Coming Back From Zero

April 16, 2014 By Aundaray Guess

Medication adherence is a commonly used term to describe the ability to consume your medication at the appointed time and the right dosage. Although I was fully aware of this phrase the meaning didn't have an impact on me until I witnessed the consequences of not sticking to a consistent regiment. You can say I was provided this lesson when I skipped too many dosages and eventually found myself with t-cells not too far from hitting the single numbers. As an African-American I was in a group of those who didn't and couldn't adhere to medication for my HIV. Seen as one of the biggest obstacles to helping one live a healthy life, it's also one of the largest barriers for many and at one time also me. As I have progressed and lived a healthy life with HIV I still have to remind myself the lessons I learned by being non-adhering.

I was never a pill person. Even before my diagnosis I would have much rather rest my body than take an aspirin for my headache. The pill also represented a weakness and that I needed assistance. I always considered myself a strong person and could handle my own. I wanted to heal without the aid of something made in a lab. So when I was diagnosed with HIV I knew it was going to be a struggle for me. It was one of the reasons I didn't commit to seeing a doctor on a regular basis. Since I wasn't placing myself on pills what need was there for a doctor. All he was going to do each visit was to confirm that I still had HIV. I told myself as long as I eat healthy and take care of myself I can manage on my own.

I knew I was playing with my health but the idea of swallowing a pill for the rest of my life was not appealing. I was only 19 when diagnosed so that meant a long road ahead. I was also concerned about what any long term damage I would do by taking pills for so long. Would my body be able to handle it and would my liver or other organs pay for my decision? I wasn't a conspiracy nut like some people are. I didn't think the meds were designed to harm me or make it so I would never get better. I simply felt I didn't have the will or the desire to take medication for a lifetime.

My change in thinking came when one year I was constantly sick. I started the year with bronchitis and ended the year with bronchitis. It was then I realized my method of avoidance wasn't working. My doctor who I was always running away from confirmed it for me when he told me that my t-cells were starting to dip below fifty and heading to zero. Someone without HIV has a t-cell count of 1500 and here I was on my way to zero. That's when the fear set in. In a weird way it was okay for me to have HIV as long as I didn't have a diagnosis of AIDS. AIDS was for others who truly didn't take care of themselves. AIDS was Rock Hudson with sunken skin and hollow eyes. So I was okay with HIV, but my reality was realizing since my t-cells had dipped below 200 I was now classified as having AIDS.

I had AIDS.

I was defeated and felt like I was on my final chapter of life. I felt that once you had the scarlet letter A scribed on your records that there was nowhere else to go but down. I gave in to the doctor and stopped fighting him. I allowed him to prescribe me HIV medication. It was only a square piece of paper he handed me, but it felt like an anvil. It felt heavy. But I also told myself this was my life preserver from sinking further than I wanted to.

The kaleidoscope of color and sizes intimidated me. The instructions were just as puzzling. It was a brain teaser as I had to remember to take some pills twice a day, the others once a day and the other with food one hour after eating. It felt like the math class I always skipped when I was in school. I didn't know it was going to be so complicated. Then there was the matter of how did I keep it hidden so if someone visited my home they wouldn't discover my secret. This in itself was another reason I didn't want to be placed on meds.

My will was tested when the side effects came. I heard horror stories from others sharing their experience, which added to my reluctance to taking medication. People shared stories of nausea, cramps and constant diarrhea. In the scheme of things I got off pretty lucky as the only effect I had was loose stool. Eventually that went away and so did my opposition. I was starting to feel better and my doctor confirmed it for me many months later when I went in for my lab results. My t-cells were inching up. He was still concerned why my levels were rising so slowly. When he asked me if I was missing dosages I looked him in the eye and lied. I said no.

The truth was I was taking many holidays. Holidays refer to a period when you stop taking medication. My holidays were scattered and incomprehensible as routine involved me taking just the morning dosage and missing the evening or vice versa. And some days I just wouldn't take it at all as I was tired, out later than I thought or just didn't feel like making the effort. My unspoken reason was suffering from an untreated depression that made adhering to my medication unrealistic.

My punishment? I eventually became resistant to not only my medication but to others class of HIV meds. There was nothing the doctor could do for me as anything he prescribed would have no effect. My subconscious spoke to me and simply said, "Well this is a fine mess you got us in" To add to my bad news I was reprimanded by a nurse who had befriended me and told me she would rather have me not take the pills than to take them irregularly.

My stubbornness was affecting my life and although I had the tool I was being reckless. I had to get my act together and if there was something that can help me, I should stop complaining and do what I needed to do.

Medication adherence is an important issue when discussing HIV. Resistance to taking HIV medication can have an impact on your life and health. The discussion should be based on the fear people have and how to provide reassurance and education on the importance. I would state that taking medication is harder than having the virus as the HIV can remain static and not affect your day to day life but medication is an action that requires thought and commitment.

My advice to anyone having inconsistency it to first realize you're playing with your health and when that realization hit you, find a way to create a realistic manageable schedule. Look at your life and see what's blocking you. For me it was the depression that I had to address and get it out the way. Also talk to your doctor and come up with a regimen that works for you. Since my diagnoses new pills have been introduced and can afford someone to take one pill. And any experience of side effects should be quickly discussed with your medical provider as they want to see you healthy and won't keep you on a pill that's making you sick and causing you to miss dosages.

I was fortunate when medication was finally introduced that I could take. I felt that this was my second chance to get this right. I've since dedicated myself to being devoted and my reward is seeing my t-cells climb. Where I was close to zero I can now say that I'm at a healthy number of 632. That's a long way from zero. Although I take the daily medication I still don't lose sight of my ability to take care of self, it's just that I have a little help. And that's okay.

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