The Journey From Grief To Growth: A Daughter's Viewpoint

Julie and Jade Carter are a Mom and Daughter team from Montana who are battling Chiari together; Julie has Chiari and Jade has both Chiari and syringomyelia. Together, they started and run a support group, Chiari People of Montana, and devote a tremendous amount of time, money, and energy to their cause. Jade is also a musician and uses her music to help spread awareness, especially among young people.

In Viewpoints, Julie and Jade present two distinct points of view - those of a mother and a daughter, on issues affecting the Chiari community.

March 20, 2006 - I am 19 years old and my symptoms began around the age of 10. My mother says there were many symptoms all along. But I have been living with these setbacks for half of my life. Now that I put it like that-dang I am tough! However, I have not always felt so strong.

It took years for my awareness that something was wrong to turn into true grief. I was in elementary school and all I knew was that my head hurt!

As the years went on, the bizarre symptoms increased and we were all getting scared. By the time I got to high school, we were going from doctor to doctor, trying to find the culprit. My heart was tested, my eyes, blood; I had CT's, MRI's, EKG's, EEG's, you name it--they all came back "normal". My problems were blamed on puberty, and it was finally determined that I was bored, depressed, and needed a psychiatrist. I had "sympathy pain" for my mother and she was making me this way; that hurt.

When my 3.8 GPA dropped considerably, my teachers called a conference with my mother. I had begun misspelling my own name and they brought the papers to prove it. I was falling all over the school, blacking out, knocking other people over (or down the stairs) on a regular basis. The school was demanding answers, and we were trying to find them!

This is only what they saw. I eventually wound up eating lunch in the bathroom; it smelled, but it was quiet. I'd lie on the floor in there, some empty classroom, or go take a nap in my car just to get through the day. I clung to the handrails hoping no one would notice. It was all very lonely.

They ended up putting me on handicapped status, without a diagnosis. Embarrassing as it was, this was at least a form of confirmation from others that something was indeed wrong with me. Finally, we met with genetic counselors and were referred out of state for an expert opinion on Chiari, something we had long been waiting for, really hoping for, but dreading.

I use the word dreading because this was so unknown. My mother had the decompression surgery when I was a sophomore (a different kind of grief altogether), but time and again I was told that this couldn't possibly be the same thing. As much as I wanted these problems to be fixed, part of me almost wished I were crazy. It is a hard feeling to explain.

In Jan. of 2004, I received a diagnosis of CM1, SM, spinal stenosis, scoliosis, a retroflexed odontoid process, etc…so many new words! It was when I found out what the words meant that the fear began to sink in.

I cried for two days. I had spent the last few years -not in denial, but in hiding. There was only the smallest handful of my peers that had any idea that something was truly wrong.

I had my first surgery in April 5th of 2004. The 2 months I spent waiting for it with my new words seemed like the longest in my known life. The word was out: Jade has something wrong with her brain, a big step from "normal."

I am not a vain person, but I realized how attached I was to my hair when I lost it. It had been very long for years; it was like my identity. I gave a 16-inch braid to Locks of Love, leaving it at my shoulders for a short time. I went into a deeper depression. I didn't recognize myself when I looked into the mirror. Mostly I was numb. I didn't cry until the night before the surgery when my mother shaved the back half of my head, crying herself the whole time. I joked that I finally had a "bowl cut", then went to my room and broke down.

Recovery was hell and I thought more than once that I had made a huge mistake. I did make it to the last couple days of school and to my graduation. The support I received from my school was amazing. I got literally hundreds of cards and I read every one.

People treat you differently though, when you return with a shaved head and a scar that looks like some kind of nasty shrimp protruding from the back of your head. It was like I was inferior; they feared me. I was truly broken----this is when I started to push people away, and I became very good at it. This includes my own family and a young man who loved me dearly, who stayed by my side throughout the entire ordeal and slept on the hard floor in the hospital for a week after my surgery.

I didn't know anyone my age that knew what I was going through or how I felt. I really felt so alone. Thankfully, (in a terrible way) I have met many "Chiari People" since then and that has given me tremendous hope. It's not that you are glad they have Chiari, just glad to have a pain buddy who understands; who speaks the same language.

Three months after recovering from surgery, I went back to work. For a couple of months I felt all right. But things started to go downhill, and fast. I got progressively worse as I pushed myself through a full-time job. I had to keep my insurance, however, so I struggled through each day. I was terminally late because pain & morning really don't work well together, and I was finally written up. I needed the job very much, but I felt like such a burden. After all, people like me "make insurance rates go up" -a few of my fellow employees let me know.

The hunt for the new culprit began. After extensive testing, it was determined that I had cranio-cervical instability, and what I needed was a fusion. I was fused Sept. 8th of 2005. What I thought was misery after the first surgery went straight out the window. This was so much worse; I couldn't even believe it! But I knew mostly what to expect, and coped with the excruciating pain a bit better.

This has been a much longer, and more difficult recovery. I am now six months out, and still in physical therapy. Many of my symptoms are gone, not completely, but more than enough to make getting fused worthwhile. I forgot what it was like to live without crippling headaches every day. My mother said it was as if I had been missing for the last couple years, my behavior had become so unpredictable, mostly because of the pain, but the sadness and the losses played a huge part There was so much I had to give up. At the time, it made me even angrier, but it was true.

For years, I had this…ugly look of pain on my face (pain does make you ugly). I always had huge eyes, but it seemed they had sunk into the back of my head, and now they are back! My "headache wrinkle" has eased up also.

This change includes attitude as well. When you focus on coping with pain on a daily basis, it makes you mean. And bitter. I had no grace or patience for other people complaining about their seemingly tiny little problems: "Oh boo-hoo, you have a cold. Until you've had traction-bolts screwed into your skull-you do not know pain!" That was my attitude.

I have realized that just because I am in pain, it does not mean others' pain doesn't matter. I have learned that emotional pain can be nearly as crippling as physical pain. I saw a sign on a church billboard the other day that said "If you have pain, don't be one." I have a new passion in me to try to help people appreciate what they have, or still have.

For a while, I had given up. I had so many dreams that now seemed impossible; how could I ever do a normal thing, like move out, when I couldn't even hold down a job? As a musician, how could I play full concerts when a 20-minute-set sets me back for several days?

Furthermore, I have lost the motion in my neck since my vertebrae are fused together. This has been the hardest change both physically and mentally. I feel so literally trapped; my head really is in a vice. The fusion is not reversible. Driving is permanently very hard, my mouth will only open a small amount, swallowing is difficult, and even the act of having dinner or conversation is frustrating because I cannot look at the person I'm sitting next to without awkwardly turning from the waist. I have lost the ability to do so many other things that are normal to most people. Things I never even pondered, or seemed trivial previously, are now things I literally mourn.

But if you focus on and keep a scorecard of your losses, without looking for what you have gained, that grief will defeat you. Why bother rolling the dice, if you are unwilling to move forward?

People judge others for numbers of reasons, but I have found that age remains one of my biggest setbacks. I am young, but I am well acquainted with grief and this is what I have learned thus far: No matter how it feels, you are not alone in this feeling. But you must face this yourself; it is in your heart and mind that the battle takes place. There is always hope for the future and the opportunity for growth, but first you need to accept your situation, and move on.

When every day is a struggle and things that should be easy throw you for a loop, know that it could always be worse. I was told that it is not people who have "perfect lives" that change the world, but those who overcome. You don't have to set out to change the world, however.

I have a friend a few years younger than me who is going through the same things I am, and I know I can speak for her when I say I don't know what we would do without each other. If you have the chance to impact even one life in a positive way, to me it is worth all the pain and suffering.

I have said so many times that this isn't what I wanted for my life, but that is not for me to decide. This is what I've been given. I don't look at Chiari as a curse anymore, but a gift. For some reason, I have been trusted with this life-changing dynamic; now I have to decide what to do with it. It took a while for me to realize, cliché as it sounds, that it is not all about me. There are bigger wheels in motion and I will do everything in my power to help so that people don't have to suffer as I have.

For so long, I tried to do this on my own. People stopped calling after a while, so I set my heart on not needing people. Those were my lowest times, when I made no progress. Putting your head in your hands and staying there will never help. The journey from grief to growth is not easy. And in order to grow, we need people. Do yourself a favor: dust off your shoulders, make them available to heavy heads, and take action.

-- Jade Carter, Daughter

Read Julie's Point of View

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