



Chiari Academy Video Transcription

Navigating the Chiari Experience – Talking About Chiari

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[Music]

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In this module we will cover two important topics, how people react

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to a Chiari diagnosis and specific tips for talking about Chiari with others.

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In general, people react in one of two ways to being diagnosed with Chiari. For

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people whose symptoms came on suddenly, the diagnosis can come as quite a shock,

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and the thought that there is something seriously wrong is difficult to comprehend. Someone who was

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healthy and active may have trouble accepting that they face a serious medical issue.

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In contrast, for people who have struggled for years to find out what is wrong with them,

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and have been told over and over it's all in their head,

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a diagnosis can be a watershed moment with strong feelings of relief and vindication.

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One common response that people have to a Chiari diagnosis is actually a worsening of symptoms.

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It's as if once someone is made aware they have a disease,

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they become more in tune with what is going on with their body

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and symptoms that were previously in the background come to the forefront.

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Another common response people have is to try to connect every symptom they have ever had to

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Chiari. They may wonder whether this pain or that peculiarity is due to Chiari. However,

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this can lead to frustration if they expect their doctor to go

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into an in-depth discussion about every symptom. Because from the

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doctor's point of view they only need to understand the most troublesome symptoms.

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Parents of young Chiari patients may be especially hard hit by a diagnosis. The resulting fear,

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anger, and even guilt can bring overwhelming stress into the family dynamic. The thought

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of surgery on a young child, and not knowing what the future will bring, can be difficult.

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Nancy, is one of the many parents who have dealt with these emotions and fears, this is her story.

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"I felt like I had been hit by a truck. I was totally unprepared for it. I

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thought the whole thing was handled poorly and for a whole month I

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was in a daze...I'm trying to wade through all the information. I could

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think about nothing else, I was completely consumed. I kept thinking,

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how am I going to let them open up his skull? How could I get through

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it...[he] was going around saying, 'I have to have surgery and I could

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die.' Every time I heard that I cried. It was really hard because he's

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only 7 years old... I was a wreck."

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Whether it's an adult or a child, a Chiari diagnosis can be an extreme shock. What's

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important is to work through the initial emotions as quickly as possible so that you can take

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control of the situation, educate yourself, and make intelligent decisions moving forward.

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Once the initial shock has worn off, something every Chiari patient must face is how, when,

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and what to tell other people. Each person must decide who to tell at work, in social circles,

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etcetera. Parents must decide who in their children's lives needs to know,

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such as teachers, coaches, babysitters, the list goes on. In fact, this is an

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issue that those with Chiari will face again and again throughout life.

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There is no right or wrong way to talk about Chiari,

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but there are some steps which can be taken to make the job easier. The

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first thing to remember is that 99% of people don't know what Chiari is,

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so telling someone about a diagnosis by default includes educating them to a certain degree.

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With that in mind, the first tip is to Practice a short explanation

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In the business world, entrepreneurs are told to develop what is known as an elevator pitch about

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their company and product idea. The concept is that they should be able to convey the general

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idea in the time it takes to ride an elevator in an office building. To get comfortable telling

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people about Chiari, develop a short, elevator explanation and practice it. Try different

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phrases on people to see what works and what doesn't, and don't be shy about practicing it

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in front of a mirror over and over. There may be times when explaining Chiari in a clear,

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concise manner is very important. A sample elevator explanation may be, "Chiari is a

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serious neurological problem where part of the brain - point to the back of your head - ends

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up crowding the top of spinal cord causing all kinds of problems." This short explanation conveys

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a good deal of information and allows people to begin to frame a mental picture of Chiari.

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It tells people that Chiari is neurological in nature, that it can be a serious life event,

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and if you remember to point, it even tells people where the problem is.

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The explanation can be extended to create different, longer versions which can be used

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when there is more time. The key, just like any public speaking, is to be prepared and practice.

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The more you practice, the easier it will become, the more natural it will sound,

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and the more effective you will be in getting your message across.

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The next tip is Don't use medical jargon

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Once you have the basics down, it's easy to slip into med-speak and throw

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out words like foramen magnum and CSF flow. However, this is not a good idea.

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Try to remember what it was like when you first started learning about Chiari

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and how confusing all the new words were. Don't try to sound like a neurosurgeon,

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using plain English when telling others about Chiari is much more effective.

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Next, it can be helpful to Let the other person guide the discussion

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Many people are uncomfortable talking about medical issues, especially of a personal nature.

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One way to alleviate this is by starting with the elevator explanation, and then letting the

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other person lead the discussion. So rather than dumping years of frustration and anger

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on one person in a 20 minute session, try to read what the other person is interested in.

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For example, one person may focus on the medical and scientific aspect and ask detailed questions

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about treatment and outcomes, while someone else may focus on the impact it can have on

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people's lives and families. Letting the other person be the guide in the type and amount of

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information that is given will greatly increase what they learn, and retain, about Chiari.

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The next tip is Don't be negative, be matter of fact

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It is almost universally true that negativity and anger turn people off. Many people will

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tune out someone who is ranting or venting a lot of emotion. Unfortunately, it is also very natural

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for people with Chiari, especially if it took them years to be diagnosed or if they are severely

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affected, to have a lot of negative emotions associated with it. While it may be difficult,

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it is also very important to not be negative when talking about Chiari. It is best to just be

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matter of fact, or even understated. This way more information will be conveyed in a clear manner.

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It's also true that people like, and respond to, fighters. They want to see people persevere

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through adversity and show resolve and determination to win. People most of all

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want to hear that someone will be ok; that it's a tough break but they'll get through.

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In general, people don't want to hear how difficult it can be to get out of bed,

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or get through a day of work or parenting, or how the pain is so all consuming. This can be

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true even among close friends and family. It doesn't mean they're callous and don't care,

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it just means they don't know how to handle something like that. It is difficult to hear

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about someone's pain and suffering, especially a loved one, and not be able to do anything to help.

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Obviously, people need to be able to vent their emotions and express their anger and

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frustration. It is just important to carefully consider who to do this with. Before unloading

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emotionally on someone, be sure they are ready, and willing, to take the load.

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It is important to Be prepared for common questions

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Over time you will likely realize that people will tend to ask the same initial questions.

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Being prepared with short, precise responses to these questions will make you sound knowledgeable,

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keep people engaged, and make your life easier.

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These common questions include...

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How many people have it ? We don't know for sure,

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but it's considered a rare disease.

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What are the symptoms?

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The most common symptom is a severe, disabling headache in the back but it also causes a ton of

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symptoms like balance problems, weakness, trouble swallowing, and cognitive issues.

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How did you find out you have it? I had a car accident that caused

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me to have horrible headaches that would not go away. So, my doctor ordered an MRI,

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and the results showed I had Chiari Malformation.

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How do they treat it?

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The only real treatment is surgery to create more room in that area

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Wow, I've never heard of it... I know, most people haven't, but

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now that we've talked about it, you'll probably hear about it again in the next couple of months.

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Finally, the most important tip of all is Don't judge how other people react

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While some people may seem very empathetic, many won't and may say

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strange and even inappropriate things. They aren't saying these things to be malicious,

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rather it is likely that they just don't know how to handle what they are hearing. Disease is

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an uncomfortable subject for many people, and their stress response to it may come across

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in a negative way. If you take offense with how someone reacts, you are letting Chiari interfere

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with relationships just when you need them the most. Give people time to digest what they

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are hearing and don't place any expectations on what they may or may not say when you tell them.

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Telling others about Chiari can be difficult, especially at first, but it is an important part

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of navigating the Chiari experience and hopefully these tips will help make it a little bit easier.