

## Nephrotic Syndrome

This handout will tell you how to take care of your child with nephrotic syndrome. If you have any questions, ask your doctor or nurse. We are here to help you.

### What 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 help the body get rid of waste products, excess salt, and water. When diseased, they may leak red blood cells and protein into the urine. Blood and protein are not in the urine if a person's kidneys are healthy and working well.

### Nephrotic Syndrome

This is an illness where proteins leak through the kidney into the urine. These proteins would normally stay in the blood where they work to keep fluids from leaking into the nearby body tissues. In time, if the body is losing protein faster than it can keep up with, the blood protein levels will drop. Fluids will leak out of the blood vessels into the body tissues. This leads to swelling which is most often in the eyelids. It may also be seen in the feet, legs, hands, face, belly or scrotum.

When your child has nephrotic syndrome, they will pass urine less often than normal and the urine will look very dark yellow.

It is most common in young children between the ages of 18 months and 5 years, but you can get it at any age. It happens twice as often in boys than in girls.

The most common cause in this age range is **minimal change nephrotic syndrome (MCNS)**. Children with MCNS tend to respond well to treatment and do very well.

There are other kidney diseases that cause nephrotic syndrome. If your child does not respond to early treatments, we may need to look for other causes. This could be a serious chronic disease that will need special care over the years. Many children outgrow this illness over time with no lasting harm to the kidneys.

### Cause and Treatment

It is not known what causes nephrotic syndrome or how long your child may have it. It may be a problem with your child's immune system. This problem only affects the kidneys. Your child will **not** be more likely to get infections.

Our goal with treatment is to try to control the swelling and to stop the leakage of protein in the urine.

### Diet

The best way to control your child's swelling is to limit the amount of salt they eat and drink. Even normal amount of salt will cause the body to retain fluid. A dietician will work with you to plan a low salt diet. **This is a very important part of the treatment.** Don't decrease the amount of fluid your child drinks. The amount of fluid your child drinks does not affect swelling.

### Medicines

#### Prednisone

Your child may be given corticosteroids. The most common form is prednisone. It is given to treat:

- A large amount of protein is present in the urine
- Swelling
- Weight gain

Prednisone is like a hormone made by the body. It is a very strong medicine that has many side effects. Some of these side effects are:

- Increased appetite
- Acne (pimples) in teens on the face, back and shoulders
- Mood swings
- Overactivity
- Increased risk of infection
- Upset stomach, increased stomach acid

For children who are taking prednisone for a long time (months), there are more side effects to watch for, such as:

- Slowing of the growth rate
- Cataracts (all children taking prednisone for long periods should have their eyes checked once a year)
- Weakening of the bones (osteoporosis)
- Hip and knee problems
- Ulcers
- Diabetes
- Severe headaches
- High blood pressure
- Increased risk of infection

### **Baby Aspirin**

Some children who have this illness are at risk of forming blood clots. Your doctor may have your child take a daily baby aspirin. This will help prevent any clots from forming. Taking the baby aspirin is only needed while your child is in relapse. When taking the aspirin, if they get a viral illness, you should stop the aspirin.

If your child has not had either chicken pox or the chicken pox vaccine and they had contact with someone with chicken pox while taking prednisone, call your doctor right away.

If your child has severe pain, uneven swelling, or changes in the color or temperature of an arm or leg, call your doctor right away.

### **Penicillin**

Children who have this illness are at risk for peritonitis (infection in the abdomen) and sepsis (infection in the blood stream) while they are in relapse. We can lower the risks with a vaccine and penicillin to be taken twice a day while in relapse.

If your child gets a fever or belly pain while nephrotic, you should call your doctor right away. These can be signs of life-threatening illness, and your child's condition can get worse quickly.

### **Diuretics**

We may prescribe a diuretic "water pill" to help control the swelling. These pills can be hard to use safely in children with nephrotic syndrome, so we do not use them often.

### **Monitoring**

You need to test your child's urine at home using urine dipsticks to track the amount of protein in your child's urine and their response to treatment. We will teach you how to do this and how to record the results. Your child's response to prednisone helps the doctor figure out how to adjust the dose.

### **Remission**

A remission is a response to treatment with a drop in the protein in the urine. A remission is defined as your child's urine is trace or negative for protein for three days in a row.

### **Relapse**

A relapse is when protein returns to your child's urine. It may be hard to know when your child has a relapse. Call our office when your child's urine protein is greater than trace to discuss further treatment.

Treatment does not cure this illness. It only treats the symptoms. Most children (80%) will have a return of protein in their urine.

Relapse can occur:

- If your child has an infection
- If the prednisone is not taken as prescribed
- For unknown reasons

### Checking for Signs of Relapse

- Weigh your child at least once a month to figure out their normal weight. Record the weight.
- Watch for signs of swelling:
  - Sudden weight gain
  - Swelling around the eyes (most often seen in the morning)
  - Ankle swelling (often seen before bedtime after the child has been up all day)
  - Swelling in the legs, hands, belly, and genital area
- Routine testing of the urine

Check your child's urine for protein at least once a week even when in a long remission. The reason for testing is to "catch" a relapse early **before** swelling occurs. If you are not checking the urine and your child has a relapse, you won't know about the relapse until you notice swelling.

Once swelling occurs, it becomes much harder to get rid of the excess fluid that your child's body is storing.

It is much easier to care for your child if you know about the relapse early and tell us before the swelling starts.

If your child gets a viral illness, you should check the urine more often since an infection can trigger a relapse.

### If Your Child Has Swelling and Protein in the Urine

- Follow a low-salt diet. If you have questions about the diet, call **608-263-6420 extension 1** to schedule a visit with a pediatric dietician.
- Give medicine as prescribed and keep track on the record sheets.
- Weigh your child at the same time each day. Record the weight on the record sheet. Keep weighing your child every day and watch for a sudden increase in weight.
- Test the urine for protein once a day while your child is having symptoms. Check in the morning. Record the results of the test on the record sheet.
- Protect skin: Swelling not only puts excess pressure on the skin but will also make the skin look shiny and stretched. This can cause the skin to become fragile and easily break open. To protect the skin:
  - Avoid constant pressure on swollen areas. For example: do not sit or lie in one position for a long time.
  - Avoid tight clothing, such as tight elastic around ankles and wrists.
  - Remove watches, rings, belts, or other items that could constrict the skin.
  - For boys, briefs are the preferred underwear because they give more support than loose fitting boxer shorts.
- Watch for swelling, redness and any infections, such as a cold or ear infection, etc. If your child has swelling or an infection you may call your child's doctor or the pediatric specialty clinic at **(608) 263-6420 extension 1**.

### **The Future of the Disease**

Children who have MCNS may have different outcomes after their first treatment.

- About 1/3 will never have a relapse.
- Another 1/3 will have a relapse of their illness a few times a year.
- Sadly, the other 1/3 will have frequent relapses. They will need prolonged use of prednisone to keep their illness in remission. This group is the hardest to care for.

Many children no longer relapse once they enter puberty.

Despite the pattern your child follows, treat your child like a normal child. Your child needs to have a routine, such as going to school and seeing friends.

### **Vaccines**

While your child is nephrotic and taking prednisone, avoid getting any vaccines. Your child **must** avoid all live vaccines such as varicella (chickenpox), MMR and oral polio since your child's immune system is suppressed by the prednisone. They would be at risk of getting an infection from the vaccine.

Avoid even killed, inactive vaccines, since the prednisone would most likely affect how your child responds.

Wait until your child is in remission and off prednisone for at least 2-4 weeks before they get any vaccines.

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 11/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved Produced by the Department of Nursing. HF#4327

**Month**

<b>Date</b>	<b>Dipstick</b>	<b>Weight</b>	<b>Prednisone</b>	<b>Comments</b>
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