

MND Carer Perspectives

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As a Carer, how have I coped? Firstly, it would seem that here in NZ we enjoy a higher level of Government support than do you in OZ so I have probably found the job a little easier than have many OZPALS.

For instance: From the date of my first wife's diagnosis we had "as required" visits from the local Community Nurse through whom we had access to many of the services which we eventually required. As the disease progressed we had home care assistance, reaching a peak of 16 hrs per week towards the end.

My current wife, who is a long term PALS, living alone since she drove her very reluctant children out into the world to university and beyond, had 6 day, 24hr care for 5 or 6 yrs before entrapping me. This has been reduced to 28hrs weekly since my entrapment (A joke my dearest). In addition I, as principle Carer, have funding made available to allow 28 days p.a. 'respite care'. Certain equipment is also available but the 'red tape' requirements often try ones patience too much. On the other hand, I, a 66yr old superannuate have had my pension reduced by 20% as a result of marrying a younger woman. Thus bureaucracy penalises a dirty old mans urges. No health subsidy on Viagra either.

My first Wife, Alison, began to have difficulty in jumping fences late in 1990. Quite soon she became unable to run our goat farm by herself so I gave up my off farm employment, no sacrifice, I much preferred to stay at home. In March.1992, after many GP's, Physios and assorted witch doctors, our worst suspicions were confirmed, Alison had MND and possibly 3 to 4 years to live. This came as no surprise. Alison had been an Enrolled Nurse before we left Auckland to farm in the North (Waipu Cove) and had seen one case and an old friend contracted MND shortly after we came to the farm. Nevertheless, the diagnosis hit very hard, we sank into unimagined, unimaginable despair, despair so black and deep that I have no remembrance of our 60km drive home. We clung together in bed, speaking little, weeping lots and during the early hours climbed out of the bleak pit to sleep, waking, still entwined, feeling quite ready to face the world and make the decisions. Oh how brave, it didn't last, we adjusted day by day.

The Neurosurgeon had been very open, very frank and visibly distressed when giving his diagnosis. Without embroidery he told us what we could expect and left us in no hope of a miracle cure. He outlined many of the methods of retaining quality of life and, most important of all, recommended that we contact an MND support group and requested our permission for him to contact a group on our behalf. I retain the most enormous respect for that man and do you believe, I can not even remember his name! Once we had survived the agony of telling our family and friends we were able to make a positive beginning to the last season of our life together.

Although this is contrary to popular belief, our greatest strength was that **we totally accepted that there was no hope**. Our decision was to live almost as if there was going to be no tomorrow. Our house had a beautiful view, coastal and pastoral, but was totally unsuited to our future requirements. Did we want to forsake the country life and return to the city? NO NO NO! So, bring in a bulldozer to reshape the terrain to provide vehicle access to the living level. Widen doors, wet area bathroom etc. FUNDING?? Sell the farm, our retirement investment, retaining 7 acres and buildings. No sooner said than done. Advertised on a Friday, sold on Saturday. Negotiated boundaries and terms with the Buyers, retained a Surveyor to fix the boundaries then off to the Whangarei District Council to have it all made legal. "No problems" they said. "Just fill in these forms and we will put them with the Surveyors report and your proposal will go before the Planning committee in 10 days time"

We believed them! 11 months later we were still waiting, never any concrete reasons for the delays. I could write a book about it but not just now. Suffice to say that I well understand the occasional massacre that occurs in public offices. No Council assent= no land titles, no titles= no transfer, no transfer= no money. What to do? Alison's condition was visibly deteriorating, we had things to do, Family & friends to visit and Alison wanted to have a last look at many of our favourite places in this so beautiful country of ours. So we did them. Made arrangements for the conversion work to begin. Played Bank accounts against credit cards and cards against banks and took off in our old Nissan Patrol to tour the North Island.(although comparatively asset rich we had no income. At that time the banks assessed risk based on income, so would not lend to us).

After 2 months away we returned to find the house mostly finished, thanks to the very capable supervision of our Pommie son-in-law, piles of bills and threatening letters but we had done it. I would do it again. There did not seem to be much progress on the Council front so we contacted the prospective buyer to offer them cancellation of the contract. They responded by paying us a large sum to ensure that they did not lose the property. All without a lawyer in sight, or even a hand shake. This settled most of the bills and we ourselves settled down for the siege. I can not

pretend that the following 30 months was easy, but neither was it too hard to bear. Alison kept in touch with her many friends, using first my old steam driven Hewlett Packard portable computer and later a Health funded Toshiba laptop with "scanning WYSKE" software (the precursor to "Words Plus" "EZKeys") and "MultiVoice" speech synthesiser. Oh how she would have loved Email!

Also Health funded was an electric wheelchair which Alison was able to operate herself until about 9 months from the end. The 'chariot' helped a lot, allowing Alison a little independence around the home and even on our monthly shopping in the City. She would take off by herself to buy woman's things, after her speech got bad we strapped her laptop to the chair and she would talk to the shopkeepers in a deep, male, American accent. Supermarket shopping was a ball, she would charge around the aisles, leaving chaos in her wake, and find all the specials. Alison's decline could be likened to descending a series of terraces, periods of relative stability, punctuated by the sudden, never gradual, loss of yet another function. The grief at the loss had, each time, to be put aside in the attempt to adjust and compensate. Frustration was the main problem.

Soon after diagnosis she had extracted from me the promise to help her die when she was ready. On Boxing Day, 1994, Alison called in my promise and we set the date, 20 March, our 41st wedding anniversary. However, early on 13 March, while being showered, she had pain in her chest and 3 hrs later, in my arms, her breathing slowed, slowed, slowed, and stopped. Our youngest daughter and a friend were with us and for us all it was a peaceful, beautiful, experience. For me, a new life began. I had deep sorrow for my loss, I still have it today. After all, Alison had been the centre of my life since we were 16, at High School. No grieving though. That had been shared and dissipated over the previous 3 years. For Alison I was glad that her travail was over, for myself, relief, unashamed, to be free of the work load.

I don't think it necessary here to analyse the work load. You Guys & Gals will know all about that. I believe that I was more fortunate than most in that I am big and Alison was small. I had always thought of sleep as a waste of time and existed for many years on 'catnaps'. Our surviving children were all gone, with families, and quite self supporting and I was able to focus entirely on the job in hand. When things became really tough I was able to step back, so to speak and watch what was going on over my own shoulder, free of emotion. Written down that looks stupid, but it worked and stood me in good stead in my next short career and in my present marriage. However, the 3 yrs did exact a toll. A routine medical check, my first for 18 months, revealed that I had become a rampant diabetic (type 2) with a blood sugar of 35ml. This was ascribed to stress as the onset had been so rapid. I could not believe it as my diet was always low in sugar and I presented with none of the classic symptoms. Nevertheless a visit to the diabetic clinic convinced me and I got stuck into the medication, diet & exercise regime. Non insulin, thankfully, I doubt that I have the courage to inject myself.

It took 6 weeks for my blood sugar to get back to normal and I then followed the plan for my future that Alison & I had decided upon. Northaven Hospice in Whangarei had been most helpful to us so, to repay, I volunteered as a Hospice carer. For the next 30 months I was kept far too busy to mope and moan. Now I am again a married man with new challenges and, I know, more sorrow and pain ahead. I will cope. I will cope.

That had better be enough. It's taken 10 days to get this far. Sorry to ramble on. One of these days I shall write about my Jilly, what a story.

Regards to all.