



Chiari Academy Video Transcription Impact of Chiari – Psychological Impact

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[Music]

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This video encourages focusing on positive aspects of life and abilities,

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especially in the face of challenges. However, we recognize that this approach

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may not be appropriate or helpful for everyone, particularly individuals living with chronic

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depression or other mental health conditions. If you're struggling, please know you're not alone.

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We encourage you to seek support from a mental health professional. Your experience is valid,

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and healing looks different for everyone. If you need immediate help, please call or

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text 988 for the Suicide and Crisis Lifeline. So far in this course we have looked at the

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impact that chronic pain from Chiari can have on a person, the physical disabilities that often

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come with Chiari, and the cognitive impact of Chiari. In this final module we'll take

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a look at the psychological impact of Chiari. Like with many other chronic, painful conditions,

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Chiari patients suffer from high levels of depression, anxiety,

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and stress. But what does this actually mean? Depression is defined as a mood disorder

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characterized by persistent sadness which interferes with everyday functioning. A

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Conquer Chiari research study of over 1,000 adult patients which used a common depression

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scale found that 44% scored as being moderately to severely depressed. Interestingly, there was not a

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significant difference in the rates of depression between patients who had had surgery and those

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who hadn't. That means nearly half of adult Chiari patients have depression at a level that

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should be addressed by a mental health expert. Clinically, anxiety is defined as excessive,

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persistent, and often unrealistic fear or worry about future threats, leading to significant

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distress and impairment in daily functioning. The same study found that 60% of the adult

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patients scored as moderate to extremely severe on a widely used anxiety scale. This means that

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more than half of adult Chiari patients suffer with anxiety at a level that should be treated.

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Among the same group of patients, 63% of adult women and 67% of adult men were found

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to suffer from severe to extremely severe levels of stress. Finally, three out of four adult women

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reported high levels of loneliness. Although it is rarely talked about,

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the combination of physical disability and psychological distress caused by Chiari leaves

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some patients at a higher risk for self-harm and suicide. In fact, a Conquer Chiari study of 372

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adult patients which included a suicide risk screen found that 44% were at an elevated risk

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and that within the previous month 43% had either wished they were dead or had suicidal thoughts.

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Those with a moderate level of depression or worse were four times more likely to be

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at higher risk than patients with low or no depression. In addition, those under the age

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of 30 years were three times more likely to be at risk compared to older patients, and those

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with severe or complete neck related disability were twice as likely to be at higher risk than

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patients with lower levels of disability. While the mental health impact on adults has

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been well characterized, as with other aspects of Chiari there is less information available about

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the psychological impact on pediatric patients. Although it is based on much fewer patients,

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data from the Chiari1000 project indicates that depression and anxiety are also a serious issue

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for at least a portion of young patients. In addition, there are indications that there are

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higher rates of attention deficit hyperactivity disorder among Chiari children which can lead to

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behavioral challenges in the school setting. However, much more research is needed on

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pediatric patients to understand the situation and provide parents with the information they need.

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Despite the obvious need, the mental health of Chiari patients is largely

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ignored by the medical community. However, Conquer Chiari has funded a series of studies which have

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shown that a self-guided program of Acceptance and Commitment Therapy can be effective in improving

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Chiari patients' lives. Acceptance and Commitment Therapy, is a mindfulness-based therapy that helps

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people build psychological flexibility in order to live valued, meaningful lives.

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This is accomplished by focusing on accepting difficult thoughts and feelings rather than

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fighting them, and committing to positive actions, rather than trying to eliminate distress.

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Conquer Chiari is working on a web-based, self-guided, Chiari specific program that

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we hope to roll out by the end of 2026. This course included a lot of disturbing

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information about the impact that Chiari can have on patients. While what was presented is based on

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research, it is important that patients and their families do not lose hope. You don't have to let

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Chiari take over your life, but understanding it is a good first step to conquering it.