Nephrotic Syndrome

What are the kidneys?
The kidneys are two bean-shaped organs located in the lower back area. The body pumps blood through the kidneys. The main job of the kidneys is to get rid of the waste products from the blood.

Each kidney has about one million tiny filters called nephrons. Nephrons do the work to filter out waste products in the blood. The waste products end up in the urine. The nephrons also hold in things that the body needs such as water and protein.

What is Nephrotic Syndrome?
Sometimes, the nephrons let protein leak into the urine. This is called Nephrotic Syndrome. The exact cause of Nephrotic Syndrome is not known. It is normally found in children under the age of six years and is more common in boys than in girls.

What does Nephrotic Syndrome do to the body?
When the nephrons in the kidney are working well, protein stays in the blood. Protein helps keep the right balance of water in the blood. In Nephrotic Syndrome, the nephrons are not working well so protein leaks out of the blood and into the urine. When the amount of protein in the blood is too low, water leaks into the body tissue. The water in the tissue spaces makes the skin look puffy. This is called edema. The skin around your child’s eyes, hands, feet, abdomen and genitalia may stretch out (swell) because of the puffiness.

How is it diagnosed?
Urine and blood tests and a physical exam can help diagnose Nephrotic Syndrome. Swelling is normally the first symptom that is noticed, although it is often mistaken for an allergic reaction. In Nephrotic Syndrome, swelling will not improve until treatment is started.

How is it treated?
Your child will take a medicine called prednisone to help the kidneys recover. Prednisone is a steroid. Your child has to take this medicine every day for 6 weeks and then every other day for 6 weeks to stop the protein from leaking into the urine.

Prednisone is like a substance made in the body. Your child’s body will naturally stop making this substance while taking the medicine. Once your child stops taking prednisone, it takes a while for the body to make this substance again. If your child suddenly stops using the medicine, your child may vomit, sweat or be dizzy. Your child’s blood pressure may also decrease enough to make your child faint. Do not stop giving your child prednisone unless your child’s doctor tells you to stop.
Treatment (Continued)

In most cases, Nephrotic Syndrome can be treated at home. When at home, it is important for you to:
- Test your child’s urine for protein. The nurse will show you how to do this. Test your child’s urine every day if your child is sick or has edema.
- Give your child prednisone as prescribed by the doctor.
- Give your child a “no added salt” diet.
- Watch for the signs and symptoms of relapse. A relapse means that Nephrotic Syndrome has come back again. The main signs of relapse are edema and protein in the urine.
- Take special care of your child’s skin to avoid dryness or flaking when your child has edema. Do not use rough soaps or put too much pressure on the skin. There may be times when edema or an infection does not improve with care at home. Your child will then need treatment in the clinic or the hospital.

What is remission?
When your child’s body responds to treatment, this is called remission. Signs of remission are:
- Your child’s urine will be negative for protein when tested.
- The edema will go away. When the edema goes away, your child will be urinating more. Your child will weigh less.

Will my child get it again?
Even though your child may respond to treatment, there is a good chance that Nephrotic Syndrome will occur again. This is called a relapse. A relapse can occur if your child does not take the medicine correctly, or gets an infection or virus. If you find protein in your child’s urine when testing it, or your child’s skin gets puffy from edema, call the doctor or nurse. Do not start, stop, or change the dose of prednisone without talking with your health care provider.

There no way to know if or when the symptoms will occur again. Many children outgrow this problem by the time they are teenagers. Others do not outgrow it. A small number of children do not respond to treatment. These children may need to take different medicines or need to have other tests done.

**ALERT:** Call your child’s doctor, nurse, or clinic if you have any questions or concerns or if your child:
- Has increased protein in the urine.
- Has swelling.
- Has a swollen and bloated (distended) belly.
- Has severe pain in the abdomen.
- Is vomiting.
- Has diarrhea.
- Has special health care needs that were not covered by this information.

*This teaching sheet is meant to help you care for your child. It does not take the place of medical care.*

*Talk with your healthcare provider for diagnosis, treatment, and follow-up.*