Sickle Cell Disease: Helping your Child Manage Pain

As a parent or caregiver for a child, one of your main jobs is to provide comfort. This is especially true when that child has sickle cell disease.

Living with sickle cell disease can be painful. But you can find ways to help them ease and treat pain.

When your child has sickle cell disease, the red blood cells become rigid and sticky. They are also shaped more like the letter C, or a sickle tool. As these sickle-shaped cells travel through the body, they can bunch together and get stuck in smaller blood vessels. This block in blood flow can cause episodes of sudden pain.

These pain events are called a sickle cell crisis, or pain crisis, and can last from hours to days. Your child may feel pain in any part of their body, but it is most common in the chest, arms, and legs.

Treatment depends on the level of pain and how long it lasts. You and your child’s doctor will create a pain management plan to help during a sickle cell crisis.

This plan should include not only the types of medicines your child can take at home but also other things you can do.

Sometimes, nonprescription, or over-the-counter, pain relievers such as ibuprofen can help.

Other times, they may need stronger pain relief medicine prescribed or given by a doctor.

And some painful episodes may need care in the hospital for I.V. therapy for fluids and more powerful pain medicines to ease your child’s pain.

Work with your child to help them find other ways to ease their pain. Some children find guided imagery, deep breathing, and relaxation exercises can help. You can try applying heat to the painful area with a heating pad set on low or a compress. Put a thin cloth between the heat source and your child's skin.

Other things you can do for your child include encouraging them to drink plenty of water. Staying hydrated helps prevent the blood from becoming too thick and can help reduce pain crises.

Make sure they don’t get too hot or cold, get plenty of rest, and avoid high altitudes for example flying, mountain climbing, or visiting cities with a high altitude.

You know your child best. And you’re a part of their care team.

So it can help to learn as much as you can about sickle cell disease, speak up with your questions and concerns, and trust yourself—even when you feel unsure.

It can help to know that you have a right to health care that gives your child their best chance at a healthier life with less pain.

“When I look at him now, I'm just amazed at how far he's come, because it was the simple things that he couldn't do before. ….He's doing everything that he couldn't do before.”