

MND Sufferer Perspective

Jill Braddick Story

I was born 27 September 1950 in Whangarei. I went to school in Auckland and Wellsford. We were a nomadic family. I was 17 years when I went to Teacher's Training College on the last of their two year courses

I married a Kiwi six months before going on the big Overseas Excursion. I married and then joined a shearing gang with my husband, Martin, shearing and me as shed hand or cook. This was an experience that made me grow up fast as well as learn how to work hard. It was also a good way to make big money, working every day of the week for three months with only the very occasional wet day off. Although we worked hard, we also played hard. Our honeymoon was shearing in Gore. I was then 20 years old and 21 when I was pregnant.

We rented a farm cottage off an old neighbour when we came home, for the first year, east of Wellsford before buying our first small farm nearer to Mangawhai We were rearing sheep and cattle and were shearing and fencing around the area, which is almost certainly the reason why my baby was stillborn. My baby was born at National Women's Hospital

Hamish was born a year later, in 1973. When it seemed was going to lose him, I was put in hospital where I couldn't feed calves, or work.

We bought our second farm at Mangawhai probably about 1978. As well as working all the time on the farm, I did remedial reading and a bit of teacher relieving in Hamish's class. Bianca was born in 1975, only 16 months after Hamish. The children were both born while I lived on the first farm.

I became aware that something was wrong when I would have been about 30 years old. I got really tired and then I had trouble with my fingers, but only at night. There was nothing obviously wrong with them except they didn't do the same finger movements.

I thought I must be getting older and I would have to slow down. I worked really hard physically on the farm while at the same time developing another new garden on a near impossible site, which required long hours. Also, because I had no physical limitations such as bad back or headaches, I was able to work until I dropped so the process was very gradual.

Prior to being diagnosed with MND one of my concerns was that we used a lot of sprays, both on the farm and in the garden. I was an avid gardener, going overboard as is my way. When I was diagnosed, I asked them to check my blood. They did that every day for about two weeks. No traces of chemical poisoning were found

I went to a Doctor when things people were asking me to do became difficult. I was dropping everything. Someone suggested that maybe I had arthritis. At that time there was nothing wrong with my legs. Nothing else was a problem, only one hand and then only the fingers. I began to think I did have something wrong although I didn't know what it was. It made me pretty frustrated.

My first contact was with the local GP. By the time I went, it was obvious something was wrong. He told me that often middle-aged women retained excess fluid and that does something to the tendons. I was only 31 He said I would have to have an operation if the pills didn't work, but I knew that I didn't have any excess fluid. I have the skinniest wrist of anyone who ever lived. I wasn't in any hurry to go back to the Doctor. I took the pills to start off with but they made no difference.

The children were young at this time. Hamish may have been 6 and Bianca 5. Martin noticed something was wrong and was supportive at this stage. I couldn't do the housework and washing so Martin's sister came to live with us and she was just wonderful. She did all the things I was struggling with, like hanging out washing and doing vegetables. I continued to work on the farm and I drove for several years. Janie, Martin's sister, did all the difficult stuff for me. I was really lucky. So too was Martin pretty lucky. He was able to carry on with only a few minor changes to his everyday life, allowing him a couple of years to ease in to the changes ahead of him.

I was still tired but I never thought that I was having serious trouble with my hands because it was at night and I had been fine in the day. I just got grumpy. I have learned a bit of self-discipline since then. At this stage I wasn't anxious about what was happening to me

I gradually got worse, but very slowly. I had trouble locking the car, starting it, opening the door, doing up buttons and tying shoelaces - all the little things that one does. I was also having trouble during the day, not being able to do everything. But because it was so gradual, I was unaware of the progression. I really never noticed and with Janie living with us to help with the every day chores, it was no big deal.

Then I went to another local Doctor who was no better than the first, a dodderly old fool. He said that my hand was really cold and that I must have poor circulation so he gave me some more pills. I have a lot of trouble with medication because of palpitations and these pills really threw me. I wasn't on them for long and by this stage I was pretty grumpy with doctors and rather strongly conveyed this message to the third Doctor when I went back. I demanded he send me to a Neurologist rather than put me on another lot of drugs which would probably knock me off this time round!

This Doctor had no idea so he arranged (because I wasn't leaving till he did) for me to see a Neurologist in Auckland who had an idea what was wrong but wasn't prepared to enlighten me until after he had conducted the necessary tests. It was two months before I went into hospital and they did a whole lot of tests.

I was in hospital for two weeks. My hands were all shrivelled up and I was also having muscle twitching all over. It was very obvious. I felt no different but I wished I could die right then. I even had a lumbar puncture, which was very painful.

Every time I moved my head I vomited. After a week of this they came round and told me, I had MND (Motor Neurone Disease).

In October 1982 when I was diagnosed, I had never heard of MND/ALS and apart from the basic facts, which were almost nothing, I had no idea what it was. It was a difficult time for both Martin and I to come to terms with it.

I told the kids as soon as I got home from hospital. They knew something was wrong with me and I am of the opinion that certainty is far better than uncertainty. In fact it was a relief to know what it was. I don't believe in hiding the truth from anyone, particularly my kids. Besides, if they're old enough to understand, then they're old enough to know the score. Life is all about death and it's always going to have problems along the way.

I thought I was only one of a dozen people in NZ to have MND and as I was told I could expect to live two years, we decided to take six months holiday as a family in the States. All the locals were really good - they even raised the money for us to go away. We took the kids out of school for six months at the beginning of 1983.

Before we left a friend gave us a brochure that his Doctor had given him when he had asked what M-N-D was. My Doctor had no idea. On the brochure it was called ALS. It sounded the same as what I had, but I wasn't sure. We went to Hawaii, then on to Los Angeles where we rented a campervan and travelled all around the South over to the Mid West. That was the very first time I met someone with MND and also the reason I went to Kansas. We called a number on the brochure and met Judy and Peter Oliver. In fact we stayed with them for about a week during which time we found out that they had a support group for MND/ALS locally as well as a National Association. There was so much that they did for each other. I found that MND/ALS were one and the same, as well as everything about it at the same time as the importance of support groups.

MND can start in one of three ways - the feet, the hands or mouth (I don't know how). Pete was about 40 years old and had been an airline pilot. He was diagnosed about a year before me and had it in his legs.

Coincidentally, we met the President of the MND/ALS Society of America, Ames Bishop at a meeting in Salt Lake City, Utah, while staying with a very good friend who now lives in Dunedin. He was so disgusted with the attitude of the medical profession here that he advised me to seek a second opinion from a very good Research Neurologist in San Francisco, which I did. Mr Bishop also urged me to start up a support group in NZ as it was desperately needed and gave me support group contacts in Victoria and Queensland, Australia.

Victoria, Australia, put me in touch with patients in Timaru and Christchurch another MND/ALS woman from North Shore, Auckland, contacted me soon after we had organised the World's Largest Garage Sale. We raised with the support of locals and family, \$10, 000. She had heard that I wanted to set up a support group and that was the birth of support groups in NZ. It continued to grow in Auckland, with information and support now extending throughout the North Island. We have a group in Whangarei, where I am, in Wellington and Auckland as well as contacts in the South Island. I am now a delegate for the National Council in Wellington.

But I have diverged a little! When we returned home from our trip overseas, not a lot was happening to me. Jane, Martin's sister, left soon after. I tried to see a Neurologist for another EMG test at Auckland Hospital because the IVINDIALS Specialist I saw in the States had advised that the first test had been conducted when I was cold, therefore the result was inaccurate. However, I never received the result from this test despite efforts to obtain it.

Later I had difficulties obtaining help in the running of the home. With two young children, a new home in the country, our lives changed dramatically. I had worked full time on our farm, which we were developing with a large mortgage and no money. Now I was struggling with the running of the home as it was my hand and arm that were affected first. I think someone in the community must have talked to the right people, because at the time I began falling over, I was given ten hours home help a week.

Because we were well known and involved in the community, we were well supported in this way. I taught my then 8 and 9 years old children the run of the home and garden so Martin could work on the farm. This was not a bad thing. I had my two Moms' support as well as neighbours and numerous friends to assist and encourage the children.

The farm was the problem, particularly as I required more personal help. Farmers didn't qualify for sickness benefits or the like. This was, perhaps, more due to an attitude among Government Agencies than to Government policy. Our farm went backwards, along with our income, and our expenses multiplied along with my increased needs. I didn't want Martin to sell or cease farming because that was all he was qualified for.

He resented the forced nursing he was now thrust into and limited time in which to manage his pride and joy - the farm. He sought the comfort of other women because he couldn't see any way out of the situation. He was still young and vital and could see life passing him by.

My daughter came home from Primary school one day to find me in a heap at the bottom of the stairs. She had to lift me up, help me up the stairs, clean up the blood, then warm me up as I had been there an hour and was now in shock. This happened for four years or so, often several times a day. My children were incredibly strong physically but the emotional strain became too great and they volunteered to take me on full time because they no longer wanted the added burden of their father. This happened in their last year at school, by which time we had no paid help because I hadn't replaced the woman we had had three months previously because of the affair she was having with Martin.

Hamish had two terms left to sit Bursary, and then he wanted to go on to Art School in Auckland. Bianca had been accepted by the AFS to go to Brazil the following year, so she was striving to gain top marks in 6th form to go on to University on her return from Brazil.

Had we had more Government help back then for us as a family, perhaps this situation would never have happened. There was no help at all when Martin left in May. After the holidays, my Mom came when the children weren't able to stay home. Martin's Mom relieved them one day a week as I was in need of full time help. For the past three years I had become incontinent urinary wise and if I wasn't toileted, would often need a change. There was generally someone to fill in until after the children came home from school. I had notified the Multiple Sclerosis Society that Martin was leaving in two weeks and I think they were responsible for Rodney Home Help being brought in. Within two weeks 15 hours help had been allocated which helped relieve my poor mother a little as she was also nursing my Dad who had Parkinson's Disease.

I got off to a bad start with Rodney Home Care and my home help was later reduced to 13 hours. My Mom and sister-in-law encountered the same attitude when we approached Income Support, Orewa and a Social Worker at North Shore Hospital. Because I had a farm, it was suggested that I sell it and put myself in a Home.

I then had to establish whether I was in the Auckland area or Northland Eventually I obtained, after much battle, Northland District Nursing Help three days a week. She was basically a neighbour while the Auckland District Nurse was 45 minutes away. This lack of area definition posed constant trauma every time I dealt with any Government Agency, which was too often.

Because I had very little Government help, the community realised that both my Mom and children required more help. They organised a roster of helpers to make up the hours between the paid help leaving and the time when the children returned from school. My Mom did one full day, my Mom-in-law did another and the children did weekends and holidays. The strain on them was immense. For the first time ever there was dissension between them resulting in Hamish moving out for two days at the end of the school year, before reconsidering his stance.

When Martin left I had to transfer power of attorney from him to my Mom and I organised for my friend and neighbour to sign cheques for me. I was lucky in that I had such great friends and family whom I could rely upon. Esther, my Accountant, would organise one or two days a month in which to help with the farm and personal accounts.

At this time we were also considering what we would do when Hamish went to school in Auckland and Bianca left to go to Brazil. Bianca would have foregone her year in Brazil to care for me if necessary but two weeks before her departure date, the MS Field Officer saved us yet again. Under the Domiciliary Care for families, everything was organised for me to have live-in care and Bianca was able to help this person adapt to the requirements of the job.

Up until this time I had received no advice, much less help, from Government Agencies. The job was full time with payment little over that of the dole. Rodney Home Care withdrew their hard won hours now that I had a live-in helper. Fortunately, my brother and his family moved to the area from Auckland at the end of the year in order to help us. But even then, it soon became obvious that this was not enough help, so Lynn (my sister-in-law) approached Rodney Home Care. After great Resistance, because she was family, they finally paid her to do five hours a week. It wasn't a career and after sacrificing eight months, we had the task of advertising for another minder. This was not easy and we were not so lucky with the next minder. Lynn rescued me again and the next minder, Barbara, realised the complexities of such a job and coaxed Rodney Home Care into providing another five hours. This was still horribly inadequate so Barbara, Lynn and I, approached Whangarei Income Support in the hope that we could increase the hours.

However, we discovered that Government policy needed to be changed. We wrote to relevant people in Government without success. In the meantime, Barbara left and I lived with Lynn's family until a young friend and earlier helper, Cathy, returned from overseas to take a turn at minding me. With assistance from Lynn and Michael, I wrote to everyone I could to seek help and after exhausting every avenue, eventually went public.

We featured on the Paul Holmes Show twice. That, along with the support of MND/ALS Society, MS Society, friends, family and Doctors, Government conceded 40 hours home help for people like myself, reliant on Domiciliary Care. This worked adequately provided one was able to find a Domiciliary Care person.

It was at this point in time that we changed from Rodney Home Care Support to Northland WDF (Women's Division of Federated Farmers). Obtaining Domiciliary Care was difficult because it was a commitment of self-sacrifice. Conditions of employment also posed problems. The only suitable applicant was a Swiss girl but because she was not a NZ beneficiary, Income Support was unable to place her on Domiciliary Care. The fact that no New Zealander would undertake the job, was irrelevant.

This occurred just after I had moved. Lynn had helped me with selling the farm, which I had subdivided into three lifestyle blocks to maximise my returns and make it easier to sell. It was basically uneconomic and I was tired of relying entirely on Government help, Lynn, family and friends for my well being. My house was falling down around my ears, the garden had over grown everywhere and everything required much time and money. I had two children at University always needing money. I wanted to live better than just making do as I had been doing. Subdividing the farm had been a major task and Lynn said she didn't have the strength to lobby the Government any more.

After selling the farm I bought the local shops and also built two more. Hamish, along with a few other people, worked for me on this project which proved to be far greater than I had ever imagined. My other brother, Peter became responsible for all accounts, wages and as much of the management of the shops as he could in addition to his own farming responsibilities on the other side of Dargaville. Lynn struggled on with caring for me and I was able to recompense her somewhat with the sale of the farm. I was now in a position where I was able to pay my way minimally.

I no longer had Domiciliary Care. Towards the end of Hamish's final year, he moved home full time to care for me, with breaks from Lynn, my other brother and his wife, and a friend. Then, at the end of her year, Bianca took over under the Domiciliary Care system. Hamish would quite often do the weekends and help during his holidays. Between the two of them and with Lynn's constant help we managed until Bianca had to return to Canterbury University at Christchurch

When it became obvious that I wasn't going to get Erika, the Swiss girl, on Domiciliary Care, I wrote to express my dissatisfaction over such an uncompromising system to support the disabled, which is battle enough on its own. It was at this point that the Northland Disabilities Resource Centre came on the scene. NDRC arranged a meeting with WDF, Rodney Home Care and themselves, at my home. Consequently, Rodney Home Care paid Erika a similar wage to that of Domiciliary Care (with Cathy and Lynn doing four days between them).

Erika was a gem. When the final payment for the farm came in, she and I left Hamish at home and we had a month in the South Island visiting Bianca and friends before flying from Christchurch to Switzerland where we stayed with Erika's family.

We were away just over four months. Erika took me down to Italy where I stayed three weeks with our AFS student of five years previous. Renata (the exchange student) took me back to Switzerland via another friend of mine on the Swiss border. He had loaned, delivered and set me up on a laptop computer soon after we arrived in Switzerland. He had encouraged me to get a computer years before. I was lucky in that I had become aware of CHAT by the voluntary Field Officer for MND/ALS soon after I had broached the subject with her. They were part of CCS and very quickly came up with a complete package deal that set me up in my first computer. They even did an article about it in The NZ Herald.

My friend in Switzerland had been a partner in the business that developed the programme I was using then. He had stayed with us years previously after being given our number at an MND/ALS symposium in Japan where he met an IVIND/ALS woman whom we had met in the States. After leaving Switzerland, Erika and I stayed with this woman in Colorado for five days.

We also stayed with several other friends I had made when in the States just after I was diagnosed. We had time in Kansas, the Rockies, San Francisco and Los Angeles. It was something that would never have been possible without Erika and Renata and her family in Italy. We flew back to Christchurch where I stayed with Bianca and Hamish who now had his first art job and was flating with Bianca

Difficulties with my care arose when Erika eventually left but life improved when the

NDRC Needs Assessment Service arranged for my next Carer. Esther (my Accountant) and I were able to manage my own full time care. This made such a tremendous difference to the running of my total care. I could now hire and fire, set out work contracts, set job description and arrange the hours, as I needed. I already had computer banking, was paying wages and had a fantastic band of helpers and friends. My children had grown up and were now independent and useful.

I am now responsible for my own care. After my husband left and my children went away to University, the Government realised the importance of care for disabled people. Life for disabled people living at home improved, as it did for me. However, there were always problems with the employment of minders because it was always administered by Agencies. In my case, I and the people working for me, were at the mercy and whim of the appointed Administrator.

When the Government eventually conceded that there were problems with the current system, it was agreed that I and one or two others, trial self-management. As on many previous occasions, NDRC Needs Assessment Service assisted me in every way possible, allowing me to slip into a smooth and easy transition with the new system. I was set up in business after having subdivided and sold my farm to buy a block of local shops which provided me with a more manageable income than that of the farm only a couple of years earlier. I had all the systems in place to manage this new programme with such incredible success.

However, even with the support of NDRC Needs Assessment Service, I have never managed to have a direct credit of available moneys from Government without it first going through the appointed Agency. This would save Government much money, I feel.

The self-management regime gave me the freedom to join the MND/ALS National Council, becoming the only patient on the committee as delegate for the Northland MND/ALS Support Group. This involved two to three meetings in Wellington a year but I needed someone to take me. Lynn managed the first but Cathy (my other helper) felt inadequate, so in desperation she phoned an MND/ALS friend of mine to see if he would take me to the second meeting.

This led to a romance between Roly and myself. After sorting my life out, I had never been more settled in my MND/ALS life. Now I had turned it upside down. But once again, with the help of the NDRC Needs Assessment Service, I had the confidence to embark on this new phase of my life. Five months later Roly and I were married.

I am writing this at the very southern most point of the South Island, in our caravan, with my ever loving husband.

Postscript ~ Jill Braddick

Jill lives in Mangawhai in her own home. She is next door to her Mother, overlooking the spectacular vista of Mangawhai Heads.

Jill has minimum movement of her right thumb only but this allows her access to her computer, which in turn, is her access to wider communication. Jill corresponds with many people around the world via the Internet, sharing experiences of MAID and her own courage, humour and inspiration. She declares herself to be "public property" and has lost her inhibitions regarding her "plumbing" and personal needs. She continues to be a vibrant member of her community and has assisted greatly in NZ with the acceptance of MND and living with MND.

Jill takes great care of her own personal health. She eats only organic food, does not allow smoking around her, drinks a lot of water and currently eats quantities of garlic and chilli to assist with breaking up mucus. She requires a high level of care and is grateful that this can take place in her own home.

Jill continues to run her business so that she does not become benefit dependent. She remains in control of her life and impresses with her quiet dignity, optimism and humour.

Jill Braddick