

Sue Martin Philosophizes About Chiari & Her Life

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. My employer and insurance company hear how Chiari prevents me from working, so this is the "disability" perspective on the story. Friends hear how Chiari has influenced my life and relationships. Medical professionals hear the chronology of symptoms and their ever-changing severity. As a chatty and gregarious person, I find myself developing short accounts of my story for store clerks, restaurant servers and other folks who enter my life only briefly: these people get a quick explanation, with a humorous reference to my current brain capacity.

The reasons for telling my Chiari story are even more diverse. To some extent the story is offered on a "need to know" basis. Clearly my employer has to know how the diagnosis impacts my job performance. The insurance people get the most detailed description of every allied condition and all of the symptoms, as otherwise they won't continue paying me! My best friends want to know every nuance, so they can try to empathize and "be there" for me. Most people are interested and want a brief anatomy and physiology lesson so they can appreciate what this condition is all about. At times I save people some of the more intimate and frustrating parts of my story because I want to protect them from those details, or protect myself from being too vulnerable, because ongoing empathy is unlikely. Most friends, family and acquaintances cannot offer the kind of emotional and practical support that I need. A few, though, offer much more than I expected.

"Life must be lived forward, but can only be understood backward" said Soren Kierkegaard. Telling my Chiari story has helped me to understand better what has happened and how it now shapes my life. The biggest hurdle is accepting that it will affect me for the rest of my life.

It would have been great if I had known earlier in life that I had Chiari. Soon after the diagnosis my neurologist pointed out that this was almost certainly why I had been so clumsy and hopeless in Physical Education classes and all sports. It would have been so good to tell all those teachers how they hurt my feelings when they ridiculed me for my inadequacies! I'd like to think that teachers today are more flexible in their thinking and more understanding and accommodating in their methods and feelings than the demi-gods of my strict English prep and boarding schools.

Since I live in Canada, with my public system college job I had and still have a terrific benefits package that includes long term disability (LTD). This means that I continue to get paid, through a combination of private and federal government disability schemes that replace almost all of my former salary. I also get free prescription drugs, along with dental, hearing and optical plans. And all primary and hospital treatment is free at the point of delivery. Chronic illness is always terrible, but I cannot imagine what it would be like to confront it without income security and medical benefits.

Officially I still am a professor, but I haven't returned to work since the surgery because I cannot manage a regular schedule. This is a huge loss for me because I always defined myself as a teacher and see myself as a people person. Now I realize that my second career - writing, even though it's mostly boring textbooks - is most likely to offer fulfillment. One generous friend, who has lived my story as it unfolded, suggests that my teaching days have changed, not stopped, and that my voice can now be heard on paper rather than in the classroom. That idea has helped.

My work in adult learning has not stopped me from continuing with my own education, although my goal of attaining a PhD seems harder now that I cannot drive to class. I'm seeking ways of completing my doctoral work through distance education, but I may have to do this through a US university because there are none in Canada that meet my learning needs. Although there has been some challenge to my cognitive processing, I remain confident that Chiari is another mountain to be climbed, and that I will be successful in getting to the top of this particular steep incline.

While at graduate school I came across the idea of studying phenomena. The existentialists had the notion that "happenings" might be studied. Although the choice of phenomena and the methods for studying them were contentious issues, the act of phenomenology (studying phenomena) seems a useful tool for both examining life experiences had by others, and oneself. For me, Chiari is the catalyst for a phenomena I think of as my "life altering" experience. Although I tell my life as story much as other people might do, I use the lens of phenomenology to help me examine the "essence" of my experience. This concept of "essence" is central to phenomenology. The reader might be happy to know that the phenomenological work is undertaken by the writer, not the reader. It may be true that the reader gains a secondary idea of the essence of my story, and I will be happy if that is indeed the case.

For some time before I consulted my general practitioner about some new signs and worsening symptoms, I noticed a number of perplexing difficulties. I denied that they were problematic at first, and then I tried to explain them away to pre-existing conditions, and my advancing age (moving towards menopause). A few years earlier I had a bout of shingles that left me with post-herpetic neuralgia. This was in my head and face and was so debilitating that my workaholic life was put on hold for several months. I lay in bed with agonizing lancing pains that no drug could soften. As I emerged for short periods, I tried every type of therapy available, including some complementary medicine that my husband thought close to voodoo. Only anti-seizure medication and narcotics made any sort of life possible. My GP saw me regularly, was very sympathetic and tried to get my medication recipe at optimal levels. I gradually returned to work but had to learn how to work differently - the college's disability program allowed for some minor scheduling and physical accommodation which helped a little. Post-herpetic pain remains a problem. Interestingly the place where it hit me was close to the Chiari compression location, although we didn't know it at the time. Perhaps the shingles zeroed in on what was already my weak spot?

Pain management became a way of life. I paid for a series of sessions with a pain-management psychologist who provided equal amounts of encouragement and strategies to help me to prioritize and to make life more manageable. Pain makes me feel very alone at times. This doctor explained how I had to accept that along with realizing that people cannot really empathize. They cannot know what it is like to experience a phenomenon so much outside their own frame of reference. That alone-ness remains my greatest challenge even though I am well supported by friends, my children and, particularly, my husband.

Symptoms - actually, a strange set of symptoms - crept up on me. Their disparity made me ignore them until they stopped me in my tracks quiet literally. Along with increased clumsiness and dropping things (the doctors' had previously tried to rectify this with what we now know were useless carpal tunnel releases on both the left and right) my walk became erratic. I stumbled, my gait was all over the place, my gross motor skills showed real deterioration. Most of all, my headaches were getting worse, sleep issues were ruining my life and a variety of sensory difficulties became apparent. My GP listened and referred me to a nearby well known neurologist. She saw me after a few weeks and, after a quick examination and history taking, suggested that an MRI was needed but that she thought I probably had a syrinx. When I got home I started my syrinx education on the internet. The short wait until the MRI was an anxious time, but I ploughed on with teaching, learning, driving, researching for my papers and writing.

I was referred to a neurosurgeon. My husband was able to establish a rapport with him, but I was intimidated and felt like a lamb to the slaughter. He read the MRIs and offered the full diagnosis: Chiari malformation and syrinx (with all the measurements and clinical language) along with his recommendation to have decompression surgery as soon as possible. He offered almost immediate surgery dates. But my father would be visiting us in July, and at over 80, this wasn't a trip we wanted to postpone. Somewhat to the doctor's concern, we settled for the morning of his return from vacation, and a few days after my father's return to England, July 30th 2001.

Why me? I have often wondered. I now reframe the question - but why not me? Rabbi Harry Kushner has offered his readers some thoughts about the reasons why "bad things happen to good people". His thesis is that bad things happen fairly randomly, and the world is full of occurrences that can be deemed neither good nor bad, but just happen. The natural world's complexities mean that this will continue to be the case. Whether or not we can find goodness, learning or insight from a "bad" happening is up to us. And, he suggests, if we choose to let God walk with us on that pathway, then that too is our choice.

There was a perturbing session with the surgeon prior to surgery, when he explained with great clarity what might happen during surgery. I can't recall his exact words, more my reaction to them. I fixated on the 'you might die' phrase which was actually a small part of his short speech, but after that I couldn't really think of much else. Fortunately having helpful hubby along allowed us to revisit what he actually said and meant. It involved explaining to us that the surgery might prevent the further progression of symptoms - with the emphasis on "might" - but that he could not reverse the damage that has already occurred. "Decompression" was the only available treatment, at least as a first step.

Fluctuating between feeling that the world should stop because I was to have "brain surgery" and thinking that what was happening to me was of little significance because most "neuro" patients have conditions worse than my own, I wasn't sure how to position my health status. How and what to tell family presented a problem, but I soon realized that there wasn't one reality. Many of the people connected to me had their own stance, and needed to hear different explanations. Sometimes even close friends were a bit egocentric in how they thought my condition affected them. This is perhaps quite reasonable, considering that ultimately we each have to carry our own burdens. Those folks with a queasy disposition clearly didn't want to know the details of the operation, but just to get a measure of my situation by asking how many days I would be in hospital, and when I might be back at work. Often I made light of my situation because I didn't want to have to deal with the emotional reaction of a friend. Frequently I entered the world of the person to whom I was talking, but few of them, sadly, could reciprocate.

After a follow-up MRI, I went back to my surgeon, who told me that the decompression surgery was successful and there was some shrinkage of the syrinx. Subsequent MRIs in the intervening three years suggest no further deterioration. Symptomatically, some of the issues have got better, others remain the same and some have recently got worse. I haven't returned to teaching. I have managed to do some writing during my erratic hours awake. I decided I was unsafe to drive, and many activities have therefore been curtailed. Having carved out a slower life style I look as though I am managing, but I don't feel that the quality of my life is everything that it can be.

There are days that I feel a complete fraud, that there is nothing wrong with me! But most days present me with a pain or disability challenge that reminds me how life has had to change. I'm trying to make accommodations to how I live my life so that I can maximize what I have - but my spoken optimism often hides a feeling of a broken life. I didn't want this to happen but I have to get on with it.

So what of the future? Just like most people, I haven't much idea of what is going to happen on either a personal or global level. That doesn't mean that I don't worry about it, but I try not to let it consume my energy. One of the main things I have had to deal with is the loss of control that Chiari has inflicted on my life. That has left me with a generalized feeling of disempowerment, most particularly because its effects are so erratic in manner and severity.

If I could simply accept that I cannot know what I'll be able to accomplish, and when I might be able to achieve things, I could "go with the flow", but my personality doesn't lend itself to handing over the reins to anyone, so accepting help can sometimes be difficult for me. Those who want to help may be offended at times, not because I'm not grateful, but because I really want to do things myself. The convergence of Chiari's impact and the increasing independence of my adult children has its benefits - mostly because they don't need me in the practical ways they once did - but has also emphasized my sense of loss as a parent and teacher.

As a person who has defined herself as a competent teacher, it is phenomenally difficult to accept that that descriptor is no more. What am I if no longer teach? Coupled with the decreasing demands placed on me in my mothering role (as my children became adults) I found my self - my categorical self, the part of my being that helps me know what I am in terms of what I do - completely confounded. The transitional stage for me - and perhaps others who undergo a big life change - is to find a way of starting over with a self that is made up of who I am rather than what I do, or did. This is a tough metamorphosis, partly because I was raised with the notion that my role or label was important. After all, society tends to ask children "what are you going to do when you grow up?" Maybe a better question would be "who or how are you going to be when you grow up?" Further reinforcement of the protestant work ethic and a supposed requirement to be useful in life, has

made that transition even harder.

I am not there yet. I haven't found a way of measuring my worth in any terms other than in the activities I can do, and the things I cannot accomplish. I don't see the value in taking up space, being dependent on others and using up time just to be reflective about life, read and watch more television. If I were to advise others in my situation, I feel sure I would be able to develop a strong argument for valuing their life however limited, to assist them to embrace the rich relationships that are possible, and to make them feel that being human has a dimension that is spiritual, and transcends the physical elements of the here and now, but I'm not progressing very far with convincing myself.

If I can stand outside myself, I begin to approach my being with some detachment, almost as a researcher documenting the progression of a disease. This stance can allow me greater freedom and some degree of objectivity. When I ask myself the question "what is it like to be Sue with a disability?" I am posing a phenomenological question that is relatively easily answered because it is targeted, and allows for a more structured answer, than I might reach through rambling self examination. Treating my experience as research 'data' enables me to transform the experience. At this point in my life I am trying to transform my experience so I re-frame it using various filters. These have been such things as trying to see how my mother might have perceived my condition, why it is that many people cannot appreciate that my physical and other aspects of my 'self' have radically changed, how my life affects those close to me - and other vantage points. "... experiential accounts or lived-experience descriptions- whether caught in oral or written discourse- are never identical to the lived experience itself", suggests Max van Manen. I remember this when examining my own lived experience and appreciate that I can deliberately frame my experience in a positive or negative way; I try to be positive but something frequently pulls me back to a negative way of looking back, understanding 'now', and projecting forward.

A few things have fallen into place that couldn't have been planned. My husband and I moved house shortly before I became seriously sick. This has meant that, because of our current urban location, I can get out and about more easily. Also, I have found out who my real friends are and they are more accessible than they once were. Some colleges are using the first book I wrote about observing children, so I can feel that I am present in colleges although I am not teaching. My life hasn't stopped because I'm not working every hour of every day - I have found that there is life beyond the workplace. I have to learn to go with the flow and make the best of what life does allow me. For one thing I have more time to observe people (I have always been nosy) and in the observation of young children I have found to be true what my historical mentor had to say: "*Observation of children is just as important for us too. In doing so, we catch sight of our own far-off childhood which, like our own faces, we can see only in a mirror. Through our observation we come to understand ourselves and our own life, which then becomes an unbroken whole.*" (Freidrich Froebel)

-- Sue Martin

Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.

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