The difference between re-silence and resilience is how you see the I inside resilience.

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Working at a different middle school with a larger staff under my wing was exciting, but the reality that I would again have to have a conversation with them regarding my upcoming treatment was not. It was harder to work 10 and 12 hour days with my liver the way it was, and I had little clue that my cirrhosis had progressed as far as it had. My body would remind me that I should do well not to ignore the strength of HepC. I began to require the use of a cane as the stress began to encourage muscle wasting in my body. Within a few months I began to feel more tired, even after taking a few weeks off to deal with the stress and my body's muscle degradation. There was a lot to do at work, and I was hard pressed for time. I paid the black, tarry stool no mind and pressed on until I was too light headed to drive. Pressed by friends and family, my trip to urgent care could not have come soon enough, as I discovered I had already lost a good deal of blood internally due to my esophageal varices. The NG (a nasogastric tube, it goes from through the nose down to the stomach) tube they placed to get the remaining blood from my stomach remains one of the most painful and memorable experiences in my life. With tube still in, I felt every bump on the road in the ambulance ride from urgent care to the hospital. A few days in the ICU and some other new acronyms would teach me the importance of being vigilant about my symptoms. It was early in the morning when the GI doc came in to explain to me how the MELD (model for end-stage liver disease) system works. My MELD score of 13 meant that I would need transplant earlier than anticipated.

The reality that I would need transplant sooner than I originally thought came crashing down on me. After the GI doc left, I cried, I could do nothing else. I realized that I would need a more secure job to get my third treatment and now to manage these growing problems. I started my new job later that year, it was a rough transition to getting new health insurance, but with help I managed. Unbeknownst to me my growing encephalopathy was making my new job that much harder. A car accident would delay my treatment, and nearly broke my femur. With months of physical therapy and the assistance of a good friend, I managed to get into the best shape I could have been in prior to the start of treatment. I went from around 225lbs to 175 during the months of my prep. As I had an “event” triggered by the esophageal varicies, the treatment required me to be transplant ready. Tests, tests, and more tests kept me from advancing in my career but were serving a more important purpose.

The third treatment was different. It included a revolutionary new drug called Incivek, my Genotype, 1a, was being cured at a fantastic rate. It was still new, and few understood just how intense this treatment was in comparison. The drugs required that I eat 10-20g of fat with them, which is not easy with the loss of appetite that comes with the Triple Cocktail [Peginterferon /Ribivirin/Telaprevir (Incivek).]

The Triple cocktail managed to cure my mother, however she required four blood transfusions during it, and it took her years to recover from the other damages it caused. The real problem with this drug is that if you don't take it with fat, or enough fat it literally rips you a new one. It did a number on my lower GI, not only causing furious diarrhea that likened itself to a pyroclastic flow, but it also felt like rusty caltrops were rummaging around in my abdomen. The treatment began to work, and took down my viral load from over 9,000,000 to just about 200 within a few weeks. I was ecstatic, I'd never seen progress like this. I figured the pain was worth it. A jarring pain, and more black stool came seemingly out of nowhere. The stress from the treatment had caused my esophageal varices to rupture, I arrived in the emergency room and I began vomiting blood the moment I arrived. After transfusing two units of blood they banded the varicies, and within a few days I was back at home. There were some confusing messages from the doctor's office telling me to stop my treatment and within the next few weeks I was told to stop. My body was no longer reacting to the therapy, and this episode made me more of a time bomb than ever. The failure of my third treatment was one of the most motivating in terms of reevaluating what I want to do in life. I prepared for a career change back into the field of education.

Over the next few months I grew closer with my friends than ever before. In the summer of 2013 I was finally able to come back into the field I loved so much, working a steadier job at the elementary school I attended as a kid. I saw lots of familiar faces and was prepared on every level for a fourth treatment. But if you've noticed a trend while reading my back story here.. it's that every time things start looking up, things come crashing back down. I did not know to the extent I had encephalopathy but I would soon find out. Work became harder, but I did as best I could to keep on top of things, automating tasks which previously would require a short term memory I had a challenge keeping. It didn't hit home until i added a new word to my medical vocabulary; ascites, which had been the source of so much abdominal pain, crafted two internal casts of fluid retention around my ankles. My legs were swollen to the point that I could only move them at the hip. My new GI doc would prescribe a combo of drugs to reduce the swelling, the encephalopathy and to prepare for the next treatment.

It took months to balance out the meds properly where I could spend less than two hours a day in the bathroom, or not need to rapidly down 2 liters of water and wait for the hours of muscle spasms and cramps pulsing through my legs to subside. By then I had been fired in an explosion of organizational politics for reasons confusing to even the most logical of people. I rejoined the school where I worked in my younger days. It was home, although I was unable to work much at all due to the battle of balancing my meds. I was able to set up and arrange all of the prep for my next treatment. Friends, family and my new girlfriend have made this the best emotional support I've ever had. I am presently on the transplant list, and will remain on it until I need a new liver in a year or two, or I reach a 0 at SVR 12.

So now you know a little more of my story. I know a lot about failure, but I know even more about positivity and resilience. I began my fourth treatment a little over 4 weeks ago and it wasn’t exactly easy to do. I’m not just a cirrhotic patient, having a stage 4 decompensated liver, being banned from interferon (since the triple cocktail of the third treatment nearly killed me) makes success a little harder. I had to take on a treatment off-label, which means it’s a drug combo still in test phases and not yet approved by the FDA as a combo. It just ended phase three a bit ago and the results are amazing.