

# Managing mental health is an important part of sickle cell disease treatment

September 9 2024, by Tanesha R. Johnson

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Children who were diagnosed with a chronic condition at an early age face challenges that go beyond their physical health. Diseases like sickle cell have an especially stressful impact on not just the patient, but their families and caregivers as well.

Sickle cell disease causes severe and unpredictable [pain](#), intense fatigue,

frequent infections that lead to prolonged hospitalizations, frequent appointments and missed school and [social events](#).

In turn, the disease can have a [detrimental effect](#) on the patient's mental health; these stressors can include being worried about the long-term effects of their disease on their body, burdensome physical symptoms including significant pain crises and fatigue, trauma of frequent visits to the hospital and potentially the [emergency room](#) and feelings of isolation as they miss school and activities due to pain.

Every year, approximately 2,000 babies are diagnosed with sickle cell disease at birth. While the exact number of people living with sickle cell disease is not known, it's estimated that 100,000 people have been diagnosed in the United States, and more than 20 million people world wide.

Sickle cell disease impacts various parts of a patient's and their caregiver's life. Given the significant chronicity and pain associated with the disease, one study found caregivers of children with sickle cell disease between the ages of 5 to 18 reported that their children had statistically significant lower levels of physical, psychological and social well-being in comparison to healthy children of similar socioeconomic background.

Rates of depressive and [anxiety disorders](#) are higher in patients with sickle cell disease, compared to the general population. Additionally, children under the age of 5 with sickle cell disease and repeated hospitalizations were found to have greater levels of emotional reactivity, depression and anxiety and aggressive behavior.

When it comes to supporting a chronically ill child or teen, it's important to equip yourself and them with coping techniques to help alleviate any stress and anxiety.

## **Beware of how you respond to stress**

One study shows that 40% of sickle cell disease caregivers reported that the disease impacted their daily lives and their [mental health](#); parental psychological distress impacts their child's health and quality of life. Create coping strategies with your child, and connect with other families and organizations for support.

## **Don't focus on the negative**

As a parent, it can be hard to see your child unhappy or in pain. Try to redirect their focus with games centered around coping techniques. Find a way to celebrate any milestone, no matter how small.

## **Help your child learn to help themselves**

You and your child can come up ways to help them feel at ease whenever they feel stressed or anxious. For [young children](#), that can include singing a calming song together, practicing big belly breathing and stickers and charts for good behavior.

For older kids, include them in discussions about their treatment so they can feel some agency over their disease. Encourage them to take charge when it comes to areas such as [pain management](#) or medication, and build a foundation for independence for when they are older.

September is National Sickle Cell Awareness Month. For more information about [sickle cell disease](#), visit [sicklecelldisease.org](http://sicklecelldisease.org).

Provided by University of Kentucky

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