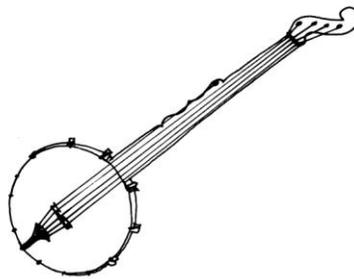


MS - A Little Piece of My Mind

by

David J. Vinci



3rd Edition - 2007

A Sample of the book

Edited by Morgan Jarema

©1995, 1998, 2007 David J. Vinci

PLEASE DO NOT PHOTOCOPY!

TABLE OF CONTENTS

FORWARD 3

THE BEGINNING..... 4

THE TESTING GETS SERIOUS..... ERROR! BOOKMARK NOT DEFINED.

AFTER THE DIAGNOSIS ERROR! BOOKMARK NOT DEFINED.

ANATOMY & PHYSIOLOGY..... ERROR! BOOKMARK NOT DEFINED.

SO, WHAT CAUSES MS?..... ERROR! BOOKMARK NOT DEFINED.

A BEWILDERING ARRAY OF SYMPTOMS..... ERROR! BOOKMARK NOT DEFINED.

DRUGS, DRUGS, DRUGS..... ERROR! BOOKMARK NOT DEFINED.

DIET AND NUTRITION..... ERROR! BOOKMARK NOT DEFINED.

DEALING WITH MULTIPLE SCLEROSIS..... ERROR! BOOKMARK NOT DEFINED.

TAKING CARE OF YOU..... ERROR! BOOKMARK NOT DEFINED.

TODAY AND TOMORROW..... ERROR! BOOKMARK NOT DEFINED.

SOURCES FOR MORE INFORMATION..... ERROR! BOOKMARK NOT DEFINED.

INDEX..... ERROR! BOOKMARK NOT DEFINED.

END NOTES..... ERROR! BOOKMARK NOT DEFINED.

FORWARD

This document is a commentary about my first year's experience with Multiple Sclerosis. I hope it provides you with some useful information and some straight answers to your questions. There are a great many unknowns with MS and questions to which there are no answers, but what I've learned is here (along with a small boatload of opinions), hopefully stated in a way that makes sense. I also hope it helps to comfort you a bit during your own first year, and gives you a little peace for that afflicted piece of your mind.

Dave

And I've updated a few things for this edition as we keep learning stuff about this disease that several folks (including me) refer to as the "really irritating houseguest that just won't go home". – DJV - February 16,2007



Yeah, that's me doing a bit of pickin'and re-enacting the late 18th century... and I made the clothes, the table and built the banjo!

THE BEGINNING

It was October 1994. The air was cool and the sun came up with the promise of another sparkling day. The oaks and maples surrounded me in a brilliant display of red, yellow and orange. Tall pines added a contrast of rich green. I walked quietly in moccasined feet along the edge of the forest, listening to the pleasant sounds; mostly songbirds and the light wind. I was dressed in natural tones with just a hint of color; brown moccasins, grey stockings, dull green breeches, a brown waistcoat, and of course my hunting frock. A pouch and powderhorns hanging by my right side and my smoothbore Brown Bess cradled across my left arm. A beautiful day to hunt. I wandered all over the forest just enjoying the quiet and day.

After awhile, I saw a fat, grey squirrel. I moved slowly and got into a good position, brought my Bess to my shoulder and pulled back the hammer. The noise must have alerted him because he started to run. I followed and squeezed the trigger. The hammer came down. The flint held in it's jaws struck the frizzen and sent a shower of sparks into the powder in the pan. A puff of smoke, then the main charge went off. About an ounce of shot was sent toward the running squirrel. The smoke from the pan and barrel was carried off by the wind. Through the haze, I saw him continue to run. All the shot had done was churn up the leaves behind him. He was long gone by the time I'd reloaded.

Ah well, there would be other chances. It was a nice day, even though I had missed the only squirrel I'd seen. I must have walked at least 20 miles by the time I got back to my truck. It was time to pack it in, put away the things of the 18th century and re-join the 1990's.

I really enjoy dressing in the clothing of the 1700's and hunting in the same way they did; it's a feeling of connection with the past. It never bothers me if I get the game or not, it's the doing I enjoy the most. There would be other trips. Little did I realize what was in store for me in the weeks and months that followed.

On Wednesday morning, I didn't feel well and called in to work. Shortly after that I got a bad fever, and the next several days I don't remember clearly. The fever,

which I'm told went to 103.5°F, alarmed my wife and she called the doctor. Over the next several days, a number of tests were done to try and find out what was going on: a CAT scan of my head to check for stroke, etc. (negative), various blood tests, X-rays, and so on. The only thing I remember of the CAT scan experience was the color of the pad on the table of the machine. It was brown. I thought for a long time that this machine was at the local hospital. It was some months later, I learned it was at a facility on the other side of town! I developed double vision for a couple of days, which we just assumed it was from the fever. This was a really strange experience. A double image of everything that I just couldn't focus into one. I wasn't frightened by this because I was half delirious from the fever, I think. I had weakness and numbness in my legs, loss of balance, and extreme fatigue. The doctor seemed fairly certain that the problem was a very serious viral infection. He prescribed a strong antibiotic and huge doses of tylenol to bring the fever under control, and advised us to wait and see what happened. When the fever finally broke, I realized what was happening to me. It was my turn to become frightened. Up until then, my poor wife was being scared for both of us.

I improved as the weeks went by, but was still very weak in the legs. My balance was better but still not normal, and the awful fatigue continued. I went back to work for 1/2 days, and eventually worked back up to whole days, but it was very, very tiring. I had to take a nap every day after work for an hour or so. By Friday I was exhausted. A strange numbness went from my waist to the floor--save a few spots-- and the bottoms of my feet had maybe 30% feeling. I staggered rather than walked, and used walls, furniture, anything to keep from falling. In spite of those efforts, I did fall a lot.

During a visit to the doctor in November he considered Guillain Barre syndrome, but he said my reflexes were too good. He still felt that the cause of my problems was a virus, and offered to send me to a neurologist. Since I had been improving, I said, no. We decided to wait and see if it kept getting better (ah, the eternal optimist). A few weeks before I had walked 20 miles through the woods. By November I could hardly walk a city block.

With the help of two friends, I did get to go deer hunting during the special muzzleloader hunting season one Saturday. So, my Brown Bess and I, hobbled along the brown cornfields in the cold and crusty snow, looking for the elusive white tails. I walked for a short way, then stop and rest, then move again. It was slow going, but I did it. I didn't get a shot though as the only deer I saw were more than 300 yards away. That's too far for my smoothbore. I was exhausted when I got home. So much so, that I slept nearly all day Sunday. Still, I did get out once, thanks to some good friends. It felt so good to get out in the woods and fields again! I was feeling trapped by my inability to walk but this days experience did me a world of good. And, I didn't fall, not even once (near misses don't count).

In mid-December I went to see the doctor again for a check-up. He noted improvement in my walking ability but it was still not good. Again he offered to send me to a neurologist. I was really concerned at this point and agreed, as my condition had not improved in the last two weeks. We made an appointment for January 5, 1995.

Three days before Christmas I caught a cold, and all my existing problems got much worse. I suppose I was more scared than before because I thought that the worst was over. This was not true, as I would soon learn. A call to the doctor revealed that there was no way to see the neurologist earlier than the appointment. I just had to wait. The holidays were not a whole lot of fun. I made a Christmas shopping trip to the local mall, which turned into near disaster. Between the ice and snow in the parking lot, and all the walking, I almost didn't make it back to my truck. When I did get there, I had to just sit and rest for about 15 minutes before I had enough strength and control of my legs to drive. I was falling occasionally, my right leg was much weaker than the left, and just to make things interesting, my right foot would drop when I walked, causing me to stumble. I tripped on anything: carpeting, grass, dust, even a pencil mark on the floor! It was embarrassing. I began to have constant low back pain all the time from compensating for my malfunctioning right leg, and pain in my knee and ankle joints. Just to round out the picture, I had some spasms in my legs and feet mostly in the evenings. And then I started having trouble with my sphincter control. I tired very easily and didn't have much energy to do anything.