Medic Alert Part 4

November 22, 2015 By Jay Squires

I met David in the spring of 1988. It began as a standard bar hookup but I never left. We became a couple and soon found a place to live together.

The sex was incredible. We fell in love and yet we itched. In time we began to have three-ways with guys we met in the bars. In the back of our minds we wondered. Are we safe?

It was David who suggested we take HIV tests. We each went to our respective doctors who drew the blood and shipped it off for analysis. The wait began.

In 1990 two weeks were required to receive results. For me that time passed with excruciating slowness. In my mind I reviewed the possibilities and of course there were only two: negative or positive, I knew (or thought I did) a great deal about HIV. I'd followed the epidemic in the Advocate since its start. I knew what a positive diagnosis meant: Death in short order.

I did not fear death. Instead I feared what I believed preceded it. During those two weeks I read all I could about the medical progression of AIDS. One result of the disease, described as common, was AIDS dementia. This terrible condition where the sufferer loses his intellect and his personality struck me in my heart. I could imagine no worse fate. To be afflicted by AIDS dementia terrified me because I saw it as a living death, that of a man trapped in a mind no longer human. As the two week mark grew closer I withdrew, sullen and angry that I was at this risk.

I pridefully held my mind in high esteem. Throughout my life I led my classmates. Now I had graduated at the top of my law school class, I was building a successful practice and I loved it. I loved the search for precedent and its incorporation into an argument to sway a judge or jury. Most of all I loved the battle, the match of wits with my opponents. I gloried in victory and despaired in defeat.

I knew this would be lost if I had AIDS. I knew if I did I would end my life rather than decline in this way. If I did not I would stand by as my mind slipped away and I descended into madness. I could not bear this thought.

I waited, fearful, for my results. They arrived on a Saturday as I recall. I had spoken with friends about the process and the advice I received reminded me of what I was told when I applied for college, but reversed. A slim envelope was good news. A bulky one was trouble. The envelope felt like nothing more than a simple business letter though the return address boldly stated “Virginia Department of Health.” What did the postman think?

My hands trembled as I slowly opened it. When the flap was ripped I placed the envelope on my desk, sat back and stared at it. In my mind I ran through the facts that frightened me. David and I had three-way sex with 6 men over a year. I knew two sessions were unsafe. I didn't pray; I didn't know how to then. I simply breathed deeply and removed the letter inside.

I was disappointed when I didn't see "You're Negative!" in 72-point type. It took some reading to find it but I did. I was safe.

I was safe for now, but for the future? I cannot tell you I made resolutions. I did not vow to change my behavior. I simply slumped limply, happy to be alive, for now.

This fear of HIV followed me for 22 years, but this fear did not change my actions. The fear simply became a part of my life, a part of me.

On March 1, 2012 I was released from Henrico Doctor's Hospital after a 6-day hospitalization during which doctors saved my life. AIDS brought something with it when we left. I was found to suffer from AIDS-related encephalopathy and that explained my inability to walk.

In time I secured my own physical therapist and over four months re-learned the skills necessary to walk. I defeated this facet of my disease. I found, though, that I had other problems.

My memory was damaged. On one hand I had a fifteen month memory hole, from early 2011 until sometime in April, 2012. Read "The Ashes of Memory.." I had no memory of this time. Closer to home and more important my short term memory was failing. In life simple things make up our days. To live successfully we need to keep these details in mind. Trivially we scream "where are my keys" or "Damn phone"! I said these words seemingly a dozen times a day.

There were more important concerns. I missed medical appointments. I forgot coffee and cocktail dates with friends I longed to see. Anyone will do these things from time to time but for me the weight of repeated screw ups weighed on me like a stone.

Once in early 2013 I laid in bed, on my back in the dark. My frustrations and fears boiled over into tears and a harsh complaint.

I began to pray but in no way I had before. I screamed at God, "Why! What have I done Lord? Stop it! Please take this pain away!" Those screams trailed to sobs. I cried myself to sleep.

Some days were good. Others were very bad. As I became lost driving roads I grew up on I felt me slipping away. I was frightened, my worst fears coming true.

Just as I had with my legs I complained. I have been served by three talented HIV specialists, two psychiatrists, two neurologists, two neurosurgeons, and five therapists. Even with all this ammo no one could offer an answer. No one could offer help. I started to believe that my specialists were too quick to disregard what they did not understand. I believe that today.

Just three months ago my sainted counselor Paula and I discovered a solution. Paula is the exception to my rule of deliberate ignorance. My research brought me to discussions of “cognitive impairment.” CI is a point in the continuum between an active mind and dementia. Everyone lives on this line. I needed to know how far along I was.

Since my earliest days with HIV I have lived with the determination to never overlook the *need to know.* For every person living with a serious medical conditions there is a deep need to know *what?, why?, can it be fixed*? For me this problem came to concern me more than AIDS itself.

I learned that a cognitive testing analysis will diagnose CI. Paula agreed this was the path for me to take to find the answers I needed. She made arrangements and I added neuropsychologist to my list of supported specialties.

I learned I had neuropsych testing before. In 2013 when my first disability claim was pending Social Security called me in for a mental health exam. I traveled to a ratty office building where I met the Government’s shrink. She had me stare at abstract designs then attempt to copy them exactly. She had me read a short story then answer questions on the plot later. She made me guess the seconds between two taps of her No. 2 pencil. All groovy stuff and no doubt meaningful.

If the results brought news it wasn’t good. My claim was denied and I was happy because I felt I obviously wasn’t disabled. (I didn’t need the money then). This time I took time to learn about cognitive testing. I found that its principles, however bizarre, had been normed over millions of tests. Fair enough. I told myself I would scribble, miscount and forget with hope and good grace.

I was nervous and edgy the morning of the test. The administrator told me the test would take about two hours. “Wow,” I thought, “that’s a lot longer than the lady with the crappy desk.” At the end there was no discussion, just a statement that a report would be delivered in two weeks. That news gave me a flashback to 1990.

The news arrived the same way it had but the envelope was large and thick. Just as before I let it sit. My hands trembled as I sliced the seal. I removed a 20-page report. As a guy used to medical reports containing only one page filled with unintelligent babble I realized that someone put a lot of effort into this work.

It took me a second to find the important part, the part that compared my functioning with the general population by age and gender. The results mortified me. In areas from memory to concentration to motivation I was below ?? sometimes far below ?? average. Some results fell below the first percentile. What’s below the first percentile? Hell?

I was confused and didn’t know what to think. I knew I had problems but I wasn’t a mental cripple was I? While words sometimes evaded me I had no problem making my thoughts clear. I would lose my place in traffic and I had accumulated a good number of stupid low-speed bumps and bruises in my always terminal vehicle fleet. Without a solution I had grown past the humiliation of not remembering the name of a new acquaintance or worse forgetting the name of a long-time one. This checklist and those terrible numbers frightened me.

I thought it was strange when the assessor said that after I received the report I could schedule a meeting with the neuropsych who authored it if I wished. That qualifier made no sense. Who would not want to talk to the doctor? With this steaming pile in front of me I made the appointment immediately.

Still more worry time but I was seen fairly promptly. I was greeted by a petite Asian woman, younger than me, who introduced herself as Dr. Su. She sat quietly across her desk, drawing me to speak first. Hurriedly I spoke of my *need to know.*

I needed to know what happened and why. How will my situation limit me? Will my condition get worse? Could it get better? How could I build a life around these defects?

We are brothers and sisters, you and me. We share much more than a simple diagnosis received a minute after a cheek swab or two weeks after a bloody needle. We share our knowledge of how to live with this thing now attached. We know what we need and we all need these same things.

During my wait for my appointment I made my mind up to be calm about the diagnosis no matter how bad. Finally I knew what caused my problem. This knowledge might be the core of a cure or it might give me the warm comfort of certainty. Having it it was mine. I earned it.

There is no cure for cognitive impairment, not even a commonly recognized cause. My condition will likely not worsen quickly though it is also unlikely to improve. With luck future declines will be at the rate we all face though I will start rungs down from the rest.

Dr. Su smiled sweetly and showed me out. She suggested that with a baseline established I should be re-tested periodically to monitor the condition as it developed. I want to do that. I want to *know.*