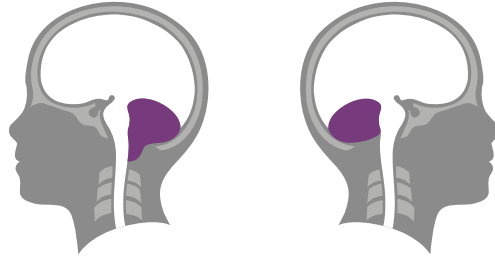


# Chiari Malformation Awareness Sheet



I **HAVE** Chiari

I **DON'T** have Chiari

**Definition:** *A serious neurological disorder where the bottom part of the brain, the cerebellum, descends out of the skull and crowds the spinal cord, putting pressure on both the brain and spine*

**AKA:** *Arnold-Chiari, ACM, ACM I, ACM II, CM, tonsillar ectopia, hindbrain herniation*

## 10 Things To Know About Chiari

1. Affects about 1 in 1,000 people
2. Most common symptom is severe headache, usually in the back of the head, and made worse by activities such as straining, coughing, sneezing, or bending over
3. Can cause **many** additional symptoms, including balance problems, pain and weakness in the arms and legs, trouble speaking and swallowing, sleep apnea and scoliosis.
4. Diagnosed through a combination of MRI's (Magnetic Resonance Imaging), a neurological exam, and other tests
5. If symptoms are bad enough, or getting worse, a decompression surgery is usually performed
6. Surgery, performed by a neurosurgeon, involves removing part of the skull and spine, and sometimes sewing a patch into the natural covering of the brain
7. While precise data is not available, about 50% of patients become symptom free after surgery, another 20%-30% improve significantly, and about 20% experience no relief or get worse
8. In some people, can lead to another serious condition, known as *syringomyelia*, where a fluid-filled cyst develops inside the spinal cord
9. It is believed that the malformation is congenital (people are born with it); symptoms can develop at any age, but commonly become noticeable either in childhood or in a person's early 30's
10. Chiari Type II, a more serious form of the malformation, is associated with Spina Bifida

## \*Chiari Affects Everyone Differently\*

### Interesting Facts:

- Size of the malformation is not related to the severity of symptoms
- There is no single test to say whether someone should have surgery
- Many doctors are not familiar with the condition, so people often go years without a proper diagnosis
- Most patients suffer from 5 or more symptoms
- Not known why surgery fails 20% of the time

### Someone With Chiari *May Not Be Able To:*

- Bend over
- Lift heavy objects
- Stand or sit for any length of time
- Walk very far
- Drive a long distance
- Work on a computer without pain
- Be in a noisy environment
- Engage in strenuous activities, such as sports
- Perform household chores

CONQUER  CHIARI

For More Information Visit: [www.conquerchiari.org](http://www.conquerchiari.org)