Nephrotic Syndrome in Children

Handbook for Parents

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Cover

महत्वपूर्ण संदेश

- पेशाब में प्रोटीन की जांच नियमित रूप से करनी चाहिए।
- प्रोटीन की नियमित जांच द्वारा रिलैप्स का जल्दी पता लगाना उससे जुड़ी गंभीर जटिलताओं को रोकने के लिए आवश्यक है।
- रिलैप्स के मुख्य जटिलताओं में गंभीर संक्रमण, पानी की कमी, कम रक्तचाप और रक्त के थक्के (थ्रोम्बोसिस) बनने का ख़तरा शामिल है।
- तुरंत चिकित्सा सहायता लें यदि आपके बच्चे को इनमें से कोई लक्षण दिखाई पड़ेः तेज बुखार, लाल चकत्ते या दाने, त्वचा की लालिमा और दर्द, तेजी से श्वास या पसली चलना, गंभीर दस्त, सुस्ती या लगातार सिरदर्द। यह गंभीर संक्रमण या जलिटता के लक्षण हो सकते हैं।
- बच्चे को दस्त या उल्टी होने पर लैसिक्स (Lasix), अन्य डाईयूरेटिक और एनवास (Envas) तुरन्त बंद करें और डॉक्टर से परामर्श करें।
- हालांकि अधिकांश टीके सुरक्षित हैं, कुछ जीवित कीटाणु वाले टीके (उदाहरण के लिए मौखिक पोलियो, खसरा एवं चेचक के टीके) उन बच्चों को नहीं देनी चाहिए जिनको स्टेरॉयड या अन्य ऐसी दवायें चल रही है जिनसे बीमारी से लड़ने की शक्ति कम होती है। बच्चे को कोई भी टीका लगाने से पहले अपने चिकित्सक के साथ अवश्य चर्चा करें।

Key Messages

- Examine the urine regularly for protein loss.
- Early detection of relapses, by detecting 3+ or 4+ protein in the urine, is essential to prevent serious complications.
- The chief complications of disease relapses include serious infections, risks of dehydration, low blood pressure and clotting of blood (thrombosis).
- Seek medical attention promptly if your child develops high grade fever, rash or redness of skin, rapid breathing, severe diarrhea, lethargy, or persistent headache. These can be the signs of a severe infection.
- Whenever child develop loose slods or vomiting episodes, stop lasix, other diuretics and enalapril (envas) immediately, and seek the help of your doctor on early basis.
- While most vaccines are safe, live vaccines (such as oral polio, measles, chicken pox) should be avoided while the child is receiving steroids and other immunosuppressive medications. Always discuss with your doctor before vaccinating the child.

Nephrotic Syndrome in Children

Your child, who was absolutely normal, developed swelling over the face. The swelling gradually increased. The doctor carried out examination of the urine and blood. The results show that the child has nephrotic syndrome, a disease of the kidneys. You are upset and deeply concerned. You may have many questions.

- What is nephrotic syndrome?
- What is its cause?
- What is the treatment? Can it be cured?
- How long will it last?
- Will it damage the kidneys?
- Can other forms of treatment (e.g., homeopathy) help?
- What dietary and other restrictions and precautions will be necessary?

This booklet has been prepared to answer most of your questions. It is meant to reassure you and allay misgivings. Your doctor will be happy to discuss with you any other matter regarding your child's condition.

Function of normal kidneys

Nephrotic syndrome is a kidney disease. Brief information about kidney function would help you understand the problems in nephrotic syndrome.

Each person has two kidneys, which perform a number of functions. Their chief function is to 'filter' the blood to remove waste products, and regulate the body's fluid volume. Kidneys also play important roles in the control of blood pressure, maintenance of bone health and formation of red blood cells. Urine is formed as a waste product. It comes out of the kidneys through long tubes called *ureters*, and is stored in the bladder.

When a person urinates, the urine passes out through the *urethra* **(Fig.1).**

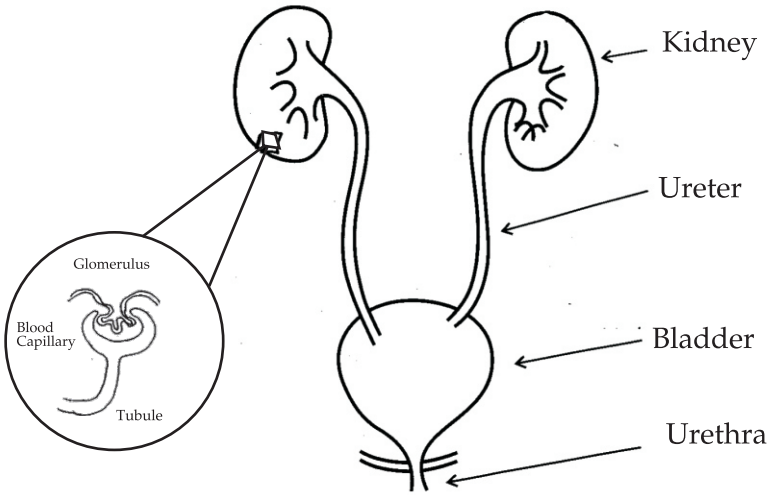

Fig. 1. Normal urinary system

Each kidney contains about a million functioning units, called *nephrons*. The nephron is composed of a glomerulus and a long coiled tube (tubule). Blood is filtered by the glomerulus and the fluid (filtrate) flows down the tubule. The tubules take back useful constituents and excrete the harmful ones **(Fig. 2)**. At the end of the individual tubule, a

few drops of urine form. The tubules join to form larger channels, which in turn unite to form still bigger channels, ultimately ending in the ureter, which carries the urine from the kidney into the bladder.

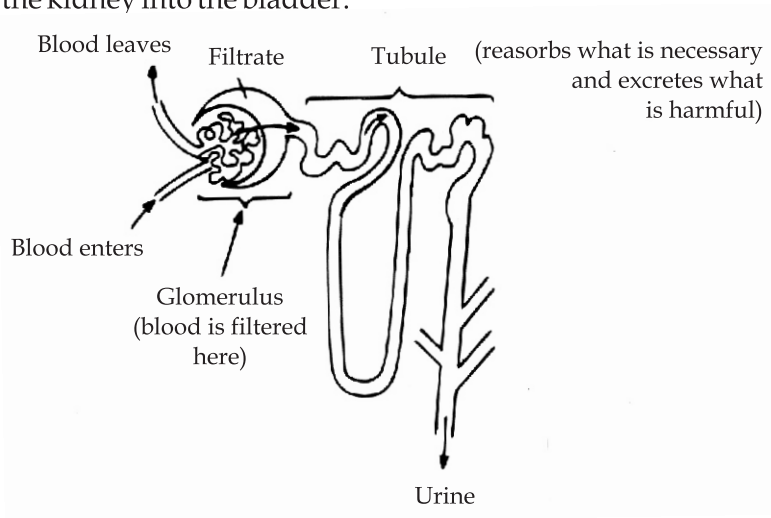

Fig. 2. Diagram of a nephron. This structure is much smaller than a dot and can only be seen under a powerful microscope.

What causes the protein leak?

Normally only very small amounts of protein and few red blood cells pass out of the blood in the filtrate. It is abnormal for large amounts of protein to leak through the minute blood channels (capillaries) of the glomerulus and appear in the urine. When this happens, we call it as 'spilling of protein' in the urine or *proteinuria* **(Fig. 3).** The exact cause of the large amount of protein leak from capillaries of the glomeruli is not known. In about 90% cases of nephrotic syndrome in children, there is no permanent damage to the capillaries. With treatment, the leakage of protein stops.

In a very small proportion of children, other diseases that cause capillary damage in the glomeruli are present. The doctor will carry out appropriate laboratory tests to diagnose these conditions.

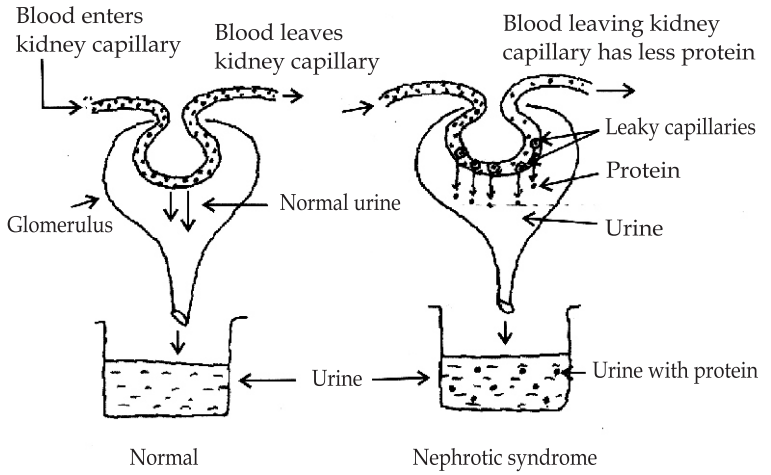

Fig. 3. Glomerular capillary in a normal child and in nephrotic syndrome

What is nephrotic syndrome?

The features of nephrotic syndrome, viz. swelling over face, legs and abdomen, result from the passage of large amounts of protein in urine. To reemphasize, only negligible amount of protein is present in urine in normal person.

The main protein in the blood is albumin. If large amounts of protein (albumin) are lost through the urine, its level in the blood decreases. When the level of protein in the blood is low, swelling (edema) will develop. This is because this protein in the blood has a sponge-like effect, holding fluid within the blood channels. With less protein in the blood, the sponge effect does not work as well, and fluid leaks out into the body tissues. This is seen as swelling around the eyes, face, feet, ankles and the abdomen.

What is the cause of nephrotic syndrome?

In most cases, the exact cause of nephrotic syndrome is not known. The disease occurs in children all over the world. It is not caused by bacterial or viral infection. There is no relationship with diet or socioeconomic status of the family. It is not infectious and does not transfer to other family members. Only in exceptional instances, more than one child in a family may suffer from nephrotic syndrome.

Symptoms of nephrotic syndrome

The chief abnormality in nephrotic syndrome is swelling (edema). It first appears on the face, around the eyes. It is most prominent in the morning when the child gets up. Towards the evening the swelling disappears. In fact, the accumulated fluid shifts to the legs where it is not so easily noticeable. The swelling is sometimes mistaken to be due to 'allergy' or 'eye-problem'. In nephrotic syndrome there is *no* itching or redness of the eyes.

Blood tests

Blood is examined for hemoglobin, white cell count, protein, albumin, cholesterol and electrolytes. Heavy loss of protein in urine leads to lower levels of proteins in the blood. The level of blood cholesterol increases. However, once proteinuria disappears with treatment, blood protein and cholesterol levels return to normal. Blood urea and creatinine levels help evaluate kidney function. Special blood tests such as complement level, antinuclear antibody (ANA), antistreptolysin O (ASO) titer and hepatitis B antigen may sometimes be required.

Other tests

A X-ray chest and Mantoux (tuberculin) test may be required at the first visit to rule out underlying infections, which, if detected, would need treatment.

Types of nephrotic syndrome

About 90% of children, in whom nephrotic syndrome first starts between the ages of 2 to 6 years, have *minimal change nephrotic syndrome.* This means that nephrons in such cases do not show significant abnormalities when examined by the microscope. Your doctor can identify these cases by the following:

i) The blood pressure is normal

ii) Urine does not show red blood cells

iii) Blood urea and creatinine levels are normal

These patients show excellent response to treatment with prednisolone, which stops urinary protein leakage. However, recurrence of proteinuria *(relapse)* occurs in most cases.

When nephrotic syndrome starts after the age of 10 years or below the age of 1 year, it may not be of the minimal change type. Your doctor will carefully evaluate all the clinical and laboratory evidence and if he suspects a condition other than minimal change nephrotic syndrome, advise the need for a kidney biopsy. If the biopsy shows significant abnormalities, prednisolone may not be effective. Other drugs are often used. Such patients are often difficult to manage and may have considerable long term problems.

When is a kidney biopsy necessary?

Minimal change nephrotic syndrome usually begins in early childhood. Such children usually have normal blood pressure, no blood in the urine and normal blood levels of urea and creatinine. Children fitting this description are treated with prednisolone without the need for a biopsy. If the child does not show reduction in urinary protein excretion after a sufficient period of time, a kidney biopsy may be done. Children with blood in their urine, high blood pressure and reduced kidney function may require a biopsy (page 21) at the onset of disease.

Treatment of nephrotic syndrome

After examining the laboratory reports, the doctor will have an idea about the form of nephrotic syndrome the child might have. If minimal change nephrotic syndrome appears likely, he will prescribe prednisolone. Infections (sore throat, chest infection, etc.) will be treated before using this medication. If the child has marked swelling over the body, appropriate medications will be given to reduce it.

Prednisolone

Prednisolone is a 'steroid' drug that is established to be safe and effective in the treatment of nephrotic syndrome. The amount administered depends upon the weight and height of the child. Tablets are available under different names (Wysolone, Omnacortil) and strengths (5, 10, 20, 30 mg). Your doctor will explain the dose, frequency of administration and duration of the treatment. Prednisolone tablets are bitter! If the child has difficulty in taking the tablets, sweetening agents (honey, sugar, jam) may be used to mask their taste. Liquid preparations of prednisolone are also available (5ml=5mg, 15mg).

i) Daily treatment

For the first 6 weeks, the required amount of prednisolone is given every day in 1-2 divided doses (referred to as **daily treatment**). The tablets are taken with milk or some food.

After a few days of daily treatment, the child becomes completely well. The edema disappears and urine no longer contains protein ('nil' test). Once 'daily treatment' period is completed, prednisolone is given over **alternate days.**

ii) Alternate day treatment

The dose of prednisolone is now given on every alternate

day at one time, as a single dose at about 8 A.M. Thus the interval between two consecutive doses is 48 hours.

The tablets are given with a glass of milk. The alternate day treatment is given for 6 weeks and then stopped. *It is important to strictly follow instructions and not discontinue the prednisolone treatment without doctor's advice.*

Diet

Protein The child should be given a diet with enough proteins. High protein dietary articles include milk and milk products, dal, chana, soyabean, eggs, meat and fish. Extra protein is necessary only while the child is passing large amounts of protein in the urine. Subsequently, he should have his usual diet.

If the child is edematous, the doctor might advise salt restriction. Once the swelling disappears, the child can take the usual diet. *It must be understood that salt has no role in the causation of nephrotic syndrome.* No benefit can be expected by prolonged restriction of salt unless advised by the doctor for some other reason (e.g., if the blood pressure is high).

Treatment of swelling (edema)

If the child has prominent swelling, treatment will be needed to reduce the accumulated fluid. Edema can be controlled with reduction of dietary salt, drugs (called 'diuretics') and, occasionally, albumin infusions.

Diuretics

Diuretics are medications that help the body get rid of extra fluid. They will be needed if your child has more than mild edema. Frusemide *(Lasix)* is often prescribed. Usually one dose in the morning is adequate. If swelling is severe, other diuretics like spironolactone *(Aldactone),* thiazides *(Aquazide)* or metolazone *(Metnex)* may also be used. **Diuretics should only be given under supervision of your doctor**. Once the swelling is controlled, the drug is stopped.

They should not be used if the child is having loose stools or vomiting.

Albumin infusions

If the child is very edematous, has large amount of fluid in the abdomen and the blood albumin (protein) level is very low, he may require one or more albumin infusions. Albumin is given through a vein. It helps replace the protein in the blood temporarily and increases urine output, resulting in decrease of swelling. Albumin infusions are very expensive and are used only when unavoidable. *They are administered under close supervision for side effects.*

General Care and Precautions

Once the urine shows nil or trace protein, the child is said to have achieved *remission.* Normal diet, activity and usual routine should be resumed. Schooling should be restarted. He should be considered a normal child.

Suspect infections

The child with nephrotic syndrome is more likely to suffer from infections, especially when receiving prednisolone. Usually the infections are mild, such as cold, sore throat and diarrhea. Occasionally, the infection is serious and may develop rapidly, particularly if severe edema is present. If the child has pain abdomen, vomiting, diarrhea and fever, or has headache, vomiting, drowsiness and fever, he must be taken to the hospital immediately. Development of red painful patches indicates skin infection *(cellulitis).* The likelihood of a serious infection is more if the child has edema. *Delay in the treatment of such infections may be dangerous.*

Children receiving treatment with corticosteroids (or other drugs) can become very ill if exposed to chickenpox or measles. *Let the doctor know at once if your child is in close contact with another child who has chickenpox or measles.*

Long term supervision and course

In most cases the child with nephrotic syndrome becomes completely well with prednisolone treatment. He may remain well for several months or longer. During this period the child should be regarded as being normal and managed accordingly. Physical activity and games should be encouraged. He should not be regarded as sick or "delicate" or made to feel different from other children. Usual disciplinary measures, as for other children in the family, should be employed.

In a majority of cases, however, nephrotic syndrome recurs. The recurrence is indicated by appearance of swelling around the eyes, which, if untreated, gradually increases to involve the face, feet, legs and abdomen. Urine examination again shows 3+ to 4+ of protein. This situation is called a '*relapse*.'

Immunization

Administration of live vaccines (e.g. against polio, measles-mumps-rubella, chicken pox) may be delayed till child is off corticosteroids or receiving a very small dose. Steroid therapy may also reduce the efficacy of immunizations. The doctor will advise on the appropriate timing of vaccinations.

Additional vaccines

Children with nephrotic syndrome are at risk for serious infections, which may be prevented by vaccines. In addition to routine immunization these children should receive the pneumococcal *(Prevnar, Pneumovax)* chicken pox *(Varilrix)* vaccine and influenza (Vaxigrip) vaccines.

Treatment of relapse

On some occasions, proteinuria develops when the child has a cold or sore throat, but completely disappears within a week or so, along with recovery from the infection. It is, therefore, important to perform daily urine tests during an episode of infection, while the infection is being

appropriately treated. Urine may show 1 + or 2+ reaction for a few days and then gradually become 'nil'. No treatment is necessary for such a short spell of mild proteinuria.

On the other hand, proteinuria may continue at 3+ or 4+ even after the infection has subsided. After 1 or 2 weeks of heavy proteinuria, swelling appears over the face and gradually increases. Such an episode (relapse) will need treatment with prednisolone, which must be started before the swelling becomes very prominent. The drug is initially given daily in 1-2 divided doses, the number of tablets depending upon the weight of the child. If the swelling has increased, Lasix may be given for a few days. The daily treatment is usually needed for about 2 weeks, during which urine will gradually become free of protein, showing a 'nil' reaction. At this stage, prednisolone is changed to the alternate day schedule, which is continued for 4 weeks and then stopped.

It is most important to treat a relapse early. Once the child develops gross swelling with large amount of fluid in the abdomen, the management becomes more difficult, and serious complications may occur.

Frequency of relapses

A child may not have a relapse for several months or longer. Some children get one or more relapses in one year. Each relapse is treated with prednisolone as mentioned above. If more than 3 relapses occur within a year, other forms of treatment are considered. A frequent method is to keep the child on a small dose of alternate-day prednisolone treatment for 1 year or more. The same dose of prednisolone is given daily for 5-7 days during minor infections. If such a regimen does not prevent relapses, other medications may be given. The need for such treatment will be discussed with you. These medicines include:

i) Levamisole tablets given on alternate days for a prolonged period can prevent relapses.

ii) Cyclophosphamide is a drug often used in various forms of serious disorders. This drug is beneficial in a large

proportion of children with nephrotic syndrome. Usually tablets are given daily along with prednisolone for 12 weeks. Rarely, cyclophosphamide may be given by injection once a month for 6 months. The side effects of this drug and other precautions will be explained to you by the doctor.

iii) Mycophenolate mofetil is safe and effective in preventing disease relapses in nephrotic syndrome. It is given twice daily, as tablets or syrup, for several months.

iv) Cyclosporine has been chiefly used in patients who undergo kidney transplantation. However, it is effective in preventing relapses in nephrotic syndrome. The doctor will discuss and explain various issues in case cyclosporine is to be administered.

v) Tacrolimus is similar to cyclosporine. It is available in tablet forms. It is equally effective and does not cause gum enlargement and excessive body hair, often seen with cyclosporine. However, both agents are relatively toxic and should be administered cautiously, under expert supervision.

vi) Rituximab, an intravenous drug is useful in difficult to treat patients. It is usually given when other agents fail to show the desired effect.

Side effects of prednisolone

There is often misinformation and apprehension about the use of steroids. Prednisolone is universally employed for the treatment of nephrotic syndrome, and the specialist is familiar with its dose and side effects. Side effects vary with dosage; alternate day medication in small amounts is associated with minimal problems.

Stomach pain Prednisolone may sometimes cause stomach upset (pain, burning, vomiting). Always have your child take prednisolone with food. Children showing stomach upset will benefit with use of antacid preparations (e.g., Digene, Gelusil) or acid reducing agent (Ranitidine).

Increase in blood pressure Blood pressure should be closely watched during daily prednisolone treatment. Blood pressure will spontaneously come down when the dose of prednisolone is reduced. Occasionally, medication may be required to reduce high blood pressure.

Increased appetite Some children show marked increase in appetite and excessive weight gain. Butter, oil, fried food, ice cream, etc. should be avoided while the child is receiving daily prednisolone. Adequate physical activity and sports is encouraged.

Cushingoid features Daily prednisolone treatment leads to change in the appearance. The face, neck, shoulders and abdomen become heavier while arms and legs look thin. Purple stretch marks (striae) may occasionally appear on the hips, abdomen and thighs if large doses of prednisolone are given repeatedly. Prominence of the cheeks and face should not be mistaken for edema.

Increased hair This may be seen on the face, arms and legs. Acne may appear or get aggravated in adolescent children. These changes revert to normal once prednisolone is stopped.

Decreased response to infection Large doses of steroids impair the ability to fight infections. Some infections (e.g., chicken pox) can become serious.

Retardation of growth Large amounts of prednisolone, if given over prolonged periods, causes slowing of growth. The height is monitored regularly and if height gain is slow, consideration is given for the use of other medications.

Other side effects Some children may show changes in mood and behavior. They may be excessively happy, quiet or abnormally active, while on prednisolone. Prolonged administration of prednisolone may result in development of tiny opacities (cataracts) in the lens of the eye. Occasionally, the blood sugar level may increase and urine examination shows glucose.

It is emphasized that serious complications of prednisolone develop only when it is used in high doses over prolonged periods. The doctor will employ alternative medications before these appear.

At present there is no alternative to the initial, and thereafter, appropriate and correct use of prednisolone in nephrotic syndrome. Other drugs are employed in 'difficult' cases.

Steroid resistant nephrotic syndrome

Nearly 10 to 20 percent of children fail to show desired response to prednisolone. Failure to show 'nil' protein in urine despite adequate doses of prednisolone may indicate a steroid resistant disease. A renal biopsy is done in this condition. In a child showing steroid resistance at the onset of disease, blood tests for a likely genetic etiology is often required.

Children with genetic forms of the disease do not respond well to prednisolone & other drugs for nephrotic syndrome. Children lacking a genetic basis to nephrotic syndrome will receive other medications (along with small doses of prednisolone) to achieve a state of remission.

Chief therapies include

1. Cyclosporine : It is available in the form of capsule as well as liquid preparation.
2. Tacrolimus : It is only available as a capsule. If your child is able to swallow capsule, your doctor will prefer to use this medication.

   Do not crush the capsule. Ensure to give a correctly measured dose of syrup. Use a syringe to measure the drug from the bottle.

Responsibility of the parents and family

Nephrotic syndrome is a disease that usually lasts over several years. It will not go away in a short time with any kind of treatment. In minimal change nephrotic syndrome

(that responds to treatment), the child remains quite normal during periods of remission. In nephrotic syndrome of the other types, the child may have several problems (e.g, high blood pressure, impaired kidney function, persistent edema. *The cooperation of parents is extremely important in the treatment of the child.*

Maintain a diary

The parents need to keep a careful account of the child's treatment, urine tests and other events. The information may be recorded in a diary, as shown below:

Date	Urine test	Prednisolone	Other drugs	Remarks
1.9.19	3+	30 mg	Lasix 1 tablet	Cough & cold
2.9.19	3+	30 mg		Cough better
3.9.19	3+	30 mg		Well
4.9.19	3+	30 mg		Well
5.9.19	3+	30 mg		Well

Records that are complete and accurate give the doctor valuable information on the child's health and progress. Treatment is mostly based on that and frequent blood tests are not required.

How often should the doctor be consulted?

The management of your child with nephrotic syndrome is the joint responsibility of the pediatric nephrologist and the child's pediatrician. The former should see the child every 3-4 months, even if the child is well, and frequently if the child is being treated for a relapse or has any complication. The pediatrician would provide usual childhood care (e.g., vaccinations, treatment of any other illness), and discuss the child's condition with the pediatric nephrologist.

If the child starts to show protein in urine, 2+ or more for a few days, the pediatrician should be consulted. Urgent consultation with the pediatrician is required if:

(i) Your child is in close contact with another child having

chickenpox or measles, or he develops that illness.

(ii) He/She gets diarrhea, vomiting, pain in abdomen, high fever, or appears ill and drowsy.

(iii) He/She has fever and cough with rapid breathing.

What is the long term outcome for children with nephrotic syndrome?

Most children with minimal change disease 'outgrow' the disease sometime during adolescence (earlier), and do not get kidney damage. Unfortunately, it is not possible to predict at what age the child will be completed cured. The 'severity' of nephrotic syndrome is quite variable, and some children suffer from frequent relapses, while others get few or an occasional relapse.

The aim of management is to treat the relapse and keep the child in remission using minimum amounts of medications, and prevent complications. The focus of the family should be more on the growth and development and normal activities (schooling, participation in sports). Parents should disregard unsolicited advice and need not discuss medical problems with relatives and friends.

Other questions that you may have

Q. Are both kidneys affected?

A. Yes, the leakage of protein occurs from glomeruli in both kidneys.

Q. Can my child participate in exercise and sports?

A. Yes, the child can participate in all sports within his capability.

Q. Is there any surgical treatment?

A. No, the defect is at microscopic level and cannot be corrected by surgery.

Q. Will kidneys fail and would kidney transplantation be needed?

A. Children with the most common type of nephrotic syndrome, which respond to prednisolone, have no risk of kidney failure. In other uncommon types, increasing kidney damage may occur.

Appendix

Examination of urine for protein

Examination of urine for protein forms an important part of the longterm care. The test is simple to perform. Urine, preferably the first specimen passed in the morning, is collected in a clean container. The specimen should have yellow tinge; urine passed after having receiving diuretics (e.g., Lasix) looks like water and is not suitable for testing. There are two common methods or testing.

Heat precipitation test

An ordinary glass test-tube is 1/2 to 2/3 filled with urine, held at the bottom and slightly tilted. The top 1-2 cm is boiled (Fig. 4). A spirit lamp or, gas flame is preferable but a candle can also be used. In the latter case, black soot will need to be wiped off. The tube should not be shaken.

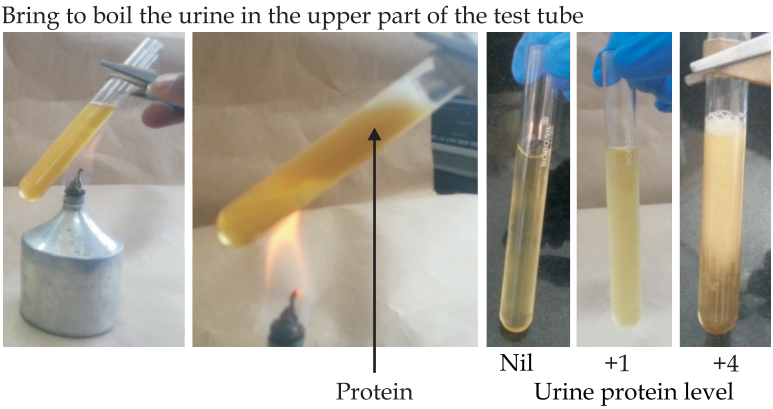

Fig. 4: Heat test for protein in urine

If protein is present, the heated part of the urine turns white. The appearance can be compared with cold urine at the bottom which should be clear (transparent). The intensity of whiteness is proportional to the amount of protein in the urine and can be graded as follows:

Nil	=	No change in appearance after boiling
1+	=	Slight haziness
2+	=	Definite whiteness
3+	=	Milky appearance
4+	=	Curd-like appearance

The grading is not difficult and one becomes an expert after a little practice. However, this method is a bit cumbersome and most parents prefer the dipstick test.

Dipstick test

Uristix or Albustix test is more convenient. A reagent-coated paper strip is dipped in urine and removed without delay or hurrying. Any change in color is compared with that printed on the label of the bottle containing the strips (Fig. 5). Nil to 4+ reaction can be easily observed.

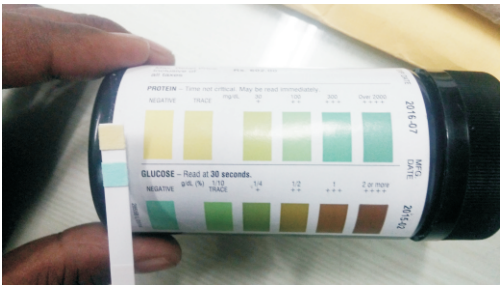

Fig. 5: Uristix test for protein

Collection of 24-hour urine

It is important to collect all urine passed during a period of 24 hours.

I) Start collection at 8 a.m. If the child passes first urine at/ before 8 a.m. discard that sample.

ii) Save all specimens of urine passed thereafter in a clean container. Accompany the child when he goes to the toilet to make sure that each drop of urine is collected.

iii) Also collect the first urine passed in the next morning.

iv) Bring the entire urine collected to the laboratory. Alternatively, you may mix all specimens of urine in a large clean glass or plastic container. Measure the total amount accurately in liters and milliliters. Bring that specimen to the laboratory.

Collection of urine for culture

A special (sterile) bottle will be given by the laboratory. Other containers must not be used. After local cleaning with copious amounts of water (soap or antiseptic solution should not be used), the child is asked to pass urine. This initial part is discarded and midstream sample collected in the culture bottle. The specimen must not be left at room temperature. If the specimen is obtained in the hospital, it is promptly handed over to the doctor or the technician. If collected at home, it should be stored in refrigerator, between 2-8°C (not in the freezer) and transported on ice in a thermos flask. The result is available after 48 hours.

Kidney biopsy

Most children with nephrotic syndrome do not require kidney biopsy. Biopsy is usually planned if suspecting disease other than nephrotic syndrome, in patients lacking response to prednisolone, and in those planned for treatment with cyclosporine or tacrolimus. Kidney biopsy should be carried out at a specialist centre and pathological examination done by an experienced pathologist.

The procedure is done in the pediatric procedure room. An ultrasound of the abdomen is done to see the location of the kidneys. Special blood tests (bleeding time, clotting time, platelet count and prothrombin time) are necessary before the procedure. The child is well sedated during the biopsy so that the procedure is not painful. Occasionally, the biopsy is performed under short general anesthesia.

Once the child is asleep, a special biopsy needle is inserted through the back muscles, into the kidney, under ultrasound guidance, to remove a tiny piece of tissue, which is examined under a microscope. After the biopsy, the child remains in the hospital for 6-8 hrs to look for any significant bleeding. Some children may require an over night observation. The final report of the biopsy result may take 3-6 days since special methods are needed to examine the kidney tissue.

If your child needs a biopsy, you will be informed about the procedure and the likely complications. The result of the biopsy and further treatment of the child will be discussed.

Important facts about nephrotic syndrome

The parents should clearly understand the treatment schedule and become familiar with the drugs used in the management. The child should not be given any unknown drugs. All prescriptions from doctors should be retained.

Few facts about nephrotic syndrome should be understood.

- The disease is likely to last over several years.
- The course of the disease is variable. Whereas some children get only a few relapses, others have frequent relapses.
- After a number of years, most children are completely cured.
- With correct management, the child will lead a normal life. If regular urine tests are done, the relapse will be detected early and treated promptly. Schooling and usual activities will rarely be interrupted.
- No other form of treatment, e.g., homeopathy or other unorthodox therapy, is likely to benefit this condition.
- The condition is rarely familial. It is unusual for more than one child in a family to be affected.

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