

The nation's children's hospital



Preventing and Managing Pain in Children and Adolescents with Sickle Cell Disease

Patient and Family Resource

www.ChildrensNational.org

You and Your Team

You and your child are important members of your child's healthcare team. As a team, we can work together to help your child develop habits to prevent pain, as well as skills to cope with and reduce the length of pain crises when they do happen.

This brochure gives you and your child tips on preventing and managing pain associated with sickle cell disease (SCD), including using relaxation techniques to reduce the frequency and duration of pain, managing stress, planning ahead, and setting goals.

Children's strives to provide medical care that includes medication and guidance to help your child live a healthy life with SCD.

We're glad to be on your team!

Here are some relaxation techniques you can practice and teach your child:

Pay attention to your breathing.

- Breathe a little more slowly and deeply than usual.
- As you inhale, think about fresh air coming slowly into your chest, out to your fingers and down to your toes.
- As you breathe out, imagine that any tension that may have been stored in your arms, neck or shoulders is moving from your body and out into space.
- Notice the muscles in your body becoming more relaxed as you breathe slowly, in and out, five or more times.

Relaxation Techniques

Picture yourself in a place where you feel calm and happy.

- Think of details you would see in this place.
- Imagine sounds you might enjoy there and think about what you would like to touch, taste, and smell in your favorite place.
- Take slow breaths and let yourself take a short vacation in your mind.

Notice if you are often thinking about situations or events in your life and feeling angry, anxious, or discouraged.

- Sometimes people have thinking habits that get in the way of effective problem-solving and relaxation.
- Use the relaxing breathing technique to shift your mind's focus.
- When you are relaxed ask yourself if there is a different way you can think about the stressful situation or event so that you can respond to it differently.
- Remind yourself that you can get assistance and ideas from other people in problem-solving.
- Ask for help. Other people can help you think differently about situations and events.
- We can provide emotional support to help you get through difficult times.

Managing Stress

Many everyday activities can increase a person's heart rate and muscle tension. This is known as stress. Frequent or intense stress increases the risk of pain crises in people with SCD. You and your child can benefit from stress management, which involves identifying sources of stress that affect you or your child often, and seeking ways to reduce those stressors.

This may mean that you:

- Develop routines so that your lives are more predictable, such as having meals and bedtimes around the same time each day
- Obtain additional help with school-related tasks
- Use relaxation techniques to help you recover from stress

We can help you and your child learn how to manage stress and practice relaxation techniques.

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Planning Ahead

Plan for your child's comfort. This means thinking ahead each morning about what your child will be doing during the day. Plan for him or her to have warm clothes on cold days, a jacket or sweater if he or she will be in an air-conditioned building, and access to water all day.

If you talk with your child about the steps you take in planning ahead, he or she will learn to think about what can be done to make certain that comfortable clothes and fluids are available later in the day.

Plan for your child to have some rest and quiet time during the day. Alternate on-the-go activities with reading, drawing or other slower-paced, relaxing activities.

The Role of the Young Person

If you are old enough to read and understand this brochure, you can do many things to help yourself, such as:

- Eat healthy food, including breakfast.
- Get enough sleep and rest.
- Get some exercise every day, and remember to take breaks.
- Drink at least 8 glasses of fluid each day.
- Learn skills for getting along well with people and difficult situations.

Setting Goals

When you set manageable goals for you and your child, you give energy toward what is important to you. Your child learns from your example, so you help both of you when you declare what you plan to do and then follow through.

Useful goals are ones that:

- Are important to you
- Give you a way of seeing progress
- Can be accomplished a little bit at a time.

You can help your child set goals to manage stress and to prevent and manage pain by:

- Organizing schoolwork and supplies so that everything is easy to find
- Dividing big projects into little ones so that the project is done on time

Remember to let your child know you are proud of all accomplishments. Giving positive feedback is a great way to encourage your child to succeed!

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The nation's children deserve nothing less.