Mind is cloudy, Focus is foggy - Not talking weather my friends

September 6, 2014 By Kimberly Morgan Bossley

Sounds like a local weather forecast but far from it.
I want to address a very sensitive and misunderstood part of liver disease. In addition to the many documented symptoms that affect those of us living with hepatitis C, we may struggle with other serious issues as the virus attacks and damages our livers over the years. I am referring to cloudy thinking, which is a part of hepatitis life, particularly anyone suffering with critical late stage liver failure/disease. More than two years ago, I noticed a cloudy, foggy feeling in my mental clarity. I own a company, which I started in 2003 prior to my hep C diagnosis. I run the whole office and various aspects of my company. My everyday job includes a variety of responsibilities such as accounting, purchasing, invoicing, answering the phone, and dealing with customers and employees. I was undergoing the harsh hep C treatment of interferon and ribavirin, and was unable to stay focused. Doing basic adding and subtracting was frustrating. It got to the point that I could not remember how to log into the computer, a task I performed every day of my life. I would answer the phone and literally “forget” how to talk. I knew I needed to say something but the words would not come out. However, I refused to give into this disease, because I am a strong-willed and probably stubborn woman (don’t let my family hear that I admitted this). I forced myself to continue to work because I had to. I put an inflatable mattress in my adjoining office so that I could lie down when I was totally exhausted.

Twelve weeks after starting interferon and ribavirin, my hepatologist stopped treatment because I was a “non-responder.” I was devastated because this was the only treatment at the time that had the potential to cure the horrible disease that I had witnessed my mother die from in 2006. Several weeks after I was pulled off treatment, I had more energy and was able to work more.

What I failed to accept was that I was still mentally foggy and I still struggled to stay focused. I was not able to get into truly deep conversations with people. After a few moments, I would lose them, drift into other thoughts, or just become completely blank. I’d see their lip move, but not hear a word, or if I did, I would not understand what they were saying.
It all came to a head one morning while taking my kids to school. I was at a very busy four-lane intersection. It was during rush hour, and traffic buzzed by me. I don’t remember exactly what happened, but I remember the sounds that still haunt me to this day... my children screaming, tires squealing, and car horns blaring. I am grateful that I did not cause an accident or hurt anyone; there certainly was the potential. It was a moment that led me to seek help, before I caused harm to my children, others, or myself.

I scheduled a meeting with my hepatologist immediately. I cried while sharing my experience with him, and then he calmly said, “Kim you are showing the signs of what is called hepatic encephalopathy. (H.E.

for short). Hep what?, I asked myself. My mind wondered, ”What else could possibly be added to my now already very “thick” medical file? I already had a deadly disease - hep C that was at stage 4 cirrhosis." My doctor reassured me that the symptoms could be managed by taking a combo of lactulose and Xifaxan (rifaximin). My mind and thoughts were racing at the thought of two more prescriptions added to my growing personal pharmacy. My mind was throwing a pity party at the time. It’s difficult not to, but I am here to tell you to try your best not to become the guest of honor at any of those parties your mind throws. It is critical to try to stay positive even during the darkest moments.

An important function of the liver is to filter out all the toxins in your body. Because of scarring due to hep C, the liver cells become damaged and hardened, and the liver begins to deteriorate. This is why doctors require regular biopsies of the liver, so they can see the progression of the liver and assess the clinical stage your liver is in. (I will go into the stages at a later point). Because the liver is highly damaged in stage 4, it is critical that you maintain a very clean diet (as we all must anyways), eating foods that are easy for the liver to digestion and filter. If you still consume alcohol, it is critical that you stop immediately. Your liver is struggling, and by adding this or any narcotics, it increases the risks of your liver failing more quickly. In stage 4, many people begin to notice symptoms such as brain fog because the liver is failing to filter out the toxins in your body and therefore these toxins settle in the brain causing hepatic encephalopathy. It is also referred to as brain fog. It is important that as soon as you start feeling these symptoms that you seek out medical attention from your health care provider. These changes can be small but key to diagnosing hepatic encephalopathy: brain fog, changes in your mental clarity, severe mood changes and sleepiness.
There are medications that can help your body manage these toxins. These medications can combat the awful helpless feeling you feel when your mind is being polluted by these toxins.
H.E. can become life threatening if untreated or not monitored closely. People with H.E. can become unresponsive and even fall into a deep coma. If you have H.E., inform your primary caregiver whether it is your spouse, family member or close friend. Those with H.E. don’t always fully understand what is happening or may not be able to communicate these feelings when they need help.
A very good documentary about hepatic encephalopathy (H.E) is: www.hesback.com. Watch it with your caregiver, especially if you are feeling any foggy, cloudy, mental confusion. This video documents true-life patients suffering from H.E. It shows the up-close personal everyday life struggling with this condition. These people were brave enough to be in the spotlight about this very embarrassing and misunderstood diagnosis.

I had the honor of getting to know a couple who are featured in this documentary - Mike Dumont, Sandy Sellers and their son Joey. I am truly thankful to have gotten the chance to get to know them. I am thankful and blessed because of their willingness to bring this to attention, enabling others to fully understand the importance of staying on top of this and spreading awareness about H.E.
However, I am sad to share that Mike Dumont lost his very strong and courageous battle with hep C and hepatic encephalopathy this past year. He was in and out of hospitals, battling this condition. His wife Sandy experienced the struggles of the caregiver, facing lack of understanding and prejudice from hospital professionals about H.E. Sometimes they were treated disrespectfully and the professionals would not listen to Sandy when she was trying to explain Mike’s diagnosis. This is why I feel compelled to educate and continue sharing Mike’s legacy and fight with hep C and hepatic encephalopathy.I will be revisiting this topic frequently and will continue to bringing awareness to this condition.
I encourage YOU, your caregiver or friend to sit down and watch this very powerful documentary. Seek out medical assistance from a medical professional who has experience treating this condition. Most of all, don’t be ashamed or embarrassed as many out there are experiencing this very same condition.

Thank you Sandy Sellers for your strength and for truly being open and public about this. Mike’s legacy will live forever in the lives of those he helped by doing this documentary. Much love to you and Joey always.

"Not without a FIGHT!~HCV~(c)
Kim Bossley

This blog post dedicated to Mike Dumont, Sandy Sellers and Joey.
Thank you for sharing your inspirational story with the world and bringing awareness to this!