



Chiari Academy Video Transcription Chiari Bootcamp- Common Questions

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In this lesson we will address some common questions people have about Chiari: including

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who gets Chiari, what causes Chiari, is Chiari genetic, is Chiari fatal, and how does Chiari

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affect pregnancy, Athletics and work. Who gets Chiari? The answer to this question depends on how

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we define Chiari. As we discussed in the what is Chiari lesson, About one percent of adults and up

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to three percent of kids meet the MRI definition of Chiari but most will never experience any

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symptoms therefore it would make sense to limit our answer to symptomatic Chiari. Although the

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precise number is not known, based on the number of Chiari surgeries performed each year in the U.S

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it is estimated that about one in one thousand people have symptomatic Chiari or more than 300

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000 people in the U.S alone. Chiari affects both children and adults and symptoms can appear at any

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age but a research study of hospital records found that about 65 percent of surgeries are performed

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on adults and 35 percent on children. Among adults there is a large sex disparity with 75 to 80

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percent of the cases being female. However, among children it is much closer to an even 50/50 split.

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The reason for this difference between adult and pediatric cases is not known. There are reports

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of Chiari cases from all over the world and it is assumed that Chiari affects all races but whether

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some races are affected more than others is not known. What causes Chiari? There are a handful

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of theories about what causes Chiari but none have been proven. Conclusively the most widely accepted

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theory is that the skulls of Chiari patients specifically the back portion are smaller than

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they should be so the cerebellar tonsils end up protruding out. While there is some evidence to

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support this the theory also has several problems. Recently two new theories have emerged one states

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that instability of the upper spine is the core problem that leads to symptoms and that

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the cerebellar tonsils herniate as a protective measure. The second put forth by Conquer Chiari

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researchers holds that subtle instability in Chiari patients leads to overworking of the

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stabilizing neck muscles which in turn leads to mechanical failure of the myodural bridge complex

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which connects these muscles to the covering of the spinal cord this then changes the fluid

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Dynamic properties in this region causing pressure spikes which damage sensitive nervous tissue.

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Is Chiari genetic? When people ask this question they often mean can I pass it down to my children.

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The answer is sometimes. There appears to be a subset of Chiari cases which are heritable

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research from the Chiari 1000 database indicates that about 12 percent of Chiari patients have at

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least one additional immediate family member who has been diagnosed and nine percent have

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at least one extended family member with a diagnosis. However the genetics underlying

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this are complicated and there does not appear to be a single Chiari Gene. Partly because of this

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there is currently no genetic test for Chiari. Another aspect of the genetics issue is whether

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genes play a role in developing symptomatic Chiari even if it was not inherited. In other words, are

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some people born due to genetic variations with a tendency or likelihood to have Chiari? Although

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the research is limited one Conquer Chiari study did find that nearly half of adult Chiari patients

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had a variation on one or more collagen related genes. However, it is important to keep in mind

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mind that environmental factors also likely play a role in developing symptoms as one quarter to

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one-third of patients report a specific traumatic event that triggered their symptoms such as a car

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accident or fall. Is Chiari fatal? While there are case reports of sudden death associated with

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Chiari these appear to be very rare and in general Chiari is not considered a fatal condition and

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five-year and tenure survival rates are not discussed. However it is not known if Chiari

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has an impact on overall life expectancy but given that many adult Chiari patients suffer

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from high levels of pain and disability it would not be surprising if their overall

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health was negatively affected. In addition recent research from Conquer Chiari has found that adult

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Chiari patients are at a higher risk of suicidal thoughts and ideation. Unfortunately social media

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also indicates that suicide is a real problem in the Chiari community. Finally it should also be

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noted that Chiari surgery does entail risk and there have been reports of mortality associated

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with it. Can I get pregnant with Chiari? Since Chiari affects a lot of women in their 20s and

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30s it is not surprising that Chiari in pregnancy is the most read about topic in the Conquer Chiari

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Online Library. Specific concerns include whether the strain of pushing during labor will aggravate

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symptoms, the effects and risks of the various types of anesthesia commonly used and what the

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effects of the pregnancy itself might be on the Chiari condition. Although there is not

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an abundance of published studies on the topic a review of 35 births which involved a variety

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of anesthesia and delivery methods found that in general it was safe. About 67 percent of

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the women were diagnosed with Chiari before becoming pregnant 20 percent were diagnosed

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during pregnancy and 14 after pregnancy about half the deliveries were cesarean many of them plan to

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avoid the risk of elevated intracranial pressure during labor. Although nearly 80 percent of the

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women did experience Chiari related symptoms during pregnancy only four reported worsening

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of symptoms and two of these cases were women who have not yet been diagnosed with Chiari.

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It is recommended that anyone with Chiari who is pregnant or considering becoming pregnant

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should discuss the topic with their physician and consider utilizing a multi-disciplinary care team

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to manage their pregnancy and delivery. Can my child play sports with Chiari? This is a

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highly controversial subject and Conquer Chiari does not advocate or endorse a specific view in

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this regard. Rather this is a topic that should be discussed in depth with each child's physician as

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every case is different. There is not a consensus among doctors on the answer to this question. At a

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Conquer Chiari Research Conference this question led to a heated debate among the neurosurgeons

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and neurologists in attendance with some saying for many of their cases they do not suggest any

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restrictions on activities. While others strenuously objected to this approach and

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said contact sports should be completely avoided. Still others said they left it up to the families

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to decide how important the activity was to each person. In 2023 the University of Michigan

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published a study in involving over 450 pediatric Chiari patients in the group there were nearly 6

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000 Sports Seasons played before surgery and one thousand played after surgery with no permanent or

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catastrophic neurological injuries reported and low rates of concussions. From this the authors

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concluded that Sports participation for Pediatric Chiari cases can be permitted in many cases. Will

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I be able to work with Chiari? Chiari affects everyone differently so this is a difficult

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question to answer. On an individual basis however data from the Chiari 1000 database

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shows that out of over 1 400 mostly female adults 54 percent were currently working with 75 percent

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of those working full-time but nearly 80 percent also report that it is somewhat or very difficult

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to work due to Chiari. 75 percent say that Chiari has negatively impacted their career and nearly

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half have had to change jobs due to Chiari. Among those not currently employed nearly 80

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percent said it was due to Chiari. Can I go on disability because of Chiari? Again this

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is difficult to say as it varies from person to person data from the Chiari 1000 database

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indicates that 32 percent of Chiari adults pursued Social Security disability and 45 percent were

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successful in securing benefits. In this lesson we addressed some common questions about Chiari

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and learned that symptomatic Chiari affects about one in one thousand people. Among adults,

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females are affected more than males but among children it is about even. There are several

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theories about what causes Chiari none of which have been proven. Definitively from a subset

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of patients Chiari appears to have a hereditary component but there is currently no genetic test

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for it. Chiari is not generally considered a fatal condition but patients are at an increased risk

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of suicide. Pregnancy and Chiari patients can be safely managed by a multi-disciplinary care team.

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For children with Chiari Sports participation is very controversial but research indicates

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that it is possible in many cases. Every parent should consider with their child's position about

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any physical activity restrictions. Chiari can have a major impact on careers and employment.