

# TAKE CHARGE OF YOUR MS

By John Blades

1

Some Background to myself first. I am nearly 48 years old and have had MS for 25 1/2 years. I have been in a wheelchair for 14 1/2 years and a motorised wheelchair for nine years which I have driven my wheelchair with a chin control for the past 6 1/2 years. This will really be an account of my journey since diagnosis and how I have lived my life along the way.

I have not done any of the things I will talk about to prove a point or to show how good I am. Only because I wanted to achieve my goals and live my life.

My Journey Begins in 1982 which has been the biggest year of my life so far. It was the year when five major things happened. I graduated from civil engineering at Sydney University. I began working as a structural engineer and worked for 16 years in the design of buildings and bridges. It was also the year when I started in radio. On the volunteer operated community radio station 2 MBS FM. Presenting a program of experimental music called Hot Dog You Bet. It was a fortnightly program from midnight to 3 a.m.. I would then get up to start work as a structural engineer at 9 a.m. that morning. I used to make my own flyers and posters for each show which I would walk the streets putting up in bookshops, record shops, cafes and cinemas in the inner-city of Sydney. I currently co-present a program of experimental music new releases from all around the world, called Background Noise. I incorporate live interviews and extensive what's ons. I am also the convener of the contemporary music collective of radio programmes at 2 MBS FM.

In 1982 my radio co-presenter and friend, Richard Fielding and I founded an experimental music group called The Loop Orchestra. We have done over 40 live performances in our 25 1/2 year history. We have had a record and two CDs released in Australia and CD releases in Europe. We have done a one-hour specially commissioned piece of music for a London radio station and created music for ABC radio national radio features. We are about to appear on a CD released and totally produced in China with three Chinese artists and a Swedish artist. So We Are Very Much on the world stage.

1982 was also the year I was diagnosed with MS. I had lived with MS for 25 years as my mother had MS although she was only mildly affected. As we know every case is different. The progress of my MS was such that during the 1980s the nerves that control the muscles in my legs became more and more damaged. In 1988 I got one walking stick and in 1990 two walking sticks, finally reluctantly moving into a manual wheelchair in 1993. My attitude towards the MS was to put the MS on the backburner and get on with my life. Rather than letting the MS take centre stage. Realising on one hand that I had MS but on the other that I had a life to lead. Me Controlling my life rather than the MS controlling my

life . Consistent with his attitude between 1985 and 1987 I did a Master of Engineering Science Degree part-time at New South Wales University. I went against the advice of my neurologist who believed it might exacerbate my condition. I was not going to let any doctor or MS or anything stop me from doing what I really wanted to do. And I am very pleased that I was determined because I was rewarded in 1987 when I received a high distinction and thesis of the year for that year. In those years before acquiring a walking stick I really struggled to and from lectures on my tired legs after a busy day in the engineering office, twice a week for three years . I was obviously suffering from MS fatigue. If I had let the fatigue stop me I would not have achieved anything. I was not going to let the MS get the better of me. I broke the MS barrier and pushed it out of the way. Which you have to do in order to live your life and achieve your goals.

In 1989 I had the opportunity to go overseas to present a paper at an international structural engineering conference in Portugal. It was the first of three overseas trips presenting and finally co-presenting papers at international structural engineering conferences. I travelled on my own, hiring wheelchairs when necessary. In 1991 on a visit on my own to five European cities I even went up the Eiffel tower in a wheelchair which I had hired in Paris . These trips were plagued by the MS fatigue and the ugly side of MS, bladder and eventually bowel accidents. But you must not give into the MS. You must push the barriers and push the envelope to achieve your goals. I pushed through the MS fatigue. You can easily dry off after bladder accidents and cleanup after bowel accidents and wear pads or whatever is necessary but do not let them stop you from doing things .

When I Moved into a wheelchair in 1993 my landscape changed forever. In 1994, as if I wasn't doing enough already, I was invited to work on a feature program at the ABC's radio national. It was the first of six feature programs I worked on for Radio National. I did this in conjunction with very long days working as a bridge engineer. I had to contend with the MS fatigue, bladder and bowel accidents. But you take all this on the chin. You push the barriers and you cope with it otherwise you do not achieve anything.

My Other Attitude has always been to do what I could until I could not do it anymore and then do something else but never ever give up. Life is too short. So it was with walking; I walked until I could hardly put one foot in front of the other, I went bushwalking (which I loved) until I was falling over on a walk in the Victorian Alps, I went swimming at the beach until I could not get myself out of the water without help . I also turned pages with my fingers until it was taking me 15 minutes to turn a page. I love reading and so I got a head pointer for turning pages. I drove my car, my main vehicle (literally) of independence and mobility until it was unsafe to do so with my legs and then rather than giving up driving I acquired hand controls in 1993. I drove my char with my hands until 1997 when it was unsafe to turn the steering wheel and in 1997 I had my driving licence removed. A sad day when they cut the corner of your drivers licence.

Once I Was in a wheelchair in 1993, through the 90s my legs continued to be affected and transferring was more and more difficult and also the nerves that control the muscles in my arms began to be affected. So that simple functions like turning the steering wheel of the car, writing, turning pages and feeding myself became increasingly difficult. For This Reason my efficiency in the work place dropped and I was asked to stop working. I decided this would be the end of one chapter of my life and the start of another chapter where I would explore much more of my cultural interests in the arts, music and radio.

Stopping driving and working were both very large blows. But I would not let anything stop me completely and the more the MS affected my body the stronger my determination and resolve became. After stopping driving I started my new life of taxi transport. Rather than stopping me completely I started being taken everywhere by taxi. It took some adjusting but actually it was much more relaxing and far less death defying. I have had four regular taxi drivers and they have been my mobility and transport independence. My current driver Ali takes me all over Sydney on my various activities. He is a wonderful support and I really recommend everyone with mobility problems latches on to a regular taxi driver.

The Next Major Thing that happened was in 2002 when I started using voice-activated computer. The computer and the Internet has totally transformed my life. It pulled me out of a hole of depression which I had fallen into and which 70% of people with MS encounter at some stage in the MS lives. I am in touch with hundreds of people all over the world through e-mail, I use the Internet for music and arts research and use wordprocessing for my radio show scripts. It has really opened a whole world to me. There will be more about my entry into the digital age at the IT conference in 2008; so please watch this space for more details.

I lead a very active life ably assisted by Ali. This year I went to 12 films at the Sydney film Festival for which I organised my own access and transport. I go to live shows such as Barry Humphries And Little Britain this year. I also go to restaurants, the Opera house, art galleries, the Royal botanic Gardens and many other films on my own. Recently I went to two films at which I was the only one in the cinema.

Two Stories from my travels. Four years ago I had been to the George Street cinemas on my own. It was about 6 p.m. and there were many people coming home from work. I waited for my taxi in George Street just down from the cinemas. Feeling pleased with myself for managing to get to and from the film on my own. I saw a very pretty blonde girl in a beautiful red dress. I was looking at her quite fixedly. She must have seen me looking at her. I saw her rummaging in her bag. She was waiting at the lights about to cross George Street. I looked away for only a split-second and in that time she raced over to me, left three dollars on my wheelchair tray and raced off across George Street.

No word, nothing. I thought I actually looked pretty good that day and not particularly down and out. I would have much preferred a kiss on the cheek. Needless to say, I am still looking for that girl. About six weeks ago I was going to regular experimental music nights in an old and refurbished two-storey building in Surrey Hills. I had to be lifted up seven flights of stairs in my manual wheelchair each time. On the last occasion there was a fellow standing dressed in black and looking on seriously and confused by the whole prospect of me being lifted up seven flights by five strong fellows in this narrow stairwell. I soon discovered he was the guest artist for the night, from Holland . Afterwards I had to be taken down the stairs backwards one step at a time. He followed behind carrying his equipment. I looked up at him and said "Martin, have you ever seen anything like this in Holland?" He Answered " Oh no, in Holland we have lifts".

On All My Outings I hardly ever see anyone in a wheelchair and never anyone with a chin control or walking sticks . Where is everybody? You must get out and leave the MS on the backburner. We live in a very wheelchair accessible city (except for old multi-storey buildings). There is no excuse for not enjoying life.

I have met several people with MS who regard themselves as "sick" . And their lives in two parts; before they they became sick when they lived a very active life and since becoming "sick" when they live a very quiet, sheltered existence chained to the MS; fatigue and fear of bladder and bowel accidents. I have never thought of myself as being sick. I believe the word is like a straitjacket which stops you from enjoying life. Do not use the word sick as an excuse for not doing things or participating in life's rich tapestry. You Must force yourself outside your comfort zone in order to live life. Don't waste your time being obsessed with your MS.

I essentially cannot move anything below the neck but I assure you there is a lot of life to be lived from the neck up. If I can do it with my level of disability anyone can. Where there's a will there is most definitely a way.

So, live life to the fullest, break through the MS barriers, do not give in and  
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John Blades, October 26, 2007