

Nephrotic Syndrome

Patient information leaflet

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please speak to a member of staff who can arrange it for you.

اگر به این بروشور به زبان دیگر یا در قالب دسترس پذیر نیاز دارید،
لطفاً با یکی از کارکنان صحبت کنید تا آن را برای شما تهیه کند.

Jeśli niniejsza ulotka ma być dostępna w innym języku lub formie,
proszę skontaktować się z członkiem personelu, który ją dla Państwa przygotowuje.

Dacă aveți nevoie de această broșură într-o altă limbă sau într-un format accesibil,
vă rog să discutați cu un membru al personalului să se ocupe
de acest lucru pentru dumneavoastră

如果您需要本传单的其他语言版本或无障碍格式，请联系工作人员为您安排。

إذا احتجت إلى هذه النشرة بلغة أخرى، أو بتنسيق
يسهل الوصول إليه، يرجى التحدث إلى أحد الموظفين لترتيب ذلك لك.

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What is Nephrotic Syndrome?

Notes

Nephrotic syndrome is a condition where the 'filters' in the kidney become faulty and large amounts of protein leak from your blood into your urine. The main symptom is oedema ('fluid retention') mainly due to the low protein level in the blood.

Various kidney disorders can cause nephrotic syndrome, some more serious than others. Treatment and outcome (prognosis) can vary, depending on the cause.

The two kidneys lie to the sides of the upper abdomen (the loins), behind the intestines, and on either side of the spine.

Each kidney is about the size of a large orange, but bean-shaped. A large renal artery takes blood to each kidney.

The artery divides into many tiny blood vessels (capillaries) throughout the kidney. In the outer part of the kidneys tiny blood vessels cluster together to form structures called glomeruli. Each glomerulus is like a filter.

The structure of the glomerulus allows waste products and some water and salt to pass into a tiny channel called a tubule while keeping blood cells and protein in the bloodstream.

Each glomerulus and tubule is called a 'nephron'. There are about one million nephrons in each kidney.

What about immunisations?

Steroids can reduce the effect of immunizations and your child may be unwell or relapse if immunizations are given without medical advice. If your child is due immunizations please discuss this with your doctor.

What about holidays?

Unless your child is having complications a 'normal' family holiday should be possible. Discuss your plans with the doctor or nurse and ensure you take enough medications with you should a relapse occur whilst you are away.

Any questions?

Please use the space below for any questions you may have for the doctor.

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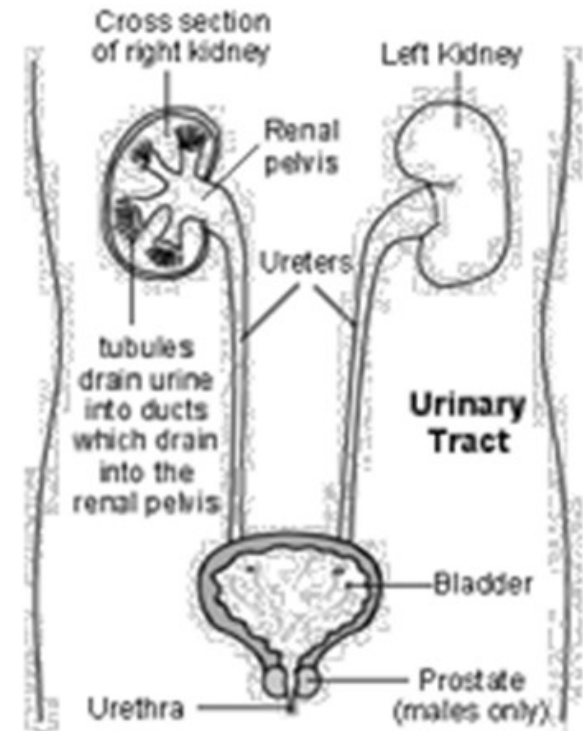
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What causes Nephrotic Syndrome?

In most cases **there is no known cause** of nephrotic syndrome but research is beginning to provide us with more information about the actual changes in the kidney. Childhood nephrotic syndrome is an uncommon condition. Every year approximately 2 to 7 children in every 100,000 develop nephrotic syndrome.

It tends to be more common in the Arab and Asian populations and families with a history of allergies. Nephrotic syndrome often starts between the ages of two to five years, affecting twice as many boys as girls.

Symptoms of Nephrotic Syndrome

Primarily in children these involve swelling (oedema) around the eyes and in the legs and feet, but can lead to swelling all over the body including inside the body around the intestines and stomach, which can make the abdomen swell. This could coincide with foamy urine and sudden weight gain due to fluid retention.

Other symptoms can include

- Reduced urination.
- Fatigue.
- Loss of appetite.
- An increased risk of infections.

How is Nephrotic Syndrome diagnosed?

A **simple urine test** will show high levels of protein present whilst low levels of protein will be identified in the blood. In a few cases it will be necessary for a kidney biopsy to take a very small piece of tissue from your child's kidney to be looked at under a microscope to find a cause and make a diagnosis. Mostly this is not necessary especially if they respond well to treatment.

How is Nephrotic Syndrome treated?

Corticosteroid medication (prednisolone) will be prescribed for your child. Most children with nephrotic syndrome respond well to corticosteroid treatment. The protein disappears from the urine and then the swelling is lost within a week or two. This is called remission.

Therefore inform the hospital if your child has been in close contact with another child who has the above and speak to your child's school about this possibility.

What is the outlook for children with nephrotic syndrome?

For some children relapses may go on happening for many years, but as they become older the relapses usually become less frequent and virtually all children will eventually grow out of it.

It is not possible to predict when the relapses will cease but a relapse is very uncommon if the child's urine has been protein free for five years.

There is no risk of developing kidney failure in children with the usual types of nephrotic syndrome that continue to respond well to steroid treatment.

Can my child lead a normal life?

Yes. In the past parents have kept their child off school when they have relapsed. This leads to a lot of missed schooling and their education has suffered as a consequence.

In nearly all cases you do not need to keep your child off school, even when they relapse.

We actively encourage activity is possible when in remission and many children continue to manage a full range of sports and activities even in a relapse.

What about childhood illnesses?

Proteins are used in the body for growth and repair and form part of the immune system. When your child has heavy protein loss in the urine they may be more susceptible to infections. It is therefore important when they are in a relapse, they take a preventative course of antibiotic (usually penicillin V) until they are in remission again.

If your child develops diarrhoea and/or vomiting while taking any of the medications contact your doctor or nurse. The steroid may suppress the child's immunity.

Your child could be very unwell if in contact with:

- Chicken pox.
- Shingles.
- Measles.

Some children take longer than others to go into remission. The term remission is used rather than cure because protein can return in the urine and swelling can come back. This is known as a relapse.

Most children will relapse once or several times. Each relapse requires more steroid treatments. Sometimes coughs and colds can trigger a relapse. Very occasionally water tablets (diuretics) and protein infusions are given to control the oedema before the steroids have worked.

Risks & benefits of treatment

When taking steroid treatment your child should carry a blue steroid card at all times.

If the child becomes ill, requiring a doctor, the card gives essential treatment details. Your child will require a course of high dose steroids with each relapse.

Not all children experience side-effects from steroid treatment and any effects are temporary and will stop when the course of steroids has finished or reduced to low alternate day doses.

Some common side-effects

- Increased appetite which may lead to weight gain.
- Swollen cheeks resulting in a 'moon face' appearance.
- Behavioural changes (Temper tantrums and aggressiveness).

What other treatment may be necessary?

Some children with nephrotic syndrome relapse more frequently and begin to have side effects from the steroids.

In this case other treatments may be considered. These treatments may help your child have longer periods of remission and therefore reducing the amount of steroids taken. There are a small group of children with nephrotic syndrome that do not respond to steroid treatment and continue to have lots of protein in their urine. It is these children who usually require a kidney biopsy to investigate what is happening inside the kidney.

The doctor will **always discuss** the need for **further treatment or investigations** before a biopsy or other medications are suggested. You need to encourage your child to eat a balanced healthy diet. It is a good idea for all members of the family to also follow a healthier eating plan.

A '**no added salt**' diet is encouraged especially when they are in a relapse. Avoid adding salt to food at the table and try to reduce the intake of processed foods for example, crisps, tinned and packet foods. Information on this is available on request if required.



What do I have to do at home?

You need to test your child's first urine for protein every morning unless told otherwise.

Normally the testing strips will be Albustix®. There is no need to test the urine for other substances at home, as this will be done when you attend out-patient clinic. It is **essential you keep a diary** of all your child's urine results for each day and bring it with you to each clinic visit. This is very important as it enables the doctor or nurse to review your child's progress.

A diary is available from out-patients clinic or if you have a computer, you may wish to make your own. The doses of prednisolone given each day and any other treatment should be recorded next to the daily urine result.

You may also wish to include any other comments, for example:

Their appearance or how they are feeling. The urine results in the diary will show how your child is responding to treatment or when they have relapsed. Records that are complete and accurate give the doctor or nurse a good idea of your child's general health and progress.

If your child shows 'protein 3+' or more for three days in a row then this could mean there is a relapse and you should contact your doctor or nurse.

If they have no protein (negative) or trace for three days in a row they are in remission and should be well.

