

Nephrotic syndrome - steroid sensitive Overview

This infoKID topic is for parents and carers about children's kidney conditions.

This leaflet has the overview only.

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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.**



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.

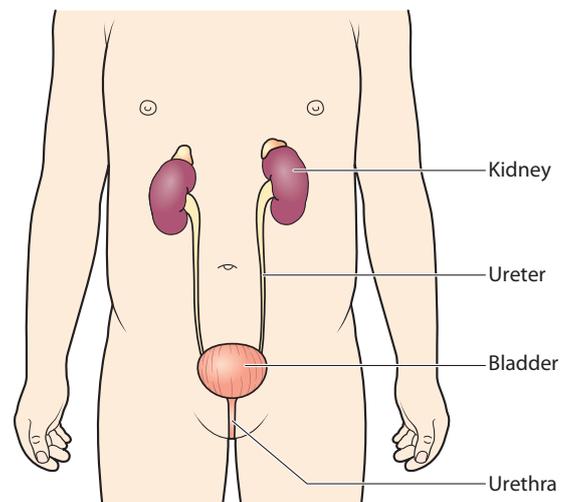
The **kidneys** are bean-shaped organs. They filter blood to remove extra water, salt and waste in urine (wee). Most of us have two kidneys. They are at the back on either side of our spine (backbone), near the bottom edge of our ribs.

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

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.

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**.

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).

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.

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.

» [Read more about nephrotic syndrome on www.infoKID.org.uk](http://www.infoKID.org.uk)

Your notes and contact information

www.infoKID.org.uk



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