



Chiari Academy Video Transcription Impact of Chiari – Physical Disability

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[Music]

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In the previous module we talked about the high levels of pain that many Chiari patients live

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with and the negative effects that can have on a person's physical, mental, and spiritual health.

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In this module we will discuss some of the physical disabilities that are common in Chiari

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adults, including neck problems, balance issues, and poor sleep, and the impact they can have on

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daily living, employment, and personal finances. According to the Chiari1000 database, neck pain

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is one of the commonly reported symptoms among Chiari adults and is present in 84%

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of adult women and 74% of adult men. Conquer Chiari explored the impact of this in a study

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which used a patient focused questionnaire called the Neck Disability Index, or NDI,

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and included 474 adult female Chiari patients. The NDI has been used worldwide since the early 1990's

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to assess neck related disability and is comprised of ten questions which ask how a person's neck

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pain affects their ability to manage everyday activities such as reading, driving, lifting,

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work, and recreation. The results can be converted into a percentage disability with well recognized

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categories of None, Mild, Moderate, Severe, and Complete. The Conquer Chiari study found that 80%

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of the women rated their neck disability at the Moderate to Complete level. Surprisingly, there

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was no significant difference in the disability scores between surgical and non-surgical patients.

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However, patients who experienced symptoms for more than two years before diagnosis scored on

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average 77% higher, meaning worse, on the NDI. In fact, the average NDI score for patients who were

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diagnosed in less than 2 years was only in the Mild category. On the flip side, the study found

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that patients with Severe or Complete levels of neck related disability scored significantly

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worse on both short-term and long-term memory assessments than patients with None or Mild NDI

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scores. Finally, the study found that patients with EDS, migraines, or scoliosis scored on

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average 13-20% higher on the NDI scale than those without any of those related conditions.

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In addition to the Conquer Chiari study, other researchers have identified structural and

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functional issues in Chiari patients that indicate that weakness and instability in

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the neck are common. For example, one study used MRIs to show that the paraspinal muscles,

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which are on either side of the spine and are critical in providing support and maintaining

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posture, are significantly smaller in Chiari patients. Other studies have shown that the

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sub-occipital muscles in the back of the neck are smaller and do not activate properly in

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Chiari patients. Yet another study found that key stabilizing ligaments in the neck are abnormally

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short in Chiari patients. And finally, imaging studies have shown that the depressions in the

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top vertebra where the skull sits are unusually shallow in some Chiari patients allowing for

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instability between the skull and spine. One aspect of neck related disability that

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needs to be explored further is the possible link with migraines. Seventy percent of adult

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Chiari women and more than half of younger Chiari girls report suffering from migraine

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headaches. It is recognized among migraine researchers that neck pain is common for

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migraine sufferers and that there could be a causal link between the two. One small

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clinical trial found that cervical stabilization training helped to reduce migraine frequency

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and intensity after only an 8-week program. Next, we will turn our attention to balance. The

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human balance system is a delicate, complex system which involves several parts. To maintain balance,

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the body integrates input from three sources: the eyes which provide information about the body's

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position relative to their environment and detects motion; muscles and joints

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which provide information about the body's position relative to itself and the ground,

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which is known as proprioception; and the inner ear, or vestibular system which has fluid-filled

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structures that detect head movements and position. All of this information

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is sent to the cerebellum, which integrates the information, sends control signals to the muscles,

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and evaluates and corrects for errors which enable smooth, coordinated movements.

Unfortunately, with

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Chiari, the cerebellum and its connections to the brainstem are compressed and under strain which

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disrupts the complicated actions of the balance system. In fact, according to the Chiari1000 more

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than 70% of all Chiari patients – adults, kids, males, and females, report balance issues as

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a significant symptom at the time of diagnosis. Conquer Chiari's Physical Impact study explored

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this topic further by using the Activities Balance Confidence Scale – Six, which asks

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people to rate their confidence in performing six different balance related activities.

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The specific activities are standing on tip toes reaching for something above your head; standing

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on a chair reaching for something; being bumped into by people as you walk through the mall;

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walking onto or off an escalator while holding onto a railing; walking onto or off an escalator

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while holding onto something such that you cannot hold onto the railing; and walking outside on an

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icy sidewalk. Each activity is rated from zero to one hundred percent confident with the responses

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averaged for a final confidence score. Sixty-two percent of the Chiari patients scored 50% or lower

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which equates to a Low Level of Physical Function and very high risk of falling.

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In addition to cerebellar issues, loss of ankle stiffness may also play a role

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in Chiari balance issues. The ankles are an important part of how humans maintain

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an upright position. When muscles are activated around the ankle during movement, the stability

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provided is referred to as stiffness. The ankle stability provided when standing still

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is called quasi-stiffness. One Conquer Chiari study which used force pressure plates found

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that the quasi-stiffness of Chiari subjects was significantly less than that of the controls.

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The combination of pain, neck weakness, and balance issues results in many Chiari adults

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disengaging from physical activities. Conquer Chiari's Physical Impact project showed that

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an astonishing 84% of patients surveyed scored above the clinical cut-off for kinesiophobia.

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Kinesiophobia translates literally as fear of movement and is a recognized condition where

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someone has a debilitating fear of physical movements due to a sense of increased pain

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or risk of injury. Of course, as someone avoids physical activity and movement,

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the worse their physical condition can become over time, thus perpetuating the cycle and

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leading to high levels of depression and anxiety. Given all that is going on physically with Chiari,

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not surprisingly patients also have sleep issues. The Physical Impact project found that 91% of

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Chiari adults experience poor sleep quality as measured by the Pittsburgh Sleep Quality Index,

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with the median score falling two times above the cut-off for poor sleep.

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One major contributing factor to this situation is sleep apnea. Research has

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shown that as many as 60% of Chiari patients, both adults and children, exhibit clinical

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levels of apnea when evaluated with formal sleep studies. Beyond daytime drowsiness,

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sleep apnea can have a profound effect on someone's health. During the apnea episodes,

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it is believed that the heart works harder to compensate for the lack of oxygen which can

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lead to high blood pressure and an elevated risk for heart attacks and strokes. In fact,

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one study found that 50% of people with sleep apnea also had hypertension. Less well known is

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the link between sleep apnea and eye related, or ocular issues. Research has found a strong

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association between obstructive sleep apnea and a specific type of optic nerve damage,

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floppy eyelid syndrome, and glaucoma, among other conditions. For example, people with obstructive

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sleep apnea are nearly two and a half times more likely to develop glaucoma than people

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without apnea. In addition, a 2025 study found a link between obstructive sleep apnea and markers

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for systemic inflammation. The researchers grouped 263 obstructive apnea patients into 3 groups based

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on severity: mild, moderate, and severe. When they looked at four inflammatory markers, the

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markers were significantly higher in the severe group than both the moderate and mild groups.

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The physical disabilities associated with Chiari can have a significant impact on patients' quality

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of life. A survey of close to 800 patients found that 96% reported that Chiari had a

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negative impact in at least one area of daily living. Consider the following findings from

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the Chiari1000 database: 78% of adults find it somewhat or very difficult to work due to Chiari;

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74% report Chiari has had a negative impact on their career; and nearly half have had to change

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jobs or careers due to Chiari. Of those not working, 80% indicated their employment status

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was due to Chiari. Approximately one-third of Chiari patients seek social security disability

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with roughly half being successful. Overall, sixty percent say that Chiari has had a negative impact

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on their ability to earn money. In terms of schooling, three fourths of patients say it

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is difficult to perform academically due to Chiari and roughly one-half of patients who

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were in school at the time of diagnosis have had to withdraw from school at some point in time.

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In this module we reviewed some of the common physical disabilities associated with Chiari,

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including pain, neck weakness, balance issues, and disrupted sleep. In addition,

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we explored the profound effects these can have on patients' lives.

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In the next module we will look at the cognitive impact of Chiari.