New Year, New Meds

January 1, 2011 By Anonymous

First, I want to wish everyone a happy, healthy new year, and thank everyone at POZ for embracing me, albeit anonymously, into the POZ-blog-family, and allowing me to share my story as it evolves.

This holiday season was unlike any other for me. On December 23rd, I went to my infectious disease doctor, to discuss the trend that was revealed by my most recent blood work; my CD4 count was steadily decreasing while my viral load had nearly doubled. With my doctor and both of my parents by my side, we all agreed it was time to start my HIV treatment.

My doctor wrote the prescription for Atripla, the once-a-day, three-in-one pill, and instructed me to come back in 1 month for a blood test to see how the virus was reacting to the medication. My doctor reminded me of the importance of maintaining a strict medication schedule. He told me that I must take the pill every day, religiously, and as close to the same time each day as possible to maintain its effectiveness. He warned of the most common side effects; drowsiness, dizziness, and vivid, “techni-color” dreams, of which he estimated about 20-30% of patients experience. He assured me that the majority of patients that experienced these side effects felt that they vastly decreased or completely disappeared after 3-4 weeks of use.

The timing was perfect. I had just finished taking my last final exam and I was at the start of a three-and-a-half week break. For just under four weeks I am now free from classes, reading, exams, and can fully focus on my adjustment to the new meds.

My parents and I left the doctor’s office, thanked him for his good advice, picked up my first-ever bottle of Atripla from my pharmacy, and headed to my home in New Jersey where I would spend my first week on medication. Normally, my holiday is spent with just my immediate family, but this year one of my sisters had a guest with her, who I have not yet disclosed my status to. Because I didn’t want to disclose my status to our guest, we didn’t openly discuss my diagnosis or my new treatment. My parents and sisters discretely checked in with me throughout the day, everyday, to make sure I was doing ok. When the time was right, I told them that for the first 5 or 6 hours after swallowing the pill I felt dizzy, fuzzy (for lack of a better way to describe the light-headed, ’out-of-it’ feeling), and had numbness in my face in the mornings and headaches in the evening. Based on my outward behavior, my family was surprised to learn that I was so affected by the meds. “But you’re acting so normal,” they said. And they were right. Even on those first few days, I was still able to take part in most of our holiday traditions; I played family games, cooked a family meal, watched movies, and even played in the snow for ’old-times’ sake.

My first few days on meds served as the perfect metaphor for my HIV journey thus far. Inside, I felt dizzy, fuzzy, and frustrated, while, just by looking, no one could see what I was really experiencing. I am now no stranger to hiding how I truly feel without others being able to visibly detect the reality of my inner experience. The more I reflected on this, the more I saw that the physical and emotional aspects of my HIV experience were parallel in various ways.

First, just as the overwhelming emotions that followed diagnosis eventually faded as I coped with my status, the dizziness and fuzziness from my new meds fortunately faded as well. I felt more and more like myself with each passing day. Second, just as my friends’ and family’s support got me through the emotional experience that followed my diagnosis, I also felt comforted when I talked about what I was experiencing physically with trusted friends and family. Verbalizing the worst of the side effects helped me realize that they were actually quite manageable, and I was in fact able to act quite ’normal’ despite them.

Perhaps it was for the best that I could not freely complain about the side effects as I experienced them this past week. If I was with only my family, I may have been more likely to groan about how unfair this whole situation is, or even yell out in anger, letting tears form as my frustration with the side effects grew. Because I had a house guest, however, I simply had to suck-it-up, sit on my couch when I felt too dizzy, and blame my few hours of extra couch-time on fatigue from a stressful semester at school. In turn, I pushed myself a little more than I otherwise may have to go about my day as if I was not taking my HIV meds for the first time.

I don’t mean to understate the emotional or physical experience of beginning treatment. I think allowing some time to grieve for your old, medication-free self, and even allowing yourself to feel some self-pity and giving in to some self-indulgence is hugely important for the healing process. (My therapist recommends a full body massage, for example.) But it was important for me not to get wrapped up in those bad feelings of self-pity, or allow them to obscure the reality of the not-so-severe side effects of modern HIV treatment.

My reality (which of course will be different for everyone because every body reacts differently to medication), is that as I sit here, writing this blog entry, just a few hours after taking my ninth-ever Atripla pill, I feel about 90% side-effect free. I remember reading first-hand accounts of HIV positive people beginning medication even just 10 or 15 years ago, who had drastically more difficult experiences than mine. The older pills sounded awful. They were described as chalky, difficult to swallow, and created much more significant side effects for more patients.

So, as I swallow the smooth, one-a-day pill I am blessed to have for only $10 a month on my health insurance plan, I try to remember all of my ’brothers’ and ’sisters’ who came before me and had to struggle with three-a-day regimens of pills they could barely swallow, and then fought to keep down. Or worse, the millions of people around the world who today, still do not have access to these life-saving pills that I can pick up at any drug store in Manhattan for less money then I spent last night celebrating New Years Eve.

So moving into the New Year, I hope that when I swallow my Atripla every morning, rather than allowing my anger and sadness about my diagnosis to consume me, I will instead try to remember how truly blessed I am to have my medication at all.

2010 was the most difficult year of my 24-year old life, and one that I’m happy to leave behind. Despite all of the ups and the big downs of 2010, I still feel extremely lucky to be entering 2011 with access to HIV meds and access to multiple HIV support groups and networks. I’m lucky to have the support of my amazing friends and family and lucky to have the chance to anonymously share my experience with such a strong, extensive community of peers.

I hope everyone can look into 2011 and see some of the hope that I do for this year. Despite our common diagnosis, we truly are blessed to have the resources we have available at our fingertips, at our drug stores, and at our community centers.

Because 2011 marks the beginning of my physical “fight” against the virus in my body, I feel it appropriate to also start more aggressively addressing the emotional side of my diagnosis, by taking advantage of the resources I have in my community. So, in the first week of 2011, I plan to attend my first HIV support group. I’ll be back to blog all about it.

Happy New Year!
