

Submission No. 1194

(Inq into better support for carers)

AOC 15/8/08

3<sup>rd</sup> July 2008

**THE SECRETARY OF THE COMMITTEE**

I have decided to write and tell my story as a carer in the hope that your committee will see just how "The System" is sadly lacking and has so many areas that need addressing and corrected.

My husband Richard was diagnosed with a rare degenerative brain disease called Progressive Supranuclear Palsy in October 2004, one month after he turned sixty years of age. The first message he got from his neurologist was your working days are over and then he was told that there was no treatment or cure for this disease. My husband loved his work and never intended to retire. Due to my own failing health I stopped work in 2001. My immediate thoughts were that we would get through this with the help and support of "The System", how wrong was I.

I applied to Centrelink for a Disability Pension for my husband and a Carers Pension for myself. The laughable thing here was that I got mine approved but my husbands took so much longer and they could not comprehend that this was a rare disease even though I had submitted a letter from his neurologist.

Someone had advised me to ring the Carers Helpline which I did as I had no idea where to go to get help and support. They sent me a directory of the services that were available in the South West Area Health. This is where I learnt to swear and throw a phone. **MY HUSBAND DID NOT FIT INTO ANY BOX OR CATERGORY.** I was completely dumb founded that no one was prepared to help me. The only offer I got was we will come and assess your husband for a Nursing Home, I hung up after politely refusing and went about my swearing and throwing of the telephone.

My husband saw a small article in the local newspaper offering a six weeks course on living with chronic diseases, we decided to attend this. From this I was advised to ring the Allied Health at our local hospital. I was very fortunate to have been connected to the Occupational Therapy Manager who quickly offered to come and visit us and assess our home for my husbands safety. She put the wheels in motion for work to commence for bathroom modifications and a ramp for easy access for my husband. This did not go well and the original crew had to be dismissed and another lot of workers had to come in and correct the mistakes and redo a lot of the work. More frustration, tears and swearing on my part.

I had my name with the Commonwealth Carers Respite Centre for ages and was getting nothing. I was tired, frustrated and emotional all the time. One day I reverted to my directory and I rang

Centacare. I burst into tears on the phone and explained how my husband and I had no family in Sydney and no one to help us. Centacare finally came up with an offer of four hours respite a week. This was all they had to give me. I had read where the Federal Government had injected millions into dementia programmes so to get additional help and put my husband into one of the **BOXES AND CATERGORIES** I got a certificate from the neurologist to explain that dementia was part of my husbands disease. Now I was able to access more respite and have it brokered to Centacare. I now receive six hours every Wednesday and five hours every second Tuesday. I do not get to rest on these days, these are the days that I do my groceries, pay accounts and do housework. You see as a full time carer of someone with a neurological disease you do not have a life for yourself. My husband has reached a stage where he needs to be showered, dressed, shaved, toileted and fed.

When I sought assistance for help to have my husband showered and shaved the organisation that I went to advised me that their hourly rate was \$40.00 per hour. This from an organisation with Government subsidy. They came to my house and put me under so much pressure I burst into tears. Luckily I had my carers advocate here who offered to get help from elsewhere to help pay the costs. They would not accept this and would you believe after all the stress and angst they caused me they offered to do it four days a week for \$1.00 per hour. So much for the rule that no service will be refused you if you cannot afford it. Carers do not need the added stress of haggling over costs for services.

After much pressure being applied to me from our only child I agreed to have my husband put into respite care for two weeks in January of this year. My husband's disease is very complicated and I spent a good couple of hours going through the assessment with the lady from the ACAT team. My husband was assessed as high care. We admitted him on the 17<sup>th</sup> January 2008. Our son wanted me to have a complete rest so he offered to look after my husband and his needs while in the home. I missed my husband so I went to visit him on the 22<sup>nd</sup> January. The first thing I noticed was the fact that my husband did not have continence wear on. I went to the sister to complain. The next thing my husband was given a juice by the tea lady which was not of pudding consistency as required by my husband. I informed her of this and she went away to correct it. On the following Saturday the 26<sup>th</sup> January I went to the Nursing Home for the day with my husband. I came home in tears after what I had witnessed, once again they gave my husband unthickened fluids, this can cause his death. I rang my son and the next day my son went and packed his father up and bought him home. I reported my complaints to the Aged Care Complaints Investigation Scheme. After nearly six months they have completed their investigation and found two definite breaches of the Aged Care Act. **APPROPRIATE RESPITE FACILITIES ARE REQUIRED NOT AGED CARE FACILITIES WITH A VACANT ROOM FOR RESPITE.**

My husband is losing his speech, which is part of the disease. He was assessed by a speech pathologist from the Spastic Centre who came up with a marvellous device that can speak for my husband but the cost is in excess of \$8,000.00. This was put to the PADP Department at our hospital and was refused, reason being that speech was not a priority. My husband will also soon lose the ability to walk. He was assessed for a wheelchair that I could manager last February. I was told the waiting time for this would be six to twelve months. Once again more tears and frustration.

As my husbands primary carer I am the one that has had to endure all the phone calls, struggle to get him into the car to take him to appointments and deal with all the frustrations that have gone with his illness and having to fight every inch of the way for what small crumbs have been given to us.

I was a diabetic with high blood pressure when my husband took ill. I now have a bad back, bone growths on my C5 and C6 which has caused neuropathy on both hands. I already have neuropathy in both feet due to the diabetes. To cope with all that has been happening my doctor put me on stress and anxiety medication last year and I have just been put onto antidepressant medication.

So what about my life and my future ? I do not know how long my husband will live. I am not yet

sixty. I do know that if my husband should die I am expected to go back to work. My husband and I were not in the generation to benefit from compulsory superannuation and we only have a small amount which is quickly being eroded at the present moment with the state of the market. I have continued to contribute \$100.00 per month from my pension into my Super Fund, **WHERE IS MY GOVERNMENT CO CONTRIBUTION.** I believe I should be getting it. As my GP says I am working 25 hours a day. How much am I saving the Government by not having my husband in an institution ? The answer - thousands per year and I should be grateful for a lousy \$1,600.00 in bonuses. Do you know where that goes ? It pays for our Private Health Insurance which we require as my husbands specialist is only at St. Vincent's Private Hospital.

**WOULD ANYONE ON THIS COMMITTEE LIKE MY LIFE FOR A WEEK OR EVEN A DAY ? I THINK NOT. Yes my husband and I were once one of the working families of this nation. We did not get thousands in baby bonuses, we did not get child care support, we did not get compulsory employee superannuation and we paid our mortgage at a rate of 17.5%.**

**HOW ABOUT GIVING BACK SOME TO THE PEOPLE THAT MADE THIS COUNTRY WHAT IT IS TODAY ? I FOR ONE COULD DO WITH THE HELP.**

Yours sincerely,

JAN