Relationships and Hepatitis C, Part 3 - Children in the Family

February 7, 2015 By Kimberly Morgan Bossley

It can be very stressful for families of someone battling hepatitis C. I have covered every angle of the family, leaving this part for last. Personally, this one is hard, as I am putting forward the true feelings of the children of a parent or parents who have hepatitis C. This is not something often talked about, and I feel it is very important to discuss how young children feel growing up with a sick parent.

I didn't have to look far for information as I went to my own two children for my research. Who better else to ask than ones living in this nightmare. At first I was greeted with "What do you want me to say?" They were not sure what to say since no one ever asked them about this before. They thought I was wanting a particular answer or sugar coated response, but I asked for their honest feelings. I explained that if they are feeling these emotions that I there are hundreds if not thousands of young children going through the same situation. I thank both of them for being so brave to put words from little voices going through this.

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From the words of Megan 19 yrs old - I have grown up surrounded with hepatitis C. It began when my mom and my grandma Bonnie were diagnosed in 2004/2005. I was only 8 years old. Until then my life with my mom was normal. We had no sickness, no major doctor issues. We were all healthy. There were no doctor visits, blood draws, medications and limits. Life was good. Then before I could grasp what was happening, her health declined rapidly.This all really started about 5 years ago.

My life changed instantly. Witnessing my grandma who also had hep C die from the exact disease my mom had was very scary for me and my brother. Constant thoughts of worry if my mom would live or if this week would be her last. Fear is part of my life and my brother's life now.

Living with someone with hep C is extremely difficult. Things that come easy for me such as walking up a hill, or remembering things became a task for my mom that could not be done. My mom did the best she could with myself and my brother. She pushed herself to continue to run her business, volunteer for booster club, cheer mom activities, running my brother and I to and from school and our activities. I saw her push herself way too much which then resulted in agonizing pain for her later that night. It is hard to see the pain and not be able to do anything to help. I cry for her many nights. Feel helpless.

With hep C, my mom’s emotions became very unsteady. Happy one second, crying the next to pure anger. Her temper and fuse (we call it at home) was extremely short and usually came on stronger as the stress for her became too much. Getting so mad that she was not able to talk. (Riba Rage- known in the hepatitis C world)   She had told both myself and my brother that when she felt this coming on that she had a key word that was “I am putting myself in time out.” This was so that she could deal with all the feelings alone and not take it out on us two. (She does her best to protect us from seeing this.) This time out gives her a few moments alone to relax. As her liver got worse, these symptoms came on stronger and especially on the treatment. She also would become very spacey. I would talk to her and we made eye contact but she was not there. You know that parent thing where they keep asking if you are listening to them..? Often I have to repeat what was said over several times. This gets me so frustrated some times. I have since learned that my mom has been diagnosed with Hepatic Encephalopathy which is a condition that people with bad livers tend to get because their livers are not working. Knowing this and learning more about hep C has helped me and my brother so much in the fact of how I can help her by reminding her to take her medicine. My brother and I do as much as we can to help out more around the house and it really helped when I got my driver’s license as I was able to most of the driving.

The best advice I can give other kids in this situation is patience and understand that our parents can’t help what is happening to them. The three of us (mom, my brother and I) have moments where we hate this disease so much, but it has also brought us closer. We don’t take things for granted and appreciate good days. I am thankful that she has completed treatment and has been cured. I can’t thank the doctors enough. I know we have many more years now to spend with her.

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As you can see this disease takes a huge toll on families. For me, I have been truly blessed with two amazing kids with hearts of gold. I could not have fought this battle with out them. Just the fact that I fight this battle was for and about them. For we patients with hep C… learn to appreciate those caring for us. This is very hard to understand and deal with.

Link to The Bonnie Morgan Foundation for HCV for more info on H.E.

Thank you to my daughter Megan and my son Garrett for having to go through this. For forgiving me when I fall short and for truly blessing my life and giving it purpose. I love you both.

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