# Medic Alert Part 2

October 29, 2015 By Jay Squires

My hernia surgery was not unusual. A surprising number fail and mine was my fault. My hernia had nothing to do with HIV. I included that discussion in this series because the episode raises important points.

Until then I had never had surgery and I had no idea what to expect. I researched the surgery online and became comfortable with the mechanics. It seemed to me that surgery was complex and for a surgeon to be successful he needs to deal with a new situation each time and to do his work flawlessly. I decided I needed to find out about the guy behind the scalpel.

As is the case for most doctors research wasn't an option. I wish they would learn to use the net. I had a prep appointment two days before the surgery and I took that chance to grill him. I asked about the technique he planned to use, the risks of anesthesia, the expected recovery time and many more important points.

I got the impression my doctor wanted to end the appointment but I didn't let him until all my questions were answered. Perhaps I was an unusual patient.

My advice is simple: Be fully informed about every critical event in your life. Now on with the show.

I call the day I regained conscious thought "Day 1." I woke on Day 1 with AIDS and three problems that have made life less pleasurable than it should be ever since. I had chronic fatigue that often made me "fade out" in the afternoon. Sometime I could only sit and stare. My legs first spasmed then pain began at the ankles and today affects me from hips to toes. My mind was off. I could not remember the simplest things. I misplaced items every day (phone, keys, wallet) and missed appointments regularly (Sorry Paula). The chronic nature of these problems depressed me. It seemed like I was beating AIDS but I was getting bogged down in hurtful, miscellaneous crap.

I brought these problems up at nearly every appointment with my HIV managers. Three hugely qualified physicians in two cities scratched their heads and said "I dunno." That's what I heard anyway.

Damn this was frustrating! I know medicine cannot cure all. But why was I cursed with *three* mysteries?

I didn’t give up and continued to press. The answer didn’t come from the experts. It came from my husband.

Angelo spoke up one day and described how I slept. In the past when I was told that I snored I answered with the comment, “Horseshit! I’ve never heard myself snore!” Get the joke? Angelo added the key when he said I often stopped breathing while snoring. Ah, apnea, I thought.

Banks scored me a referral to a sleep specialist (So many specialties. Why no Health specialists?) I was told to report to the hospital at 9 p.m. When I arrived a nice young man took me to a room that was on par with any roach motel. He attached so many wires to me I looked like the stereo system I built in 1978. A breathing mask was placed on my faced and I was ordered to go to sleep.

This was surprisingly easy to do given the circumstances. I woke to the summer sun beyond the blackout curtains. The young man had kept watch by night and he arrived to give me his impression. He reported I stopped breathing on average every minute.  Wow.

Later I met with the doctor who described my condition as “severe sleep apnea.” Another home run. I always go for the gusto.

She explained that I would be issued a CPAP machine to regulate my breathing. I will use it for the rest of my life. Non-compliance carries the real risk of death. Great. I might have beaten one death sentence and now I had another. “Give me a break,” I wanted to scream.

The machine was easy to use, thankfully. The toughest part was finding a mask that worked over my beard, which in vanity I clung to. In use it was quiet, non-obnoxious and I shortly learned effective. I immediately began to sleep longer--a lot longer. Today I’m on a 2 a.m. to 10 a.m. schedule and sometimes I sleep until noon. If you haven’t guessed, like many writers I keep odd hours. That’s one habit that followed me across the line.

This sleep made me rested and the contrast with before was startling. I stopped fading out nearly immediately and it hasn’t happened since. This is one “severe” disease I can handle.

I got satisfaction and help because I did not give up. Despite the fact that physicians considered experts in their field had no clue, my observant (though tardy--he waited a while to bring it up) husband solved the mystery. This is a lesson I have learned over and over again since Day 1. So many times I have been blocked with failure as the only option. I won in the end because I kept pushing despite my failure. Don’t get down when you get blocked. Step back, think, relax then drive around the damn block. You control your life. Do not take No for an answer.

*I’d love to hear from you. Email to squirescomments@gmail.com. Tweet to VA_dem.*

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