

What do the kidneys do?

Your child's 2 kidneys filter all of the blood flowing through their body. They make urine to get rid of waste and extra water. Each kidney contains up to 1 million filters called glomeruli. Healthy kidneys and glomeruli help:

- Regulate blood pressure.
- Remove waste and extra water.
- Signal the body to make more red blood cells.
- Build strong bones and help children grow.

What is nephrotic syndrome?

Nephrotic syndrome is a group of signs and symptoms that happen when the kidney filters (glomeruli) are damaged and leak protein from the body into the urine. The signs and symptoms are:

- Swelling (also known as edema)
- Low albumin (a type of protein) in the blood
- High protein in the urine
- High cholesterol levels in the blood

What causes it?

Sometimes, nephrotic syndrome is caused by rare conditions. This may include:

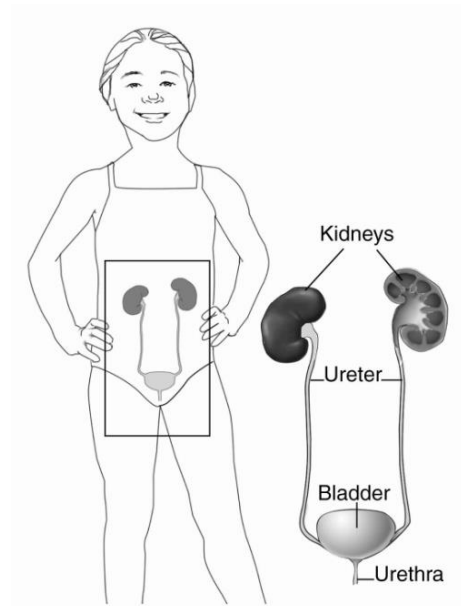
- An inherited problem in the kidney filters
- Infections
- Other illnesses, such as lupus

Most of the time in children, the cause of nephrotic syndrome is unclear. Your child's doctor may do a kidney biopsy (remove small pieces of tissue from the kidney) to find out what type of nephrotic syndrome your child has. The most common types are:

- Minimal change disease – the kidney tissue looks very close to normal kidney tissue.
- Focal segmental glomerulosclerosis – some parts of the kidney filters show scarring.

To find out what type of nephrotic syndrome your child has and how to treat it, your child's doctor will look at your child's:

- Symptoms
- Response to treatment
- Blood test results (labs)
- Biopsy results (if needed)



Urinary system

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Nephrotic syndrome, continued

What are the possible symptoms?

When important proteins are lost from the body into the urine, your child may have:

- Fatigue (extreme tiredness)
- Decreased appetite (may not want to eat and drink as much)
- Swelling. The part of the body that has the most swelling will change based on what your child has been doing.
 - Eyelid swelling shows up more after your child has been sleeping.
 - Belly or groin swelling show up more after your child has been sitting.
 - Feet and leg swelling show up more after your child has been standing or walking
- Abdominal (belly) pain
- Shortness of breath, especially when laying flat
- Fever (temperature of 100.5°F or higher) and other signs of infection
 - Fever and belly pain may mean your child has an infection inside the abdominal cavity called peritonitis.
 - Fever and rash may mean your child has a deep infection of the skin called cellulitis.
- To urinate (pee) less often and/or have less urine at one time
- Large blood clots. If the blood clots travel to the lungs, they can restrict the amount of oxygen that gets into the body. This can be life-threatening.

What is the treatment?

The most common treatment for nephrotic syndrome is **corticosteroids (steroids)**, such as prednisone (pills) or prednisolone (liquid).

Most often, steroids are used to help your child go into **remission**.

- A remission is when the kidneys stop leaking protein. During a remission, the symptoms will go away.
- When you check your child's urine at home with urine test strips, a remission is when the urine protein is negative or trace (+/- or 15mg/dL) for at least 3 days in a row.

For most children, the nephrotic syndrome will come back after remission. This is called a **relapse**.

- A relapse is when the kidneys start leaking protein again. During a relapse, the symptoms can come back.
- A relapse is when the urine protein is 3+ or higher (≥ 300 mg/dL) for at least 3 days in a row.

Your child may need other medicine if they have many relapses and needs lots of steroids or if they do not go into remission with steroids. This may include:

- Diuretics at home or in the hospital. Diuretics help your child to urinate more. This will help decrease swelling.
- Blood pressure medicine to help treat high blood pressure.

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Nephrotic syndrome, continued

What can I do at home?

Home care is very important to help control nephrotic syndrome and keep your child healthy.

Remember:

- Give your child's medicines on time. Do not miss doses.
- Check your child's urine each day.
- Follow a low salt diet during disease relapses.
- Follow a low fat, healthy diet while your child is taking steroids.
- Make sure your child gets all of the vaccines (immunizations) they need on time. Your child needs:
 - A flu vaccine each year
 - An expanded pneumonia vaccine (2 doses of PPSV23 after the PCV13 series is complete)
 - A COVID-19 vaccine
- Call your child's doctor for new disease relapses or remission.
- Call your child's doctor (or call 911 if it is severe) for any of these:
 - Fever of 100.5°F or higher
 - Swelling that is new or uncomfortable
 - Severe belly pain
 - Shortness of breath
 - Vomiting (throwing up) or trouble drinking liquids
 - Urinates less often and/or has less urine at one time
 - Painful skin rash
 - Any other concerns

How do I check my child's urine for protein?

Some guidelines for checking your child's urine protein at home include:

1. After waking up in the morning, have your child urinate into a clean cup.
2. Dip the test strip into the urine. Make sure all of the squares are wet. This should take no more than 1 second.
3. Gently tap off the extra urine.
4. Wait for about 60 seconds.
5. Hold the strip up to the color chart on the urine test strip bottle.
6. Find the protein square, and match it to the closest color on the chart.
7. Write down the test result on your child's urine protein log.

Remember:

- The best time to check the urine is when your child first wakes up. If you forget to check it in the morning, you may check later in the day.

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Nephrotic syndrome, continued

- Check your child's urine every day.
 - If the urine is negative or trace, this is normal. If your child has been in a disease relapse, a result of negative or trace for 3 days in a row means your child is now in remission. **Please call the doctor so your child's medicine can be lowered or stopped.**
 - If the urine is 1+ (+ or 30mg/dL) or 2+ (++ or 100mg/dL), this means there are small amounts of protein in the urine. Keep checking it every day.
 - If the urine is 3+ (+++ or 300mg/dL) or higher, this means there is a large amount of protein in the urine. If your child has been in remission and is doing well, a result of 3+ or higher for 3 days in a row means your child has relapsed. **Please call your child's doctor.**

To learn more about checking urine protein, scan the QR code to watch a short video (only available in English at this time).



Where can I learn more?

For general information, you may visit these websites:

- NephCure Kidney International – nephcure.org
- National Kidney Foundation – kidney.org

For support groups, you may visit these websites:

- NephCure's online chat group (NephSpace) – nephcure.org/nephspace
- Nephkids – cybernephrology.ualberta.ca/nephkids
- Kidcomm – kidcomm.org

You may choose to join social media groups, such as the Facebook groups listed below. Please keep in mind the information is not posted by medical experts.

- Parents of Children with Nephrotic Syndrome
- Nephrotic Syndrome Parent Support
- FSGS Fight Club for Parents of Children with FSGS and NS

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these Sites. Use of the links provided on this or other sites is at your sole risk.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

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