

# Sickle cell disease (SCD): iron overload

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## What is iron overload?

Iron overload means your child's body has stored more iron than it needs.

- We all need iron to grow and develop.
- When too much iron builds up to a level that overloads the body, it can cause health problems.

## What causes it?

Blood transfusions help to prevent sickle cell problems like stroke. This means some children with sickle cell disease may need many blood transfusions. Children who receive blood transfusions for a long time can have a buildup of extra iron.

- Each unit or pint of blood contains iron.
- The body can only store a small amount of iron safely.
- The body does not have a natural way to get rid of the extra iron.
- The extra iron builds up in the body over time.
- It is stored in major organs like the liver and the heart.
- The body cannot function as it should with extra iron.

## What are the effects of iron overload?

Most often, there are no symptoms in the early stages of iron overload. If high iron levels are not treated, it can cause problems in some of the body's organs, such as the:

- Liver
- Heart
- Skin
- Pancreas
- Reproductive organs (ovaries in girls, testes in boys)

## What are the symptoms?

Your child may have 1 or more of these:

- Weight loss
- Fatigue (feel very tired)
- Bronze or gray skin
- Joint pain
- Shortness of breath
- Swelling of ankles
- Abdominal (belly) swelling or pain
- Blood in the stool
- Stunted growth
- Delayed puberty
- Diabetes (increased thirst and increased urinating)

Ask your sickle cell provider for more details about problems with iron overload.

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

# SCD: iron overload, continued

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## What tests could my child have?

Several tests can check for iron overload. They include:

- A blood test called a ferritin level.
  - It tells how much iron is in the body.
  - If your child gets blood transfusions often, their sickle cell provider will order this blood test to check for iron overload.
- Ferriscan – this is a special type of MRI that measures iron levels in the liver.
- Cardiac MRI – this is an MRI of the heart that can measure iron levels in the heart.
- Liver biopsy – the doctor takes a sample of tissue from the liver and sends it to the lab. The lab then checks it for iron levels and checks for any damage to the liver tissue.

## What is the treatment?

Too much iron is treated with special medicines called iron chelators. Iron chelators may be given:

- By mouth (to swallow)
- Under the skin by subcutaneous injection (shot)
- Through an IV in the hospital with a continuous infusion

Many children with iron overload do well taking medicine by mouth as long as they take it when they should. Some children need 2 or 3 iron chelator medicines to treat high iron levels.

Other ways to treat or prevent iron overload are:

- Phlebotomy – a certain amount of blood is removed based on your child's weight and hemoglobin level. This helps to rid the body of too much iron.
- Exchange transfusion – this is done to remove sickle red blood cells and replace them with normal red blood cells. It can help stop a buildup of iron in the body and keep the excess iron levels down.

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

- Follow your child's sickle cell provider's advice for what you should do.
- Call your child's provider and **seek medical care right away** anytime your child has a fever of 101°F (38.3°C) or higher. Do not give iron chelator medicines if your child has a fever.
- 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 before going to the hospital. They call 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 they visit.

For more details on sickle cell disease and services, visit the 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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