



Chiari Academy Video Transcription Navigating the Chiari Experience – Surgery & Recovery

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In the Bootcamp course we reviewed the technical details of Chiari

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surgery along with statistics on outcomes and complications. In this module we will discuss

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some of the practical aspects of undergoing and recovering from Chiari surgery. First we

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will focus on adults and then discuss several issues specific to children.

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While only about half of adult Chiari patients have surgery,

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for those who do, it is important to realize that it is a big deal and a

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little bit of planning before the event can go a long way to make things easier.

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With that in mind, here are some things to consider before the actual surgery.

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While it is good to hope for the best, it is important to be realistic and consider

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that any major surgery can involve serious complications and bad outcomes. Therefore,

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it is important to have your legal affairs in order including a will, an advance directive,

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and a medical power of attorney. An advance directive is a document that

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lays out your wishes regarding medical treatment in situations where you are unable to communicate

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and the medical power of attorney names someone who can make medical decisions on

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your behalf if you are unable to do so. These documents are important legal tools to ensure

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that all decisions are made by you or your appointee and not the doctor or hospital.

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It is also important to consider that your physical capabilities are likely to be

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limited after the surgery, potentially for weeks. Here, a little organization goes a long way. Do

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as many chores ahead of time as possible, such as paying bills, cleaning the house,

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etc, and most importantly arrange for help during your recovery. Again, it pays to hope for the

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best but plan for the worst. What help would you need if there were complications and you

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are sidelined for months not weeks? Think through worst-case scenarios and have back-up plans ready.

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Next, if you are employed notify the appropriate people and establish expectations that you will

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likely be off work for a few weeks. If your benefits include short-term

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disability you will need to understand how that works and how to receive it.

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Think about what you want to take to the hospital. While as a patient you

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should not have anything with you, someone else can bring you things for your hospital

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stay after surgery, such as slippers, a robe, sweat pants, toiletries, etc.

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Finally, make sure you understand and follow all of your pre-op instructions

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and try your best to get a good night's sleep before you go to the hospital.

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While planning is the key leading up to the surgery, the most important actions you can

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take while you're in the hospital are to PAY ATTENTION and SPEAK UP. Unfortunately medication

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errors in hospitals are more common than you might think. In fact, it is estimated that

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there are at least 400,000 medication errors each year resulting in at least 7000 deaths.

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Types of errors include administering the wrong medicine, issuing the wrong dosage,

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giving medication to the wrong patient, giving doses too close together time wise,

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and not identifying conflicts with other medications and health

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conditions. Medications delivered through an IV have an especially high error rate.

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It is important that every time you are receiving medication you ask what it

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is. what the dosage is, and what it's for. If something doesn't seem right,

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don't hesitate to speak up. This is where it can be very helpful to have someone with you

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whose job is to monitor everything and advocate for you if necessary.

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Beyond medications, if you have any questions or concerns about anything,

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don't be shy, don't assume everything is ok, don't worry about bothering the staff,

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ask questions and make sure you understand everything.

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Hopefully, your surgery will be without complications and after a couple of days

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in the hospital you can begin to focus on your recovery. When thinking about recovery, it is

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important to realize that everyone is different. Some people recover quickly while for others it

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can take months or even years. The following quotes from Chiari patients highlight this.

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"I was home in 5 days and up to the full activities of a

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mom and mom's taxi within 14. I just did my chores slower."

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"Recovery was an adventure in and of itself. I had to ask for help

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in doing the simplest things. I had to rely on everyone to carry me through."

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"Everything was not wonderful right away. It took 18 months to get all the strength back in

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my right arm and I had really annoying myoclonus for several months afterward, I had tinnitus

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for about one year, and I had problems with balance and confused speech for about 3 months."

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Many factors can influence how quickly and how well someone recovers, such as their age,

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whether there were surgical complications, how successful the decompression was, how

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long they had symptoms before undergoing surgery, whether they have other medical conditions such as

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diabetes and high blood pressure, their overall level of physical conditioning prior to surgery,

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and last but certainly not least their mental health and attitude towards the surgery.

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During recovery, a difficult decision many patients must make is if and when to return

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to work. Unfortunately, going back to work is not a realistic option for everyone and returning to

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work too soon can be detrimental. A study of 50 adult surgical patients found that only 76%

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of those employed before surgery returned to work after surgery. For those that did,

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the median time to get back to the job was 6 weeks and the range was 4-12 weeks.

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If possible, consider returning to work part time at first and slowly increasing

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your hours. Or if your employer permits it, consider working remotely while you recover,

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then build up to hybrid, and then finally a full-time return to in-person. Similarly,

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go very slowly when it comes to using your neck muscles for lifting things, driving, and working

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on a computer. Remember that these muscles were cut as part of the surgery and need time to heal.

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Try to take frequent breaks and lie down for short periods of time during the day to

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rest your neck and let any pressure that has built up in your head to dissipate.

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Turning our attention to pediatric patients, Conquer Chiari is often asked by parents what

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to tell their child about a diagnosis or the prospect of surgery. There is no right or wrong

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answer to this question and depends on their age, maturity, personality, and temperament.

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Some children may want to know all the details of the surgery,

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while others may just want to be told that they will feel better when it's over and it won't

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hurt too badly. The answer really boils down to Parenting 101. Parents know their children and,

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hopefully, how to communicate with them. Just take your time and let your child work things

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through in their mind, but most importantly trust yourself to do what is right for your child.

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As with adults, it is best to hope for the best, but plan for complications. Proper planning can

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go a long way during what could become a difficult time. Think about what would be required if your

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child is in the hospital for more than a few days. Chances are you will be there as much as possible,

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so try to arrange for who would drive any siblings around, cook meals, etc. Also arrange

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ahead of time who else can cover during times you can't be there or when you need a break.

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Tell your relatives, neighbors and friends what is going on and ask if they can pitch in if needed.

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If you're super-organized, line up the tasks ahead of time, pick one person to be in charge of all

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the helpers, and make a chart of responsibilities. Picking one person to be in charge gives everyone

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else someone to ask questions of without bothering you, and that person knows it is ok to check in

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with you now and then. Most of all, rely on your support system. Whether it's family that lives

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nearby, good friends, or neighbors, a strong support system can make a world of difference.

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With a strong support system at home, parents can turn their full attention to their child's

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hospital experience. Research has shown that nurses can have a significant positive impact

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on the experience of the entire family during a pediatric hospital stay. Nurses can help explain

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what is going on, they can provide comfort to the child during times when parents are not

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allowed to be there, and they can solve problems. Most nurses are nurturing and

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compassionate and can be a valuable resource for parents. It is in your best interest to develop

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and utilize this resource. Ask questions, find out how you can help and develop a rapport with

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the nursing staff. Lean on them for emotional support and don't be afraid to ask for help.

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After surgery, children tend to recover more quickly than adults. In fact,

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a large report found that on average children returned to school within 12 days of surgery.

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As a parent, just make sure to understand any instructions from the surgeon regarding

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restrictions on physical activities and what to watch for in terms of complications.

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For both adults and children, Chiari surgery is a significant event, but with proper planning

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and a positive outlook, the experience can be navigated a little more easily.