



Chiari Academy Video Transcription Impact of Chiari – Pain

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Everyone knows what pain is, and pretty much everyone has experienced pain at

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some point in their lives. However, pain is one of those concepts that

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is difficult to pin down. While a person knows when they are in pain,

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describing the intensity and feelings associated with that pain can be difficult,

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and because pain is inherently subjective, it is challenging to study, diagnose and treat.

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At the highest level, pain is defined by the International Association for the Study of Pain as

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An unpleasant sensory and emotional experience associated with

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actual or potential tissue damage, or described in terms of such damage.

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Beyond this rather academic definition, experts often classify pain by its duration or source.

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Acute pain refers to pain that is relatively short

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lived such as due to some type of minor injury. Chronic pain, on the other hand,

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refers to pain that lasts for at least 3 months. Pain can be either nociceptive,

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meaning it arises from pain receptors in response to tissue damage or potential injury,

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or neuropathic, meaning it is due to damage to the central nervous system. Mixed pain refers

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to when a person experiences both nociceptive and neuropathic pain. Recently, and of direct

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relevance to Chiari patients, the pain community has recognized a third type of pain, nociplastic,

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which refers to pain that is experienced without any painful stimulation or cause.

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Turning to the Chiari community, pain is the single most common, and likely most difficult,

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problem Chiari patients must deal with. In fact, many of you watching this video right now may be

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experiencing some type of pain, because for many in the Chiari community, pain is a way of life.

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The extent of the problem was highlighted in a study by Conquer Chiari researchers

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who used a widely adopted patient reported pain scale to survey over 200 adult Chiari

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patients. The pain scale was comprised of 20 pain descriptors such as burning, shooting,

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and stabbing. Respondents were asked to rate their level of each type of pain experienced

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in the past week on a scale from 0 to 10, with 0 being none and 10 being the worst possible.

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The researchers found that 79% of the Chiari patients rated at least one of the

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pain descriptors at a level of 7 or higher and 28% rated at least half of the pain descriptors at a 7

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or higher. In addition, 28% reported the highest level, a 10, for at least one type of pain.

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So why are Chiari patients in so much pain? One possible reason is that they are suffering

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from a mix of different types of pain. For example, a typical patient may experience

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nociceptive pain due to altered biomechanics in the neck and shoulder, plus neuropathic

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pain due to damage caused by nerves getting compressed or a syrinx damaging nerve roots.

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However, Dr. Philip Allen, the Director of the Conquer Chiari Research Center believes the

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answer lies mainly in a concept called central sensitization. This concept came about in the

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1980s when a scientist named Clifford Woolf used rats to show that prolonged painful stimulation

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can alter how the central nervous system processes input. Specifically, central sensitization is when

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the brain and spinal cord undergo structural, functional, and chemical changes that make a

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person more sensitive to pain and other sensory stimuli. Essentially with central sensitization,

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the threshold of stimulation for which the brain will respond in a painful way is lowered. This can

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then manifest in several ways. First, a person may become more sensitive to actual painful stimulus,

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so that something that should only be minorly painful is perceived as very painful. This is

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known as hyperalgesia. Next is when normally nonpainful stimulus, such as a light touch,

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is perceived as painful. This is called allodynia and can mean that a hug,

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pat on the back, or even tight or heavy clothing may be painful. Finally, some

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people may experience spontaneous pain even when there is no painful or tactile stimulation at all.

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Central sensitization can also make people more sensitive to other forms of stimulation as well,

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such as bright lights, loud noises, and strong smells. This is sometimes referred to as global

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sensory hyperresponsiveness. Interestingly, in the Chiari1000 database more than 60%

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of patients reported being sensitive to bright lights and/or loud noises.

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Unfortunately, research has shown that living with this type of chronic pain

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can have a negative effect on a person's physical, mental, and even spiritual health.

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For example, one study used a large health insurance database to show that people with

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what they termed a painful neuropathic disorder were much more likely to suffer

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from additional health problems and incur much higher healthcare costs. Specifically,

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more than 70% of 50,000 people with a pain disorder also suffered from two or more

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other chronic conditions. This was in stark contrast to a non-pain control group where

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only 13% had two or more chronic conditions. In addition, people in chronic pain incurred an

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average of over \$17,000 in annual medical costs compared to only \$5,700 in the non-pain group.

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A second aspect of living with chronic pain is an elevated risk for high blood pressure,

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or hypertension. Researchers have known for some time that the systems that regulate blood pressure

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and pain are connected. In healthy people, a higher resting blood pressure is associated

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with a decreased sensitivity to acute pain. Scientists speculate that this link is a way

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to restore normal arousal levels after a painful stimulus. The body responds initially to pain, but

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then the pain signals are turned down so that the rest of the body's systems can return to normal.

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For people in chronic pain however, the relationship between the two systems

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becomes dysregulated and the pain increases the risk of hypertension.

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Studies have shown that people with chronic pain conditions have a significantly higher

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risk of hypertension than people of the same age and gender who are not in pain.

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One of the more disturbing aspects regarding living with chronic pain is that it can

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prematurely age, or shrink, the brain. One imaging study found that people in chronic

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pain have 5-11% less gray matter brain volume than people who are not in pain. People normally

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lose about 0.5% of their gray matter each year as they age, so this result translates to the

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pain patients experiencing 10-20 years of aging compared to the control group.

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Turning now to mental health, we will go into more detail into the psychological impact of Chiari in

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a later chapter, but for now it is important to note that there is a strong connection between

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chronic pain and poor mental health. While many people are aware that depression and anxiety

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commonly accompany chronic pain, research has shown that those with a disabling chronic pain

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condition are up to 10 times more likely to have a major mood, anxiety, or substance disorder than

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the general population and 13 times more likely to suffer from a personality disorder than average.

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The effects of living with chronic pain are so pervasive they can even alter a person's

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spiritual beliefs. One study of over 120 chronic pain patients found that they had less desire to

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reduce pain and suffering in the world and felt more abandoned by God than well-established norms.

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In addition, the study found that the longer someone was in pain the less forgiving they

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felt and the less support they felt they received from organized religion. This in turn led some

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to shift from organized religious activities to private ones, such as individual prayer.

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Although many Chiari patients must face the issue of chronic pain and all its effects,

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there is hope. While neuropathic pain associated with central sensitization tends not to respond

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to traditional pain medications, research has shown that cognitive therapy-based approaches

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such as acceptance and commitment therapy can have a significant positive impact on

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a person's ability to cope with their pain and allow them to re-engage in meaningful activities.

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Conquer Chiari has sponsored a series of research studies which have shown this to

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work for Chiari patients and based on this is designing a self-guided,

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on-line program which is scheduled to launch in 2026.

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In this module, we learned that

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- Chiari patients often suffer from high levels of chronic pain

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- This can lead to central sensitization which can make even non-painful stimulation feel painful

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- Living with chronic pain can have a negative effect on a person's physical,

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mental, and spiritual well being • Acceptance and commitment therapy is one

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intervention which has been shown to be effective in helping Chiari patients deal with chronic pain