My Not So Happy Holiday

A lesson that adherence to HIV medication is a reality, even for long-term survivors

December 17, 2018 By Aundaray Guess

Well, I started my holiday season on a wrong note. It's the time of the year when everyone is supposed to be happy, when we enjoy festive moments of reconnecting with friends and family, and when, if you're into it, we binge-watch Hallmark Christmas movies. So why isn't my mood so holly and jolly? It could have something to do with my doctor who called me and shared some bad news. In short, he was concerned about my HIV numbers.

I knew something was wrong when the doctor called me personally at 7 in the morning. In a way, deep down, I was able to predict what he had to say. Just recently I saw him for an office visit when, as usual, he did blood work. As the needle went into my arm I was already predicting my numbers. My anxiety over his taking my blood is that I knew that recently I was taking too many holidays—you know the type of "holidays" I mean.

A time when you give yourself a pass from taking your meds that day and explain it away by promising to take them tomorrow. In my case, sometimes that tomorrow was extended to another day and sometimes, another.

Over a course of several months, I had many holidays of not taking my HIV medication. The sad thing is that I knew better. After 30 something years of living with this disease, I knew that what I was doing could lead me down the path of becoming resistant to all my meds.

I knew this from first-hand experience. Nearly nine years ago I actually became resistant to my then HIV medication regimen. Back then it was all about holidays and only taking my pills when I felt like it. Because of that choice, HIV found a way to defeat my pills. It was a scary time as I was left with no medication options and had to look at natural solutions to keep my immune system healthy. Even a common cold could be a bad situation for me. And living in New York City, it wasn't easy to stay away from germs as they were everywhere.

And here I am again with my numbers going in the wrong direction. It was self-defeating as only recently I had shared on social media that my T-cells were close to the thousand range. And now, here was my doctor now telling me they were hovering in the low-500.

In a way, I gave myself the license to miss doses because I was always hearing that my numbers were good. I had it in my head that since I was doing so well, it wouldn't hurt to take some time off from my medication.

Medication adherence is not something that only those newly diagnosed struggle with. It also affects long-term survivors. And especially as we age, we can fall into a complacency trap in which we become overconfident of our survival rate and feel we are either invincible or don't need additional support in managing our HIV.

Sometimes, as we age, it feels like older long-term survivors don't have space or encouragement to continue to take their medication. Would a pep talk have done me good? Perhaps, but there's an assumption that anyone living with this disease and taking their medications for a considerable length of time should know better and do better.

Yet as we get older, there's also the reality that most will take additional meds for other ailments that come with aging, a burden of having to take more and more pills. Others may face different barriers such as difficulty with taking the pill in general, mental health episodes that prevent taking medication on a regular basis, unstable housing or environment or, again as we age, a simple feeling of tiredness.

The good news is that T-cells go up and down and I had one simple solution to get my numbers back up. That one thing I could do was to continue with my medication and not take any more holidays. As simple as that. My barrier was laziness, and I could easily overcome this by remembering what I went through the last time I was resistant to my HIV regimen. And in a funny way, seeing my numbers decrease was the reality check I needed to not become too complacent with taking my medications. Now that I know better, I truly can do better.

So instead of dreading my next appointment with my doctor, I'll be looking forward to it because I am taking my medications religiously. And by doing so I'm guaranteeing myself that next year can end with a truly happy holiday.

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