

MND Diagnosis Perspectives

Vern Cork

In the first few months after diagnosis in September 94 I joined MNDA and started learning about MND. I went to a second neurologist, Roger Pamphlet, for a second opinion and he thought I might have PLS which has a better prognosis. I continued working part-time for a few months then decided to stop and apply for a superannuation payout after I had broken down several times at work and had thought my life's adventure was over. I had some counseling which started me thinking I should live some of my dreams and so took a trip to Bali with the help and encouragement of my foster son in January 95. This was the start of 4 wonderful years despite growing dependence (see Cornflower Blues) of travels, study and writing. I tended to easily follow friends' ideas for alternative healing and also visited the Independent Living Centre to familiarise myself with the aids available for when I might need them.

Now because I am using my electric wheelchair at home I am finally using services like Home Care, community nurse, occupational therapist and social worker, and have set up a share-the-care group of friends, following Zana's example. Surprisingly, it's tended to be newer friends who have been helpful. All this may have been better done earlier before my foster son burnt out. I feel lucky to have degenerated slowly and been able to have had such a positive 4 years. I realise the importance of loving care and support and challenging things/projects to do: study, travel, writing. I need to keep my mind active to be an interesting and not gloomy person for friends to visit and help, while avoiding over burdening them with things government services may provide.

Jackie Williams

I was 25, newly married, enjoying work in my chosen career of nursing, when I burnt my hand on a hot dinner plate. I heard the sssss, but there was a delay before it registered with me and before I finally dropped the plate. This took me to the Emergency Department they examined me and found that my upper arm revealed muscle wasting. Two and a half years of investigations and numerous doctors later I was told that I had MND. That was April 1987. I can't remember much of what I felt on being given 3 to 5 years to live. I can only recall that I was a nurse, I had never heard of this condition and so delved into my textbooks. I was in the U.S. and the only support group available was one for people with MS, 70 miles away. I only went once, finding it difficult as MND didn't offer periods of remission! I can only say as I've been a Christian since I was 16, I was encouraged by my favourite verse "so be strong and courageous, for the Lord your God is with you, wherever you go." Joshua 1:9

That was 12 years ago and my neurologist can't believe that I am still alive. I returned to Australia in 1989 after my marriage ended and I now live with my parents/carers as in 1996 I could no longer stand without assistance for toileting etc. I regularly attend our local support group meetings and other activities in Melbourne organised by MND Victoria and am involved with promoting MND Awareness Week. As I have outlived my prognosis, I like to encourage others to have hope—doctors aren't always right! Technology and access to the Internet has widened my circle of PALS to world wide. Feel free to e-mail me at jbw@apollo.ruralnet.net.au

Zana Abdul Rahman

Being told that I had an incurable and fatal disease left me charged with a mixture of intense feelings—self pity, panic, loneliness mixed with disbelief. Images of a totally paralysed me frequently appeared in my mind and I was obsessed with the question of who would care for me. I spent quite a few months just suffering those feelings by myself as friends and family could not handle talking openly about it. Instead they took me on holidays and we focused on having a good time. In retrospect, they were too shocked themselves to talk about it and see me cry.

A year later, I gave up work and began to organise myself for the ordeal. Friends started to come together to help, we made plans about my future care and accommodation and I tidied up loose ends in my finances and other business matters. Then I was able to concentrate on enjoying life at its simplest level—getting plenty of sleep, enjoying taking my time in not rushing about, doing what I really wanted to do instead of what I thought I should do and making a point of doing things I had always enjoyed or longed to do.

Now, almost three years since diagnosis, I can't believe that I am still here, able to look after myself with only a little support. At the back of my mind I still fear the worst scenario but at the same time, I am able to ignore them and enjoy life virtually everyday. There's not a day when I'm not aware that I have the disease but I am also regaining interest in things that has nothing to do with it.

Barrie Young

Coping. Well, I have always been an emotional person so a good cry then and regularly ever since seems to let it out. But coping and acceptance are very different, coping I find related to taking each breath, each mouthful, each step, each word; but acceptance is two fold. Firstly, being positive and hoping that one day this hideous disease will be wiped out and secondly, accepting that one day one's own condition will mirror that of good PALS that have championed before us.

Rosemary Walker

When first diagnosed, Grahame and I decided we would just keep doing what we could for as long as he could and make every day count. I think our most successful strategy was to try to keep ahead of our needs by finding out what was available so that as his needs changed we were ready. It saved a lot of panic. To this end I can't praise too highly the MND Assistive Devices Expo and the Independent Living Centre.

Rob Dowling

In 1990 I attended G.P. for a tremor in my hands which I had noticed for some time, and as one of my uncles had Parkinson's, I had thought maybe I had the same. However, my G.P. noticed fasciculations in my leg muscles and asked how long had I had them. As I hadn't noticed them and wouldn't have attended him for them anyway, he sent me to the neurologist. After many tests he was of the opinion I had MND. which usually meant a survival time of 3-5 years. But he also felt that I had had this for some time, and that it could be slow moving.

Initial reaction: as I was still working and wasn't affected very much at the time, I didn't think about it too much. The fact that it appeared to be slow moving was a good thing in the beginning, as I was able to concentrate on my hobbies: building telescopes, clocks and doing general maintenance around the house.

Now that I am confined to a wheelchair and cannot do any of these things, I am beginning to think that a slow mover is not such a good thing as the quality of life decreases, the suffering will continue for a longer period. There is definitely a for and against a slow mover. The one advantage I have is that my speech and swallowing are not affected. For approximately 3 years I have been on the Riluzol drug trial, but there is no way to tell if it has been of any benefit.

At the moment I enjoy using the computer and receiving emails from Ozpals, but I'm not a very good communicator, so haven't contributed much.

Vince Fester

Julie and I walked out onto Hunter Street, she had tears streaming down her face. I was in total denial. We stopped in a nearby cafe to have a cappuccino and to regain our composure. We agreed not to say anything to anyone until we had time to absorb the shock.

It was difficult to accept that me, innocent of any crime, had been put on 'death row'. Its so bloody unfair. But I kept telling myself that there is time, albeit never enough. For the next 6 months or so I concentrated on my job. I had got a new boss who drew on my education and gave me marketing responsibility which was ironic in a number of ways. When I was well I wasn't given an opportunity to develop a career path, now I have no future and am given the opportunity to play a major role in the company's future.

My symptoms progressed. I dreaded having to tell my parents the cause of my advancing disability. I knew they'd be devastated. I struggled to find the right words. In the end I began, "Mum, I found out why I'm having difficulty going up and down the stairs..." My father died 22nd September 1997. In accordance with his wishes we buried him with his mother beside his father, at Coonamble cemetery. Through the haze of tears I wheeled my chair near the grave. During the rendition of "The Last Post" I bowed my head. My grandfather's stone marker lay at my feet—Vincent Fester—we share this name. Death was up close and personal, self-pity not far behind

My condition slowly progressed ever since the first signs back in 1992. By 1998 my speech was only decipherable by those close to me, I could no longer bare weight on my legs, nor raise my arm or hand to grasp the wheelchair controls on my own. We got a hoist from the MND Association for transfers.

How do I cope? I accept that I'm going to die which has prompted my search for the meaning of life, God and spirituality. I try to keep busy, researching my family tree and cherishing every moment with my children.

Pat Coates

I first noticed trouble with speech when I got new dentures, after 30 years. I was 8 months being diagnosed. I went back to the dental mechanic and he said you don't talk with your teeth you talk with your tongue. He was right.

Then I went to my G.P, she sent me to a speech pathologist and to have a CAT Scan. After that I went to the E.N.T. specialist, and he suggested the Neurologist. BANG I was devastated, he told me what to expect and it has all happened. I didn't know much about MND. I hadn't come in contact with it, but I know all about it now. The shock of being told you had an incurable disease put me to bed for a week. I couldn't talk about it. My family had to do all the talking. I have taken lots of herbs and vitamins it has cost me a fortune.

The embarrassing thing is the crying and laughing. One person told me years ago if you feel sorry for yourself look around and see someone worse off. There are not many. I thank God that I am able to write at the moment. I haven't been able to speak for over a year. I miss my Girl Guides and helping other people. Now I need help family friends Girl Guides and Church people have been wonderful. I just have to sit and do no work at all and I don't suffer. My large garden is a wilderness. It is hard for my husband, because our 4 children live far away.

The first thing I could not do was to read to my grand children. I can only communicate with the ones that can read. The baby one I clapped to her, now when her parents say Nanny Pat, she claps, she is one. I play cards with the older grand children, I can't teach them a new game. My District Nurse is a Guide Leader, she is very kind, she comes to me at 8pm three times a week to give me injections to dry my saliva. I have home help once a week and home based care twice a week.

I was diagnosed in January 98 at the age of 68 and a half. I have a waking frame around the house but I can't walk much and have a wheel chair to go out. We have just bought a car that will take the wheel chair.

John Cole

Two days before seeing the Neurologist, who diagnosed me, I had read the general information available on the Web regarding MND. At that time I said to my daughter, "I hope I don't have this (MND).&^%\$**.... terrible disease". Thus I was aware of the possibility and received the news in a fairly outwardly calm manner, notwithstanding that he advised that the usual prognosis was 1 to 3 years. My immediate feeling was that I needed all the information that I could get. But, I could not think what to ask. My inquiries tended to dry up completely when he suggested that I probably should not consider any "heroic" measures when I asked about losing breathing capacity sometime in the future. Thus my wife and I left there numb and frightened to return home to give our children the appalling news. Telling the children was a difficult and gut wrenching experience.

After the initial shock of the diagnosis I sought to learn every thing I could about the disease and whilst it helped to know what I was facing I nevertheless felt very angry and unhappy. At that time I felt that my life had been completely destroyed. I had no interest in my work and no longer considered that it was important enough to warrant the expenditure of my energies or attention. Accordingly I immediately retired and turned my attention solely to family and self. A very strong about face. I had regularly worked up to 50 hours a week at my job for some years and spent countless hours in voluntary roles (treasurer, scorer etc.) for the local District Basketball Club.

It seemed that all my plans for our future were no longer to be achievable, both in terms of time left before the disease took its toll and in terms of the financial impact of ceasing work. It was odd to see the world going on about its usual business when mine seemed to be spinning out of control and totally stationary, both at the same time. Time became my enemy, it seemed that there was not enough time left to do things I wanted and at the same time I felt trapped in a "time warp" of misery. I feared that the disease would soon strip me of my dignity, my humour, my independence, my sexuality. and, in seemingly too short a time, my life.

Gradually, the anger passed, as did the sleepless nights but I became very depressed and fought with that for some months. I enlisted the aid of a good physiotherapist, a good GP, attended gym, took heaps of anti-oxidants, vitamins etc. and indulged in the luxury of a monthly massage in an attempt to minimise the emotional and physical impacts of the disease. Nevertheless my depression increased as I struggled to fight it. It became a sort of vicious cycle as I became more and more unhappy about being unhappy. Eventually I realised that, to regain my happiness, I had, first to accept the emotions I was feeling and to hang on to "fact", learned earlier in life, that neither happiness nor sadness is permanent. In short I realised that I would regain my equilibrium if I just allowed it to happen, and ceased to strive to bring it about myself.

Over time, I did regain my sense of joy in daily living and learned through contact with other PALS and their carers, and from the support of my family, how lucky I am and how much that can be done and enjoyed, whatever the physical limitation. I no longer dwelt upon what was not or may no longer be possible and became wholly content to live one day at a time. Gradually it became apparent that the disease was treating me very benignly and I have suffered only a very slow deterioration. Doubts are now emerging as to the correctness of the diagnosis and further tests are to be undertaken. I was diagnosed in February, 1997 and although I have deterioration in both shoulders, weakness in my legs and sporadic fasciculations throughout my body there are no other obvious symptoms as yet.

I have ever so slowly learnt to accept that "I am I" regardless of the capacities of my body and to accept my mortality. I am not personally concerned about the outcome of the current tests but, for the sake of those whom I love and whom love me, it will be a great day if the diagnosis of MND is lifted from our lives.