

“Courage is resistance to fear,
mastery of fear, not absence of fear.”

Mark Twain

Managing with MS

By

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The summer of 1995 was building to an emotional crescendo. The previous November I had left my job with severe back pain. Workers Compensation required me to complete a six week rehab program after which I would return to work. No questions. Nearing the completion, the physiotherapist, noted a limp in my gait, my walk had not resembled somebody with a back problem. A basic sensory test on the soles of my feet revealed a lapse in reflexes in both legs and feet. Slight numbness was present on both feet, not a regular finding for someone with a bulging disk. A myelogram at the then KW Hospital revealed a bulging disk at L4 L5 region which is the lower lumbar region of my back.

However, the orthopaedic surgeon began asking me about the possibility of encephalitis as a child. I had the usual menu of childhood ailments, measles, chicken pox, and had my tonsils removed twice. I was scheduled to have a CT scan on my head to look for signs of scarring related to encephalitis, or the possibility of a slight stroke or a tumour. In addition an MRI was scheduled for May.

I wasn't fearful of the CT scan but an MRI did worry me. To my knowledge this was a test that athletes underwent to indicate injury. Once again, the object was my head. Certain acquaintances would have understood all too well the tests being taken on my head. This would confirm many friends and family suspicions accumulated from knowing me over the years.

I began to research my symptoms on the internet. They were consistent with multiple sclerosis, while a “magnetic resonance imaging” scan was a relatively new procedure at the time that helped confirm a diagnosis of ms.

I had the CT scan and the results came back negative. An appointment with a neurologist in April involved a discussion of potential problems, one of which was multiple sclerosis. He gave me a choice, investigate my symptoms or check back with him when I was ready to seek clarification of my condition. I told him to go ahead because it would be something I would worry about continually. I had to know.

He set up a visit at the MS Clinic at The London Health Sciences Centre. It was scheduled for July which would allow for the results of the MRI to be disclosed. I arrived at the MS clinic and was told that I had to have a “spinal tap” to supply them with a sample of my cerebrospinal fluid. The fluid would be tested quickly for antibodies that correlate with inflammation, a tell-tale sign of ms. I had an office physical which tested my reflexes and hand –eye movement. The “pinkie”

finger on my left hand had a slight tremor. Dr. Nichole explained that taking the results of the MRI, the office examination, and the findings from the cerebrospinal fluid indicated a positive diagnosis of ms. He said to go home and get on with my life. I was shattered. My eyes welled up a couple of times as I had known the probability of the result but held out for a “positive” outcome. I knew from my own research that it did not mean everyone who has ms is facing life dependant upon a wheelchair, but lifestyle changes would have to be made.

In late fall 1995 I began every other day injections of interferon. This was a powerful new treatment for ms that promised to slow the progress of the disease. I was faithful to the treatment. However, I didn't look outside the perimeters of Allopathic or western based medicine for a complimentary approach.

My symptoms were exacerbated by heat, and stress. The result would be an increase in muscle tightness and numbness in my feet and legs. In spite of that I walked without a cane and got around pretty well. In early 2002, I found the numbness and tightness increase. It was, I felt, time to purchase a cane. It was helpful, but more of a concern was the manner in which my condition had deteriorated in a short period of time. I continued with the interferon treatment and by late July I was getting worse. The numbness and tightness were not letting up. By September I was feeling awful, tired and irritable. The soles of my feet felt like I had steel wool knitted into the bottom of them. My balance was distorted because of my “steel wool” feet.

I huddled with my neurologist, Dr. Mandolino, the pre-eminent ms doctor in the Waterloo Region, in late September and we decided to begin a program of steroids. I would receive one week of Solumedrol administered by intravenous, followed by three weeks of the oral steroid Prednisone. This was to help arrest the exacerbation. At a follow up appointment with Dr.Mandolino I asked if I would be able to return to the pre-attack mobility which required the use of a cane but not complete reliance on it. She shook her head no. The steroids helped but I found a stronger reliance on the cane as well as the support of my family. I was at the mercy of ms, and my own fears.

After talking with my family doctor about possible side effects from steroids (which included a rise in blood sugar levels, diabetes is prominent in my mother's family) blood tests were taken in late December. The results indicated that my red cell count was dropping. Dr. Houslander referred me to a specialist, an internal medicine doctor –Dr.Spanglet... I met with him in early January, 2003. He asked me about fatigue and general well-being despite the residual effects of ms. My energy level had improved after the round of steroids and the only drowsiness was caused by the “tizanidine” medicine that I took for spasticity and numbness. Further blood tests indicated that my white cell count was also dropping. I had become anaemic and the doctor hadn't any idea why.

I researched this which revealed a possibility of leukemia. At an appointment in late January I asked Dr.Spanglet about cancer and he said that he didn't think it was leukemia. We talked about the potential of my body reacting negatively to the interferon.

After all, I had taken it for six years and had tolerated it reasonably well. He arranged for a bone marrow biopsy. Examining my bone marrow would reveal the onset of blood disorders such as Hodgkin's disease, Leukemia, or anaemia. We decided to stop the interferon four days before

the biopsy. I was vexed by the potential of having to deal with two chronic illnesses, one which could be fatal. I spent a few nights awake pondering my mortality while reflecting on my life.

The day of the test arrived and the biopsy involved a local anaesthesia to my lower back and hip. He would go into my hip with a needle to extract marrow from my hip bone. I say try because he couldn't get enough to make a proper analysis. After the procedure, routine blood work was done and I was free to go home and wait out the results.

Two days later the phone rang and it was the doctor. Both the red and white counts had returned to normal. Now I could catch my breath. Life has delivered to me many surprises and a very important one in the aftermath of my health crisis.

I met a healer. Susan uses Reiki and craniosacral therapy to aid in healing the body. She urged me to reconsider the use of interferon as it was having adverse effects. I took her message to heart after having some in depth conversations about eastern philosophy and life style. This was the beginning of my journey to improve my overall health and well-being.

The first book that I read on holistic medicine and spirituality was "Quantum Healing" by Deepak Chopra which focussed on the mind-body connection. In order to improve our health it is essential to begin at the cell level. I began meditating and visualizing twice per day. I literally visualized myself walking without a cane.

The term "our biography is our biology" is fairly common in the annals of holistic and spirituality journals. Stressful events can precipitate ms attacks. My father in law had been quite ill for some time, and succumbed to (what we thought was but had never diagnosed as) cancer in late August 1994. My former wife had a very close bond with her parents and we were all very distraught. By late October, my lower back was aching. In retrospect this was my first ms attack. Moreover, in 1981 I had experienced the loss of my four year old niece in a drowning incident, and a very good friend of mine died in a fire in 1982 a month before my wedding. Jim was going to be my best man. By 1986 I was in the throes of a messy divorce and custody dispute. I remember thinking to myself that if I survive this with my health intact it will be a miracle. My biography did become my biology.

After the ms diagnosis a physiotherapist suggested that swimming would be very helpful to improve strength and conditioning. Embarrassed, I didn't want to admit that I couldn't swim. Now, it was vital to my long term health. I signed up for swimming lessons which helped me gain confidence in the water and help dispel my fear. My weekly routine now includes two visits to the Breithaupt Centre for swimming.

The ms condition is centred around or contingent on inflammation. By summer I had started to move away from fast foods and processed foods. I located a newsgroup: ms-diet.org which offers a list of what foods to avoid and what to eat.

There is an excellent network of people and information with ms from many parts of the globe. By eating a natural diet free of meat, dairy, wheat, and sugar, I would allow my immune system to become more balanced. I plan to meet with an allergist soon to arrange for the ELISA test to locate any food allergies. Still, I have more work to do in this area.

I had heard about mercury toxicity and how it can play havoc with auto-immune diseases such as ms, lupus, and fibromyalgia, among others. I began to replace my mercury amalgam fillings, and have noticed a marked improvement in my cognitive and physical levels of functioning. A website with information on this is “noamalgam.com.”

Next, I began to research Pilates. I read about the benefits of Pilates on ms and in general. I thought, since I am being inclusive about my health, this was worth a definite look. I registered at Breithaupt Centre and was scheduled to begin in mid September. At this point I was still dependant on a cane to go anywhere. While Pilates is in the vernacular of a holistic approach I found the one hour of stretching and conditioning both challenging and noticeably helpful with my balance and stamina.

I had been walking each morning for 1.5 km with a cane. In the afternoon I do press ups to strengthen my upper body and stabilize my back, as well as twenty-five minutes on the stationary bike to maintain muscle tone in my legs. By mid October, I was feeling stronger and had a more positive outlook. On October 19th I set out for my morning walk without the cane. Before leaving I thought, “What the hell, the worst I can do is fall.” It was a “red letter” day as I made my trek minus the cane. The Pilates program was instrumental in my mobility improving to the point where I haven’t relied on the cane since. I still carry it like a staff for my morning trek, but everywhere else it is absent. I do not walk with the grace of a “Baryshnikov”, however, with a commitment to my discipline that includes Pilates, I know that I can improve my range of motion and manage my ms effectively.

Our instructor, Karen Toth, is good at communicating the message of Joseph Pilates and offers a fresh approach to each session. I recommend to anyone who has a chronic illness that causes discomfort, or people with no outstanding health issues to give Pilates a chance to improve their overall health and well-being. To learn more about Pilates, an informative web-site is “stretchyourlife.com.” as is “authenticpilatesmethod.com/harvardarticle.html.”

While I have embarked on an alternate journey with my health, if I should ever have another serious health issue, I would not hesitate to follow the advice of a doctor and reinforce it holistically.

My acknowledgement of fear that accompanied ms has motivated me to resist the given implications of the dis/ease, while adopting a balanced approach to my health. I accept more responsibility for my own health, while mastering, with courage, my fear of ms, and a future with it.

Take Care and God Bless

Kevin J Kieswetter