

## Movement Ideas

### 1. Neck Flexion & Extension:

This is a good motion to start with.<sup>6</sup> Have your child practice shaking their head “yes!” in an exaggerated way. It may be easier to practice this while lying in bed on his side at first.



**2. Neck Bending:** This motion is usually a little harder.<sup>6</sup> Have your child bring his ear towards his shoulder, first while lying in bed on his back.



**3. Neck Rotation:** This is usually the most difficult neck movement.<sup>6</sup> Have your child look from side to side while sitting or lying on his back. You can play peek-a-boo or eye spy!



## References

1. Chiari Malformation Fact Sheet | National Institute of Neurological Disorders and Stroke. Available at: <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Chiari-Malformation-Fact-Sheet>. Accessed September 29, 2017.
2. Conquer Pediatric Chiari. Available at: <http://www.conquerchiari.org/pediatric/pediatric-index.html>. Accessed September 29, 2017.
3. Manworren RCB, Hynan LS. Clinical validation of FLACC: preverbal patient pain scale. *Pediatr Nurs* 2003;29(2):140-146.
4. Smyth MD, Banks JT, Tubbs RS, Wellons JC 3rd, Oakes WJ. Efficacy of scheduled nonnarcotic analgesic medications in children after suboccipital craniectomy. *J Neurosurg*. 2004 Feb;100(2 Suppl):183-
5. Goldschagg N. Frontiers in neurology: Decompression in Chiari Malformation: Clinical, Ocular Motor, Cerebellar, and Vestibular Outcome. *Frontiers Research Foundation*; 2017;8:292.
6. McCarty D. PT for Children with Brain Tumors in the Acute Care Setting [VoiceThread]. PHYT 880: Child and Family Assessment.

## Parent Guide: Chiari Malformation Decompression

### What is a Chiari Malformation?

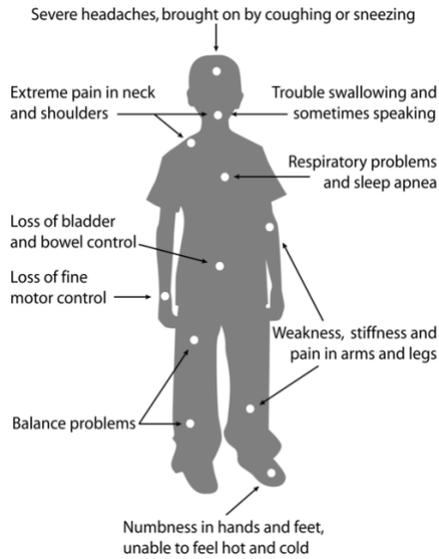
A Chiari malformation is when part of the brain (**cerebellum**) begins to extend through an opening in the skull that normally allows the spinal cord to pass through (**foramen magnum**).<sup>1</sup> This puts pressure on the cerebellum and may affect functions that it controls, like **balance and coordination**.<sup>1</sup> It may also change the flow of cerebrospinal fluid which cushions and provides nutrients to the brain and spinal cord.<sup>1</sup>



### Decompression

Surgery can **create more room** for the cerebellum to take pressure off of the brain and spinal cord.<sup>1</sup>

## Common Symptoms



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In young children, problems swallowing is one of the most common symptoms.<sup>2</sup>

Older children often also have scoliosis.<sup>2</sup>

## What to expect after surgery

The surgery usually takes around 3-4 hours, and you can expect to spend 3-4 days in the hospital.<sup>2</sup> However, full recovery can take weeks!<sup>2</sup> Most find that symptoms are gone or better after surgery.<sup>2,5</sup>

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## Pain Management

Pain is a consequence of surgery and it is important to work closely with the medical team to help control your child's pain. It may help your child to be on a schedule for his or her pain medicine.<sup>4</sup>

Your child's team may use a tool like the **Faces, Legs, Activity, Cry and Consolability (FLACC) pain assessment tool** to measure how much pain your child is in, because it can be difficult for children to verbalize their pain.<sup>3,4</sup>

You can help by watching for signs that your child is in pain.

## Get moving!

Even though he or she will be in pain, it is important for your child to continue moving the head and neck after surgery. A therapy team including physical and therapists are here to help, but you can play a large role in your child's recovery by playing games and helping them move their head and neck in 3 ways. (detailed next).

You can help your child to move, or take his head in your hands and move for him, as long as he is relaxed. You might hear this referred to as **Passive Range of Motion**. This can help your child move until he is able to do it himself!

The FLACC Scale			
Categories	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disoriented	Frequent to constant frown, quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractible	Difficult to console or comfort

*Source: Reference 20.*