

MND Diagnosis Perspectives

Keith Sunbeam

Hi, my name is Keith Sunbeam, I was born in 1946, I am a baby boomer and live in Brisbane with my wife Alexis and our daughter Hannah. I was diagnosed with motor Neurone Disease in early 1995, in hind sight I can find possible symptoms that go back to late 1989. By Xmas 1995 even though I could still flex some muscles in my thighs and twitch a couple of toes, I was in a wheelchair.

I guess I'll start my story just prior to my diagnoses, when I was enjoying a time in my life where I felt like I was completely in control. I owned a cartage contracting business that was returning good money, my wife had a good job and our daughter was doing well in high school. We had our own house and had just bought our first investment property, so of course had a large mortgage to go with it. We had set a goal of early retirement, when I reached the age of 57. Our daughter would then be in her early twenties and we were going to spend time caravanning, while we were young enough and healthy enough to enjoy it. We would do the odd job of work along the way to supplement our investment income. Once we tired of tripping about, we would get back into some small business, but more for the fun than the money. Sounds great doesn't it? Not too over the top but very achievable. Then one day I had a slight accident at work, I jumped down from my truck, stumbled and landed on my knees. Both knees were badly bruised, the right one the worst. A couple of weeks later after most of the swelling had gone down I noticed that I was starting to trip over more than usual and then I developed drop foot in my right foot. I hoped that when my knee was fully healed all would be back to normal but not so, it just continued to get worse until my good wife convinced me to see a doctor. After a series of x-rays etc, arrangements were made and the perennial nerve was operated on, where it passed under my kneecap, (the theory was that it may have been pinched) in the hope that this would solve the problem, but alas no. It continued to worsen so more tests were done, a cat-scan, MRI, biopsy and EMGs.

The end result being told by a neurologist, "You've got Motor Neurone Disease, you will end up in a wheelchair, we don't know what causes it and we can't cure it. Take this brochure home and read it".

We took the brochure home and read it in total disbelief, it took a long time for it to sink in and even now I can't accept being informed by a brochure that I have a life expectancy of only three to five years, which by the way has turned out to be totally wrong and I have not been to a neurologist since. It wasn't easy to tell the people I worked with either, how do you say to someone at smoko when they ask "So, what did your doctor say"? "Oh not much, just that I'll be dead in three years,,,,,, have you finished with the sugar?" Guaranteed to kill a conversation.

Somewhere in the deepest darkest corner of my mind lives a little gnome, called the Brain-Master, (I got him from my daughter when she was little) when things get bad, I talk to him. (not out loud) He said to me "Now you know things like this don't always happen to someone else. But hey look around, you will see the disease didn't pick on you personally, you weren't singled out. No you are not a failure either, but above all else you must remain in-charge of your mind. It will take you to places you want to go to long after your body can't." That's as close as I get to religion.

Due to a good sense of logic I spent very little time in the 'why me' denial stage and I quickly set about resetting my goals. To make my house as disability friendly as possible, to reduce my debts and to sell my business, the latter turned out to be the most painful and stress laden of all. One of the things I have learnt is that when a man has MND the animal instincts in us drives the weaker male from the herd, it is not like that with females, they will close ranks for protection and support. Having just purchased a computer for the business and my daughter's school assignments was a stroke of luck. By far one of the best things to come out of a less than ideal situation and with the help of one of my few remaining male friends, I quickly got myself up to speed. I also embraced the inter-net and for anyone with a physical disability this is their Holy Grail. On the inter-net feet are not needed, only time and I have plenty of that. I communicate with others in a similar situation, we keep each other informed, share experiences, tell dirty jokes etc. These new friends replace the friends of a life that is slowly disappearing into the past. The inter-net has provided me with much more information on my disease than I could ever acquire from any other source and in a way that is easily understandable. I guess that's because it is mostly anecdotal and not just quotes with indifference from medical books.

From the inter-net I learned of Lyme Disease and discovered an incredible amount of co-incidental evidence that lead me to believe I may possibly have LD and not MND after all. This faint spark of hope was snuffed out by the medical people I approached with this idea and they flatly refused to carry out the tests required to discount this theory. I know of other people encountering a similar situation so it is no wonder doctors are not held in very high regard by some MND sufferers. It was about nine months from the time I was diagnosed until the time I started to use a wheel chair. Another one of those psychological situations where my physical downhill slide clashed viciously with my natural mental goals of onwards and upwards, no way did I want a wheelchair. This feeling was quickly overcome when I discovered I had reclaimed my accessibility to shopping centres, movie theatres and all the other places I could not walk to. I made a point of buying a Ferrari red W/chair so I wouldn't get lost in the crowd. Now other than my wife and daughter, my wheelchair and computer are my best friends.

Pre MND I was involved in an assortment of out door pursuits, boats, car clubs, camping, I was also a very keen aerobatics rated pilot. So in my early wheelchair days I joined the Sporting Wheelies and Disabled Association and got into a few of their recreational pursuits. I played Wheelie Rugby, abseiled down a cliff in a chair, water-skied and parachuted from 14000ft, twice. I worked out at their gym too, twice a week, not bad for a body with half a century on the clock. As we know the brain is not directly affected by MND but its competitive spirit sometimes has a tendency to coax the body into pushing it's boundaries to their limits. In my case it always wants to push beyond. I have discovered that excessive exercise on deteriorating muscles takes a lot longer to recover, now maintaining flexibility is much more important. I no longer go to the gym but still try to keep as mobile as possible.

All my life I have been a typical do-it-yourselfer, a true blue 'Tool man'. It goes against my nature to pay some one to do something I could do myself. Not only did it save me thousands of dollars over the years (money that you don't pay tax on) but I enjoyed the satisfaction of dismantling something that was 'not fix-able' and fixing it. Now whenever I do manage to get to my workshop just to have a look around, my tools all stare back at me like little puppies wanting to go for a walk, I don't have the heart to tell them, no chance.

One of my ongoing goals is encouraging disabled and retired people to set themselves up with computers and the inter-net as soon as they possibly can. I want them to understand that it's easy, it's powerful and it's fun. In order to, 'still feel useful' I have now been secretary of our local support group for more than three years. I find people newly diagnosed are generally reluctant to join support groups, I think for fear of seeing other members in a more advanced state. I know in the beginning I felt that way, almost like standing in a line at a cemetery, but now I just get on with life. Unlike a sporting club or service organisation we can't offer sufferers recreational activities, one is only involved because of one's need, not one's desire. Once a victim dies that persons loved ones don't always want to be reminded of the past, they then drift away not realising what they still have to offer by way of moral support. So there is only so much that a group like ours can achieve.

The internet helps fill this void extremely well, so I set about establishing Ozpals. Firstly as a mailing list and then with the help of Robin Balsdon, the web-site. As our MND dictates we will pass the baton on to other MND victims to carry. It is my wish to see Ozpals as a useful source of MND information in Australia and New Zealand. I would like to also see Ozpals develop some sort of lobbying role to help advance awareness of MND and services for sufferers, this is something we can all get involved in. Finally, here is a thought to ponder on.

Princess Diana and Dodi, died in a car crash while out on the town enjoying themselves. Sonny Bono was out snow skiing and slammed into a tree, killing himself. John Denver was test flying his new aeroplane, he ditched into the sea and didn't survive. John F Kennedy Jr crashed his plane into the sea, killed himself, his wife and her sister.

All of these rich and famous people died very unexpectedly but were enjoying themselves when it happened.

Meanwhile here I am, still alive but slowly deteriorating from Motor Neurone Disease. (Lyme?) Which of us is the lucky and which of us is the unlucky?

Keith Sunbeam..... Enjoy today,