

Tip: Talking About Chiari

Talking about Chiari, especially when you've been recently diagnosed can be difficult. It is an emotional, often overwhelming time, and sometimes it can seem like no one really understands what is going on.

Although it is difficult, here are some tips for talking about Chiari and syringomyelia:

1. Realize that every person's experience is unique. Some people will be very empathetic, some will not. However, it is impossible for someone else to really understand at a deep level what you are going through. Everyone has unique dreams; everyone experiences symptoms differently. Don't expect too much from people.
2. Research has shown that the majority of people do not know how to respond when discussing a serious illness with someone. This leads to many people, even close friends and family, saying inappropriate things. This does not necessarily mean they are not sympathetic and caring, it may just mean they don't know what to say or how to handle their own emotions.
3. Develop different versions of your "story". Casual co-workers probably don't want to hear about your daily struggles or the details of a surgery. Many people just want to let you know they're thinking about you by saying, "How are you doing?" Obviously, close friends and family may want to know more details, but be cognizant of how comfortable someone is in talking about medical details and personal issues.
4. One way to discuss the topic with someone who knows nothing about it is to start at a high-level and then let them take the lead in determining how much they want to know. For example, start with, "Chiari is a neurological condition affecting the brain and the top of the spine" For some people this will be enough. Others may want to know how it affected you and how it is treated. Again, let the other person take the lead by asking questions, don't launch into a 20 minute monologue.
5. Even though you are talking about an illness which may have devastated your life, the reality is that people don't respond well to negativity. When talking about Chiari, it's best to try to keep emotion out of it, the message will get through better.
6. Avoid medical jargon and don't fall into the doctor trap. Use plain English, not terms like foramen magnum.
7. Practice makes perfect. Just like anything, you can get better - and more comfortable - talking about Chiari over time. Develop your own style and stick with what works.



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