

Nephrotic syndrome

Information and advice for parents and carers

Paediatrics

What is nephrotic syndrome?

Nephrotic syndrome is a condition where too much protein from the blood leaks through the filters in the kidneys and into the urine (wee). This causes children with nephrotic syndrome to have a low level of protein in their blood. Their bodies also cannot get rid of fluid as well as normal and so it stays in their body; this is called fluid retention. Some children with nephrotic syndrome also have a high level of some fats in their blood and are more at risk of getting an infection.

Nephrotic syndrome occurs in 2 – 16 out of 100,000 children each year. It is more common in boys and children of Asian origin.

Nephrotic syndrome often starts between the ages of 2 and 6 years. Some children with the condition may have it for several years.

What are the symptoms of nephrotic syndrome?

The main symptom of nephrotic syndrome is swelling around the eyes and in the legs and tummy, which may then spread to the whole of the body. The swelling is caused by excess fluid building up in the body's tissues. This happens because protein helps to hold water inside the blood vessels, but because protein is being lost in the urine there is less protein to do this, so the water leaks out of the blood vessels into the tissues.

Some children with nephrotic syndrome may also have the following symptoms:

- Being more tired than usual
- Feeling short of breath
- Chest pain
- White nails
- Frothy urine
- Diarrhoea
- Vomiting
- Poor appetite

What causes nephrotic syndrome?

Nephrotic syndrome is caused by small changes in a part of the kidney called the glomeruli. The glomeruli are the filters of the kidney. Small changes to the glomeruli allow protein to leak through them when it shouldn't. We don't know why this happens, but it is probably caused by the body's immune system.

In some children, nephrotic syndrome can be caused by other conditions such as certain infections or diabetes.

Nephrotic syndrome

Information and advice for parents and carers

Paediatrics

How is nephrotic syndrome diagnosed?

Nephrotic syndrome is diagnosed by testing a sample of your child's urine to see if there is any protein in it. If there is protein in their urine, your child will then need to have a blood test to check how their kidneys are working. Their doctor will then be able to diagnose nephrotic syndrome from the results.

Some children may also need to have an ultrasound scan of their kidneys or tummy to check that their kidneys are a normal size and shape, and to check for any swelling inside their tummy. An ultrasound scan involves some jelly being applied to their skin and a probe being passed over it to produce an image on a screen.

How is nephrotic syndrome treated?

Your child will need to be admitted to hospital for a few days for treatment and so that their condition can be monitored. Nephrotic syndrome is treated with:

- prednisolone (a steroid medication)
- penicillin (an antibiotic)
- restricting the amount of salt your child has
- restricting the amount of fluid your child has.

Some children may also need a medication to get rid of excess fluid in their body. This medication is called a diuretic.

What are the benefits of these treatments?

The benefit of prednisolone is that it stops the protein moving from the blood into the urine.

The benefit of penicillin is that it will reduce your child's risk of getting an infection.

Salt causes the body to hold on to excess water which can build up in the tissues. The benefit of restricting your child's salt intake is that this will reduce the amount of fluid building up in their tissues.

What are the risks of the treatments?

The risk of taking prednisolone is that your child will be immunosuppressed while they are taking the medication and for 3 months afterwards. Being immunosuppressed means that your child's body is much less able to fight off infections. This means that your child will be more at risk of getting infections, especially very severe infections that might not cause any symptoms until late on. They are also at risk of getting severe chickenpox or measles.

Nephrotic syndrome

Information and advice for parents and carers

Paediatrics

Because of these, while your child is taking prednisolone and for 3 months afterwards you should take the following precautions:

- Your child should not have any 'live' vaccines.
- You should contact the hospital as soon as possible if your child comes into contact with someone who has chicken pox or measles, as he/she may need an injection to prevent getting a serious form of these illnesses.
- You will be given a steroid treatment card which you must show to any nurses or doctors your child needs medical attention from, even if it is for something unrelated.

There is also a risk that prednisolone could cause your child's mood or behaviour to change. It can also cause your child to have problems sleeping.

If your child stops taking prednisolone too soon, there is a risk that their nephrotic syndrome will come back.

A full list of the risks and side effects of prednisolone can be found in the manufacturer's leaflet that comes with the medicine.

The risks of taking penicillin are:

- 1 – 10 out of 100 people have an allergic reaction to penicillin, but this is only severe in 1 out of 50,000.
- It may cause your child to have diarrhoea. This is common.

Are there any alternatives to these treatments?

There are no alternatives to these treatments for nephrotic syndrome, however if your child is allergic to penicillin they can be given a different antibiotic.

What are the risks of not having treatment?

If your child does not have treatment for nephrotic syndrome their condition could get worse and they could develop life-threatening complications.

Going home from hospital

Your child can go home when their swelling has improved and they do not need any close monitoring in hospital. He/she can go back to their normal activities and nursery/school when they feel well and the swelling is not causing any problems.

Daily urine testing and weight

When your child is home from hospital you will need to test their urine for protein every morning until you are told to stop. Before you leave hospital you will be taught how to do this and will be given a chart to record the results.

Nephrotic syndrome

Information and advice for parents and carers

Paediatrics

If your child still has some swelling in their body you will also need to weigh them every morning and record their weight.

Daily medication

Before you leave the hospital you will be told how much prednisolone and penicillin to give your child each day. Please make sure your child does not stop taking the medications until their doctor has said it is ok to do so. You will be given a supply of the medication to take home from hospital with you, and will need to get a repeat prescription from your child's GP for the rest.

Follow-up

Your child will need to be monitored by the hospital while taking steroid treatment, and for up to 2 years after completing treatment because nephrotic syndrome can come back.

You will be advised on how often your child needs to be seen at the hospital and will be sent appointments by post. It is very important that your child attends all of their hospital appointments.

When to seek medical attention

Please contact your child's GP or the hospital if:

- your child is not passing much urine
- your child complains of 'tummy pain' and their hands or feet are cold
- the amount of protein in their urine increases
- your child gains weight
- parts of their body look 'puffy' or swollen
- you suspect that your child may have developed any side effect of medication
- your child comes into contact with someone who has chickenpox or measles
- your child's mood or behaviour changes and you are worried.

Contact details

If your child was admitted to hospital, and within 24 hours of them being discharged, you have any questions or concerns please contact the ward they were treated on:

Priory Ground

0121 507 3927

Lyndon Ground

0121 507 3717

Nephrotic syndrome

Information and advice for parents and carers

Paediatrics

Lyndon 1

0121 507 3800

Paediatric Assessment Unit (ward D19 at City Hospital)

0121 507 4019

After this time, or if your child has not required hospital treatment, please contact your GP or NHS Direct on 111.

Further information

NHS Choices

www.nhs.uk/conditions/nephrotic-syndrome

For more information about our hospitals and services please see our websites www.swbh.nhs.uk and www.swbhengage.com, follow us on Twitter @SWBHnhs and like us on Facebook www.facebook.com/SWBHnhs.

Sources used for the information in this leaflet

- British National Formulary for Children, Section 6.3.2 'Glucocorticoid therapy', August 2013
- Patient UK Professional Reference, 'Nephrotic syndrome', August 2011
- Webb and Postelthwaite, 'Clinical paediatric nephrology' (3rd edition), chapter 19, 2003
- Paediatric Nursing, 'Assessment and management of the child with nephrotic syndrome', February 2002

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5495 or email: swb-tr.swbh-gm-patient-information@nhs.net



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