. In about 9 in 10 children, the nephrotic syndrome will have responded to the steroids within 4 weeks.

→ It is important that you continue giving the steroids to your child as your doctor has told you, even if your child is getting better. Stopping steroids suddenly can make your child very unwell, so you should only stop taking steroid medicines on the advice of your doctor.

Testing urine at home

You will need to test your child's urine for protein every morning – while your child is on steroids, and then for at least 6 months. Your doctor will let you know how often to test the urine and when you can stop.

When to do the urine tests

Some children, even when they do not have nephrotic syndrome or another kidney problem, have a very small amount of protein in their urine after standing or sitting upright for a few hours. For this reason, it is best to get a sample of your child's first morning urine, the urine passed when they first go to the toilet in the morning.

How to do the urine tests

You will be given **dipsticks** – these are strips with chemical pads that change colour depending on what substances are in the urine.

A nurse will show you how to use them.

- Older children can urinate over the dipstick.
- For younger children, you can get a sample of urine from a potty.

Recording the results

Read the result, using the instructions included in the package. Write in a diary - like the one below - including:

- the date

- the urine test result
- any medicines taken (e.g. steroid and dose, or amount)
- any comments about your child's health (e.g. feeling unwell)

Bring the diary to your next clinic visit.

Remission

If the urine dipstick will show either "trace" or "negative" protein for three days in a row, the nephrotic syndrome has gone into remission. The kidneys have stopped leaking protein.

Relapse

If the urine dipstick shows either 3+ or 4+ protein for three days in a row, the nephrotic syndrome has relapsed. The kidneys have started leaking protein again.

→ If the dipstick shows a relapse, contact your hospital doctor as soon as possible.

More than half of children with nephrotic syndrome have at least one relapse. By regularly testing your child's urine, you can quickly detect a relapse. Your child can start treatment, often without needing to go into hospital. If the urine tests are not used and your child has a relapse, he or she may become unwell and develop oedema, and is more likely to need to go into hospital.

Date	Urine test result	Medicines	General Health
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Follow-up appointments

Your child will need to have medical assessments in the clinic. It is important that you bring your child to these follow-up appointments even if they seem well. You will also have the opportunity to ask any questions.

Remember to bring your records of the home urine testing.

At these appointments, your child may have:

- their height and weight checked
- a physical examination
- **urine tests** – to check for protein and other substances in their urine
- **blood tests** – to check for the amount of protein and other substances in their blood; blood tests may also be used to check their kidney function (how well their kidneys are working)
- **blood pressure** measurements.

You will also have the opportunity to ask any questions.

Relapses

About half of children with steroid-sensitive nephrotic syndrome (SSNS) will have at least one **relapse** – when the nephrotic syndrome comes back. Many children have two or three relapses. Often, these relapses can be successfully treated with another course of steroids.

In most children, the SSNS tends to relapse less often as they grow into their teenage years. It is rare that SSNS continues to relapse in adulthood.

Frequent relapses

A few children have **frequent relapses** – when the nephrotic syndrome keeps coming back. This is called **frequently relapsing nephrotic syndrome**.

If this happens, your doctor will consider the best treatment for your child. For example, they may take a small amount of the steroid prednisolone every other day to prevent relapses. If that does not work, they may need to take other, stronger medicines.

Referral to a paediatric nephrologist

Some children are referred to a children's kidney specialist called a paediatric nephrologist. These children may need more tests such as a kidney biopsy or more specialised treatment.

This may happen if:

- your child has frequently relapsing nephrotic syndrome
- your child's nephrotic syndrome does not get better within 4 weeks of taking steroids, or your doctor thinks that your child has a rarer type of nephrotic syndrome, for example, caused by the conditions focal segmental glomerulosclerosis or IgM nephropathy.

Impact on your child and family

Children who have nephrotic syndrome can usually do the things that other children their age do, including during relapses. After a hospital stay, they should be able to continue going to school or nursery. They can play with other children and stay active.

If your child is in contact with measles or chicken pox, tell your hospital straight away.

Living healthily

Your child can help protect his or her kidneys 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.

Getting support

This can be a difficult and stressful experience for your child and the whole family, including other children.

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

Further information

This is the end of the information on steroid-sensitive nephrotic syndrome. 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.

Your notes and contact information

www.infoKID.org.uk



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For details on any sources of information used in this topic, please contact us through our website www.infoKID.org.uk. We take great care to make sure that the information in this leaflet is correct and up-to-date. However, it is important that you ask the advice of your child's doctor or nurse if you are not sure about something. This information is intended for use in the United Kingdom, and may not apply to other countries.

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