

**Title: My MS Experience**

**Subtitle: My MS Story**

**Second Subtitle: #0 Heather's Story**

Author: dizzylizzy

Date: 2008/5/5

URL: <http://www.ozms.org/modules/article/view.article.php/c1/68>

Keywords: rough, start, childhood,

Summary: OK! Who slipped me the Kryptonite!

Hi all

I am doing my best here, but my MS has left a black hole in which my memory often vacations.....

### The Early Years

From what I have been told I had a rough start. My mother was a single parent with two small children when her terminal Cancer was diagnosed. By then I had nearly starved and had succumbed to pneumonia, and so became the first toddler to be treated with the then brand new drugs, Tetracycline.

Following her death my sister and I were adopted by my Mother's sister and her husband who already had 3 children.

For the most part I was a very quiet child who was subject to a lot of chest problems. We all had our flu shots each year.

Other than that I suffered through all the normal childhood ailments, discovered reading and tennis and cruised through childhood. I had an extremely vivid imagination, which made up for not being very confident.

I auto-piloted through Primary School. My almost photographic memory meant that I really did not need to work at learning (I thought all but the 'special' kids were the same).

I was fascinated by the colours and textures of the world around me both apparent and under the microscope.

### High School

This was a whole other ball game!

My adoptive sister and I started at the same time, but in different classes.

I was pretty much still small and pale, she was robust and looked at least 4 years older than I.

Languages for the first time, and teachers trying to act like buddies or adversaries.

Prefects, school socials (dances) which were mandatory in the first year.

An unexpected affection for a classmate who was even shyer than I- I howled like a baby when he died of an asthma attack whilst on holidays. Never did get to tell him.....

Began competing in track and field type events with the school. Other students began to change a LOT. (One of the guys who started the school year arriving in his slippers turned into an Alice Cooper clone!) Nearly every female student had a crush on our Head Prefect who was a totally gorgeous fellow of Indian descent.

My dalliance with track and field comes to a halt after the first sports' day in my second year of High School- woke up the morning after all puffed up and lumpy. Weeks in bed with Glandular Fever. Harder to bear was the taunting over the malady's nickname 'kissing disease :(

I am informed that excessive physical activity in the next couple of years will likely result in a relapse.

But before Uni have snuck on to hockey and volleyball teams. Very distracted during my matriculation year- but that is one whole other story!

University didn't last long. Although marks were excellent, management of the DipN course didn't think much of my future in Nursing as I was incapable of emotion isolation. Also I embarrassed them a couple of times by doing the right thing on behalf of the patient before they had worked out what the impact of their actions would be. (another whole other story)

The death of that dream was hard to bear, and I do not think I slept more than 30minutes/night for several weeks. I crashed emotionally. Once over that I went to Vocational Guidance and from there into the Australian Public Service after 2 weeks of working in Promotions in a major store.

## Employment

I had quite a few happy and productive years working in the Australian Taxation Office. There was the odd niggle and the odd conflict, but for the most part the work I tackled suited me well, and I took pride in the fact that my supervisors usually gave me the backlog cases which they had not been able to fix, and those cases usually were all resolved well before anticipated time of completion. Enjoyed the running around and digging for precedents and consulting the 'experts' prior to working out my approach, and the surprised expressions with each success.

Resumed participation in hockey, then having moved away, took up tennis instead, finally trading that in for the dizzying world of amateur theatre. It was during this time that I became pregnant, and also started to experience some disconcerting episodes of 'drunken walking' even though I was totally sober. Investigation of my inner ear revealed some pressure problems but not enough to explain my difficulties. The specialist put in grommets anyway, and I improved.

Soon after my post maternity leave return to work I had a 'nervous breakdown' and also succumbed to chronic bronchitis, but returned as soon as I was able. I found everything a tad more difficult then, and also developed a ganglion cyst on my writing wrist, but the office got me into the part time

employment listing as soon as they could and Centrelink subsidised my reduced earnings with a small but welcome part sole parent pension.  
Finances were tight - but we managed.

Over the next few years I signed up for my very own mortgage, my daughter started school and I married. Part way between my daughter starting school and my wedding I had another weird episode. My entire abdomen went numb and I could not get out of bed without assistance. This was accompanied by a feeling almost of euphoria. My GP was perplexed but advised me to let it go for another week. By the end of that week I was able to arise without assistance, so back to work I went. Again I found I was having to work that bit harder to achieve my desired outcomes.

A change in vision led to a new glasses prescription.

Now I found myself needing to write stuff down- or forget appointments and must-does. Hello? Whatever happened to my almost photographic memory? The tasks within each separate area seem to be changing on an ever increasing basis and I am finding it difficult to keep up. ME?!!!!

Turning Point

July 1997 arrives and I awake one morning with a 'dead' foot which does not come good with moving around. Over the next few days the numbness climbs higher, then the other foot goes numb too. My GP makes an appointment for the next week with a diagnostic physician. By the time I see him I am numb to just under my breasts and have had no bowel control for days and I am panicking!  
The diagnostic physician tells me I am stressed, accept it and get over it.

Initially shattered I then become very very angry and back to my GP I go. He writes out a referral for a Neurologist. The Neurologist sends me off for an MRI. He was so peeved at the MRI tech who wrote that the only times he has seen this type of scarring on the spine has been in MS. The Neurologist will not commit to a diagnosis which leaves me in a bad place. By now I am moving like a woman with two wooden legs, cannot have a BM and I am constantly on the verge of swooning away with overwhelming fatigue.

But without some sort of official report the office will insist that I conform to the set hours and tasks.

I am already mentoring fellow officers in the new section tasks, and I have been ensuring that my supervisor's statistics are in on time and drawing up and/or flow charts for the new tasks as there has been inadequate training time allotted. It is marathon level difficult, almost impossible, and I have nothing left by my return home each day.

My supervisor had taken to 'riding' me. In spite of knowledge of the ongoing tests, and the provision of much material to explain what I am experiencing she remains insistent that I am capable of doing all that she directs. Not at my best at that time I am unable to maintain my equilibrium against what is basically the same few questions asked over and over. She never raises her voice. And she does not stop until she has caused me to raise my voice or cry and leave.

My wages have dropped below survival level as I have only been attending work occasionally, and then leaving or napping when the fatigue makes it impossible to continue. It is against my personal ethics to stay when I am unable to contribute to productivity, so THANK GOODNESS there is no limit

to the amount of leave I may take without pay, providing that for whole days or consecutive days I still obtain a sick leave certificate. The prospect of enduring the quiet bullying of my supervisor probably contributes to the reduction in time before fatigue overwhelms me.

At the first Neurologist's suggestion I commence taking an anti depressant. Looking back, that medication made me worse. By now the office has me on a 'work hardening' regime, plus a 'Graduated return to work' schedule, and I am at risk of losing my home. I cannot meet my mortgage and can barely pay my Health Insurance cover etc.

In desperation I request another Neurologist referral for a second opinion.

The first thing this marvel does is change my medication to Zoloft for anxiety. The difference is immense. My daughter who had apparently decided I had gone early onset gaga almost wept for joy two days in on the new medication.

It is suggested (by Multiple Solutions?) that I may be eligible for a supplementary disability payment. So I write to Centrelink. They arrange an appt with their CMO.

Tests at the hospital are organised. The results of the Evoked Response Tests and the Lumbar Puncture leads her (the second Neurologist) to definitely confirm MS.

Before the report has been written I am advised by Centrelink that I am eligible for a supplementary pension and that they will backpay to the beginning of my 'graduated return to work', and also back pay me for the difference in Family allowance back to that date. WOW! By then I have cancelled my Private Health insurance as there is definitely not enough income from work to pay for it. Centrelink's CMO is satisfied that I have MS., my own is yet to be convinced.

Finally the CMO has the report and forwards it on to the powers that be. Is there any ease up by my supervisor? No Way. She continues to harass me at every turn. She seems to have taken it upon herself to 'prove' that I am still as capable of high level high quality output. I am riding the invisible wheelchair which she is certain does not exist.

Eventually the decision is made to retire me on the grounds of invalidity. I am to receive a pension, and the lump sum payment of my Superannuation contributions. In the interrim I am to receive a fortnightly payment which is actually higher than my fortnightly wages before my 1997 attack and also higher than the pension that I am to receive. Way too exhausted to feel relief at the possibility of keeping my home.

In a way I suppose I should be grateful to that B\*\*\*\*. I am certain that her needling made my fatigue worse- it was very noticable to everyone else at my workplace. And I would have mourned the loss of my vocation, the companionship of workplace peers and the affirmation of my value in the form of a pay packet a whole lot more if I had not to endure her. (I did try to get transferred into another team more than once).

Now

It is now more than 5 year since my retirement. Sometimes I still miss my job. But I cannot see myself ever being able to hold down a job again. Eventually I experienced the remission of nearly all of my physical symptoms. But the black hole (that my memories vacation in) seems if anything

larger. The mortgage was paid off just as soon as I was assured that Centrelink would not seek any of my lump sum payment, and I also paid (way too much) to have my bathroom renovated to make it more user friendly for me, and had my roof repaired and painted professionally. I have helped with wedding expenses for my now adult daughter, and purchased a gopher for those days when my legs co-operate even less than usual.

I discovered eBay and on line (play money) poker and have self taught myself some craft skills and belong to several on-line forum groups. Very handy because I find myself at my best during the good dark hours. Sunlight makes my eyes very tired very quickly.

I look back and think 'Who slipped me the kryptonite!!'

If anyone had told me that I would ever have to live such a life of limitations ten years ago I would not have believed them. But I am now reasonably content with my life of frugal comforts and bite sized aspirations.

Heather