

Discharge Instructions for Sickle Cell Anemia and Sickle Cell Crisis (Child)



Your child has sickle cell anemia. That means the red blood cells are abnormally C-shaped (like a sickle) instead of round. This can cause the sickle blood cells to get trapped in blood vessels. It can affect the blood's ability to carry oxygen. Sickle cell anemia runs in families and often affects African Americans. It can be controlled with treatments. But the only cure is a bone marrow transplant. Your child was born with this condition.

A sickle cell crisis happens when many sickled cells stick together and pile up in the blood vessels. During a sickle cell crisis, your child can have severe pain in the chest, stomach, arms, and legs. The crisis can last for hours, or even days. It can happen several times a year. Over time, organ damage can also occur. Here's what you can do to help your child.

What to watch for

Be on the alert for:

- Complaints from your child of feeling sick, tired, or having trouble seeing or hearing
- Any possible signs of infection, such as fever or shortness of breath
- Swollen, painful, red, or hot hands and feet
- Swollen belly
- Signs of fluid loss (dehydration)
- Sores (ulcers) on your child's legs. These are caused by poor blood flow. They are a sign that your child's sickle cell anemia is not under control.
- Yellowing of the eyes or skin (jaundice)
- In boys, an erection that doesn't go away
- Pain that does not go away with treatment
- Abnormal speech, weakness in arms or legs, or uneven face that may mean a stroke

Treatment

What you can do:

- Get treatment right away if your child has a fever of 101°F (38.3°C) or higher, pain, infections, illnesses, or other health problems. This includes flu, colds, and skin infections.
- Call your child's healthcare provider if you are unsure about how to treat your child. It is very important your child get correct treatment of health problems. This can prevent complications of sickle cell anemia.
- During a sickle cell crisis, keep giving your child pain medicine as prescribed by your child's provider. If the pain continues, call your child's provider.

Home care

Do's and don'ts once your child is home:

- Encourage your child to get plenty of activity, but not to the point of becoming overly tired. Be sure your child drinks plenty of fluids during activity.
- Have your child wear a medical alert bracelet or necklace.
- Alert appropriate school personnel to your child's medical condition and provide emergency contacts and instructions.
- Add emergency contacts to your child's cell phone.
- In an age-appropriate manner, teach your child about sickle cell anemia and its care.
- Discuss with your child's provider which sports and what type of exercise are appropriate.
- Alert your child's coaches to any additional safety precautions needed for your child.
- Encourage your child to drink plenty of liquids, especially during warm weather. This helps to prevent dehydration.
- Dress your child in warm clothes if they will be outside during cold weather. Or if your child will be in air-conditioned buildings during hot weather.
- Don't allow your child to swim in cold water because this may cause a sickling crisis.
- If your child must travel by air, they should fly in pressurized aircraft only. Talk with your child's healthcare provider about extra safety steps if your child must travel in a nonpressurized plane.
- Consider accessing reputable online and community-based resources for support. The Sickle Cell Disease Association of America (<https://www.sicklecelldisease.org/>) is one place to start looking for resources. Your providers can also give you suggestions.

Follow-up care

Make a follow-up appointment as directed by your healthcare provider.

Seek immediate care

Call 911 or seek immediate care at an emergency room, urgent care, or your provider's clinic if your child has any of the following:

- Fever of 101°F (38.3°C) or higher, or as directed by your provider. A fever in a child with SCD can sometimes be a first sign of infection or other SCD problems, so be alert to fever and follow your provider's specific instructions.
- Trouble breathing
- Chest pain
- Seizure
- Severe headache
- Belly swelling
- Sudden weakness
- Weakness on one side of the body
- Loss of feeling and movement
- A painful erection of the penis lasting more than 4 hours
- Skin gets pale

When to call your child's healthcare provider

Call your child's healthcare provider right away if your child has any of the following:

- Change in behavior, fatigue, or complaints of not feeling well
- Swollen hands or feet
- Pain that doesn't get better with medicine
- Sudden paleness of the skin or nail beds
- Worsening yellowish color of the skin or eyes (jaundice)
- Trouble hearing
- Trouble with vision or seeing
- Change in speech
- Limping, joint swelling, or joint or muscle pain

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