



Childhood Nephrotic Syndrome

Patient information Leaflet

May 2020

Introduction

This leaflet aims to help you understand what childhood nephrotic syndrome is and how we treat and care for children with this condition.

What is Nephrotic Syndrome?

The main function of the kidneys is to help the body get rid of waste products and excess water. Blood filters through the kidneys, which act like a sieve, allowing the body to get rid of waste products in the urine and prevent the loss of essential blood components such as protein and blood cells. Healthy kidneys control the water and salt balance in the body and therefore regulate the blood pressure.

In childhood nephrotic syndrome, the sieve mechanism of the kidneys isn't working properly. The holes in the sieve are too big which allows large amounts of protein to be lost from the body in urine.

In most cases there is no known cause of nephrotic syndrome. Childhood nephrotic syndrome is very rare, every year 2 to 7 children in every 100,000 develop this condition. The condition often starts between the ages of 2 to 5 years, and affects twice as many boys than girls.

Signs and Symptoms

Swelling is one of the most common signs of nephrotic syndrome. This is caused by the loss of protein in the blood. Protein in the blood keeps fluid within the blood stream. When this is reduced fluid can leak into the body causing swelling (oedema). Most of the swelling occurs around the eyes and lower legs, but the swelling can occur all over the body.

Diagnosis

Doctors can assess how well (or poorly) your child's kidneys are working by testing their blood and urine to detect if there are high levels of protein in the urine and low levels of protein in the blood.

Treatment

There are many causes of nephrotic syndrome and the treatment depends on this; some causes are more serious than others, therefore some can be treated more easily than others. Listed below are several treatments that may be carried out:

- Your child may be prescribed a steroid medication called prednisolone which usually works well to stop the leak of protein from the kidneys. Some children may experience side effects from this treatment, the Paediatrician will discuss these with you.
- Your child may require an Intravenous Infusion of Albumin. This is to replace the main protein that leaks from the blood into the urine.
- It may be necessary to limit the amount of fluid your child drinks. This will be discussed with you and monitored by medical and nursing staff. Daily weights may be required in order to ensure fluid retention is reducing. Your child's urine will be measured and tested to monitor the amount of urine passed and the amount of protein it contains. It is important that your child's urine is collected and given to the nursing staff for testing each time your child goes to the toilet.

- Your child's blood pressure will also be monitored, as quite often with kidney disorders, high blood pressure (hypertension) can occur. This is because the kidneys make chemicals involved in the control of blood pressure which can be affected due to the loss of protein.

The paediatrician will advise on the treatment options dependent on the severity of the disease.

Discharge

Once the disease is under control your child will be discharged home and you will have to continue to check their urine for protein in the morning. Please document these results in a chart/diary along with medication being given in order to take to future clinic appointments. Documenting these results will show how your child is responding to the treatment being given.

When to seek medical advice/attention

- If your child is puffy and unwell, with any of the following symptoms: Fever, dizziness, feeling sick or complaining of abdominal pain, cold hands, feet and nose.
- If your child has diarrhoea or vomiting.
- If you think your child has had close contact with chicken pox or measles.

Discuss with your doctor prior to immunisations being given as the steroid treatment can reduce the effect of the immunisation or the immunisations could cause your child's condition to relapse.

If you have any concerns about your child's condition please contact the Children's Unit or Children's Community Nursing Team.

Useful Contact Numbers:

- Contact your GP for advice.
- Children's Community Nurses 0161 922 5251 (8am – 8pm)
- Children's Unit 0161 922 5252 (24 hrs)
- NHS Direct 111 (24hr helpline)

Useful Websites/information:

- Department of Health (www.dh.gov.uk)
- NHS Choices (www.nhs.uk/conditions)
- NHS institute for innovation and improvement (www.institute.nhs.uk)
- NHS Improvement (www.improvement.nhs.uk)

If you have any questions you want to ask, you can use this space below to remind you

If you have a visual impairment this leaflet can be made available in bigger print or on audiotape. If you require either of these

options please contact the Patient Information Centre on 0161 922 5332

If you require an interpreter, please ask an appropriate person to contact our central booking office between Monday to Friday 8am to 5pm on 0161 922 6991 to arrange this for you.

語言翻譯及病者支持服務 (LIPS):

如果閣下需要翻譯員在您的預約當日幫助您的話 請找一名合適的家庭成員 0161 922 6991 聯絡本中

央預約辦事處來您您安排 我們的辦公時間是星期一至星期五 上午 8 時至下午 5 時

Językowo Tłumaczeniowa Usługa Pomocy dla Pacjenta (Language, Interpretation and Patient Support Service LIPS):

Jeśli potrzebujesz pomocy tłumacza w trakcie swojej wizyty, proszę poprosić odpowiedniego członka rodziny o skontaktowanie się z Centralnym Biurem Zamówień (Central Booking Office), w celu zorganizowania tłumacza pomiędzy poniedziałkiem a piątkiem w godzinach od 08:00 - 17:00 pod numerem 0161 922 6991.

لینگویج، انٹرپریٹیشن اینڈ پیٹینٹ سپورٹ سروس (Lips)

اگر آپ کو اپنی اپائنٹمنٹ کے لئے مترجم کی مدد کی ضرورت ہو تو براہ مہربانی اپنے خاندان کے کسی موزوں فرد سے کہیں کہ وہ ہمارے سنٹرل بنگ آفس سے پیر سے جمعہ 8.00 بجے صبح سے 5.00 بجے شام کے دوران 0161 922 6991 پر فون کر کے اس کا بندوبست کریں۔

References:

Armitage, A (2019) Guidance on assessment and management of first presentation nephrotic syndrome. TGH, UK

NHS Choices (2019) Nephrotic Syndrome in Children.

<https://www.nhs.uk/conditions/nephrotic-syndrome/> accessed 11.5.20

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