



Chiari Academy Video Transcription

Navigating the Chiari Experience – Surgery & Recovery

0:00

[Music]

0:19

In the Bootcamp course we reviewed the technical details of Chiari

0:23

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

0:28

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

0:33

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

0:38

While only about half of adult Chiari patients have surgery,

0:41

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

0:45

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

0:49

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

0:54

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

0:59

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

1:05

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

1:09

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

1:13

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

1:18

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

1:23

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

1:28

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

1:32

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

1:36

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

1:43

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

1:47

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

1:52

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

1:56

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

2:02

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

2:08

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

2:12

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

2:16

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

2:20

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

2:24

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

2:29

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

2:34

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

2:38

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

2:42

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

2:47

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

2:52

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

2:59

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

3:03

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

3:09

and not identifying conflicts with other medications and health

3:12

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

3:17

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

3:22

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

3:27

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

3:31

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

3:36

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

3:40

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

3:46

ask questions and make sure you understand everything.

3:48

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

3:52

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

3:57

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

4:02

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

4:07

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

4:11

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

4:16

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

4:20

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

4:25

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

4:30

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

4:35

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

4:40

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

4:46

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

4:51

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

4:56

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

5:02

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

5:07

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

5:12

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

5:18

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

5:25

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

5:30

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

5:36

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

5:41

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

5:47

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

5:52

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

5:57

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

6:03

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

6:07

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

6:12

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

6:16

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

6:22

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

6:28

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

6:31

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

6:36

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

6:43

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

6:48

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

6:53

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

6:58

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

7:03

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

7:08

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

7:14

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

7:19

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

7:25

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

7:30

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

7:35

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

7:41

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

7:46

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

7:51

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

7:55

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

8:01

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

8:06

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

8:11

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

8:15

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

8:20

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

8:26

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

8:31

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

8:35

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

8:41

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

8:46

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

8:51

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

8:56

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