Non-Pharmacological Pain Management for Children with Sickle Cell Disease and Other Sources of Pain

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Non-pharmacological pain management refers to any method of pain management used that does not involve medications (Geziry et al., 2018). As child life specialists, we use these techniques on a daily basis in providing coping strategies and opportunities for distraction from pain and discomfort. We aim to promote coping with acute and chronic pain by teaching children coping strategies such as guided imagery, deep breathing, and distraction techniques. While this article highlights the significant need for non-pharmacological pain management in children with sickle cell disease, these resources may also benefit the many children coping with acute and chronic pain associated with other illnesses, disabilities, and hospital experiences.

Children with sickle cell disease (SCD) can often struggle with acute and chronic pain associated with vaso-occlusive events (VOE). VOE not only causes pain crisis for some patients with SCD, but may also cause damage to bones, spleen, brain, liver, lungs, kidneys, and joints (Zouki et al., 2018). This organ damage can result in additional need for pain control. VOE occurs when “sickled cells” stick together in a blood vessel blocking blood flow to a certain part of the body. VOE is the most common reason for hospital admission for children and teens with SCD (Zouki et al., 2018). Increased pain and suffering can escalate a patient’s vulnerability to psychiatric illnesses such as depressive disorders, anxiety disorders, and post-traumatic stress disorder (Geziry et al., 2018). It is vitally important that all pain is acknowledged and that non-pharmacological pain management techniques work in partnership with pain medications to provide better pain management for SCD patients and other children coping with pain.

Many families may not be aware of or have access to options for non-pharmacological pain management due to lack of insurance coverage, lack of availability in the community, or lack of education and referrals for services. Child life specialists, social workers, hospital psychologists, and health care providers are often the medical team members best positioned to provide education, information, and resources to encourage and equip patients with tools and ideas for non-pharmacological pain management. The resources below will provide a starting point for professionals seeking to support their patients as they are coping with pain. While many of these ideas are from clinical experience working with children with sickle cell disease, most of the ideas are applicable for children coping with pain due to other sources. Some ideas include massage therapy, acupuncture, guided imagery, meditation, progressive muscle relaxation, music therapy, effective pain rating scales to identify pain accurately, and deep breathing exercises.

REFERENCES

ARTICLES & INFORMATIONAL GUIDES FOR PARENTS
- **Kids Health.** This website provides a basic overview of sickle cell pain crisis, what it is, how it is caused, what it feels like, how to respond during crisis, and how to try to prevent a crisis from occurring. This is a great teaching sheet available in English and Spanish for helping educate teenagers about their pain and for starting the conversation about pain management strategies. [https://kidshealth.org/en/teens/sickle-crisis.html](https://kidshealth.org/en/teens/sickle-crisis.html)
- **Centers for Disease Control (CDC).** This organization offers multiple PDF fact sheets about sickle cell disease that can help promote understanding for parents, teens, school teachers, or other members involved in supporting a child with sickle cell disease. Through additional education and clear, concise teaching resources, patients and families can have a better understanding of pain, pain management, and how to partner with healthcare providers to manage pain. [https://www.cdc.gov/ncbddd/sicklecell/materials/factsheets.html](https://www.cdc.gov/ncbddd/sicklecell/materials/factsheets.html)
- **Practical Pain Management.** This website provides an excellent article written by Rosemary Black that can be a helpful tool for parents as they care for a child with chronic pain or long-term frequent acute pain. It gives great tips for how to react when a child is in pain and how to help a child manage their pain. [https://www.practicalpainmanagement.com/patient/resource-centers/chronic-pain-management-guide/when-your-child-living-chronic-pain](https://www.practicalpainmanagement.com/patient/resource-centers/chronic-pain-management-guide/when-your-child-living-chronic-pain)
MAKING A PERSONAL PAIN SCALE

- **About Kids Health.** This website is a source of helpful information for parents who are parenting an older child with chronic pain. This specific article provides ideas for keeping regular routines, establishing good sleep patterns, supporting children through transitions in school, taking care of yourself as a parent, and advice for when to seek professional help for your child. [Link](https://www.aboutkidshealth.ca/article?contentid=3651&language=english)

- **Health Engine.** It is so important for non-pharmacological methods of pain management to be used in combination with pain medications. Health Engine acknowledges how important this is in their article and provides a list of 10 examples of methods of non-pharmacological pain management. [Link](https://healthengine.com.au/info/control-of-pain-in-children-paediatric-pain-management)


- This article from the Joint Commission lists evidence-based, non-opioid options for treating pain. It provides a thorough list of non-pharmacological pain management ideas that are supported and validated by research.

### BOOKS

- **Clarke, T., & Kajander, R. (2007).** *Be the boss of your pain.* Free Spirit Publishing.

This book is an excellent tool for providing education about non-pharmacological pain management and teaching tangible skills to children. Some skills discussed include acupressure, aromatherapy, biofeedback, the jettison technique, changing the image of your pain, and belly breathing.


This peaceful, calming story has beautiful illustrations that promote relaxation and encourage children to use their imagination. This book can also create the opportunity for a child to learn how to use imagination as a technique for distraction from pain. This book is available in both English and Spanish versions for purchase.


This book provides guided imagery stories for each season of the year and for specific environments in nature such as rainbows or waterfalls. Some stories are lengthy but are perfect for pain management moments when a longer reading is preferred.


A wonderful children’s book that provides prompts for leading a child or teen through guided meditation. Additionally, this book provides information about the basics of yoga and yoga routines for kids of all ages to enjoy for relaxation and stretching.


This is a workbook and learning guide designed specifically for adolescents with sickle cell disease. It provides education about types of pain and provides a place to track pain and symptoms. It also offers learning activities and journal pages to write about challenging experiences.

### OTHER RESOURCES

- **Sleep Talk Down Guided Meditation: Fall Asleep Faster with Sleep Music and Spoken Word Hypnosis.** This YouTube video shows soothing images of outer space and guides the listener through soothing spoken word and guided meditation to help promote sleep and relaxation. [Link](https://www.youtube.com/watch?v=69o0P7s8GHE)

- **Moshi.** This app has wonderful guided imagery and relaxation stories that are designed to help children fall asleep. Many of the stories are free and do not require additional payment within the app. There are also “sounds” available without words that could be used as background music for story time, guided imagery, or as a sound machine for relaxation. [Link](https://www.moshisleep.com/?gclid=Cj0KCQjw-af6BRC5ARIsAALPIIVnrLzop88lmxOuluw8YzyeyRH4w8_D_RVo88w8U3aSuyvQszWjgAk_9EALw_wCB)

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- **Breathe2Relax.** This app provides guided deep breathing exercises which can help with relaxation and non-pharmacological pain management. The app helps remind the listener to create a calming environment before beginning each deep breathing exercise. It also provides reminders for best body posture and reminders to breathe intermittently throughout the exercises. [https://apps.apple.com/us/app/breathe2relax/id425720246](https://apps.apple.com/us/app/breathe2relax/id425720246)

- **Calm.** This App is free with the opportunity to purchase additional resources within the app. It provides 7-day educational sessions such as “how to meditate” or “7-days of calm” which could help introduce these concepts to patients and families. There are guided relaxation sessions catered to sleeping and in the “more” section of the app you can find “breathing exercises” which guide the user through deep breathing with a visual bubble. [https://www.calm.com/](https://www.calm.com/)

- **Pain Scale.** This app not only creates a place to document pain level and pain’s location on the body but it also helps document triggers and patterns as each person tracks their pain over time. It provides daily ideas for pain relief, videos for daily guided meditation, and additional articles and videos for education, encouragement, and building a base of non-pharmacological pain management strategies. [https://www.painscale.com/](https://www.painscale.com/)

- **Fully Loaded Electronics.** This company offers virtual reality (VR) systems that are already pre-loaded with games. Their VR systems are user-friendly for child life specialists and they offer payment by invoice (which most hospitals need). They offer a wide array of games that can promote relaxation, diversion, and pain management with multiple bundle options. [https://fullyloadedelectronics.com/collections/virtual-reality-vr-therapy](https://fullyloadedelectronics.com/collections/virtual-reality-vr-therapy)

- **Childrens Healthcare of Atlanta Virtual Reality Case Study.** This article provides an overview of a case study done at Children’s Healthcare of Atlanta to assess the benefit of virtual reality to patients while coping with procedures, pain, and/or anxiety. Overall, the article highlights games that were beneficial to promote patient coping, previous studies done showing the effectiveness of VR, and patient and staff quotes after the use of VR in this study. [https://www.wsbtv.com/news/national/hot-topics/children-s-healthcare-of-atlanta-using-virtual-reality-to-help-young-cancer-patients/943030453](https://www.wsbtv.com/news/national/hot-topics/children-s-healthcare-of-atlanta-using-virtual-reality-to-help-young-cancer-patients/943030453/)

Jessica Westbrooks has been a child life specialist for six years and has worked with patients and families in an outpatient hematology/oncology setting for five years. In her time working in this environment, she has created functional pain scales with patients to help with better pain rating and she has used techniques such as virtual reality, diversion, guided imagery, essential oils, and deep breathing to promote non-pharmacological pain management. Jessica is passionate about connecting patients with resources to support their coping in the hospital environment and at home. Jessica can be reached at jessica.westbrooks@choa.org. ☑