Kidney Kids NZ

# Nephrotic Syndrome

*Facts for whānau*

**Advice in this pamphlet is only intended as a guideline.**

**Please check with your GP or specialist if you have any questions relating to your child's condition.**

# What is nephrotic syndrome?

## Nephrotic syndrome is when the kidneys leak protein. This is an autoimmune condition that can come and go (relapses and remissions).

Too much protein loss in the urine (wee) leads to swelling ***(oedema)***. Important proteins that protect you from infection ***(antibodies)***, regulate metabolism ***(thyroid binding proteins)*** and bind fat ***(lipid binding proteins)*** are also lost. A kidney biopsy is sometimes needed to determine which type of nephrotic syndrome it is.

## When and why does it happen?

Nephrotic syndrome usually occurs around 2–3 years of age. The swelling happens over a period of 2–5 weeks but most people don't immediately realise it's due to low protein in the body, so often children are treated for allergies or eczema, as facial swelling is the most obvious first sign.

Doctors don't know exactly how the immune system causes protein leaks. Children with nephrotic syndrome are more likely to have other allergies/autoimmune conditions, such as eczema and asthma. Most children with nephrotic syndrome have a relapse during or shortly after an infection (usually a cough or cold).

## Can it be treated?

Yes, it can be treated. The main treatment is ***prednisone***, a ***steroid medication***. Most of the time, treatment is only needed when there is a relapse. If there are many relapses, then doctors might recommend other medications to stop these from happening.

## Will it go away? Can this disease be cured?

In a minority of children, this condition only happens once. Most children with nephrotic syndrome will have relapses 1–3 times per year. In general, there will be less relapses over time, until there are no more relapses.

- **80%** of children with nephrotic syndrome will have no more relapses around the time they reach adulthood.
- **20%** of children with nephrotic syndrome will have a more severe form that has lots of relapses, causes scarring in the kidneys and kidney dysfunction or failure.

# Relapses and remissions

## How do I know when a relapse is happening?

Initially, you may notice swelling on the face, legs and tummy. Sometimes, an infection occurs at the same time as a relapse. Urine and blood tests can confirm protein leaks and low protein in the body.

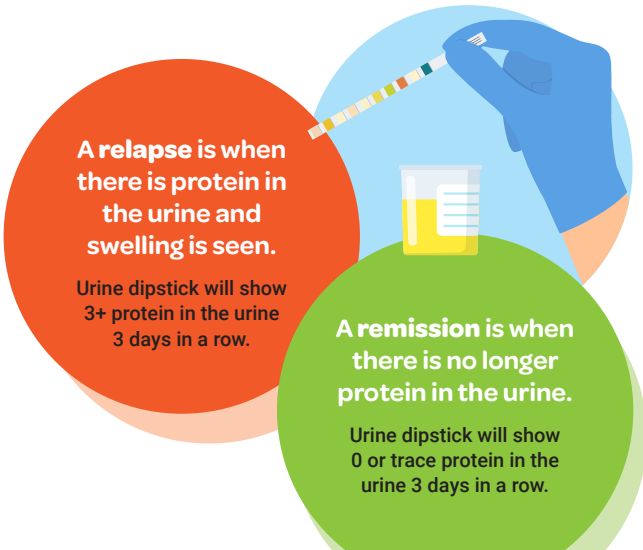
After the diagnosis is made, you may be asked to test your child's urine each morning with a dipstick to check if protein levels are high, which could indicate a relapse. Testing is easy and involves dipping a plastic dipstick into the first urine specimen that passes every morning. Checking for urine protein is important, as this is usually seen 7–10 days before you can see swelling.

## How do I know when remission is happening?

Usually, the first sign is an increase in urine output. Your child may be wetting the bed. The swelling then goes away and weight is reduced. When the urine dipstick shows 0 or traces for three days in a row, it's time to reduce the treatment dose (except the first time your child is treated).

## What if the urine testing shows a high protein level?

The kidneys can leak protein appropriately in an infection. You might see this when the urine dipstick shows **1 or 2+ protein levels**. This happens in children with or without nephrotic syndrome. If this is short-term (2–3 days) and goes away, then it does not need treatment. If it doesn't go away, talk to your child's doctor.



# What else can be done to help tamariki?

## In relapse:

**Admission to hospital may be needed when:**

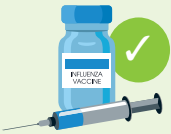
- There is gastroenteritis, skin and soft tissue infection, fever, or abdominal pain.
- There is gut swelling, your child may be vomiting and have diarrhea if they can't absorb food and fluid properly.
- There is too much swelling that prevents your child from moving easily (in boys this may be scrotal swelling, so check this).

**Diet and water:**


- Your child needs a low-salt diet diet when in relapse. Salt pulls water and makes the body more likely to swell up.
- Fresh fruit, vegetables and meat contain enough salt to maintain salt balance in the body. Avoid adding salt to meals or eating processed/ canned foods, or takeaways.
- Do not give more protein in relapse. The kidneys will leak any extra protein that is eaten (food protein or powder protein).
- No fizzy drinks. Carbonated drinks have salt.
- Your doctor may also give your child a fluid restriction (maximum amount of water to drink each day) to avoid swelling.

## In remission:

- Normal diets and drinks are recommended.
- No need for extra protein.
- Extra vaccinations may be recommended to protect your child's immune system (for childrenwho have more than two relapses in a year).




- Yearly influenza (flu) vaccination is also recommended.

# Using prednisone

## 7–14 days of daily prednisone is used to reverse urine protein leak.

The first time your child has nephrotic syndrome, the total prednisone course is about 8–12 weeks long. Your child will have a minimum of 4 weeks on daily prednisone, and 4 weeks on every other day prednisone.

From the second episode onwards, daily prednisone is used only until your child is in remission, then you complete the course with 4 weeks of every other day prednisone.

If your child relapses while taking prednisone, other medicines can be used to stop your child from having relapses.

## What are the side effects of prednisone?

Big doses of prednisone to treat this condition are often used. In the short term, this may lead to:

- **Increased hunger and appetite**
- **Emotional dysregulation (temper tantrums)**
- **Sleep disturbances (prednisone is given in the morning to avoid this)**
- **Not all children will have side effects**

The side effects should go away after stopping prednisone. In the meantime, maintain normal routines and offer healthy food options like fresh fruit and vegetables.

Long term use of prednisone can lead to:

- **Stunted height**
- **Weak bones (more likely to break)**
- **Increased risk of infections**
- **Suppressed body's stress response**

These symptoms can sometimes persist after stopping prednisone and are the reason doctors won't recommend big doses of prednisone for more than 6 months in a year.

*Kidney Kids has plenty of information about conditions that can affect children's kidneys. If you can't find the information you are looking for, please contact us.*

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***Our vision is for all Kidney Kids and their whānau to lead their best lives and to feel supported, understood and connected in a caring community.***

## Get in touch

If you would like more information about our organisation, or if you, your whānau or friends have a child with a kidney condition and you would like to register with us, please get in touch.

## Find us

**0800 215 437** – Monday to Friday 8.30am to 5pm
or email **support@kidneykids.org.nz**

**kidneykids.org.nz**

**Pamphlet prepared for Kidney Kids of New Zealand Inc. by the Nephrology team at Starship Hospital**