

# Sickle cell disease: nephropathy

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## What is sickle cell nephropathy?

Sickle cell nephropathy occurs when there is damage to parts of the kidney.

- The kidneys are filters for the blood. They make urine, which allows your body to remove salts, waste and extra water from your blood. They also help your body to keep the important parts of your blood, like proteins and cells inside the blood.
- In sickle cell nephropathy, parts of the kidney can get damaged by sickle cells. This does not cause pain. You may not know there is any damage to your kidneys unless it is found in blood or urine tests.
- Sickle cell nephropathy happens very slowly. If it starts in childhood, it may slowly cause more damage over several years and be more severe in teens and adults.

## What happens from sickle cell nephropathy?

When the kidneys are damaged by sickle cells:

- Small amounts of protein in the blood can leak out of the blood and be lost into the urine. One of these proteins is called albumin. Having too much protein in your urine is called proteinuria or albuminuria. This is an early sign that kidney damage has started.
- Blood can sometimes appear in the urine when the kidneys are damaged. This is called hematuria. The bleeding can last for a few hours or a few days.
- As damage to the kidneys gets worse over years, the kidneys may stop working (kidney failure). A person with kidney failure may not be able to make urine. People with kidney failure need dialysis (a machine to help the body get rid of waste) a few times each week to survive. They may also need a kidney transplant if the condition is not improved with dialysis.

## What are the symptoms?

Your child may not have any symptoms. **Early signs of kidney damage often show on a routine urine test done in a clinic.**

Your child could have 1 or more of these:

- High blood pressure
- Protein in the urine
- Blood in the urine

## What should I do if my child has symptoms?

Call your sickle cell provider if you notice any symptoms.

- If your child has blood in their urine, call the sickle cell disease clinic. If after hours, leave a message with the on-call service and ask to talk with the hematologist on call.

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

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## What tests could my child have?

Your child will need a complete physical exam and blood pressure check. They may also need:

- A urine test to look for blood and protein in the urine.
- Blood tests to check blood counts and kidney function.
- An appointment with a kidney doctor (nephrologist).
- A kidney biopsy. This is a test that uses a tiny sample of kidney tissue. It tells doctors how much kidney damage has occurred and the type of treatment needed.

## What is the treatment?

Your child's treatment may include:

- Intravenous (I.V.) fluids if there is blood in the urine.
- An appointment with a kidney doctor.
- Medicines to treat sickle cell disease, such as hydroxyurea.
- Medicines to decrease protein in the urine, such as losartan, lisinopril or similar medicines.
- Medicines to treat high blood pressure if needed.

Your child's sickle cell provider will talk with you about other treatments your child needs. Please ask questions.

## What follow-up care does my child need?

Your child will need continued care after they leave the clinic, emergency department (ED) or hospital. Make sure you follow all discharge instructions.

- Take your child to a follow-up clinic visit as your provider directs.
- Give your child plenty of fluids to drink each day. Ask your provider how much fluid your child needs.
- Make sure your child is urinating well. Look at the urine to make sure there is no blood in it. The urine should be a clear, pale, yellow color.
- Follow other instructions as the provider directs.

## How can I help prevent kidney damage?

To help prevent kidney damage:

- Give your child plenty of fluids to drink each day.
- Know what your child's normal blood pressure is and when the numbers may be too high.
- Avoid medicines that can harm the kidneys. Ask your provider or pharmacist about the medicines your child takes. This includes over-the-counter medicines.
- Ask your provider about how nephropathy is treated.

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## What should I do if my child is sick?

- Follow the sickle cell provider's advice for what you should do.
- Call your child's provider anytime your child has a fever of 101°F (38.3°C) or higher and is sick. Your child will need to be seen **right away**.
- During the time when the clinic is closed (between 5 p.m. and 8 a.m. during the week and on weekends and holidays), call the hematologist on call. They will contact the emergency department (ED) and help with your child's care.
- **ALWAYS** tell the ED doctors and staff that your child has sickle cell disease. Also tell them which sickle cell clinic your child visits.

For more details on sickle cell disease and services, visit Children's Healthcare of Atlanta website at [choa.org/sicklecell](http://choa.org/sicklecell).

**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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