

I am a 66 year old male , who has lived with back problems since 1973, mid 1986 while holidaying in Oregon I went white water rafting on the Rogue River on an inner tube, unfortunately I was thrown off and hurt my spine, my legs were paralysed for a period of about 20 minutes but I still managed by the grace of God to get down the rest of the river using upper body only, did not attend hospital.....

Late 1987 I stretched in bed and the unbearable pain travelled up my spine to my head, this resulted in a period of 6 weeks being unable to work, was sent to Bridge of Earn Hospital in Scotland, nurse walked straight passed me as I was lying in agony on the floor they were useless, finally got back on my feet thanks to a brilliant Sports Medicine Chiropractor from Dundee.

1988 we moved to Australia to live, in 1989 I had motor vehicle accident that again exacerbated my back problem. In 1995 I was given a spinal manipulation and fitted with upper body brace.

1996 completed RPA Pain Management Clinic; very successful, excellent programme covered all of the different aspects, and excellent clinicians in the main.

1997 Bilateral Facet Block RPA Hospital, total waste of time.

1999 diagnosed with severe disc degeneration L2-3, fitted with a Poly Spinal Jacket made to exact measurement by being put in a plaster cast, very scary.....

I had X-rays CT Scans, Discograms, Bone Scans, MRI's, blood tests, Psych Tests, multiple times during the period 1973 – 1999.

From this period forward my mobility went downhill, I was unable to lift my legs to climb ladders during a period when I was doing consultancy work for a large distribution company, this resulted in me being unable to work and in 2000 I was placed on a Disability Support Pension the Centrelink Doctor was astounded I had been able to work that long.

My journey with SPS? I believe began around 1997 then aged 50 it manifested itself by my lack of ability to move any part of my body apart from my head when lying on the floor something I frequently did to relieve back pain, very alarming, I mentioned this to my excellent physiotherapist during my treatment, she then arranged for me to see a specialist at Royal North Shore Hospital what a waste of time . while driving my car both breaking or accelerating I would often lose the ability to move my legs without lifting them with my hands, this got progressively worse through time, to the point I knew something was wrong.

October 2004 I was lying in bed at night and I was unable to move my legs, and had severe tremors, terrifying, so much so that an ambulance was called and I was hospitalised.

During my time in hospital I was found to be severely B12 deficient, and was

suffering from Subacute Combined Degeneration of the Spine?? , this was diagnosed by a myriad of tests including standing upright legs together and close your eyes I just fell over, sitting on the edge of the bed arms folded and try and get up, I could not.

Was then started on a monthly regime of intra muscular injections, all was good for about 3 months and then the stiff muscles ataxia cramps loss of various movements oedema etc started so my Neurologist increased the injections to fortnightly, he was just not listening to my concerns he had diagnosed my condition end of story , we were not impressed.

I was then put on an weekly exercise programme at the Rehab department of my local hospital, by my Rehab Specialist oh' and by the way I was told I was not allowed to drive, I had already been told that in hospital by umpteen other Doctors, at this time I was put on Baclofen, which I was unable to tolerate.

I started to get on with my life bought myself a mobility scooter to get around on and then I started to have intermittent paralysis of both legs, arms. and hands, I could not eat a meal without the arm paralysis happening so I was unable to go anywhere without a carer in most cases my wife taking me and was not allowed to use my scooter any longer.

Early 2007 we decided to ask for a second opinion so we went to a Neurologist recommended by my GP there I underwent further tests MRI, SSEP (evoked potentials) Nerve conduction tests EMG, specialised Blood tests all normal, so of course what does the good DR say It's all in your head, my own GP and the people who saw me at Rehab did not agree with this diagnosis, so I had further Nerve Conduction Tests they too were normal also.

2008 to enable me to again control my situation, I was scripted by Paraquad and Camden Hospital for a powered chair complete with captains chair, tilt mechanism and chin control , it was so good to have regained my independence once again. I nicknamed it THE BEAST, as it is very large.

About late 2009 I was beginning to have upper body seizure episodes in bed sometimes quite violent they would be anywhere in number from 1 – 8 times and had different levels of strength and duration, also my legs would get incredibly tight and very painful during the later part of the day.

My condition began to improve in regards to my arms and hands but as soon as I did any exercise especially in the gym or walking my legs become very heavy and painful and the paralysis episodes would occur, or my legs just collapsed below me, I was then having physio every 2 weeks at my local hospital this was stopped in late 2012 now 65 no longer met the criteria for funding.

During 2011 - 2012 I then started having very severe upper body seizures this would result in my body being propelled backwards at speed anything I was carrying would go flying, you should see the roof in my lounge where the TV controller has hit it, these were

up to 6 times a day at one point then 5-6 times a week

With prompting from my Lung Specialist we decided to search for a new Neurologist one who specialised in movement disorders, I searched the internet and found this Neurologist she was on the Periodic Paralysis International Medical Advisory Council, sent her an email and overtime she responded to it.

November 2012 took delivery of a new manual wheelchair, much improved on the old one, much lighter easier for my wife to handle fits nicely onto our new wheelchair rack on the rear of the car...

So in December 2012 the real journey of discovery commenced after a physical examination and the way I presented my Neurologist thought I had a variation of Stiff Person Syndrome and at least two other neurological deficit, blood tests were unremarkable have had further EMG testing done, needles in hand, thigh, eyelid and left of off spine, these results, were unremarkable , just had a full spine and brain MRI, in the meantime she started me on Gabapentin, as I could not tolerate Baclofen or Valium.

About 3 months later I then started having very severe leg spasms whole leg and feet twisting violently inward resulting episode pulling the muscles all the way to my hip, very painful,

Started hydrotherapy on weekly basis with constant supervision, during this time my condition became much worse, my legs hands arms and feet would invert to the point of agony as soon as they were unsupported.

Then in late June I presented to my local hospital in terrible agony, but I had the presence of mind to ask them to contact my Neurologist, this they did, she although on leave arranged for me to be transferred to one of the top hospitals in Australia, under the Professor of Neurology, then I was put through so many tests, Ultrasounds, Ct Scans etc further needle nerve tests, this picked up the Neuro Myotonia they prescribed Clonazepam which was then changed to 3600mg Gabapentin and 75mg Dantrolene during this time I was in a very deep depression, I was shell shocked, did not know what was going on, every time I tried to walk my legs collapsed below me, I had full body paralysis lying in bed very frightening, upper body seizures, throwing things every where eventually through medication and my own ability to better control the spasms things started to get better, even the geniuses at the hospital would still not give me a definitive diagnosis, I lay between Stiff Person Syndrome and Isaacs' Syndrome or a syndrome called after me, Stiff Person being the most likely

After 3 weeks I was then transferred back to my local hospital to begin extensive and exhaustive rehabilitation that took a further 5 weeks, they had to teach me to walk again, something we take for granted, this was incredibly hard as you have to retrain the brain again, they also gave me access to a psychologist, this along with the visits from the pastoral care worker, who actually was a friend from my Church brought me out of my deep depression, during these sessions I really opened up and laid all things bare, I was then allowed to return home but was still having to use my walker or wheelchair, and had to have services put in place to shower me etc, this was tough for me as I am a very independent person, and stubborn as a mule..

Now private Physiotherapy is ongoing and has helped me immensely to get fitter and stronger; it took me 6 months to be able to walk confidently without any aid and to walk up some stairs. I am not allowed to walk outside for fear of seizure's or falling, and I still must have a carer with me at all times, my beloved wife usually fulfils that demanding role.

I have since seen my Neurologist again and we are greatly comforted that any future episodes that require hospitalisation will be at St Vincent's and nowhere else and it will be under her care.

The seizure's and stiff legs are a constant reminder that I have to take it easy I have to stay safe and not put myself at risk, and outside I have to be in my wheelchair at all times, a timely warning of this happened the other day I was sitting in the pub having lunch when I had a seizure it was so violent that it thrust me backwards I overbalanced in my wheelchair my knees hit the table and I was saved from serious injury by my wife and patron grabbing hold of my chair, very frightening..

Although I have concentrated on Back Problems and SPS / Isaacs' Syndrome? I also have Osteoporosis, Osteo Arthritis, Type 2 Diabetes, diet controlled, Asthma, Biapical Pleural Plaques, Tachycardia, Gastric Reflux and Depression which all require medication and ongoing care and intervention.

My disabilities do not define me and have in many ways been a blessing, it has allowed me to be a very significant part of my grand children's lives and to volunteer in many capacities, and to advocate for others with disabilities and their carer's, so often the unseen and unsung heroes of our society. I also have a strong faith and that and the love and care of my wife is what keeps me going in our daily struggles.