

A.O.C. 27/6/08

## Submission No. 191

(Inq into better support for carers)

17 June 2008  
Committee Secretary  
Inquiry into Better Support for Carers  
House of Representatives Standing Committee on Family  
Community Housing and Youth  
PO Box 6021  
Parliament House  
Canberra ACT 2600

Dear Secretary,

I appreciate the opportunity to forward my submission to the House of Representatives Standing Committee on Family, Community Housing and Youth Inquiry into Better Support for Carers.

At the age of 58, my husband, Don, had a severe stroke on 3 December 1999. He spent two and a half months in Intensive Care at Royal Prince Alfred Hospital. Doctors at RPA told me that my husband was incapable of rehabilitation and that I should "look for a nice nursing home" and "get on with my life". Husbands and loved ones, it appears, are easily disposable commodities.

He was discharged and spent another two and a half months to Royal Ryde Rehabilitation Hospital and subsequently transferred to Bathurst Rehabilitation. While undergoing further rehabilitation at Bathurst, he was permitted to come home with me at weekends to gauge my ability to care for him. He was at the time in a wheelchair with minimal ability to manage even his most basic personal needs.

We were living on a farm at Mount David, quite isolated from any support, being 65kms from Bathurst and 36kms from Oberon. I had been working in Sydney during the week and going home at weekends as we had been two years without income on the farm and going through drought.

**My husband's condition left me with only two choices: to resign from my well paid professional position in Sydney to support his further rehabilitation, or to put him in a nursing home. I chose the former, little realising the financial outcome, nor how lifechanging chronic illness and permanent disability would be.**

In the past eight years with the help of acupuncture, massage, nutritional supplements and lots of ongoing encouragement and support, my husband is now managing to paint pictures with his left hand. His dominant right side was paralysed by the stroke. He now walks with a stick, but only for short distances, as he tires easily.

I had only been working in Sydney since February 1999, living with my sister-in-law and her husband. In September 1999, three months before my husband's stroke, we had purchased our current townhouse in Epping, a suburb of Sydney, and with that I had a mortgage of \$2500 per month, which would have been manageable while I was employed, but an enormous financial burden after I resigned.

The Epping property was considered an "asset" and so precluded us from any Disability payment and I received \$90 per fortnight, which did not even cover the cost of petrol. In the following six years we were obliged to live off our savings and my

superannuation, and liquidate assets just to survive, until we reached rock bottom, which enabled us to receive a Disability and Carers payment.

I sold our farm in 2006 and paid off the mortgage in Sydney where we now reside. We now have no savings, and subsist on the “benefits” from Centrelink. I have found dealing with Centrelink extremely humiliating and feel that my role and struggles over the past eight and a half years are little understood or appreciated.

I have a \$6000 overdraft and do not know how I will ever be able to discharge this debt. I must run a car as my husband’s current level of mobility does not permit us to use public transport. I have tried to give my husband a good quality of life rather than simply letting him sit and watch television day after day, but this is now becoming the norm, as petrol and other prices escalate.

I attempted to establish a home-based business in nutritional supplements, but it actually deepened our financial problems and proved to be a costly exercise. I have an undergraduate degree and two postgraduate qualifications and have tried in recent times to seek employment, but I am now 63, and except for one interview, I have not succeeded in even making it to interview.

This is not where I expected to be at this time of life. In February of this year I was admitted as an emergency to Ryde Hospital with congestive heart failure. I was a very healthy 54 year old in 1999 before the financial struggles began in earnest. I have always been a resourceful and hardworking woman and resent the attitude that we are social pariahs or “rotting The System”, whatever that may be.

My husband was in the paid workforce for over 36 years until he was made redundant at 51 and lapsed into a deep depression. I agreed to the farming venture in an attempt to raise his spirits. It was never a financially viable venture, though we learned a great deal about life in rural Australia and the hardships of farmers and their families. We do not regret the experience although the isolation and other factors made life very challenging for me after he had the stroke at the farm.

Bad times and ill health eroded any opportunity to enjoy an independent retirement. After bringing up three children and contributing to their education and development, without any family allowance, we expected to be able to start saving in our fifties for our retirement.

I worry about the future EVERY DAY. The money we receive from Centrelink is pitiful, and well below the poverty level, given that the cost of living a decent lifestyle is impossible without incurring debt. I now have to consider even the cost of having my hair cut, and have recently allowed it to grow to avoid hairdressing costs. Taking pride in one’s appearance is part of the collateral cost of caring.

I needed help much earlier in the situation I found myself in, rather than watch helplessly as everything we had worked for over the years was eroded. Onerous bureaucratic hoops for carers to jump through is of no help whatsoever. Respite and other “support” are complex to access, although it seems to employ an army of assessors to determine our needs. What is offered by way of “packages” is ludicrous in view of the income we receive and quite out of touch with our reality.

I cannot speak for other carers, but by far the best and simplest way to assist our situation is by giving us a proper level of financial support. I am worried, as most carers are, about what happens to my husband, now 68, if something happens to me. Also what happens to me if my husband dies, and I then have to try to exist on a single Centrelink "benefit", and slide even further down the greasy pole to poverty.

I have recently taken out monthly funeral insurance of over \$100 a month for both of us, another cost eating away at our meagre means, but necessary.

I had to have periodontal treatment last year at a cost of \$1500, or lose my teeth. I am due to have more now, but am postponing treatment, at my peril. I simply cannot afford the expense. Even with pharmaceutical assistance, our combined cost for medication is \$50 per month.

Ongoing costs include car insurance, maintenance and petrol, home insurance, Strata levies, Council rates, water, gas and electricity, telephone and bigpond accounts, household maintenance, and if something breaks down God help us.

There are ongoing medical and dental costs, gifts for family and friends, contributions to our Church and other charities. We support a child in Malawi through Save the Children Fund at \$40 a month and I transfer \$10 each month into our three grandchildren's bank accounts.

I have brought our situation to the attention of both the previous Member for Bennelong, John Howard, and the current incumbent, Maxine \_\_\_\_\_, whose campaign I supported last year. Mr Howard at least initiated a "bonus" payment for carers which was much appreciated, but the current Labor Government, in its ignorance, was not planning to pay this again until public outcry made them do what was politically expedient.

Ms \_\_\_\_\_ handwritten response was disappointing and unhelpful. She made the comparison with her mother who cared for her father and uncle AND, she stressed, held down a full-time teaching job. She also reminded me that at the time there was no Carers payment. I think such a comparison deeply hurtful, ignorant of our situation and insulting. It was certainly anything but progressive and has caused me to seriously reconsider any future support for Ms \_\_\_\_\_ political ambitions.

I think the Government can relieve the stress we feel as carers by publicly acknowledging the contribution we make, at considerable personal sacrifice, paying us a fair and reasonable allowance, and not treating us as a burden on the public purse. Sadly, for many, awareness only comes from personal experience, and the Government's aim should be to simplify the complexity of "the health system" and service delivery and treat carers with the full respect they deserve.

Yours sincerely,

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