

SPRING 2019

SICKLE CELL NEWS



Welcome

Sickle Cell News is a newsletter for children, adolescents and adults with sickle cell disease (SCD) and their families, produced by the Hematology team at Children's Hospital Los Angeles. Stay tuned for more information about living with SCD, upcoming activities and special events.

Coates' Corner: Understanding Pain in Sickle Cell Disease

Pain is the one of the most evident manifestations of sickle cell disease (SCD). Pain is a natural defense mechanism that sends a signal to our brain when there is damage occurring someplace in our body. The severe pain that occurs with acute sickle crisis is similar to what is felt with a bone fracture, and it is due to tissue damage from sickling. It often requires relatively high doses of narcotics, and usually gets significantly better within minutes of administering an appropriate dose of a narcotic pain medicine.

However, when the pain is not quickly and properly controlled, biochemical changes occur in the nerves themselves and the spinal cord that amplify the signal sent to the brain. In fact, these biochemical changes can cause the nerves to fire pain signals even when the tissue damage has stopped. This kind of pain is called "nerve pain" or "neuropathic pain."

This type of pain is actually made worse by narcotic pain medications. It is extremely difficult to treat and does not quickly respond to any kind

of medicine. However, we have seen that it is helped by distraction. For example, focusing on a difficult video game or writing rap music has been very effective for some of my patients. Medicines like Neurontin and Cymbalta can help manage nerve pain, but take many days or even weeks before they have a significant effect.

Being in a hospital is absolutely the worst place to be for the treatment of neuropathic pain. Being alone, staring at the ceiling and thinking about your pain, being awoken all night long by the staff and not getting any sleep all make neuropathic pain much worse.

It's critical that severe pain from a sickle crisis be treated with adequate doses of medicine right away to try to get pain under control quickly. If after five to seven days in the hospital your pain is not getting better and narcotics don't seem to be helping, nerve pain has probably started and more narcotics are likely to make it worse. We are beginning to understand how to better treat neuropathic pain. We'll talk a lot more about this kind of pain in subsequent articles.

Managing Screen Time

The following are excerpts from a New York Times article called "How (and When) to Limit Kids' Tech Use," by Melanie Pinola.

A few basic parenting guidelines will help you establish ground rules and maintain tech harmony at home.

Aim for Balance

"The most important step is to establish a balanced or sustainable relationship with tech," says the social psychologist Adam Alter, author of "Irresistible: The Rise of Addictive Technology and the Business of Keeping Us Hooked." You can liken it to aiming for a healthy diet, Dr. Alter explains: "Older kids understand the concept of balance intuitively—they know that it's important to eat healthy foods alongside candy and dessert, and the same is true of the 'empty calories' that come from spending too much time passively gazing at screens. There's a time for screens, but not at the expense of time for physical activity and connecting with real people in real time."

Some things to keep in mind as you try to strike this delicate balance:

There's no single recipe for success, but you'll know it when you see it. Balance for your family will look different than it will for your neighbor because every family is unique and parenting styles and values vary.

Watch for the warning signs of unhealthy tech usage. The psychologist Jon Lasser, who co-wrote "Tech Generation: Raising Balanced Kids in a Hyper-Connected World," says parents should note when:

- Kids complain that they're bored or unhappy when they don't have access to technology
- Tantrums or harsh resistance occur when you set screen time limits
- Screen time interferes with sleep, school and face-to-face communication

Be prepared to revisit this topic again and again. As your children grow, so will their involvement with technology. Also, it's difficult to predict what the digital world will look like even just a few years from now. Your definition of healthy and unhealthy tech usage will need regular updates. Fun times ahead!

Some tips to evaluate the quality of your children's digital interactions (which you should do regularly):

- Are they accessing age-appropriate content?
- Are the apps they use interactive and thought-provoking rather than passive? Not all screen time is equal. Going back to the food analogy, 100 calories from a doughnut is not the same as 100 calories from a salad; an hour watching YouTube videos isn't the same as an hour spent in a digital art program.
- Are the privacy settings for older children's social media and other online accounts set to restrict what strangers can see and who can contact your children?

Still set screen time limits to balance online and offline activities.

Although quality is most important, you'll probably still want to set some screen time limits for your family to preserve time for activities beyond screens and tech. While the debate on exactly how many hours kids can spend on their screens before it becomes unhealthy rages on, you can draw firm lines for tech-free times, such as during dinner, in the car, or on school nights.

Be a Role Model

Technology draws in parents as much as it does kids. We check our phones every hour, log late hours working or surfing the internet on our laptops, binge watch our favorite shows, and even engage in dangerous "distracted walking." Children are likely to not only copy our behavior, but they also feel like they have to compete with devices for our attention.

Set boundaries for work time and family time. A few key times to stay unplugged include:

- When picking up or dropping children at school, as this is a transitional time for them
- After coming home from work, as that's time to reconnect with your family
- During meals, including when dining out
- During outings like trips to the park or zoo, or vacations when the focus is on family time

As with most parenting topics, constant, open communication is key to helping your family reap the benefits of technology without experiencing too many of the negative effects.



We miss you!

If you have not been to see us in a while, please call the sickle cell team at 323-361-3414 to schedule an appointment.

Send your suggestions or comments about the newsletter to tpeterson@chla.usc.edu