

The 10 Most Common Chiari Symptoms (Chiari1000 Data)



Listed below are 10 of the most common Chiari symptoms, according to the Chiari1000 database.

1. Headache- Affected 95% of Participants

Chiari headaches are usually described as starting in the back of the head and sometimes radiating forward to behind the eyes. The pain is described as a feeling of intense pressure, or even explosive in nature, and is brought on or aggravated by straining (known as a Valsalva maneuver), coughing, sneezing, posture, singing, laughing, etc.

Conquer Chiari On-Line Library Resources:

- [Study Analyzes Chiari Headaches & Treatment Outcomes](#) (Article)
- [Headache in Chiari I Malformation: An Appraisal with Real-time CSF Flow Imaging](#) (Video)
- [Association Between Resistance to CSF Flow Near the Foramen Magnum and Cough Associated Headache in Adult CMI](#) (Poster)

2. Neck & Shoulder Pain- Affected 84% of Participants

Pain in the neck, shoulder, and upper back is a frequent issue in Chiari patients, stemming from various causes. Nerves serving these regions originate in the upper spine and may be compressed by herniated tonsils or affected by syrinxes. Nerve damage can also disrupt muscle coordination, leading to pain, dysfunction, and impaired task performance.

Conquer Chiari On-Line Library Resources:

- [A Syrinx Can Be Tough on the Shoulders](#) (Article)
- [High Levels of Neck Related Disability Common Among Adult Chiari Women](#) (Article)
- [Neck Related Disability Is Common Among Adult Females with Chiari](#) (Poster)

3. Difficulty Sleeping- Affected 82% of Participants

The changes in breathing during sleep are particularly evident during the REM (rapid eye movement) stage of sleep, which is considered to be when a person dreams. During REM, breathing becomes very irregular and will switch quickly from rapid breaths to slow breaths and from shallow ones to deep ones. During the altered breathing states of sleep, problems which can be quite serious sometimes develop. The term apnea refers to a temporary stop in breathing. Sleep apnea is a disorder characterized by repeated incidents where a person stops breathing, partially wakes up, then starts breathing again. The frequent episodes of apnea and arousal often lead to daytime exhaustion.

Conquer Chiari On-Line Library Resources:

- [Chiari Surgery Helps But Doesn't Cure Sleep Disordered Breathing \(Apnea\)](#) (Article)
- [Children Suffering from Sleep Apnea Caused by Chiari 1 Malformation](#) (Article)
- [Chiari and Sleep](#) (Poster)

4. Fatigue- Affected 79% of Participants

Fatigue is a state of extreme tiredness or exhaustion, both physical and mental, that can result from various factors such as lack of sleep, prolonged physical or mental exertion, illness, stress, or certain medical conditions. It is characterized by a reduced ability to perform tasks, think clearly, and maintain concentration. Fatigue can manifest as a feeling of weakness, weariness, and a strong desire to rest or sleep. It can have a significant impact on a person's overall well-being and functioning.

5. Dizziness- Affected 79% of Participants

Dizziness is a sensation of unsteadiness or spinning, often accompanied by lightheadedness or vertigo. It can result from various causes, including inner ear issues, changes in blood pressure, dehydration, and neurological problems. Dizziness can lead to a feeling of imbalance and can sometimes be accompanied by nausea or loss of equilibrium, making it challenging to maintain normal activities.

6. Balance Problems- Affected 73% of Participants

The human balance system, or vestibular system, relies on the input from the eyes, muscles, joints, and inner ear to maintain equilibrium. Fluid-filled structures in the inner ear communicate balance information to the cerebellum and brainstem. Compression of the cerebellum or brainstem, as seen in Chiari, can disrupt this system's function.

Conquer Chiari On-Line Library Resources:

- [Compression Garments Improve Balance For Those With hEDS](#) (Article)
- [Chiari & Balance](#) (Social Media Image)

7. Cognitive Issues- Affected 70% of Participants

The CCRC (and now others) have published studies involving validated cognitive testing, electroencephalogram (EEG) testing which looks at the electrical activity of brain waves, and DTI imaging which is an advanced MRI technique which can show damage to the connections in the brain. Across these studies, Chiari patients have been found to have deficits in working memory, processing speed, inhibition, immediate and delayed recall, visual-spatial reasoning and attention. While these studies have consistently found a cognitive impact in Chiari patients (both adults and children), the details are not always consistent across studies. It is important to note that the DTI imaging studies have shown damage in certain areas of Chiari patients' brain connections, although interpreting this damage is difficult. It can also be challenging to distinguish between whether the cognitive effects are due to chronic pain or more directly to the Chiari anatomy.

Conquer Chiari On-Line Library Resources:

- [Cognitive & Emotional Impact of Chiari](#) (Video)
- [Functional connectivity abnormalities in Type I Chiari: Associations with cognition and pain](#) (Poster)
- [CCRC Researchers Find More Evidence On The Cognitive Impact Of Chiari](#) (Article)

8. Visual Problems- Affected 67% of Participants

Chiari can impact the eyes in various ways, including nystagmus (involuntary eye movement), blurred and double vision, and light sensitivity (photophobia). Swelling of the optic nerve, called papilledema, is also a serious issue resulting from elevated intracranial pressure and may indicate intracranial hypertension. Papilledema, if untreated, can lead to permanent vision loss. Strabismus, misalignment of the eyes (cross-eyed), also appears to have a connection to Chiari. This could be due to muscle impairment or increased susceptibility. Other unrelated eye problems may also occur.

Conquer Chiari On-Line Library Resources:

- [Chiari II Affects Normal Eye Movements](#) (Article)
- [Treating Chiari Related Eye Problems](#) (Article)

9. Audio Problems- Affected 63% of Participants

Auditory problems as a symptom refer to issues related to hearing that can arise due to various underlying medical conditions or factors. These problems can include hearing loss, tinnitus (ringing in the ears), sensitivity to loud noises, difficulty understanding speech, ear pain or discomfort, and balance issues. Auditory problems can be a sign of ear-related conditions, neurological disorders, or systemic health issues.

Conquer Chiari On-Line Library Resources:

[Chiari Related Hearing Loss in Children](#) (Article)

10. Hand Numbness- Affected 57% of Participants

From a high-level point of view, body parts such as the extremities (arms, legs, hands, and feet) are served by both sensory and motor nerves. Therefore, when problems develop, they can come in the form of sensory disturbances and/or muscle weakness. When sensory nerves are affected, problems can include both loss of feeling in certain areas, and feeling unusual sensations such as tingling. When motor neurons are affected, muscle weakness and atrophy can ensue. In either case, pain is always a distinct possibility.

Source: Conquer Chiari Research Center- Self Report Symptoms Results. <https://chiari1000results.info/symptoms/#>