



Chiari Academy Video Transcription Navigating the Chiari Experience – Conquering Chiari

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This module is intended for patients who are dealing with Chiari issues on a chronic,

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long-term basis and will focus specifically on how to fight back and Conquer Chiari.

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By far the single most important action you can take is to move past anger to acceptance.

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Anger is a very powerful emotion, and when confronted with what seems like a gross injustice,

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a very understandable one. While anger is a very natural, and probably necessary part of

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coping with the shock of dealing with a disease like Chiari, it should also be a temporary one.

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Many people are familiar with the five stages of grief: denial, anger, bargaining, depression,

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and acceptance. Interestingly, the five stages of grief were originally the five stages of receiving

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catastrophic news. One would have to consider being diagnosed with Chiari as catastrophic news,

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so the five stage model applies here as well. It is important not to get caught up in the details

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and order of the stages, human emotions don't always fit easily into well-defined

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categories. However, it is also important to note that anger is a transitional phase and

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not the end goal. Someone who works through their emotions in a healthy way will in the end reach

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some level of acceptance. Unfortunately, far too often people get stuck in anger.

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The power of anger becomes all-consuming and they are never able to accept the situation and

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take positive steps to improve their health and lives. This is a terrible situation,

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with patients feeling they have been hurt and treated unfairly by life.

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While in one sense this is true, it is also counterproductive to dwell on it.

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As patients, at some point we must accept the situation and move on with our lives. After

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a normal period of adjustment, we must let go of the anger, recognize that our lives have changed,

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and move forward as best we know how. Research supports the idea that acceptance is critical

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in dealing with a chronic disease or disability. Multiple studies have shown that whether someone

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with a chronic disease or disability has accepted their situation has a strong influence on both

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their quality of life and overall health in general. Letting go of the anger and accepting

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the situation at hand is the first step in dealing with, and overcoming, Chiari on a long-term basis.

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Once you have accepted the situation, it is much easier to take positive,

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productive steps towards building a good quality of life. One of the most important steps you can

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take is to prioritize what is important in your life. If you have real limitations,

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whether they involve pain, mobility, or something else, they will have an impact

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on your life. The key is to manage their impact and maximize your capabilities and

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resources. To do this, you need to decide what is important in life and focus on that.

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Chiari strikes many people at a time in their life where they are extremely active and involved in

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building careers, starting families, and other activities. It can be difficult for someone

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who is used to being able to accomplish many things to really slow down, look at their life,

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and decide what is important. But the payoff is worth it. Focusing on fewer things and being able

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to do them well will lead to a better quality of life than falling short by trying to do too much.

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What is important to you? Just because some dreams may no longer be possible,

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doesn't mean you can't have new dreams, hopes and aspirations. It just takes the

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mental effort and discipline to decide what to focus on, and the creativity and willpower

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to make it happen. It may involve sacrifice. It will involve hard work,

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but nothing good is easy and with some focus and effort you can find a new path.

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Once priorities are established, it is important to be smart and creative both in pursuing those

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priorities and in the mundane activities of everyday life. Many Chiari patients have

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limited physical resources, but by being smart and creative these resources can go a long way.

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It's important to not hold onto the old ways of doing things if they aren't working for you.

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Don't waste time and energy bemoaning what you can't do. Instead, use your mind to compensate for

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what your body is not able to do. Be creative in how you approach your daily life and find ways to

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modify your activities to fit your situation. Just because you can't do something the way you used

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to doesn't mean you can't find a new approach or a whole new solution altogether. In other words,

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maximize your brain and minimize the pain. Be relentless in finding ways to ease the burden

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of Chiari. Use technology to your advantage. New apps are coming out all the time which

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can make life easier and help people with physical limitations engage in meaningful

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work and fulfilling hobbies. Instead of saying 'I can't do this; I can't do that',

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think 'How can I do this, how can I do that.' The benefits of this approach are tremendous.

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Not only will you get more done day in and day out which is good for mental attitude, but by

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reworking taxing activities, more energy will be left to focus beyond the basics of daily living.

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Another way to minimize the pain is to focus on getting physically stronger.

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Patients may be weak and out of shape due to their symptoms. Because of this,

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it is important to work at getting stronger day after day and year after year.

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Try to do something physical each day, even if it's just a short walk,

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and then slowly build from there. Once you've done an activity for a few weeks try going further,

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or faster, or adding something new so that your body has to work harder. Continue to

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build up slowly and change things on a regular basis. Once you become used to a certain level

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of physical activity you will likely find that you can begin to do things that you

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thought you weren't going to be able to do again, and your quality of life will improve

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dramatically. It's important to find what works for you, whether it's swimming, yoga, cycling,

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or weights. Keep trying things until you find something you can do with no or minimal pain.

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Research has clearly demonstrated that the neck muscles and shoulders are affected in Chiari

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patients. Consider finding a physical therapist or trainer to work with who is willing to learn

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about Chiari and devise a program specifically for you. If your neck muscles go into spasm easily,

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consider exercises that are in a heated environment that will help keep them loose.

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When nerves are damaged, it can take a very long time to recover. Don't get discouraged

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if progress is slow at first. The keys are consistency and patience. Even a modest amount

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of physical activity can have a very positive effect over time if done on a regular basis.

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It is also important to live a healthy lifestyle overall. Chronic disease and

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pain take a high toll on the body and often lead to other health problems. Therefore,

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it is critical to minimize this impact. First, this means giving up, or at least minimizing,

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alcohol and nicotine usage. Consider that both alcohol and nicotine have a direct effect not

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only on the neurotransmitters in the brain, but on blood flow as well. The natural flow

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of spinal fluid is directly influenced by blood flow, so it is natural to think that

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ingesting something that affects blood flow may also affect the flow of spinal fluid.

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For similar reasons, it is important to achieve and maintain a good weight. Beyond the general

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health benefits, excess weight is linked to higher levels of inflammation and may elevate

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the spinal fluid pressure in the brain. The best way to maintain a good weight is to eat a healthy,

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balanced diet and get plenty of exercise. While this is easier said than done if you

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want to Conquer Chiari you have to develop the discipline to eat well and exercise.

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An often-overlooked aspect of a healthy lifestyle is getting plenty of rest. Adequate sleep needs

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to be a priority. Keep in mind that Chiari patients often suffer from sleep apnea,

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so consider getting a sleep study to see if you need treatment. Beyond that, make sure you

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are practicing good sleep habits and set aside the time your body needs to recover each night.

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A healthy lifestyle also means engaging in meaningful social interactions and activities.

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Research has consistently shown the benefits of social engagement. This can be particularly

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challenging for people with Chiari and there is a natural tendency to socially isolate. It is

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important to fight this urge and plan activities that you can participate in without too much pain.

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The next step in conquering Chiari is to realize that you are more than your

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disease and act accordingly. Dr. Carol Greco, a psychologist who specializes

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in helping chronic disease and pain patients, says, "Probably the most

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important thing for people to keep in mind is that they are more than their disease,

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and realize that there is always more that is right with them than wrong with them."

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Just because you have Chiari, doesn't mean you can't live a purpose driven life, have dreams,

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and pursue goals. In fact, you will likely find that as you begin to look beyond Chiari

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you will begin to feel better. Focusing your mind on achieving something means that your

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mind will not be focused on the pain you are in or thinking about how life used to be. Realistically,

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some dreams you had may no longer be possible, but the human imagination has a near limitless

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capacity to conceive of what might be. Use your imagination and stretch your mind to think about

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what you want to accomplish. The importance of this step cannot be overstated. It is

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essentially the difference between trying to make it through the day and living life. We are all

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more than our disease, we just need to prove it to ourselves by not letting Chiari control our lives.

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In the end, Conquering Chiari is more mental than it is physical. It's about discipline,

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mental toughness, inner strength, willpower and making the decision that you are not going to be

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controlled by the disease. It's about saying that no matter how many times you get knocked

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down you are going to pick yourself back up and keep trying. It's about never giving up,

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never giving in, and not surrendering to despair. It's about being more than a disease.

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Once you have made that decision at a deep level, you have already won. It doesn't matter what you

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can or can't do physically. It doesn't matter how much pain you're in or how Chiari has affected

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your life. If you've made the decision not to let Chiari control you then it won't. Face it

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head on and believe in yourself. And most of all, never give up and never give in.