

A World Full of Questions

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When looking back on the course of my life, I often find myself asking a lot of questions; questions that have no answers because the truth is, there's just too much uncertainty and confusion going on. Questions that have no answers because it just may not be the right time to answer them. Although my family wants the questions to be answered now, it just may not be the right time. It's hard for my family to deal with everything that's going on; all of the questions without answers, all of the uncertainty, and all of possibilities. It seems that I constantly think of the questions even though I know that there are no answers to them. My whole life has been one big series of questions, ever since I found out that Amanda was sick. I even find it hard to carry out a single day's activities without my mind being plagued with those questions; those questions which never seem to go away. Lately, the questions have been getting more and more frequent and more and more distracting. There have been new complications with Amanda's illness. Of course the disease is progressing and there are physical affects which are progressing but is the mental affects which are getting to me. Watching Amanda be bound to a wheelchair yet retain the mentality of a normal sixteen-year-old makes the questions in my mind arise.

Sometimes, when I start to feel depressed or sad, I find myself asking, "Why?" Why did Amanda have to be inflicted with Sandhoff's Disease? It's hard for me to comprehend the, "Why," in this whole situation because upon doing research I came across certain numbers. The numbers, although not all corresponding, told that you basically have a better chance at winning the lottery than being stricken with this disease. So why? Why my family and more specifically, why Amanda? Because I keep thinking of all of the, "why's" that my family is faced with in this

situation, I can't help but think about the, "What." What did she do to deserve being bound to a wheelchair at the young age of fourteen? What possibly could have happened to make this rare chance come true? The, "what" holds irony because although my family is wondering, "what made this happen," we are also hoping towards a different type of, "what?" What can the doctors do to help her? What, if anything, is there out in the world that could cure her? The cure, as well as all of the answers, are out of my family's hands. All we can focus on now is the question, "what can we do to make her comfortable?"

Although there are a lot of questions in my life pertaining to my sister, there is one that scares me the most; the, "When?" "When will the disease finally take her?" I try to look at the time I have now with her and have as much fun as possible but I know that the inevitable is, well, inevitable. I can't help but think about the times we used to have when we were younger; before she was sick, before I was at college and was around the house more, before all of the questions came into mind. I know that this paper was supposed to answer the questions about how dealing with this illness has affected my life but the truth is, I can't answer any questions because there are still so many pulsing in my head. No matter how scary the questions are; however, my family has always been there for each other and I know that we will always be there. Whatever the future holds my family can overcome it even if it seems unbearable. We have always been there in the past and I know that I can count on them to be there in the future.