

# Nephrotic Syndrome



Name:

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Who to contact and how:

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Notes:

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# Information for patients

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## Introduction

The aim of this leaflet is to provide you as carers or parents all the relevant information regarding Nephrotic Syndrome and answer some of the common concerns and queries.

## What is Nephrotic Syndrome?

Most people have two kidneys situated at the back of the abdomen. These act like a 'filter' by removing waste products and excess water from the blood to make urine. At the same time they prevent the loss of protein from the blood. Protein is essential to the body as it helps to balance the amount of water in the blood.

Nephrotic Syndrome is a collection of symptoms which occur when the kidneys 'filter' does not work properly and allows large amounts of protein to be lost from the body in the urine. This is known as proteinuria.

## How does this affect normal body function?

Proteinuria results in an overload of fluid in the blood. This fluid can leak into the body tissue causing swelling or oedema.

Oedema (swelling) is usually more noticeable in the legs but can occur all over, including around the stomach and may cause vomiting and diarrhoea.

## Why does Nephrotic Syndrome occur?

Although research continues, Nephrotic Syndrome is not common and the main causes are unknown.

However, some rare causes may include kidney growths or the use of certain drugs and therefore resolving these problems may improve the symptoms.

It is suggested that Nephrotic Syndrome affects twice as many boys as girls and usually first occurs between the ages of 2-5 years.

## How is Nephrotic Syndrome diagnosed?

The condition is diagnosed by testing the blood and urine to determine the levels of protein.

In rare cases or if there is a family history of nephrotic syndrome, a renal biopsy may be required (taking a small piece of kidney for examination).

## Treatment

Treatment usually involves the use of steroids. Steroids are a type of medication that may be used to reduce swelling in the body and help stop the loss of protein.

Diuretics (water tablets) may also be used to treat symptoms of Nephrotic Syndrome. These are a type of medication used to help the body get rid of excess water.

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A type of protein may be given via a drip to replace the protein which has been lost in the urine. Diet is an important aspect of treatment and your child may be referred to a dietitian for information, advice and support.

## Benefits

Treatment aims to reduce the symptoms of Nephrotic Syndrome. Presently, there is no cure and children may have multiple episodes or relapses. However relapses may become less frequent and virtually all children will eventually grow out of the syndrome.

Steroid treatment aims to reduce the swelling within 2 days to 4 weeks. The dose of steroids is usually given over a period of about 12 weeks in total and is gradually reduced before stopping. Your child will be weighed regularly during treatment to measure how much of the excess fluid they have lost.

An antibiotic may be prescribed to help fight infection that may occur as a result of swelling in the body. There may also be an increased risk of an infection due to low levels of protein in the body as protein is particularly important to the body's immune system.

Increasing protein content in the diet may help to replace protein lost in the urine.

A no salt diet during a relapse is advised. Reducing or avoiding salt in the long term is also important to promote healthy kidneys as well as your family's general health. It should be noted that many processed foods may have a high salt content.

## Risks and Side Effects

Side effects that may occur include increased appetite (which may lead to weight gain), swollen cheeks (sometimes termed 'moonface') and some behavioral changes such as aggressiveness.

## Alternatives

Steroid therapy remains the main treatment for Nephrotic Syndrome but where some children do not respond to this, other drugs are available.

These are usually considered for children who have needed a renal biopsy.

## What happens if the syndrome is left untreated?

Without treatment kidney failure may occur. Infection may also occur as the result of swelling in the body.

## Can my child lead a normal life?

Yes. There is no need to restrict activity. However the condition does require careful monitoring and you will be asked to check your child's urine on a daily basis using a simple dipstick test to determine the level of protein. You may be asked to record the levels.

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When taking steroid treatment your child should carry a steroid card which will provide essential information should your child become ill.

It is advised that childhood immunisations should still be given but some may need re-scheduling following any treatment for nephrotic syndrome.

### Contact Details for Further Information

Family support is very valuable and relatives / family friends / carers will need to know which foods your child may have. Regular medical checkups will provide the opportunity to discuss any problems.

Support can also be accessed from:

The British Kidney Patient Association  
3 The Windmills  
St Mary's Close  
Turk Street  
Alton GU34 1EF  
Tele: 01420 541424  
[www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)

### Any Comments, Compliments, Concerns or Complaints

If you have any other concerns please talk to your nurse, therapist or doctor. Our Patient Advice and Liaison Service (PALS) are available on 03033 306518 (Grimsby, Scunthorpe and Goole). You can also contact [nlg-tr.PALS@nhs.net](mailto:nlg-tr.PALS@nhs.net)

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