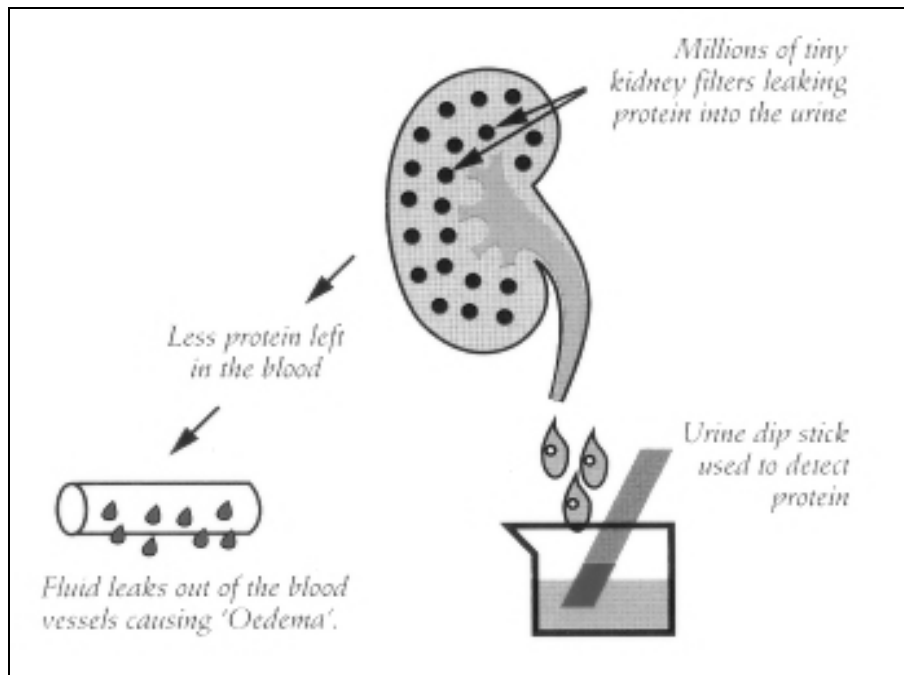


## CHILDHOOD NEPHROTIC SYNDROME

**“The more you know,  
the better you can help your child”**



This fact sheet has been written to tell you some facts about a kidney disease called the nephrotic syndrome. This illness also is called nephrosis or minimal change disease. This brochure will give you and your family information about your child's illness. You also should talk to your doctor. The more you know, the more you can help your child.

### **What do the kidneys do?**

The kidneys are two fist-sized organs found in the lower back. When they are working well, they clean the blood, and get rid of waste products, excess salt and water. When diseased, the kidneys may leak things that the body needs to keep, such as blood cells and protein.

### **What is nephrotic syndrome?**

This is an illness where the kidney loses protein in the urine. This causes protein in the blood to decrease, and water moves into body tissues, causing swelling (edema). You will see this swelling around the child's eyes, in the belly, or in the legs. Your child will not go to the bathroom as often as usual and will gain weight with the swelling.

**Do other kidney diseases cause edema and protein in the urine?**

Yes. Edema and protein in the urine are common in other types of kidney disease, especially a disease called glomerulonephritis.

**What causes the nephrotic syndrome?**

In the majority of cases, the cause is not known. The National Kidney Foundation has active research programs into causes and treatments of the nephrotic syndrome.

**Who gets it?**

Usually, young children between the ages of 1 1/2 to 5 years. It happens twice as often in boys as in girls. However, children of all ages and adults also can get it.

**How can you tell if your child has it?**

You may see that your child has swelling around the eyes only in the morning. You may think that your child has an allergy. Later, the swelling *may* last all day, and you may see swelling in your child's ankles, feet and belly. Also, your child may be:

- More tired & more irritable
- Eating less
- Looking pale

The child may have trouble putting on shoes or buttoning clothes because of swelling.

**How is nephrotic syndrome treated?**

The treatment of nephrotic syndrome will try to stop the loss of protein in the urine, and increase the amount of urine. Usually, the doctor will start your child on a drug called prednisolone. Most children get better with this drug.

**What does prednisolone do?**

Prednisolone is used to stop the loss of protein from the blood into the urine. After one to four weeks of treatment, your child should begin going to the bathroom more often. As your child produces more urine, the swelling will go away.

When there is no protein in the urine, the doctor will begin to reduce the amount of prednisolone over several weeks. The doctor will tell you exactly how much prednisolone to give your child each day. Never stop prednisolone, unless the doctor tells you to do so. If you stop this drug or give your child too much or too little, he or she may get very ill.

Sometimes, your child will stay healthy after treatment. Your child may relapse (get sick again) at any time, even after a long time with good health. This may happen after a viral infection, such as a cold or the flu.

### **What problems can occur with prednisolone?**

Prednisolone can be a very good drug, but it has a number of side effects.

Some of these side effects are:

- being excessively hungry
- gaining weight
- acne (pimples)
- mood swings (very happy, then very sad)
- being overactive
- \* more chance of infection
- slowing of growth rate

Side effects are more common with larger doses and if it is used for a long time; once prednisolone is stopped, most of these side effects go away.

### **What if prednisolone does not work?**

If prednisolone does not work for your child or if your child has serious side effects, the doctor may order another kind of medicine, called an immunosuppressive drug. These drugs decrease the activity of the body's immune system. They are effective in most, but not all, children. Your doctor will discuss in detail with you all the good and bad effects of the drug. The side effects of these drugs include: increased susceptibility to infections, hair loss and increased blood cell production.

Parents also should be aware that children taking immunosuppressive drugs may become ill if they develop chicken pox. Therefore, you should notify your doctor any time that your child is exposed to chicken pox while on these medications.

Your child also may be given diuretics (water pills). These drugs help the kidney get rid of salt and water. The most common water pill used in children is called furosemide. If your child starts to have a problem with vomiting or diarrhea, you should call your doctor as the child can lose too much fluid and become even sicker. Once protein disappears from the urine, diuretics should be stopped.

### **What other problems happen with nephrotic syndrome?**

Most children will have problems only with swelling. However, a child with nephrotic syndrome can develop a serious infection in the belly. If your child has a fever or starts complaining of severe pain in the belly, you should call your doctor *at once*.

Sometimes, children with nephrotic syndrome get blood clots in their legs.

If this happens, your child will complain of:

- Severe pain in arm or leg
- Swelling of arm or leg
- Changes in colour or temperature of arm or leg

If any of these things happens, you should call your doctor right away.

### **What can parents do?**

Much of your child's care will be given by you. Pay attention to your child's health, but do not overprotect the child. If your child is ill or taking prednisolone, the doctor will recommend a low salt diet. This type of diet will make your child more comfortable by keeping the swelling down. Try to give your child foods that he or she likes, but that are low in salt. Ask the dietitian for suggestions.

Usually, the child will be allowed to drink as much as he or she wants if there is no swelling, but liquids will have to be restricted if there is swelling. A child's natural thirst is the best guide as to how much to drink. You should also weigh your child and keep a record of weight to spot a change in the disease.

The first sign that your child is getting sick again is the return of protein in the urine. Because of this, many doctors ask you to check your child's urine regularly. To do this, a special plastic strip with a small piece of paper on the end is dipped into the urine. The paper will change color when protein is in the urine. This test can be done easily at home and it can detect a relapse before any swelling is seen. Check with your doctor to learn how to do the test and how often to do it.

When there is swelling, check that your child's clothing is not too tight because the clothing can rub the child's skin over the swollen areas. This can make the skin raw, and it may get infected.

Your child will probably have this disease for several years. It is very important to treat your child as normally as possible. Your child needs to continue his or her usual activities, such as going to school and seeing friends. Your child should be treated just like other children in the family in terms of discipline. Occasionally, your child may not go to school for some time. Your doctor will let you know if this is necessary. Keeping your child out of school or not letting him or her see friends will not change the illness.

### **Does the disease ever go away?**

Sometimes, even though nephrotic syndrome does not have a specific cure, the majority of children "outgrow" this disease in their late teens or early adulthood. Some children will have only one attack of nephrotic syndrome. If your child does not have another attack for three years after the first one, the chances are quite good that he or she will not get sick again.

Still, most children will have two or more attacks, the attacks are more frequent in the first one to two years after the nephrotic syndrome begins.

After ten years, less than one child in five is still having attacks. Even if a child has a number of attacks, most will not develop permanent kidney damage. The major problem is to control their accumulation of fluid using prednisolone and diuretics. Children with this disease have an excellent long-term outlook.

**What else should I know?**

1. Most children with nephrotic syndrome respond to treatment.
2. Most children with nephrotic syndrome have an excellent long-term outcome.
3. You should feel free to ask your child's doctor any questions.

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