Chiari Academy Video Transcription
Navigating the Chiari Experience – 3 Keys

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In this module we will discuss three actions that are key to

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effectively navigating the Chiari experience.

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In addition to the physical symptoms that come with Chiari, those affected often

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struggle with three specific things. First is the feeling that no one understands what

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they are going through. Second is the feeling that their questions aren't being answered,

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and third is the feeling that Chiari has taken over their life.

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These feelings are natural and very common and understanding

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and adapting to them are vital to navigating the Chiari experience.

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The first key is to realize that each person's Chiari experience is unique.

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It can be difficult to accept, but the reality is that no one will truly understand what you,

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as an individual, are going through. Some people will be helpful and supportive while others will

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appear to be callous or even cruel, but your Chiari experience belongs to you.

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Chiari is difficult for other people to understand for several reasons. First, in general people are

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not aware of what it is. This makes it difficult for someone to really understand what a patient is

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going through. They will listen to the description but not realize how it can affect a person’s life.

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Second, many Chiari symptoms are invisible and hidden, and a Chiari patient can look perfectly

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healthy. This is a difficult obstacle for people to overcome, and they may think, or say,

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Why can’t you do this? Why can’t you go here and there? For most people, seeing something makes

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it real, so when symptoms are invisible, some people may have doubts about how serious it is.

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Third, even among Chiari patients, everyone is different. Chiari involves a wide range of

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symptoms and severity. While there is commonality between patients,

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each patient’s manifestation is different. One person may struggle with headaches from bright

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lights and loud sounds, another may struggle with balance problems and walking. Together,

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they share a bond, yet each person’s battle is unique.

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Finally, pain and illness are by their very nature subjective. No one can tell

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how much pain someone else is in, or what they are feeling. It’s just not

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possible. Yet a common reaction people have to someone in pain is to feel that

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they are exaggerating their plight. For whatever reason, many people feel

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they would handle the situation better and that the person in pain should be tougher.

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This does not mean that people are by themselves in their battles,

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but it does mean that the support and empathy they can expect has limits. Because of this it can be

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frustrating when those affected look outward for validation of their experience. Rather,

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those affected should look internally for validation. Your Chiari experience

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is valid for the simple fact that you are experiencing it.

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The second key is accepting that not every question has an answer.

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Unfortunately, many Chiari questions don't yet have an answer. It is important to realize and

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accept this. There is no objective, definitive diagnostic criteria for symptomatic Chiari. There

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are no widely accepted non-surgical treatments, but at the same time it can be difficult to

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predict what symptoms will improve with surgery and whether symptoms will come back over time.

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We are still at the early stage of understanding Chiari and key issues remain unsolved. Does this

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mean patients and parents should just throw up their hands? No, it means the opposite. It means

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it is even more important that those affected take the time to educate themselves and understand what

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the issues are. While there may not be definitive answers to some questions, there is a growing

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amount of information and data available. It is vital for patients and parents to be able to

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communicate with their doctors, understand what is being said, and sort through different opinions.

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It would be preferable to have definitive answers, but when these are not available,

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it is just as important to seek out what is known, what is not known, and what is suspected.

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The third key is taking control by educating yourself.

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When confronting Chiari, people are faced with two choices. They can either let Chiari take control

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of them, batter them around, and hope their doctors will help or they can take control,

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educate themselves and those around them, and make informed, intelligent decisions.

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Educating yourself is beneficial in several ways. First an educated patient or parent will

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have an easier time navigating the healthcare system and rallying the support they need.

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They can find a doctor appropriate for their situation, bring critical items to

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the attention of their medical team, and solicit support from others by being able

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to clearly explain what is happening. Second, after treatment an educated person is better

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equipped to deal with any residual symptoms or chronic issues. In fact,

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research across health conditions has shown that patient education improves outcomes when dealing

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with chronic diseases and there is no reason to think that Chiari is any different. Finally,

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many Chiari patients report feeling depressed, anxious, and overwhelmed after being diagnosed.

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Being proactive and taking back some measure of control can provide a mental and emotional

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boost. Keeping the mind busy leaves less time for negative thoughts and imagining the worst.

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To summarize, the three keys to navigating Chiari

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experience are realizing that every person’s Chiari experience is unique;

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accepting that not every Chiari has an answer, and taking control by educating yourself.