

# ***MND Sufferer Perspective***

**Vince Fester**

## **First Signs**

From January through to August 1990 I spent every spare moment building an addition to my small house in order to accommodate my growing family. I promised Julie that the 3 new bedrooms (the main with an ensuite), laundry and double garage underneath, would be finished by the birth of our third child. I kept my promise with a whole 24 hours to spare, Patrick was born on the 20th August. This was also in my last year of my part-time economics degree at Newcastle University.

Strict adherence to a ritualistic timetable was the key to my time management. I was generously given one day a week off work to attend some day lectures, I also had some evening lectures and all my tutorials were of an evening. Every afternoon I'd go to the university on the way home from work. On tutorial and / or lecture evenings I'd get home about 9.30, a few beers to unwind, then to bed (having eaten over at the uni cafeteria). On the other evenings I'd get home about 7.30. Poor Julie led a sole parent's life. Nearly every Saturday and Sunday afternoon back to the uni library I'd go. The additions were worked on Saturday and Sunday mornings and occasionally under floodlights after uni.

The few weekends I missed were a result of pleading by Julie for me to spend more time with the family. I was a good student, a so-so builder, but a lousy husband and father. Julie raised two toddlers almost single handedly. Carl was born in December 1985 and Andrew in January 1987. I had commenced uni in 1986, so I missed most of the first five and four years of their lives. Not entirely though, long uni vacations gave me some time with them, Carl was always a step behind me belting a nail into something. I used 20kg of nails on the addition - 10kg by me and 10kg by Carl. Andrew didn't show much interest in the building project being 13 months younger than Carl. Andrew though was not entirely disinterested- he and Carl managed to leave their foot prints in the garage floor a few hours after the concrete finisher had gone home. All this after a lengthy explanation of why not to walk around on the wet concrete down there. Its a good talking point now.

By the summer of 1991-2 my left knee started to play up, only going downstairs, my years of rugby and cross country running were beginning to catch up. By now we'd saved enough money to do up the old downstairs bathroom. It was blue and yellow tiled with musk stick pink toilet and bathtub. Thirty years out of fashion. I gutted it out and had framed a new large white triangular corner bath. The plasterer had sheeted the walls, I thought it best to paint the ceiling and upper walls before the tiler came in. To reach up I laid a 4x2 across the bath to stand on. Part of the way through painting I bent over to reload the brush, I over balanced and fell with my right wrist catching the edge of a tile on the way down. I got 4 stitches for my trouble. A month later I was up on the pergola painting again, again I fell, into the neighbours yard this time. I put it down to wet paint on my shoes. All the time I worked up high on the addition, which was considerably higher, I was as sure footed as a mountain goat.

I was working for a Newcastle based chemical company and was out at Narrabri visiting Cargills Cotton Seed Oil mill in early March 1992 Its about a 5 hour drive from Newcastle, I'd gone up there to meet the production manager as they had just agreed to give us their business. When I got up to leave my leg had a little spasm, I put this down to the long drive and I'd been sitting all morning. I thought no more about it.

Hannah was born mid March, Julie's 4th Caesar went off without complication. I was looking for a new job. I had a business degree but little business experience, most of my work time was spent building processing plants. Despite my employer advising that to have a future in business I needed business qualifications, and them paying my way through university, they refused to let me have any substantial commercial experience. When I told my boss that I had won the University Prize for Marketing, topping a class of 310 (about 20% of which were like me - 'mature aged' and already working in industry) all he could say was "Yeah, but its not the real world is it?" "Within a week I was pulled back out of sales and put back onto building plant and equipment. My degree proved to be a monumental waste of time, energy and money.

It was mid May of '92 when I went to my graduation ceremony in the Great Hall of Newcastle University, Elizabeth Evatt the chancellor handed out the testamurs. I'd worked bloody hard for this degree and was determined to enjoy the occasion. Finally my name was called. As I moved forward my left leg trembled - "what the hell is going on?" I thought. To leave the stage there was a movable stair case with no hand rails, in centre stage. For the first time I was scared of walking. When I rejoined the family no one commented about my on stage difficulty, I figured that maybe my anxiety was the cause and maybe my perception of this episode was exaggerated. A celebration dinner out at yacht club with a fellow mature aged student, John Parker and his family washed away my concerns.

This tremble in my left leg became more frequent. By the end of winter I was unable to jog without leg spasms. I coached Carl's under 7 soccer team which at this age requires the coach to be on field directing the kids - no one ever commented on my gait. I was finding stairs more and more difficult. Julie suggested I go see a chiropractor. I went through the mill - consults, x-rays, therapy - the chiro maligned conventional medicine at every opportunity and advised me to keep his therapy up for a few months. He implied that he had identified the problem and could fix it - what an arse hole. After a few fruitless weeks I gave him away.

I used to play backyard cricket and football with the kids. Around September (football season finals time) it was me and Andrew against Carl and his cousin James. They kicked off, I got the ball and side stepped, my ankle gave way. Hmm.

I began to drop plates when drying the dishes. My thumb went floppy. I noticed twitches in my calves and shoulders. Everyone now noticed my difficulty with stairs, I knew there was something major wrong, but I kept it to myself. I got our Home Medical Advisor book and scoured the pages - Ataxia, MS, a weird virus? Motor Neurone Disease, it read " general weakness (atrophy), muscle twitches (fasciculations) ..... with the use of simple physical aids many suffers lead fulfilling lives " Okay, I thought, so I'm going to be handicapped, it could be worse.

My brother -in- law and Julie's sister, Tim and Karen, had not been back long from England, Tim an ophthalmologist had a twelve month stint in Bristol. While visiting them one weekend at the house they'd recently bought, Tim remarked that my knee was getting worse. He suggested that he take a look down at his surgery. He followed me up the stairs watching my gait. He checked my reflexes. They were sharp, I thought that was good. Tim suggested I see a neurologist. I told him I thought I had MND. He didn't comment.

## **The Realisation**

I visited my GP Geoff Lambert, who referred me to a neurologist, by now it was early November. The earliest I could see Dr David Floate was 19th January 1993. I still hadn't told Julie that I thought that I had MND. Why spoil everyone's Christmas, especially this Christmas.

My father's emphysema was well advanced. We had given him a 70th birthday party back in '91, but all his family hadn't spent a Christmas together for years. My brothers, sister, uncle, aunt, cousins and I reckoned we should all get together for perhaps his last Christmas. Dad was living with my brother Doug and his family near Gwabegar in the middle of the Pilliga Scrub in central north of New South Wales. My parents had split up back in '69, mum lives in Sydney. Dads brother Arthur, aunty Doalas, their son Neil, their daughter -in- law Di and kids have a property about 80k north west of Gwabegar over on the black soil plains toward Coonamble

Early Christmas eve we piled the kids, presents, all sorts of luggage into the van. By Maitland, 45 minutes from home the "how much further?" chorus began. We wound our way up through Hunter Valley vineyards to Merriwa. We stopped for morning tea, let the kids out for a run etc. Our van was a 7 seater, the front seats are high to allow for the wheel arch. I grabbed the hand rail to pull myself up and fell flat on my back. I think this was the first time Julie knew something was seriously wrong Eight hours, 525k and 40c after starting out we arrived at our dingy motel on the outskirts of Coonamble.

My brother Stephen was already there. My kids immediately joined his kids in the pee-soup pool, while we parents took refuge in an ice-cold beer. Later we met up with Neil, Di and the kids for a Chinese meal. . It was a balmy night so we all went back to the motel to sit and drink around the pool. It was a very pleasant evening until I got up for a pee. I was very unsteady on my feet, I knew it wasn't just the booze. Everyone laughed at my apparent intoxication.

The kids of course were up at the crack of dawn, very much relieved that Santa was able to track them down. Santa had delivered the highly prized Sega Megadrive. Wrapping paper, toys, clothes, pillows everywhere - not the ideal Christmas morning. Christmas lunch was out at Neil's, the old man enjoyed it and I think everyone thought it worthwhile. By the same token it was an effort that none of us would like to become a habit. Going all that way was very tiring especially on Julie having to attend to and keep entertained 4 small children.

The 19th of January came around quickly. Dr Floate examined my gait, co-ordination and reflexes. He checked the nerve conductivity of limbs by putting an electrode at the top of the limb, another at the end and gauging the electrical resistance. When he finished leant over me on the examination table and said "Tim tells me you think you've got Motor Neurone Disease." "I know I shouldn't be diagnosing myself ..." I was cut off "Well, I think you may be right "he said Bloody hell I thought, I was in shock. I was prepared for something other than being correct.

He sent me off for a series of tests and scans, this was to rule out other conditions which exhibit similar symptoms, for example stenosis of the spinal chord. There is no specific test for MND, they diagnose it by what they call 'diagnosis by exclusion'. In other words they test for other conditions and if its proven not to be anything else, then it must be MND

As I lay on the gurney waiting for the MRI technician to decipher the pictures I prayed that they'd find an anomaly. The nurse bowed in, cheerfully saying "Good news Mr Fester, no sign of any abnormality. "The doctor strode in behind her. "That's not the news he wanted to hear." The poor nurse felt awful. I told her it was okay. We went back to David Floate.

"The tests didn't indicate any other underlying condition, so we must conclude that you have MND. "

"Okay, so what have I got to do? "Go home, sort out your affairs - make out your will, that kind of thing. "

"What?" "You've got 2-3 years."

"Surely there must be something that can be done? " " Unfortunately not, in a year or so you'll be in a wheelchair, there's an MND support group in town, they can probably help with equipment etc."

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 I, 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 said "Mum I found out why I'm having difficulty going up and down stairs ".

"Oh, why?" "I have a degenerative nerve condition. "

"What do you mean - degenerative?" "I will degenerate. "

It sounds somewhat comical when written down like this but we were both hedging around the words trying not to use painfully frank language. There was no mistaking my meaning. Mum's uncle Lionel died with Parkinson's disease. Mum knew full well what degenerative meant and so did I.

A lady named Marge B from Boat Harbour somehow got wind of my diagnosis and telephoned one evening and told us that her husband (also an MND sufferer) had been seeing a Dr X at Dee Why in Sydney. She went on to say that his unorthodox approach seemed to be helping her husband. She explained that the good doctor believed that MND was an autoimmune disease triggered by food intolerances and. .... .

Dr X office had bundles of records and notes on top of filing cabinets, on tables and on the floor. It was a big office but no room was wasted. In fact it looked like he'd just moved in and hadn't time to unpack. He was an amicable character, slightly built, about 60 years old and had a slightly English accent. Eccentric with a capital E.

After pleasantries were exchanged he launched into a lengthy explanation of "the toxic fractions of food, their effect on the immune response and the bio-chemical pathways of vitamins and minerals with reference to their impact neurone death."

Occasionally he'd jump up, rifle through papers about the room and give me photocopies of hand drawn diagrams on bits of varying size and varying quality paper. He lost me on about the third turn. But he was kind enough to repeat the lecture every time we met. After a while I began to think that he sensed my lack of comprehension and was desperately trying to get it through my thick skull. But I eventually concluded that he started every consult with every patient (regardless of their complaint) with this lecture.

At my first consult he arranged a number of tests which included hair as well blood analysis. These provided a measure of minerals and chemicals present compared to an "accepted norm ". From this he prescribed a course of vitamins and minerals. Some of the dosage rates were substantial, for example I was taking 2 grams of B3 per day. The tests weren't cheap and not covered by medicare or private health insurance. I ended up taking daily over 30 tablets of a variety of shapes, colours and claimed benefits. These weren't cheap either, costing about \$10 a day.

He also put me on a very difficult to achieve diet. All bovine, lamb, spice, legume, wheat, oat, barely, yeast and potato products or products containing these were out. I couldn't stomach the smell of goats milk so I used to tip pure fruit juice over my rice bubbles for breakfast and have rice with vegetables, chicken or fish for lunch and dinner.

Every month I'd visit the good doctor, during one of his lectures I was able to read all his qualifications which hung on the wall behind him. Bachelor Agricultural Science, Bachelor of Medical Science, Bachelor of Surgery and Bachelor of Psychiatry he is no dumb bunny. After each visit he'd send a letter to my GP Geoff Lambert, one time I needed to see Geoff on an unrelated minor medical matter. On the way out Geoff enquired as to how things were going with Dr X, I told Geoff about his lectures and Geoff said "Yeah, he sent me all these diagrams, I can't make head nor tail of them." I didn't know if this was good or bad.

On another visit to Dee Why he gave me the test data for about 12 other MND patients (with names deleted) and asked if I would do statistical analysis of it. Needless to say I couldn't draw any inference from any of it. He also showed me AMA articles which were very detrimental to his practice of "ortho molecular medicine", I have no idea why he chose to do this. Perhaps the most comical (from my view at least) thing he did was to tell me about one of psychiatric patients. On this particular occasion he was more animated than usual. Every now and then he'd go to the window; he must have seen a quizzical look on my face. He explained "I'm nervous as anything, one of my patients from Kenmore (Psychiatric) Hospital was incarcerated on my testimony, he gets out today. He swore he'd kill me. He's mad. Mad I tell you "It took me all my time not to laugh.

I stuck with the diet, supplements, and Dr X for about 6 months. My symptoms progressed relentlessly. I was going to my neurologist every 3 months. The poor bugger, I wrote to him every time I heard anything remotely related to a neuromuscular condition. I learnt that he didn't share my enthusiasm (desperation), initially I was angry, but this was very unfair. I couldn't see the point of continuing to see him. I knew that if any new drug were being developed some where I'd have to find it, no one else.

At every opportunity I'd go to the university library and rat through the neurology journals. To my relief there was a fair amount of research going on, but clinical trials were few and far between and they were all taking place overseas. And, there was a substantial time lag between trial conclusion date and publication in the journals. I soon realised that any drug treatment was not going to find its way to local pharmacy shelves in the time frame I was given this explained David Floate's lack of enthusiasm. To have any chance of beating this horrible disease I had to get myself on a drug trial.

The clinical trials I'd read about in the medical journals listed inclusion and exclusion criteria. The main stipulations being -

1. Candidates must not be suffering any other chronic condition
2. Candidates must not have been diagnosed more than 3 years prior to the trial date
3. Candidates must have a Forced Vital lung Capacity of no less than 60% of normal.

This meant that in the normal course of the disease there was a limited period where one is eligible. We had a ' use by ' date

Up until this point I had not bothered with the local Motor Neurone Disease Association. I thought that if anyone had up to date information, especially on trial treatments, it would be them.

Julie and I went down to the meeting, there were about 10 people there, 5 on the long executive desk, 5 others and us. They were all at least 20 years older than us. No one appeared to be a sufferer. We were warmly welcomed and they explained that after the business was attended to there would be an opportunity to get acquainted. They went through the dreary but necessary bullshit. The last item dealt with was the forthcoming fund-raiser, the ' Pie Drive '. They argued about the price to be charged for the best part of an hour. Some old battle axe who was treasurer couldn't, wouldn't agree with anyone.

Eventually we met everyone, all congenial enough. My focus was on gathering information. I quizzed everyone about research, drugs, trials, etc. None of them had a clue. This was my first and last MND Association meeting. For a long while I was angry with the association, on reflection I was expecting too much from them. They were all widows or widowers, they'd fought their battles and lost. Their motivation was different to mine. They had kept involved out love for their partner, to empathise with new carers and perhaps to perform a civic duty via structure they were comfortable with. They weren't crusaders. I don't mean to be patronising in saying this nor critical, its just my perception.

The detection of an inherited genetic abnormality in familial MND made the press. I contacted Dr Laing of the Institute of Neuromuscular Research in Perth who had been involved in the discovery. Geoff Lambert drew a sample of my blood and sent it over to the Institute for analysis. Even though I was unaware of any MND in the family, both Dr Laing and I thought it a worthwhile exercise. I called him a few months later, he couldn't find any defect on gene 21, the location of the familial abnormality. Then I forgot about trials for a while.

Meantime my symptoms progressed and my disability was obvious to everyone. On Father's Day weekend 1993 I had my first of many falls. We were down at Brashes music store, we'd just bought a CD stereo system. The muscle on the shin was one of the first to weaken resulting in the front of the foot drooping, so tripping over becomes an unfortunate habit.

Soon after this I began to walk with a cane. I still worked for the chemical company and traveled about seeing customers and business contacts. The company was contemplating the establishment of a manufacturing facility in Brisbane. I made a number of journeys to Queensland, each in turn becoming more difficult. Everything became more difficult. I had the fitter at work (who happened to be my wife's cousin, Peter), make up some wire hooks. These I used to zip my trousers, my thumbs had become all but useless.

Once I walked in to the laboratory to speak with one of the chemists, there was a lino tile missing from the floor about a 1m away from a work bench. The toe of my left boot (coming from the country I always wore riding boots) clipped the edge of the tile. It wouldn't have protruded any more than 2mm. I lurched forward; the spasms in my leg stopped me from correcting my balance. In slow motion I shuffled and fell forward, my face hit the glass beakers on the bench, glass went everywhere. The chemists picked me up off the floor, my forehead was cut, my cheek was sliced like delicatessen salami.

It was clear that my house needed modifying to suit my creeping disability. We put our home on the market for 3 months but were never offered anything like what the agent suggested. Julie's parents came to the rescue and paid for the modifications which included a veranda and raised walkway from the front door to the footpath. I got a copy of the Australian Standard and designed a proper 'disability' bathroom.

The 31st of January 1994 was set as my retirement date. The boss asked me to tell our major customers and contacts that I was retiring. I told a few, but I didn't have inclination to repeat my story over and over, besides they dusted off my recently retired predecessor to fill in while a more permanent arrangement could be made. Negotiations relating to the sale of the company were well advanced, so they didn't want to, perhaps unnecessarily, appoint a replacement.

When the day came they presented me with a small TV for the bedroom. Mid way through the farewells I broke down and cried like a baby. I had contemplated not going in on my last day, I should have listened to myself.

## **Trials and Tribulations**

Sitting at home alone turned my mind back to getting myself on to a clinical trial. I had read that trials were being conducted in the US, Canada, France and Japan. I said to Julie, "How about a year in Japan? " She said "it'd be great for me but too hard for you and the kids, remember how homesick you got when we went to visit my host parents in '83 because you couldn't speak the language? "(Julie had spent a year in Japan as a Rotary Exchange Student in '76). She was right of course.

Somehow I got hold of the phone number of the American equivalent of our MND Association, the Amyotrophic Lateral Sclerosis Association of America. I called them and asked if they had any information about forthcoming clinical trials. A very obliging lady asked for my postal address which I duly gave, " Australia? You're not calling from there now are you? "

"Yes" "The line is so clear, I'd swear you're just around the corner. What time is it there? "

"9am tomorrow morning." "Oh? ..... Well I'll post these today. Have a nice day. "

“Thank you” “You’re welcome”

About a week or so later the ALSAA package arrived complete with a commentary on the drugs being trialed, contact names and numbers of the 25 or so study centres across North America. I read about Myotrophin, Ciliary Neuro-Trophic Factor and Brain Derived Neuro-trophic Factor. BDNF sounded the most promising to my 'totally unqualified to make an informed choice' ears. The trial centres were sprinkled all over the continent with only one centre per city. BDNF was in trial phase II which meant that the drug was ready to be safety evaluated on MND affected patients after having been cleared of any deleterious effect on healthy subjects. Although efficacy was not the primary purpose of this phase, it would be the basis on which the drug company would decide whether to proceed to much larger phase III efficacy trial. The forthcoming phase II trial was to be carried out on just 250 people across North America. That's just 10 patients per centre. I thought if it trialed really well there would be no chance of getting on phase III.

I telephoned San Francisco, they had their quota, I couldn't even get through to Los Angeles, the person in San Diego said that he had only 2 vacancies left. When he heard where I was from he said they didn't take anyone from out of town, let alone from out of the country. He also advised that if I took a turn for the worst U.S.hospitalization would be very expensive. With my first choices out of contention I re-examined the list. We didn't want to go to a winter snow climate.

By the time I get to Phoenix she'll be..... It doesn't snow there I thought. The Mayo Clinic Scottsdale (a suburb of Phoenix) was the next centre heading east from the west coast. I'd never heard of this mob before. I spoke to a lady named Sandy, her reaction was similar to the guy in San Diego. I told her that I'd live in Phoenix for the trial duration, no problem. She said she would check with the drug company and call me back in a day or so. A week later I hadn't heard back from her so I called, but she wasn't in, I suspected that she may have been avoiding me. The next day I caught up with her, I had given her the country code for New Zealand by mistake. The upshot of our communiqué was that I was accepted onto the trial subject to meeting the medical criteria, agreeing to stay for the duration and understanding that I would not be permitted to carry on receiving the drug if I left the U.S. (the inducement offered to trial candidates was continued free supply of the drug after the study had concluded). I asked to send me all the paper work including the entry tests so that I could evaluate my candidature before traveling all that way.

By now it was April, the Country Week Rugby Carnival was held up at Tamworth that Easter. My old New South Wales Country rugby team manager, Doug O'Neil and a former team-mate, Paul Southwell had organised a testimonial dinner for me. I had been a veteran of 9 carnivals and represented NSW Country during 1980, '81 and '84.

It was a great weekend up there and I was deeply moved by the event. The only sour note was my in-laws were burgled whilst up in Tamworth with me.

The paper work arrived from the Mayo Clinic. I went and had my lung FVC measured - it was down to 80%, I already had MRI pictures, I got a letter from my neurologist, updated my FBC etc-. Sandy also sent me a real estate rental guide. I was concerned about the expense of living overseas without either of us earning an income. With my retirement payout I paid my car loan off and all but \$13,000 off my mortgage. I held \$10,000 to fund the air fares and to set up house in Phoenix. We'd rent our house to pay our mortgage and live on our pensions and family payments.

I had everything worked out, but during a lull in proceedings I began to get cold feet, I asked a few people if I was insane, no one said I was - not to my face at least. I decided to visit Neil Lewis, an MND sufferer about my age who was about 3 years ahead of me in symptom progression terms. His body was frail and wasted, he sipped tea through a straw from a mug that he couldn't lift from the table, his speech was barely intelligible. After spending an hour with Neil any doubts about going to the U.S. evaporated.

We checked with the Department of Social Security to ascertain whether our entitlements continued when we left Australia. Our pensions were unaffected but the children's family payment would cease the moment we left Australia. Bloody hell, I hadn't anticipated this. We spoke to the DSS Area Manager explaining our predicament, "unfortunately we have no discretionary powers, there is nothing we can do. I suggest you write to the federal Finance Minister and ask for special consideration, but expect to wait up to 3 months for an answer. In my experience I've yet to see them grant special payments. "He said.

Somewhat deflated I wrote to the Finance Minister of the day Mr Beazley , I included a letter from my GP who explained why I was planning to take my family with me and I courteously reminded him that it was the International Year of the Family . Within a fortnight a Finance Ministry staffer called to say my request had been approved.

I made an appointment with Sandy at the Mayo Clinic for a Monday in mid May. The plan was for me to travel to Arizona with my mother, once formally accepted into the trial the family would follow a month later. My sister-in-law, a travel agent made the arrangements. When it came to the visa I asked her if the American consulate required any documents in relation to my purpose for traveling there. I was assured not. Which I thought was peculiar. My visa application was sent in on the Monday preceding my Mayo appointment, "plenty of time to fly out Friday night." All Julie's family came for a farewell dinner on Wednesday night. Robyn, the travel agent arrived about 6pm "They knocked back your visa, they need a letter from the clinic, a bank statement and an explanation of how you would support yourself while in the US."

"When did they tell you all this?" "This morning."

"Why didn't you tell me then? I could have started getting all together." "I was afraid."

Fortunately I had a letter from the Mayo Clinic referring to my participation in the trial. I had a reasonable sum of cash in the bank which included enough to pay 12 months mortgage and to buy the family's air fares. We sent all the necessary documentation down to Sydney on Thursday and got it back Friday. It was extra stress we could have all done without.

My father was down from the farm visiting when I left, I thought this may be the last time I would see him. I could see the anguish in his china blue eyes. And I guess he could see it in mine. My sister Gae rang from Port Macquarie when I left, Doug up in the Pilliga also rang (he was a bit emotional) my other brother, Steve came up from Canberra to see us off. My aunt and uncle came from Moss Vale and some friends from my old hometown of Grenfell also came to the airport

We had a night in LA, which was blur. We were met in Phoenix by a lady named Carole who had corresponded with mum since they met in South Africa on a bus tour some 10 years earlier. She took us to her lovely home in North Phoenix. Mum had written to her about a month earlier explaining my circumstances, but only telephoned a few days earlier to confirm our itinerary, I think she was caught a little off guard by the short notice. Nevertheless Carole and her husband Paul made us very welcome.

The Mayo Clinic is to the north east edge of greater Phoenix, beautiful buildings 4 stories high surrounded by the large saguaro cactus, typical of the Sonora Desert. The initial visit involved a number of tests to define a baseline from which my progress or otherwise could be compared. This included a particularly long and uncomfortable series of nerve conductivity tests, muscle strength and co-ordination tests. It was nice to meet Sandy whom I'd corresponded with; she was the trial coordinator - a very compassionate lady. At the very end of the day I met the supervising neurologist, Dr E. Peter Bosch. His demeanour was somewhat abrupt, not rude, but to the point He explained that there were 4 different doses of BDNF being trialed with 1 in 5 candidates to receive a placebo. Not bad odds I thought. Then he dropped a bombshell. He said "The drug company said this morning that there is an indefinite delay and we're not to enrol anymore patients, because you're here already we'll let you in, (assuming your test results are favourable) but the delay could be months. You can either stay and wait, or go back to Australia then re-enrol when they've sorted out their problem I'll give you a few minutes to think about it. "I knew that if I went home I'd never get back, so on his return I told him that I'd stay put. That evening I phoned and told Julie that I wouldn't know for a week or so if I had met all the criteria. I didn't mention the delay.

Paul and Carole showed around Phoenix and some of the picturesque towns to the north like Jerome and Sedona. Not wishing to wear out our welcome and while we had the opportunity mum and I decided to take a trip. The America West airline had a 'buy one, get one free' ticket deal so went to New Orleans (Nawlins) Louisiana (Looseyanna) for 5 days. The cobbled footpaths of the French Quarter got the better of me and I had a fall, ably broken by mother, assisted by some passer-by. I decided not to tempt fate by sampling the famous night life. We took a few tours, out on the bayou, southern mansions and a cruise up the mighty Mississippi river. A very interesting and enjoyable few days.

When I went back to the Mayo Clinic Dr Bosch told me that I'd made the correct decision in electing to stay because the drug company had overcome its problem, so they were back to schedule. I reckon the story was bullshit, I think that maybe they were testing my resolve. But, who knows - one thing for sure the Austrian, Dr Bosch wasn't the warm and cuddly type.

So it was full steam ahead. Poor Julie back in Australia had 2 weeks to organise passports, visas put all our belongings into storage and pack. All this with 4 children under 10 years of age. Meantime in Phoenix Paul took me around looking at rental properties, buying second hand furniture, el cheapo appliances etc. It was like being back at

college, mattresses on the floor, TV on top of a box, borrowed pots, pans and glasses. The house I settled on was about 20 minutes drive from Paul and Carole's and about an hour from the Mayo Clinic. It had a pool and reverse cycle air conditioning, both absolute necessities in Arizona. Rental USD 700 a month, in a cul-de-sac, in a quiet suburb. Thank God I had Paul and Carole Yelton, without them setting up house would have been impossible.

Mother and I stayed at the Yeltons until Julie and the kids arrived in LA. Then we went to meet up with them and took them to Disneyland. Julie's sister, Robyn traveled with them to lend assistance. Just as well, Andrew had a massive nose bleed, about 2 hours out of LA. The evening before our meeting I fell over again, this time landing face first onto the carpet grazing my nose and forehead. We all met up at a motel at Anaheim, it was great to see the family again. We spent 2 days at Disneyland - marvelous. From there mum went back to Sydney, we and Robyn went to Phoenix. Robyn hired an 8 seat van for a few days, Julie's parents gave us \$6000 to buy a car, we were set.

By now it was mid June. The American school year ends late June, with almost 3 months summer vacation following. Definitely not an ideal time for my kids to be kept busy, no friends and way too hot to go sightseeing. The swimming pool was great but it was far too hot to stay out doors for any appreciable length of time. Phoenix has over 100 days with maximum temperatures exceeding 37c, averaging 43c with peaks of up to 50C, over night minima of 30c, often still 37c at 10pm. We were in a very harsh environment. People just don't go outside during the day. Supermarket car parks fill after sunset. One day we saw a woman opening her car door with an oven mitten on her hand.

We all went to the clinic on the day I commenced taking the BDNF (or placebo, it was a double blind trial - only the US Food and Drug Authority knew who was on what ) , my dose was 0.01 cc per kilogram of body weight daily via subcutaneous injection. They dispensed 31 vials at each monthly visit for Julie to administer. They showed the procedure to Julie and she practiced on an orange. No sweat.

Every few days one of Julie's family would call, my mother every week or so. We'd see the Yeltons every 3-4 days which was great. Our kids looked to them through grandchildren's eyes. They became big brother and sister to Julie and me. They were in their mid 50s. They embraced us with the wisdom of a parent but with the expectation of a lifelong friend. Their son and grandson live in LA, so we all benefited from our new found friendship.

Early, 6am on a Saturday morning in mid July the phone rang. Julie sprang out bed and rushed into the kitchen to answer the call. I heard her say "hello Stephen", a quick calculation told me it was midnight back in Australia. I staggered down the hallway convinced my father had died. I could hear Julie saying "oh no, what happened? When?"

But, it was Douglas my brother who had been killed. Not my father. Gut wrenching pain followed frequent periods of disbelief.

After grief, periods of anger, then anger replaced by guilt. This cycle went on for days, weeks. My passport was in a security box in the bank- by Monday there wasn't enough time to make it to the funeral, I couldn't travel on my own and couldn't afford the air fares anyway. I didn't go to my brother's funeral.

He had been working in a shearing shed pressing wool, a few hours from home. He was going home for his son's birthday. He stopped at the pub. Rolled his ute on the way home, he wasn't wearing a seatbelt. I was angry at him for throwing his life away. Like him I'd done reckless things on many occasions. MND is a harsh way to learn about the fragility and value of life. I was angry at him, then I felt guilty for thinking this way. Such hypocrisy. We come from a line of heavy drinkers.

## **Progress**

Sandy at the clinic arranged a loan of a 4 wheeled walking frame, with brakes and all, for me. It was great, I could walk around the shops, house etc with greater speed and safety. Occasionally I'd get too ambitious and take a tumble - mostly around our yard, thank God. A major concern was finance, I'd under estimated the costs of utility changes, electricity was 80% dearer per kilowatt hour than back home in Newcastle, gas and water were all dearer. Not surprisingly utilities were billed monthly. Running central air conditioning was essential 8 months of the year, mid summer our bill was AUD 350, averaging AUD250 per month for the time we were there. The phone bill was sizeable as well. We were given \$15, 000 by my parents. My old home town of Grenfell held fund raising events, my school friends passed the hat around and my old rugby club at Port Macquarie auctioned an autographed Wallaby jersey to raise funds. All in all around \$10, 000 raised. Julie's work mates at Merewether High School contributed \$1, 000 Relatives and family friends all chipped in. A very humbling experience. Many wrote letters of support. I felt very unworthy.

Once a month we'd go to the clinic, strength, co-ordination and serology tests would take around 5-6 hours. A big day with an early start demanded military - like preparation. Prior to their commencement of school we'd leave the boys with the Yeltons and take Hannah with us. By month 3 of the trial my strength and lung capacity had registered significant improvement. I was delighted.

Late September Carl and Andrew started school, in 3rd and 2nd class respectively. Their school was within walking distance but Julie drove them anyway. . Patrick's pre-school wasn't far either, we could only afford 2 days a week for him. The school day started at 7.30 and ended at 1.30 for infants and 2.00 for the others. The boys soon developed friends and Patrick played with the Mexican girls next door. On clinic days Paul or Carole would collect the boys and we'd have an easy dinner with them. Gifts of money made our stay financially possible, the gift of friendship made our stay emotionally possible. Friendship is much more durable.

By mid October my strength had gone down a little, feeding myself became more difficult, I had Julie modify my fork and spoon so I could grip them with my hand making a fist. Julie's parents arrived for a 2 week visit. They hired a big 10 seater van so we could tour -Tucson, Tombstone, Flagstaff, Canyon de Chelley, Montezuma's Castle, North Rim Grand Canyon (Arizona), Monument Valley (Utah), Durango (Colorado) and Las Vegas (Nevada). This was the highlight of our stay in America

In November Julie's brother-in-law had an ophthalmology conference in San Francisco. Julie's sister Karen and their children came too, we met up with them at the South Rim of Grand Canyon. They stayed with us for a week. My mother came for Christmas, my brother Steve came late January, then Julie's other sister Robyn and her husband Peter came in February. While Robyn was visiting Patrick pushed Hannah into the fence breaking her arm. Julie called emergency, they sent paramedics (disguised as firemen), they splinted her arm. Fortunately there was a hospital a few kilometres away. Mercifully it was an uncomplicated break. We sampled first hand the American health system, health industry, more aptly. No change out of AUD 3, 000.

By February '95 it was clear that the medication I was on had not stopped the progression of my MND, but seemed to have slowed it down. My speech had become slurred. The fasciculations in my tongue were now relentless, and my arms got very thin. Psychologically I was still strong and was rarely pessimistic.

One of the rewards for trial participation was the promise of free continued supply of the drug. However from the outset and at every stage the drug company via the clinic asserted that the drug would not be shipped out of North America. I'd have happily stayed on in the US if it was the only way to stay on the medication, but finances dictated we return to Australia. I didn't feel a bit homesick but Julie sure did and so did the children.

At my mid March appointment at the clinic I raised with Sandy the issue of returning home with continued access to BDNF. She gave me telephone number of the drug company's (Amgen), head of Clinical Affairs. I got through to his secretary who suggested I put my request in writing, which I did.

My return airline ticket was only valid till mid May (Julie's and the kids' were valid till mid June), this was another reason we couldn't stay, one way fares are almost equal to the cost of a return ticket. I asked Julie's sister to approach the airline to request a waiver of the time limit on compassionate grounds. Apparently my request was denied. I mentioned my predicament to my mother during one of our frequent phone calls. A few days later mum rang and said that one of the ladies, in the retirement complex she managed, had her sister dining with the General Manager of the airline later that week. And, to photocopy our tickets and fax them, along with a letter explaining the situation, to a lady named D S at a well known Hotel in Perth. Julie and I joked about D possibly being connected to the Sydney underworld figure A.S. A week later D sent a letter saying our request had been granted with instructions to present our tickets to the airlines' US manager etc.

I waited 2 weeks for a reply from Amgen, nothing, so I again rang the head office in California. They put me through to the deputy head of Clinical Affairs. Robert someone. He apologised for the delay in responding, but explained that my request had been handed to him to deal with and he'd only just got back from vacation. I braced myself for the worst. He said "We understand your need to go home, we've an office in Australia, I've asked them to pursue the regulatory authorities their end so we can ship the drug and monitor your progress. When is the latest you can leave?"

"Mid May" I said, keeping our ticket extension up my sleeve.

"We'll work toward that. Do you know of a good hospital staff neurologist near where you live who we can get to be involved with the monitoring? "

"Give me a week. "You bloody beauty. We were coming home. About week later I called Robert back to give him Dr David Williams contact details, but he already had them. Their Australian people came up with the same name that Tim did when I asked him to investigate.

## **Be it Ever so Humble**

Departure preparations went smoothly. Paul took all our furniture and later sold it for us, likewise our '87 Chev, which was a great help. Julie's sister Robyn made her 3rd trip within 12 months to Arizona to help our mass exodus. We all spent our last night with the Yeltons. It was an emotional farewell, but excitement at prospect of being home outweighed our sadness of leaving Paul and Carole.

We didn't get quite all the way home. We stayed with Julie's parents for about 6 weeks until our home became vacant. All up I'd been 13 months out of my own bed, Julie and the kids just over 12 months. While the house was empty we took the opportunity to extend the kitchen. It was evident that soon I'd be in a motorised wheelchair which would have been difficult to navigate through our pokey, ill conceived, galley.

Robert from Amgen flew to Australia a day after us. He visited their Melbourne office, by all accounts spending 3-4 big days assembling protocols and submissions for various authorities, including the Neurology Department and the Ethics Committee of the John Hunter Hospital. Robert and his Australian counterpart flew up to meet Dr Williams and then called in to meet Julie and me. I was surprised and very pleased that they had gone to so much trouble. They said it was a good exercise to do, and mentioned that they already had a number of drugs (for other conditions) on trial in Australia.

My monitoring consisted of Dr Williams taking my vital signs, checking reflexes and lung capacity. Pathology took about 30mls of blood to ship to the US. Visits were every 3 months, at the end of each visit I'd collect 93 BDNF vials from the JHH pharmacy. A refreshing feature of my visits was the good nature of Dr Williams who has a well developed sense of humour. A number of jokes being exchanged at the end of each visit.

A few weeks after we got home, we left the children with their grandparents and traveled up to Gwabegar. Douglas's grave is one of about only fifty in the Gwabegar cemetery. At that time there was only a mound of red sandy soil with simple wooden cross to identify his resting place. Again I felt grief, anger then guilt. Doug's family were coming to terms with life without him. My father, who was always on Doug's back harboured a great deal of anger. Anger at himself, for "letting it happen ", perhaps for setting a poor example.

We'd been home about 2-3 months when the Sydney newspaper, "The Daily Telegraph " ran feature about police corruption in Kings Cross. There was a great deal of ink dedicated to the infamous Mr. S, including a photograph of him and his wife D! My mother rang me. "Did you see the paper? I had no idea about D's husband; did you know who he was? She was aghast.

## **Confinement**

By January '96 my ankles had become so weak that getting around was dangerous. Like many MND sufferers, I resisted to the bitter end having to rely on equipment to perform any task. But once I moved into my motorised wheelchair I was so relieved of the stress associated with walking that I declared that I would not resist any future move to using disability aids. So often we regard a reliance on aids as an admission of defeat. This attitude can be counter- productive. We all crave health stability, each sign of symptom progression being a grim reminder of what lies ahead.

By this time my arms could no longer lift cutlery from the table. I had to be fed and my food needed to be cut finely, my swallowing was okay, chewing was becoming more and more difficult. Julie began bathing me. I lost a great deal of my independence. I buried myself in my computer, my final bastion of productive and creative independence.

The Yeltons made a surprise visit over Easter, Steve and I took them up to Gwabegar, Coonamble and then onto my uncles opal mine Near Lightning Ridge. They had been to Adelaide, Canberra and Sydney. We showed them where our family had lived for the past 100 years. Paul, an avid gold prospector from Arizona loved it, so did Carole. I knew that this was my last tour for pleasure out west, if I outlived my father - he always said he wanted to be buried with his mother at Coonamble.

At each visit to the hospital my lung capacity dropped, sometimes just 25mls, sometimes 100mls, as a consequence sometimes I was happy with my visit, sometimes not happy. I was glad I was still on BDNF. Mid '96 the internet

magazine "ALS Digest" posted a bulletin "BDNF Has not proved to be effective in treating ALS sufferers when dosed by subcutaneous injection." Barbara from Amgen Melbourne called and confirmed the article. It wasn't effective even on sub groups. I was convinced that helped me. They offered to continue supplying me, but I declined, any placebo effect would no longer apply. The efficacy or non efficacy of the drug only indicated a justification or non justification for going on the trial. My condition at that time was an indisputable fact. If the trial indicated a 50% slowing of symptom onset it would justify the trip to the US. The results didn't alter the facts, the facts altered the results. Would I do it again? Bloody oath.

My computer and the internet provided an escape from my shrinking world, as long as I could type and manipulate the mouse there was a medium through which I could exercise my mind without dwelling on the negative. Initially I typed with a mouth pointer onto the keyboard - a real pain in the neck. Julie rang around and found there was an onscreen mouse activated keyboard available but cost over \$400. On the internet I came across a much cheaper and more versatile brand, after some discussion I obtained their distribution rights in Australia and New Zealand for their range of disability software. This little business (Ergosoft Australasia) provided a fresh interest and at times made a welcome, albeit modest, boost to household funds. We developed an internet website where demonstration versions could be downloaded by anyone interested and developed marketing relationships with the main players in the disability - assistive technology retail market. The cash flow was somewhat erratic, so we never developed a financial dependency on the venture, and our exposure never exceeded \$1500. However it did take 2 years to show a profit. It was a hobby which allowed me to put into practice my otherwise totally wasted years at university. Julie's enthusiasm for the business rose and fell in synch with the cash flow, but after a while grew used to the ebbs and flows.

When you're held hostage by an affliction like MND your mind (my mind at least) is never too far from searching for an escape route - a miraculous cure. The internet is fertile ground for both the desperate and those who prey on them. All sorts of 'snake oil' is out there and often championed by well meaning but unqualified fellow travelers who have unfortunately have gained from a short run placebo effect. Vitamins, essential minerals, herbs, drugs for other ailments, low level electric currents, meditation, aroma therapy, acupuncture ...the list goes on.

I did however read about a properly conducted trial of a drug called Neurontin which was already used widely for the control of epileptic seizures. This Parke-Davis drug was thought to act as a glutamine blocker, excess glutamine production being thought to be cause of neurone death. I corresponded with Professor Burke of the MND Research Institute of Australia about the bona fides of taking this drug; he cautiously agreed that it may be of some benefit. The dosage was 6 times the recommended epilepsy patient dose and wasn't available through the Pharmaceutical Benefit Scheme (because it wasn't approved for MND treatment) which meant I had to pay full price. My local pharmacy sold it to me at cost. \$130 for 17 days supply. NIB Health kicked \$600 a year. Not cheap. I gradually increased from 400mg/day to 2400mg/day over a month. Even at this rate I was wobbly for a few months.

Genuine research is agonisingly slow. If a new drug was thought to be a possible cure, it would take 3-4 years to be cautiously be promoted as a potential cure and another 2-3 years to be available. A total of 5-7 years for miracle cure. This fact takes a while to sink in. Reality is of no comfort. Not only are you a hostage, you're tortured and murdered as well. And your family get a front row seat. They too are tortured - kicked in the guts every time they see another kids father playing back yard cricket, taking the family to the beach, building a billycart, taking the kids to the football, cooking the barbeque, tickling the kids. .... My wife having to be mother, father, nurse, and breadwinner. Physically, emotionally and financially ruined. We all strive to contain our pain, letting it out only impacts the others.

My lung capacity kept going down and down. In early March 97 Dr Williams invited Julie and I to a meeting of the Respiratory Department of the John Hunter Hospital. There were about 30 doctors and 4 of us civilians. The meeting chairman began by stating that the department only had enough resources to cater for 30% of patients requiring their services. Was there shock, horror or disgust? Of course not. They simply spent the next 2 hours selecting the prioritising care criteria. They didn't give a shit about insufficient funding. I wrote to the meetings front man criticising their lack of concern and their failure to even contemplate systems of resource rationing. He immediately wrote back denying that they prioritised patients. This letter was written for the benefit of his recorded response. It bore no resemblance to the events.

Motor Neurone Disease Awareness Week was in early April, I wrote to the Newcastle Herald, in the concluding paragraphs I said

MOST MND PATIENTS DIE DUE TO RESPIRATORY FAILURE. LUNG VENTILATION VIA TRACHEOSTOMY IS USUALLY THE LAST RESORT BUT CAN NOW PROLONG SURVIVAL IN EXCESS OF 10 YEARS. IN THE U.S. VENTILATION IS A COMMON OPTION FOR THOSE WITH HEALTH COVER.

AT A MEETING CONDUCTED BY THE RESPIRATORY DEPT. OF THE JOHN HUNTER HOSPITAL IT WAS ESTIMATED THAT ONLY 2 OUT 6 CANDIDATES FOR HOME VENTILATION WOULD HAVE THEIR NEEDS MET AND MND PATIENTS IT SEEMS WOULD BE THE LOWEST PRIORITY.

ABOUT 1 IN 20000 PEOPLE ARE DIAGNOSED AS HAVING MND EACH YEAR. EACH YEAR MORE PEOPLE DIE OF MND THAN AIDS IN AUSTRALIA, YET ONLY A FRACTION OF THE MONEY SPENT ON AIDS RESEARCH AND TREATMENT IS SPENT ON MND.

THE ONLY RECENTLY PROVEN DRUG TO BENEFIT MND SUFFERERS (RILUTEK) HAS BEEN APPROVED IN THE U.S. AND BY THE EUROPEAN UNION BUT WAS REJECTED BY AUSTRALIAN HEALTH OFFICIALS. I UNDERSTAND THAT THEY DIDN'T EVEN HAVE A NEUROLOGIST ON THE ASSESSMENT PANEL.

FACT IS MND SUFFERERS ARE EXPENSIVE TO KEEP ALIVE, I WONDER WHERE DRS WOOLDRIDGE, REFSHAUGE AND SMYTHE DRAW THE LINE? PERHAPS THEY CAN TELL MY CHILDREN.

My letter was paraphrased and made the front page, this ruffled a few feathers at the JHH. A national magazine, The Australasian Post picked on this and after an interview ran a human interest story.

Not long after this I asked my neurologist Dr Williams to approach, on my behalf, the appropriate person in Hunter Health with my request to have available to me "full home ventilation" when the need arose. He approached Professor Z of the Hunter Area Health Service who told Dr Williams they would make this available when the need arose. I felt very pleased with this. I half expected written confirmation but didn't push for it.

After my brother Douglas died my father moved off the farm and went to live with his brother and his family over toward Coonamble. The old man's emphysema was well advanced so he required a deal of care which fell on my aunt to provide. Over time the care required grew and my aunt and uncle certainly weren't getting any younger - anyway to cut a long story short - he moved to the coast to live with my sister. During his infrequent visits his breathlessness became noticeably worse. Eventually spending over 20 hours a day in bed. His complexion became pale, then almost bluish grey. Oxygen deprivation at its worst. 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. 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 / hand to grasp the wheelchair controls on my own. We got a hoist from the MND Association for transfers.

Around March I was sent for a 'barium swallow' test to see if I was aspirating food. The muscles that control swallowing deteriorate resulting in choking episodes, food stuck in the lungs quickly leads to chest infection, pneumonia and death. A fellow sufferer Peter Martin, 10 years older and diagnosed a few years later than me died this way, he flatly refused to have a feeding tube inserted in his stomach or any other intervention for that matter. I knew the tracheotomy operation wasn't far off either so I asked Dr Williams about whether I should have Professor Z's undertaking in writing.

My 'barium swallow' test was inconclusive. By May I couldn't swallow anything with confidence. I had begun tapering off my dose of Neurontin, clearly any benefit from this epilepsy drug was marginal and the expense couldn't be justified, but a nose dive in symptoms was experienced at this time. By the 9th May I couldn't even swallow thick liquids, so a nasal gastric was put in - twice, initially a young intern put in the wrong one. It was way too thick, with my hyperactive gag reflex I dry-reached uncontrollably and my throat quickly became painful. Having a tube shoved up your snout and down your throat isn't fun. I came home from the hospital until my more permanent 'G-tube' procedure could be scheduled.

Seeing me this way really upset the children. To add to my trauma I was taken off Neurontin - cold turkey. I couldn't sleep, couldn't sit up - lay down - get warm - get cool. The withdrawal was horrendous. Julie told the doctors it was anxiety causing these events! I resumed my Neurontin weaning and the symptoms disappeared. It was substantially more than anxiety.

On the 13th May I very nervously went in for my G-tube, I'd heard of an MND patient in Queensland who died during this procedure. Sedation and anesthetic greatly suppress respiratory function; I was cautioned the ventilation used during the procedure may prove to be difficult to withdraw once started. I said my prayers.

I came to, a few hours later with a pipe jammed down my windpipe and was weaned off the ventilation over an hour or so. Back into my wheelchair that afternoon and back home the next day. What a relief. Not all plain sailing though with an infection a week or so later, followed by profuse wound bleeding and a trip in an ambulance to casualty (with the standard 3 hour wait, by which time the bleeding stopped, followed yet again a few weeks later by another wound infection. Apart from these initial dramas the G-tube has been fine.

A few months later at one of my regular clinic visits with Dr Williams came the bombshell. "Professor McGrath (new CEO of Hunter Health) has knocked back your application, but don't worry there are other means " "I thought the deal had been done David?" "It was"

I could tell David was pretty well churned up, no point chewing his ear. At the June meeting with Williams, Ambrogetti, Saul and Vamos Julie and I had agreed to attend fortnightly sessions with Marina Vamos, the psychiatrist. Ostensibly to explore the impact that my MND had on us, and perhaps more importantly how we may cope with invasive mechanical home ventilation.

Like many women Julie opened up pretty well after 5 minutes, though steadfastly avoiding being dragged into the home ventilation decision which, from the outset Julie rightly said was a decision for me alone. Like most men I was not particularly interested in saying anything. After about our 5th meeting apart from trying to figure out why Marina always wore black and purple, I figured that the best way out was to give something to run with, I did this for this and the next session then bailed out. I guess this was frustrating for Marina, but I couldn't see the point of it all.

### **The Bitter End**

On the 31st December 1998 the current Chief Executive Officer of Hunter Health, wrote to Dr Williams in reference to the provision of my full ventilation. She said "I have established a working party to advise me regarding the issues to be considered in making a decision in relation to Mr. Fester's request for home ventilation."

This "working party" was convened over 18 months after Dr Williams indicated my request had been granted and many months after I sought reassurance from Dr Williams, which was given, and with a report of this assurance going to the Professor Z (the individual who Dr Williams met to gain approval).

Incredibly further on it says. "The group has reviewed the issue of whether a clear promise was made and can find no evidence of anything other than general support for appropriate care. "

The bastards had duded me and Dr Williams. I immediately wrote to the Health Care Complaints Commission who forwarded it straight to Hunter Health recommending both parties meet, I couldn't see the point. Hunter Health was only interested in what could be proven rather than what was said. To sit and listen to someone feign concern for my family would have made me throw up.

My lung capacity is now so low it was decided that there was no point in trying to measure it. My clinics were now on a monthly basis.

I wait for God.

**Vince Fester**