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The Journey From Grief To Growth: A Mother'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 - When extreme personal losses occur, there is a process of grieving that must take place, and a measurable amount of healing should eventually begin. But when a person is living with a chronic illness, this grieving can be a daily, ongoing process. The losses can pile up, making the sufferers quest for some sense of wholeness and joy - a continuous battle that must be fought; it is exhausting.

My grief began with the awareness that something was terribly wrong, with me, and also my young daughter, Jade; we both had the exact same symptoms, but no one could find anything wrong with either of us. The frustration was overwhelming, I feared for myself, but more for her as she was so young and had such a bright future ahead of her. My daughter had so many dreams, and goals that seemed unattainable, even for a well person. I didn't want to discourage her, but as her physical health declined I began to lose hope, however, she became even more determined to achieve all that she had planned for herself.

Grief over loss usually follows a somewhat expected pattern, beginning with shock. Shock, when the awareness of the problem comes to light. I was so shocked when I was finally diagnosed with the Chiari 1 malformation, that even I was rendered speechless, for days. Then came the fear, not knowing what the future was going to hold for me, and fear of what I now knew; I needed brain surgery and the sooner the better. I also went through a period of disbelief, and denial; "This is not happening to me, it is just a bad dream…" Then came the anger. Had I really been searching for this answer for more than 25 years? What had taken all those doctors so long? Hadn't it been there all along? (Yes, it had been there all along).

Eventually, I began stumbling through the house in a state of numbness, wondering what would happen next, and if this surgery could really help me or just make things worse. It was my brain going under the knife this time, not an ovary or tube, or some other part I felt I could live without. Fear entered the scene often, and reason went out the window. Gone was the confident, self-assured person I knew, and in her place was a distracted soul whose future seemed to be a mystery. Lifelong friends heard of my distress and arrived to lend their support to try and make light of the situation; this did help me get through it.

I felt some sense of guilt over poor choices I had made, mostly as a youngster, regarding the care of my physical body. For instance: "I bet hurling myself down that mountain on ski's at high speed and hitting a tree didn't help my condition", and, "I wonder if falling off the back of a snowmobile and landing on my head made this worse?" Good grief, I was such a tomboy and a daredevil to boot, plus my brothers always needed an extra player for their football team, I was constantly on the ground, battered and bruised. Had I known I had a Chiari malformation, maybe I would have behaved much more cautiously- nah…

I chose to have the decompression surgery; the healing process was long and painful and there were times of rather deep depression. Day after day, and week after week, then it ran into months as I tried to come back from the extreme trauma this kind of surgery produced for me. Being allergic to most all types of pain-killers didn't help the healing at all, so it was mind over matter, a way of coping I knew well already. As the journey dragged on, friends stopped coming, they got on with their lives, but mine became an exercise in loneliness. I felt like I was a burden to my family, sadness was overtaking me. I missed my job, my friends and co-workers, life outside of my home; my social life was non-existent.

Much of this was my own fault. I was afraid of being bumped in public, riding in the car seemed to be terrifying to me. Everyone seemed to be careless, reckless and disrespectful of their own healthy bodies. I was truly miserable to be around, even I didn't want my company. It became clear to me that I had major adjustments to make if I was going to ever be a happy, useful part of society again. I truly needed someone who understood what I had gone through, someone who could comprehend how defective I felt. So I began to look for companions, I found none locally, but I joined an on-line support group and I made new friends who understood exactly how I hurtful this was.

Just as things began to look up, and I had returned to work, I took a severe blow to the head. I was put into a brain rehab. program where I spent months relearning everything, and in physical therapy to regain my motor skills again. I was right back where I started before, actually worse, losses mounting, at the very beginning of the grieving process again. But this time I had learned a thing or two, I was unwilling to spend that amount of time dragging myself through the entire journey. My attitude was changing, it was plain to see that if I did not find acceptance in the new me, I could not move forward. Living in the past would do me no good, I had to re-write my story. No, it had not gone as I had planned, I may not achieve all of my goals, perhaps none of them, but life was still worth living and joy could be found in other places. I had to give up most of my previous hobbies; this was emotionally excruciating. So many things I used to be fully able to do were now out of the question, although I certainly tried over and over.

In the midst of these struggles, my daughter Jade's health deteriorated rapidly. I cannot tell you how scared I was for her, her days had become like a bad dream. She had all of the same symptoms as me, but I was not aware of the genetic factor yet, so I dragged her from physician to physician, asking the same questions repeatedly, and getting the same answers, none of which made any sense to us. Finally, it was a genetics specialist who advised us to get Jade to a Chiari expert, so we traveled to New York in search of wisdom.

What had been dismissed by our doctors at home, turned out to be a Chiari 1 malformation, syringomyelia, some scoliosis, and odontoid issues. Jade underwent her first surgery 6 weeks before she was scheduled to graduate from high school; she then began the grieving process for herself. She was already mourning for not only what I had lost, but what the entire family lost when Mom suffered; I was now thrown back into the whole process again, from the beginning, but this time for my daughter.

We have learned much about this grieving; number one: it is a well-traveled road. Many carry this burden, some gracefully, others with much bitterness and self-pity. When you find yourself living with a chronic illness, the journey can begin again before you've even made it to the end of the dark tunnel you were just walking, or crawling through. It can be one thing after another, isolating, and frustrating; number two: you must grieve each loss and let it go, so you can move on and not fall into hopelessness. When it was just myself that had to walk this path, accepting it was easier; when it was my daughter's future also, embracing it has been much more difficult.

It feels as if we've had entire portions of our hearts removed, never to be replaced; they are devastating blows, losses that cannot be measured. We determined that this could not be done alone, we needed comrades for this kind of battle. We knew there were others, but was there anyone in our area? We contacted a local writer who agreed to tell our story, and soon it was on the front page of the gazette. Phone calls began to stream in, and continue even today, two years later. We have seen tremendous growth in our personal lives, our attitudes toward the future, even with additional surgeries and complications. We have a tight circle of friends we call the Chiari People, they are a gift to us.

The losses have been great, and we are changed, but not destroyed. We have made new goals, if those goals cannot be attained, we will make others. Finding a purpose in life makes it worthwhile, and our purpose has been to serve others with these disorders, and to teach those who have yet to learn. We continue to grow from despair to dare; we dare to hope for cures, we dare to hope that our local doctors will someday understand and know how to treat us. We dare to believe that there is a reason for all of this suffering and that someday it will all make sense. We dare to feel important again, as if we are an asset to society and not a burden. We dare to believe that our friends will not always suffer, but will one day be pain-free.

Growing means stretching, and stretching is always painful. This task of living with chronic illness can be merciless at times, and we have spent many days wandering through the ruins of our lives, but we won't do it alone anymore. The grieving process is not a set schedule, it is a painful but necessary journey. Giving our pain a voice has brought healing, and allowing ourselves a time and place to rest gives us strength to face each new problem bravely. Having loyal Chiari friends has helped us to walk down roads that many have crushed us before.

If you are the parent of a child with the CM/SM disorders, your grief can literally cripple you, I have certainly been there. There have been days when just breathing seemed to be a chore, and the tears would not stop, nor the anger or the bitterness. I shook my fists toward Heaven and blamed anyone I could. Jade was saddened and mortified by my loss of hope and faith, it was hurtful to the entire family. You cannot stay in the beginning stages of grief, it is dangerous, you must move forward. The counsel and fellowship of others who have walked the same road before you can make all the difference in the world.

You must believe that your child will also find joy in his or her life. If you cannot locate a support group in your area, start one. We started with just Jade & I, then found a few others. We talk to our doctors, and many have begun to study these disorders and get interested themselves; they will go on to teach others. What appeared to be lives ruined by chronic illness have turned into consistently bright days, made so by being persistently positive, with determination to "live" all the days of our lives.

-- *Julie Carter, Mom*

Read Jade's Point of View

Ed. Note: *The opinions expressed above are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.*