



CONQUER CHIARI WITH EVERY STEP[®]

Key One:

Each Person's Chiari Experience Is Unique

The following is an excerpt from Conquer Chiari: A Patient's Guide. It focuses on the first of three key concepts when confronting the reality of Chiari, the fact that everyone's Chiari experience is unique. Conquer Chiari's posts tomorrow and the next day will address the second and third keys respectively.

"No one understands what I'm going through"

It can be difficult to accept, but the reality is that no one does understand what you are going through. People can empathize to different degrees; some will be helpful and supportive, others will seem like they are completely clueless, but each person's Chiari experience is unique to themselves.

Chiari is difficult for people to understand for a number of reasons. First, as discussed before, in general people are not aware of what it is. This makes it difficult for someone to really understand what a patient is going through. They will listen to the description, but not realize how it can affect a person's life.

Second, many Chiari symptoms are invisible and hidden. Headaches, fatigue, weakness in the legs, blurred vision, ringing in the ears. A Chiari patient can look perfectly healthy. This is a difficult obstacle for people to overcome. *Why can't you do this? Why can't you go here and there?* For most people, seeing something makes it real, otherwise, it is always open to interpretation. So, when symptoms are invisible, many people will have doubts about the reality of the illness and these doubts will come out in things they say. If someone has a visible disability, it is easy for people to picture some of the hardships they face; when the disability is hidden, however, this is not the case.

Third, even among Chiari patients, everyone is different. Chiari involves an incredibly wide range of symptoms and severity. While there may be two patients with the exact same symptoms, it is more likely that each patient's manifestation is different. So while one Chiari person may struggle with headaches from bright lights and loud sounds, another may struggle with balance problems and walking. Together, they share a bond, yet each person's battle is unique.

Finally, pain and illness are, by their very nature, subjective. No one can tell how much pain someone else is in, or what they are feeling. It's just not possible. Yet, a common reaction people have to someone in pain is to feel that they are exaggerating their plight. For whatever reason, many people feel they would handle the situation better and that the person in pain should be tougher.

This does not mean that patients are by themselves in their battles. Rather, they should seek out the support of friends and loved ones. It does mean, however, that that support, and empathy, has limits. It is often futile for patients to look outward for validation of their experience. In the end, the Chiari road is walked alone, and patients must find it in themselves to validate what they are experiencing. If you are a patient, what you are feeling and experiencing IS real, precisely because you are feeling it.

