

Tell me all about

CHILDHOOD NEPHROTIC SYNDROME





What is Nephrotic Syndrome?

Nephrotic syndrome occurs when the kidneys leak large amounts of protein (mostly albumin) into the urine. Protein lost in the urine results in a lower level of proteins in the blood. It is these proteins in the blood which help to hold water within the blood vessels. Therefore, when the protein level is very low, water passes into the tissues and this is recognised as swelling (oedema).

What is the cause of Nephrotic Syndrome?

The cause is still unknown but research is beginning to provide more information about the actual changes in the kidney.

Nephrotic syndrome affects boys more than girls. The usual age at which the problem begins is 2 to 5 years.

It is a rare condition which affects approximately 1 in 50,000 children per year. The condition tends to be more common in families with a history of allergies.

What is the treatment?

Prednisolone (steroid) will be the drug prescribed for your child when he/she is first diagnosed.

Most children respond to this drug with disappearance of the protein in their urine and loss of swelling within 1-2 weeks (this is called **REMISSION**).

Diuretics (water tablets) may also be given to control the oedema (swelling) before the Prednisolone has worked.

Penicillin V may be prescribed if your child has a lot of swelling as excess fluid in the tissues provides a good environment for bacteria to grow.

As a precaution...

Children who are receiving steroid treatment should carry a steroid warning card with them at all times. Such steroid warning cards are available from the hospital pharmacy. Children who have recently been on steroids may require increased doses if involved in an accident or requiring an operation. This is the reason for carrying the steroid warning card. You may wish to consider purchasing a Medic Alert pendant or bracelet (this provides emergency identification for medical problems).

What are the side effects of treatment?

When Prednisolone is prescribed for short periods of time there are usually no serious or permanent side effects.

However, we have listed below the side effects which are most common

- Decreased resistance to infections such as coughs and colds.
- Increase in appetite which may lead to a rapid increase in weight.
- Flushed, swollen cheeks and stretch marks on the skin.
- Rise in blood pressure which will be monitored at the clinic or at home.

Behavioural problems e.g. temper tantrums, bed wetting or mood changes.

Steroids in very high doses can cause an increase in blood sugar and fat (lipid) levels. Sugar in the urine does not mean your child has diabetes.

What do I have to do at home?

While your child is having treatment with steroids you will be taught to:

- Test your child's first morning urine for protein with the urine testing sticks on a DAILY basis, unless told otherwise by your doctor / renal nurse.

Keep a diary of all urine results so that your doctor can review your child's progress in clinic. The dose of Prednisolone and any other medications and other comments should also be recorded.

Why is keeping a diary important?

The urine test results will show if your child is responding to the prescribed treatment. If your child has a large amount (2+) of protein in the urine for three days in a row this could mean there is a **RELAPSE** of the condition and you should contact your doctor / renal nurse.

If your child has **NO** protein in the urine he/she is in **REMISSION** and should be well. Records that are complete and accurate give the doctor a good idea on your child's general health and progress and this record should be brought to each clinic visit.

Clinic Visits

After your child has been diagnosed as having Nephrotic syndrome he/she will be followed at regular intervals in the Hospital out-patient clinic. Even if your child is well it is important that the consultant or his deputy sees your child at regular intervals in order to keep an eye on his/her overall progress.

At each clinic visit your child will have his/her height, weight and blood pressure recorded as well as analysis of the urine. Physical examination will usually be carried out and only if it is necessary will blood tests be performed. If your child is very worried about blood tests then we can try using a special cream, or spray which makes this procedure less painful.

It is a good idea for you to write down any questions you may wish to ask the doctor before coming to the clinic.

Is there a special Diet?

When in remission a '**Healthy Eating**' diet is generally recommended for your child. It is a good idea for all members of the family to also follow a healthy eating plan.

At other times when your child may be in a '**Nephrotic state**' diet and fluid restrictions or guidelines may be in place – and should be followed.

Guidelines to Follow

no added salt - avoid adding salt to food at the table and try to reduce the intake of processed food e.g. crisps, tinned and packet foods. **Ensure an adequate protein intake** - it is not usually necessary to take extra protein in the diet, a good healthy appetite will usually ensure an adequate intake. **Eat more fibre rich foods** - try using wholemeal bread, wholewheat breakfast cereals, fruit and vegetables. **Reduce sugar** - try to avoid adding sugar to drinks and food, replace fizzy drinks with sugar free varieties. Try to cut down on sweets and chocolate. **Replace saturated fats with mono or polyunsaturated** - use margarines and oils labelled 'high in polyunsaturates, low in cholesterol'

This advice should be treated as a HEALTHIER way of eating rather than as a diet.

Can my child receive immunisations while taking prednisolone?

Not usually. Steroids can reduce the effectiveness of immunisations and relapses can sometimes be caused by the vaccination.

Children who are having steroid drugs or cyclophosphamide can become very unwell if exposed to **CHICKENPOX** or **MEASLES**. Let the hospital know if your child is in very close contact with another child who may have chickenpox or measles.

Speak to your child's school teacher about the need to be advised in the event of infectious conditions in their class.

If your child develops diarrhoea and/or vomiting while taking steroids contact your doctor.

Will my child continue to suffer from Nephrotic syndrome?

Most children will have at least one relapse, with significant protein in their urine (2-3+ for 3 days or more) and requiring a further course of steroid treatment.

If they have many relapses they will need to take their steroids for a longer period of time.

As the child becomes older the relapses usually become less frequent. It isn't possible to predict accurately when the relapses will cease but a relapse is very uncommon if the child has been free of protein in the urine for five years.

Will my child's kidneys fail as he/she gets older?

Children with the usual types of nephrotic syndrome which responds to steroids have no increased risk of the kidneys failing with time.

Are other children in the family likely to be affected?

There are a few rare types of nephrotic syndrome which do run in families, but it is extremely unlikely that your child will suffer these.

Can my child continue to participate in exercise and sporting activities?

YES. Exercise is important for all the family.

The school should encourage the child to participate in all sports within the child's capabilities.

If you are unsure about certain sports ask your doctor .

What about holidays?

Unless your child is having complications, a normal family holiday should be possible.

A copy of your latest clinic letter should accompany you and also an adequate supply of prednisolone in case of relapse.

Remember the need for extra sun protection when taking specific medications.

Always ensure adequate hydration and movement if undertaking a long haul flight.

Tell your doctor about your plans.

When should I get in touch with the doctor?

If your child has nephritic syndrome and is in close contact with chickenpox or measles, contact the hospital unit within 24 hours as he/she may need a special injection to boost his/her resistance to these infections.

If your child has protein (++) or greater) in the urine for three days.

If your child is puffy, unwell or has a fever.

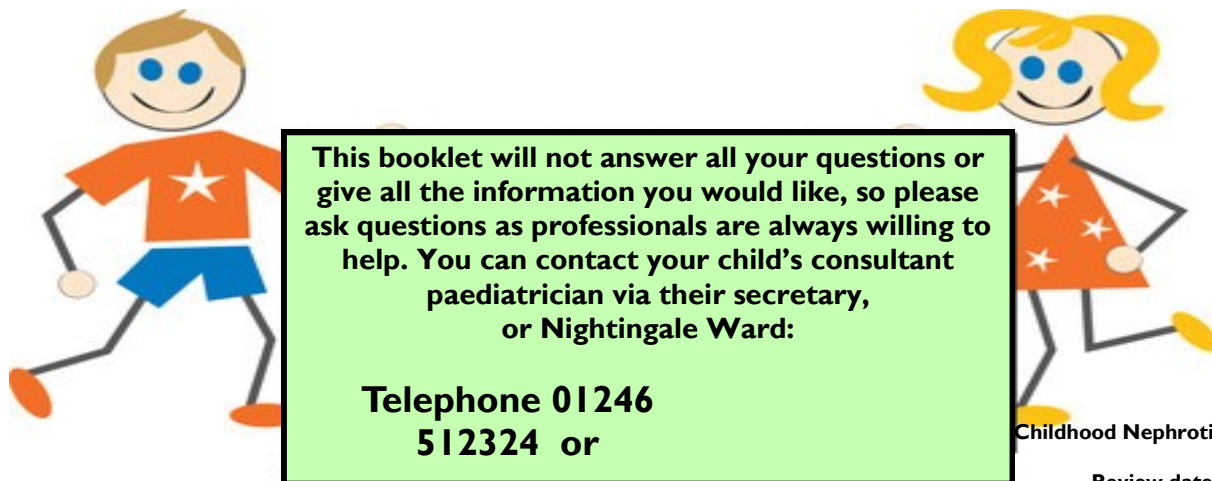
If your child has diarrhoea and vomiting.

For any small worry it is best to phone, no matter what time, as it may be important.

THE PARENT'S ON-LINE RESOURCES

http://www.ich.ucl.ac.uk/gosh_families/information_sheets/nephrotic_syndrome_childhood/nephrotic_syndrome_childhood_families.html

<http://www.cafamily.org.uk/Direct/n23.html>



Childhood Nephrotic Syndrome
Version 1

Review date: March 2015

Next Review Date: March 2018

Division: Women's & Children's