

Helping Your Child Live Well with Sickle Cell Disease

Living with sickle cell disease means becoming an expert on caring for your child through their health care journey.

There are always new things to learn and to think about when you are the caregiver of a child with sickle cell disease.

As you may know, sickle cell disease is a blood disorder. It turns round red blood cells into C-shapes or sickle shapes.

These blood cells are hard and stiff so they don't flow easily through blood vessels.

This can cause pain and anemia. Having anemia means your child's body doesn't have enough healthy red blood cells. This means the organs and tissues of their body don't get enough oxygen.

Your child may feel tired or short of breath.

And some children with sickle cell disease may be at risk for long-term complications like stroke.

Some children may need regular blood transfusions to treat anemia and other problems.

A stem cell transplant or gene therapy can be an option for some children.

Children with sickle cell disease may also have to take medicines to help prevent complications and relieve symptoms.

Caring and regular treatment of sickle cell disease focuses on treating anemia, avoiding complications, and helping prevent and treat pain.

And there is a lot you can do, at home, to care for your child.

Make healthy choices for your family, including choosing healthy foods, and if your doctor says it's ok, staying active. Other healthy choices include getting enough rest, and making sure your child stays hydrated. And try not to let them get too hot or too cold.

You can also help your child avoid complications by keeping them from getting sick. Have them wash their hands often and make sure they're up to date on all vaccines, including flu vaccines.

Be sure to keep all their healthcare appointments including health screening appointments such as for vision checks and tests to check their risk for stroke.

Living with sickle cell disease can be painful. You'll learn ways to recognize what triggers your child's pain, and how to ease, comfort and treat it.

Show them patience, love and affection while helping them deal with the pain.

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If you haven't already done so, work with your child's doctor to create a care plan that will cover medicines, pain management, ways to have a healthy lifestyle, and what to do if you need emergency help.

You may want to share this plan with your child's day care, school, or play groups so they know the signs and what to do.

It's a lot. If you ever think that what you're doing for your child isn't working, talk to your healthcare team.

They can work with you to help your child feel better.

Your care team is there to support and guide you so you can help your child live a long and happy life.