

## Talking About Chiari With Others

[Ed. Note: The following is excerpted from [Conquer Chiari: A Patient's Guide to the Chiari Malformation](#)]

*"My Chiari story differs according to my audience. It isn't as though any version is incorrect, but where my narrative starts, what it focuses on, and how much emotional content I let it convey depends on many factors." ~Sue~*

Sue, like many Chiari patients, has developed her own strategy for telling other people about Chiari, and her strategy is a good one. One thing every Chiari patient must face is how and when to tell other people. The first time a newly diagnosed patient tells someone they have Chiari is likely to be filled with emotion driven by shock and fear of the unknown. However, once the reality begins to sink in, people realize that this situation, namely deciding who to tell and how much to reveal, is one which will be faced over and over for many years to come. Each person must decide who to tell at work, in social circles, etc. Parents much decide who in their children's lives needs to know: principals, teachers, coaches, dentists...the list goes on.

Obviously, there's no right or wrong answer to how to tell someone about Chiari, especially a loved one, but based on the experiences of other patients, there are some steps which can be taken to make the job easier.

The first thing to remember is that 99% of the general public (this is not a scientific number) don't know what Chiari is, so the job of telling someone about a diagnosis by default includes educating them, to varying degrees, about Chiari. Each person must be their own Chiari ambassador, and they should not resent this fact. Some patients get angry at people for not knowing about Chiari, but this is likely misplaced anger. There is no reason for most people to have heard of Chiari, and it is only through positive action that awareness will spread.

This is where Sue's approach comes into play, because there are many different audiences for the Chiari story, and they don't all need, or want, to hear the same thing. A close friend may be willing to listen to symptom details or the emotional turmoil of facing surgery, but this may be inappropriate for a work colleague who is just curious why someone has been absent. Either way, each is an opportunity for a patient to spread the word about not only himself, but Chiari in general.

Each person has their own story, so in turn must develop their own method and style of telling others. However, listed below are some tips to consider when dealing with this inevitable task.

### Practice a short explanation

In the business world, entrepreneurs (those starting their own business) are told to develop what is known as an elevator pitch about their company and product idea. The concept is that they should be able to convey the general idea in the time it takes to ride an elevator in an office building. To get comfortable telling people about Chiari, develop a short, elevator explanation and practice it. Try different phrases on people to see what works and what doesn't, and don't be shy about practicing it in front of a mirror over and over. There may be times when explaining Chiari in a clear, concise manner is very important (such as an employment situation or to a teacher, dentist, etc.). A sample elevator explanation may be, "Chiari is a serious neurological problem where part of the brain (point to the back of your head) ends up crowding the top of spinal cord causing all kinds of problems." This short explanation actually conveys a good deal of information and allows people to begin to frame a mental picture of Chiari. It tells people that Chiari is neurological in nature, that it can be a serious life event, and if you remember to point it even tells people where the problem area is.

The explanation can of course be extended to create different, longer versions which can be used when there is more time. The key, just like any public speaking, is to be prepared and practice. The more you practice, the easier it will become, the more natural it will sound, and the more effective you will be in getting your message across.

### Don't use medical jargon

Once you have the basics down, it's easy to slip into med-speak and throw out words like foramen magnum and CSF flow. However, this is not a good idea. Try to remember what it was like when you first started learning about Chiari and how confusing all the new words were (or still are). Don't try to sound like a neurosurgeon, using plain English when telling others about Chiari is much more effective.

### Be prepared for common questions

As you gain more experience telling other people, you will realize that there are common questions people will ask. It is best to be prepared for these questions with short, factual answers. Being prepared will make you sound very knowledgeable, will keep people engaged, and will help spread awareness of Chiari, making life easier for both yourself and future patients.

Here are some common questions with short answers:

Q: How many people have it (most people, when first hearing about Chiari, will struggle to remember/pronounce the name and will instead use the pronoun it)?

A: We don't know for sure, but we think about 1 in 1,000 which means about 300,000 people in the US. It affects people of all ages.

Q: What are the symptoms, what does it do?

A: The most common symptom is a severe, disabling headache in the back of the skull which is made worse by exertion, coughing, sneezing, etc. However, it also causes a ton of symptoms like balance problems, leg weakness, trouble swallowing, etc., and eventually it can lead to paralysis (this lets people know that it's serious).

Q: How were you diagnosed or how did you find out you have it?

A: Supply your own story here, but keep it short!!

Q: How do they treat it?

A: The only real treatment is a very traumatic surgery where they create more room around the brain and spine. The surgery doesn't always take away all the symptoms and fails outright about 20% of the time.

Q: Wow, I've never heard of it...

A: I know, most people haven't, even a lot of doctors. Before MRIs it was difficult to diagnose. The lack of awareness is a real problem. People can go years before being properly diagnosed. But now that we've talked about it, you'll likely hear about another case in the next few months.

Obviously, these are just a few of the most common questions people are likely to ask. To effectively talk about Chiari with other people requires a commitment to understand the fundamentals yourself, so you can explain them to others.

### **Use comparisons that people are familiar with**

One way to help talk about Chiari is to provide a frame of reference that people are familiar with. Interestingly MS, or Multiple Sclerosis, is a neurological disease which affects about the same number of people (estimates for MS range from 250,000 - 500,000 in the US) as Chiari, and the similarities don't end there. Many of the symptoms of MS are similar to Chiari, even to the point of Chiari being misdiagnosed as MS as mentioned previously. In addition, MS often strikes young adults just like Chiari and outcomes are widely variable, meaning that some people are mildly affected and some are completely disabled.

Obviously MS and Chiari, while similar, are different diseases and the comparisons should not be taken too far. One major difference is that MS is treated with drugs and Chiari with surgery, but perhaps the biggest difference is that virtually everyone has heard of MS and very few have heard of Chiari. But that's why it can be useful to compare Chiari to MS, because it provides a benchmark for people to begin to think about and understand Chiari.

If you're curious why MS is well known and Chiari isn't, one of the main reasons is that the advocacy groups for MS are extremely vocal, well organized, and have been active for decades. In fact, MS research gets a significant portion of the National Institute of Neurological Diseases and Stroke annual research budget, and MS advocacy groups were in no small part responsible for much of the overall increases in the National Institutes of Health (NIH) annual budget.

### **Say Chiari over and over**

Chiari is a person's name, and many people are not good at remembering names. When talking about Chiari, try to work in the actual name several times so that it is likely to stick in people's minds.

### **Let the other person guide the discussion**

Many people are uncomfortable talking about medical issues, especially of a personal nature. One way to alleviate this is by starting with the elevator explanation, and then letting the other person lead the discussion. So rather than dumping years of frustration and anger on one person in a 20 minute session, try to read what the other person is interested in. For example, one person may focus on the medical and scientific aspect and ask detailed questions about treatment and outcomes, while someone else may focus on the impact it can have on people's lives and families. Letting the other person be the guide in the type and amount of information that is given will greatly increase what they learn, and retain, about Chiari.

### **Don't be negative, be matter of fact**

It's a fact of life that negativity, and especially anger, turn people off. Many people will tune out someone who is ranting, or venting a lot of emotion and anger. Unfortunately, it is also very natural for people with Chiari, especially if it took them years to be diagnosed or if they are severely affected, to have a lot of negative emotions associated with it. So while it may be difficult, it is also very important to not be negative when talking about Chiari. It is often best to just be matter of fact, or even understated. This way more information will be conveyed in a clear manner.

It's also a fact of life that people like, and respond to, fighters. They want to see people persevere through adversity and show resolve and a determination to win. People most of all want to hear that someone will be ok; that it's a tough break but they'll get through.

In general, people don't want to hear how difficult it can be to get out of bed, or get through a day of work or parenting, or how the pain is so all consuming. This can be true even among close friends and family. It doesn't mean they're callous and don't care, it just means they don't know how to handle something like that. It is difficult to hear about someone's pain and suffering, especially a loved one, and not be able to do anything to help.

Obviously, people need to be able to vent their emotions and express their anger and frustration. It is just important to carefully consider who to do this with. Before unloading emotionally on someone, be sure they are ready, and willing, to take the load.

### **Be prepared for, "My sister's cousin had..."**

It is human nature to try to relate to what someone is saying; in fact in one sense that is the basis of communication. Because of this, people often respond to being told about Chiari with some medical story of their own. It may be a bad back, or it may be some surgery that some friend or relative had. It really doesn't matter, it's just a natural response. While the story may seem completely irrelevant and nothing

like Chiari, it is best to ignore this fact when talking about Chiari. If it provides a way for people to relate, and if it keeps them engaged, all the better.

### **Don't judge how other people react**

This may be the single most important piece of advice when it comes to talking about Chiari with others. Don't judge how other people react to what you are saying. While some people may seem very empathetic and immediately show insight into the Chiari struggle, many won't and will end up saying strange and inappropriate things.

This does not mean that they are saying these things to be malicious, it is often more likely the case that they just don't know how to handle what they are hearing. Disease is an uncomfortable subject for many people, and their stress response to it may come across in a negative way. If, as a patient, you take it as a personal insult, you are letting Chiari interfere with relationships just when you need them the most.

Give people time to digest what they are hearing and don't place any expectations on what they may or may not say when initially told about Chiari.

Many patients report that they feel alone because no one seems to understand what they are going through. This is true at the most fundamental level; it is impossible to really understand how much pain someone is in or how hard it is to do certain activities, but this does not mean people don't care. If someone is empathetic and can offer emotional support all the better; but if they say the wrong thing, is it really worth getting upset over? Save your strength and redirect it in a positive direction. When the time is right, take the time to educate and make people aware. Until then, sometimes it is best to look inside for validation, no one knows what you're going through like you do.

### **Awareness sheets**

Conquer Chiari has developed single page Awareness Sheets to help people tell others about Chiari. These pdf files are great for emailing to friends and family, or for taking to meetings with teachers and even doctor appointments. They provide a simple description of Chiari (or syringomyelia) along with some key facts and have been used by thousands of people in the Chiari community. The sheets can be found on the Conquer Chiari website at:

[Education & Awareness Sheets](#)

### **Personal Experience:**

I remember (sort of) the first time I told someone I had Chiari. I had just been given the results of the MRI and I had no idea what Chiari was or what it would mean, but I remember wondering how I was going to tell my wife. Our first child was only a couple of months old and thinking about the future was like standing on the edge of the abyss and looking down.

Since that time, and over the ensuing years, I've lost track of how many times I've told people about Chiari. Now, there is no anxiety when I talk about it, no embarrassment or discomfort, just an attempt to pass on some bit of information which will stick in a person's mind; an opportunity to educate one more.

It wasn't always like that. Beyond my family, I didn't really like to talk about it with anyone else. I literally hated the thought that people might feel sorry for me or take pity. I also didn't like the thought of people thinking of me in any way different than their original impression. I was used to being strong and capable and I was not adjusting well to not being able to do things.

Some of my reluctance came from the incredibly inappropriate things people would say in response. When I told my boss I was putting in for short-term medical leave and why, he stammered for a second, then mumbled, "Well, they're doing wonderful things in medicine these days." When I told a co-worker I was going in for brain surgery, they just nodded and asked if I was still going to some party that Friday.

Despite this, I eventually made the decision that not talking about it was unproductive. I was in the restroom at a restaurant when a guy came stumbling in, apparently from the bar. As he stood next to me, he blurted out, "Hey, what's that scar?"

At first I cringed. It was late in the day, I was tired and my head hurt. The last thing I wanted to do was try to explain to some drunken buffoon the nuances of Chiari. But then it hit me, why not? Why not take the opportunity? He was interested and in one sense a captive audience. So, I started with a simple explanation (thus began the elevator explanation) and let him ask a few questions, which to my surprise were reasonably intelligent.

For that moment on, I decided if people asked I would answer. Now, of course, it goes further than that; I often talk about it whether people ask or not. When people ask me what I do for a living, I have an opportunity to talk about Conquer Chiari and how Chiari affects so many people.

I can understand why some people don't like to talk about it, I was in that place; but I would also encourage them to try. It's a simple choice really, talk about it or try to avoid it. If you choose to talk, the tips above worked for me, I hope they work for you as well.

--Rick Labuda

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