

## Double Whammy

Created 26 Feb 2010 - 3:02pm

It was September 2006 and I was reinventing myself in a new city with a new job. I was yet to make any friends but I had a great apartment and a two-door sports car. I was Mary Tyler Moore.

Christmas came and went. I returned to work but suddenly one morning I had to call in sick.

The next nine days were spent in a delirium of high temperatures, night sweats, fatigue and headaches that defy description. Then things subsided enough for me to get to a doctor.

After a battery of tests revealed nothing, one explained everything. I had sero-converted. Santa had been a real asshole.

Then the headaches returned. I couldn't sit upright, and light of any kind was excruciating. I remember lying on the bathroom floor after trying to have a shower, holding my head in my hands crying for the pain to stop. I knew something was seriously wrong and drove myself to the hospital.

By 7am the next morning I'd had scans and tests and was asked to sign a waiver for a neurosurgeon to open my skull. But before that happened, the results of a lumbar puncture came back. It turned out that Santa had been particularly generous and had also given me syphilis.

I had never felt more alone or vulnerable. There simply wasn't anyone to go through this with me. I was on my own.

The treatment turned out to be massive injections of penicillin. After a few days I was discharged and went to a GP for the injections. Two hours later I was in an ambulance, sirens screaming, with a temperature of 43°C, violently convulsing and slipping in and out of consciousness. They were administering intravenous adrenalin every seventy seconds. My heartbeat was so forceful and fast I honestly thought I was going to die. Apparently, I was allergic to penicillin and so the treatment, considered successful, was halted.

It took a few months, but I got back on my feet and took a job with a community organisation. I thought helping others would be good therapy. And it was. But within a couple of months I started getting really tired, sleeping from the time I finished work until eight the following morning.

The headaches returned like before and my new boss ordered me to the doctor. It turned out the syphilis hadn't been treated as successfully as we thought.

Another ambulance and another hospital stay. This time it wasn't as simple. I had a picc line inserted into the vein in my [arm](#) [1]Any of the treatment groups in a randomised trial. Most randomised trials have two "arms," but some have three "arms," or even more. that led up to my head as well as into the main ventricle of my heart. At the other end sat a huge bottle of penicillin that needed to be changed every morning. To avoid the same reaction as last time I was also put on a [steroid](#) [2]A substance which is structurally similar to human sex hormones which is used for therapeutic purposes due to its anti-inflammatory effects. that, over night, turned me into Michelin Man, complete with dimples instead of knuckles, and swollen ankles.

After three weeks of the penicillin bottle, I was feeling much better and decided to again move cities. I applied for a job and set off for yet another new start.

Soon after starting my new job I noticed that it was an effort to perform simple tasks that I had been doing for years. I'd dial a number and forget who I was calling. I didn't understand what was happening to me or why things I once did perfectly well were becoming increasingly difficult to remember. There were issues with my performance.

I soon found myself out of work. I was again in a new city, unwell and afraid of what was happening.

Fortunately, I had two flatmates who understood that I needed help.

My temperature started to rise, I had night sweats and couldn't lift myself out of bed. An ambulance was called. The diagnosis was PCP — a kind of [pneumonia](#) [3] An inflammation of the lung, usually caused by infection with bacteria or other microorganisms, in which the air sacs of the lung become filled with inflammatory cells which solidify and inhibit breathing.. My T-cells had dropped from 900 to 287 in what seemed like a matter of months. My red blood cells were disintegrating as soon as my body could produce them and I was dangerously anaemic. Bactrim was prescribed but I turned out to be allergic to that too. The reaction wasn't good but two weeks later I was allowed home with instructions that I'd have to start meds as soon as I was well enough.

It was the sickest I'd ever been. I had to take things easily. I wasn't capable of moving about too much and could barely feed myself. But I decided I wasn't going to be sick anymore, that I would take back control and get on with the rest of my life. I got well, for about a week.

Then my temperature started to fluctuate and a strangely familiar headache returned. Over a few days it got progressively worse and I again ended up in hospital.

A lumbar puncture was ordered. The tests came back positive for neurosyphilis. Another picc line, more blood, more bottles of penicillin, more steroids, more getting fat.

During this hospital stay I spoke to the HIV team about the problems I was having with my memory and coordination. I saw a leading neurologist and after much testing and many questions I was told I was suffering the effects of HIV Associated Neurocognitive Disorder (HAND).

The HIV and syphilis were present in my cerebral spinal fluid and were affecting my central nervous system and consequently, my cognitive functioning. [Antiretrovirals](#) [4] A medication or other substance which is active against retroviruses such as HIV. that cross the [blood-brain barrier](#) [5] A selective barrier (obstacle) between circulating blood and brain tissues that prevents damaging substances from reaching the brain. Certain compounds readily cross the blood-brain barrier; others are completely blocked. would go a long way to repairing this.

Finally, in December 2009 I was well enough to start meds and (cross fingers) I've been well since.

I've noticed a huge difference in my memory and coordination since then and there's clarity to my emotional headspace that I haven't experienced for a long time.

I'm feeling pretty good and am really keen to return to work and for life to be a little more normal.

- [sexually-transmissible infections](#)
- [syphilis](#)

#### Links:

[1] <http://www.napwa.org.au/glossary/term/470>

[2] <http://www.napwa.org.au/glossary/term/354>

[3] <http://www.napwa.org.au/glossary/term/351>

[4] <http://www.napwa.org.au/glossary/term/122>

[5] <http://www.napwa.org.au/glossary/term/415>