When the Pain Won’t Go Away

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Pain can not be measured the same from person to person. Sure we have those 1 -10 scales to try to share with medical professionals what we are experiencing.

What if our pain is not abled to be measured? My 6 may not be your 6 type of thing. All of us have variable pain tolerances. So for me to completely understand pain I turned it inward. I am going to share what I personally go through day to day and how I manage it, even with trying humor.

My experiences are by no means the “norm” but it has become “mine”.

My day begins very stiffly. I look more like a cardboard display figure than a human being. My muscles feel tight, my joints are frozen and to move my arms or legs can be painful. I do some stretching to the best that I can, trying not to aggrevate and start my pain. The more I move and start moving, the more limber and better I become. (When I say limber, it’s not what a normal person calls limber - with my feet over my head sitting on the floor. But rather moving with a more normal walk not the shuffle flat foot across the floor.)

I try to take a warm shower, as warm as I can stand to help loosen muscles. I have to be careful however with temperature as the nerves in my feet and legs have become more sensative and with the wrong temperature can shoot me to the roof. It feels like tiny needles stinging my feet and legs as the water hits my body. I muster through that sensation to finish my shower for the day.

My movement throughout my house is slower as the hardwood floors under my feet cause me to be overly cautious with my steps. Throughout my journey with hep C, I have lost feeling in my feet. Sure I have nerve pain, but there is a numbness that warrants me to insure each step is planted firmly.

I have found bending over or squatting to be the most awful thing since eating liver as a child. It hurts my knees; my stablity is compromised by the lack of feeling in my legs and feet. The muscle tone and strength in my body is like a very much older person than that of my 48 year old stature.

Once down, I either yell for help from one of my kids to lend me a hand to stand or I go down on all fours and then use walls, chairs whatever to pull myself up. True story…my daughter and I were out shopping at a very busy department store when I found the coolest item on the very bottom

shelf. Not thinking, I began my descent downward to that item. The closer I got to it, my legs began to shake and I dropped to the floor. Being embarrassed as we all do, I looked around to see who just saw that crash and burn I just did. I immediately looked for my daughter to help me back up, but she was nowhere to be found. I stared at those shelves made of plastic and I knew they would not hold my physical weight if I used them to pull myself back to my feet. So, I did the next best thing....sat crisscross apple sauced on the floor, up close and personal with the items I so wanted to see in the first place. I sat and sat for what seemed liked hours (not really) until my daughter peeked around with great suprise to see me on the department store floor. Giggling she asked, “Mom what on earth are you doing?” My witty responce, “Shopping, what else?”

This type of thing is very humiliating for me as I have always been a rather fit person. Seeing my body and its muscle movements deteriorate throughout the years has been the most difficult and that is what angers me most.

I can not plan events that far in advance as I am not able to know my physical healthiness for that day until it is here. I do work outside my home for a local coffee shop and that has been my motivation to try to maintain a “normal” life to a certain extent. I refuse to succumb to how I truly feel on a daily basis. By knowing I have to be somewhere and held accountable, it puts in my mind that I am still a valued and needed person in society. Crazy as it sounds it is true. I do have my own business here at my home and run a foundation as well but having those here in the comfort of my own home has secluded me from the outside world. I have found that being stuck here all day... I don’t push myself as much, which in turn gives my condition the power over me instead of me over it.

I have seen my liver specialist and family doctor about the issues with neuropathy pain and muscle, joint aches. I have been prescribed medication to help me deal with the nerve pain. I manage to take that when I remember to, but there are times I am out with my family and enjoying everyday life when sudden the pain is there full force. It causes us to stop whatever we were doing to rush home to take the medication to relieve the pain and wrap up in hot blankets, hot bath whatever it takes to ease the pain. I feel bad as I see our lives being pushed around a condition, my condition. I hate it, it angers me but after stepping back I realize it is up to me to remember to pack these medications and take them BEFORE the pain starts. It is not the fault of my body (as it has been through the fight of its life beating this disease). It is my responciblity to not be so arrogant to think I can “push” limits within my own body.

I have learned to listen to my body more. I am still a work in progress when it comes to managing my thinking that I can do it all. I know it will take time, time to adjust to my new normal. Pain can be managed like all things. I know for myself the quickest way to sooth nerves and joints screaming at you: place a blanket in the dryer on high for a few minutes, remove and wrap up in it. Voila you have a instant pain killer, naturally.

My personal life is not there for anyone to compare to but rather to relate to. We as creatures on this earth find humor in someone else’s mishaps. I describe my blunders vividly on purpose for you to find the humor in visually seeing me do the robot shuffle stiffed legged across my wood floors

as if back in the 70’s doing the robot stiff armed dance; some of you know what I am talking about there..

Don’t let your journey with hep C be one of negative adventure. Learn to smile at your blunders and make fun of yourself doing goofy looking things. Life is what we make it, even during our most painful moments.

Stay strong, Stay positive (no matter what) and SMILE…

“Not without a FIGHT!~HCV~(c)”

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