

A.O.C. 14/7/08
Submission No. 754
(Inq into better support for carers)

From: jenny
Sent: Sunday, 29 June 2008 7:50 AM
To: Committee, FCHY (REPS)
Subject: Govt Carer Survey

June 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I feel that my role as carer is not only my responsibility but also my privilege. The two people that I care for have made a contribution all their lives to support themselves and their families, having only to rely on Government support when they were no longer able to support themselves.

My husband suffers with Huntington's Disease, (HD) a degenerative neurological disorder that has a 50% chance of being transmitted genetically from parent to child. He also has an ex-tradesman's body that is in pain all of the time. His quality of life is being sapped away as this disease kills off brain cells and robs him of his ability to think, work and perform tasks. It also causes him to become obsessive about things, which is a constant source of stress for himself and others.

My mother is 83 and suffers from arthritis. She was widowed at 43, when my father died suddenly from a heart attack. She still had children at home, so with debts and a mortgage to pay, she went to work full time even though she was suffering from depression and grief. In her later years she still suffers bouts of depression now and then as do a lot of older people coming to terms with their own mortality.

Both have hearing difficulties as a result of their former employment.

Both have physical problems that cause them enormous pain on a daily basis. Neither of them are complaining souls and I am blessed in many ways with both of them.

I receive a Carer's Pension and allowance only for my mother at this stage as my husband is not deemed "disabled" enough at this point in his illness. I am hoping to apply for the Carer's allowance for him shortly as his condition continues to deteriorate. Hopefully this will offset the cost of food a little.

I face the following problems...where I live (Batemans Bay) there is no public transport to speak of. There are no buses that link up with Country Link trains. Country link is non-existent here, which makes trips to Sydney (to visit family) an expensive exercise. It would be nice to be able to use that which others in the city take for granted.

Fuel costs make going anywhere a financial burden. My husband, my mother and myself are somewhat house bound because we cannot access affordable transport. I would love to be able to take them out for daytrips just to get out of the house to break the monotony but it's too expensive. Shopping is about all we do apart from the odd visit to our children (15 minutes away) and my going to church.

I cannot comfortably leave those I care for, for more than 1 night as they are both prone to falls. We have not had a holiday for over 15 years.

I am financially struggling because of obvious reasons. All pensioners are struggling. Trying to live in a place with no access to public transport means you have no choice but to drive everywhere. Our Neurologist is in Canberra, 2 hours away. \$\$\$

Maintenance on our car is crippling. We struggle to pay for repairs and then get slugged with GST on top of the repair bill. Even a basic service is expensive. \$\$\$

Utility bills continue to rise and the rebate for pensioners is swallowed up by the GST again. \$\$\$

My husband's illness means that his appetite has increased four fold, meaning that he eats and drinks pretty much all day long. Metabolism is sped up with this disease so the eating is necessary to keep their weight up. Food costs are soaring. \$\$\$

30/06/2008

We have been on the waiting list for dental services here for years and now my husband needs 10 fillings because the high calorie (high sugar) foods he needs to maintain his weight have caused his teeth to decay. We can't seem to access the free dental scheme. Private dental work would involve us paying off our credit card for years. \$\$\$

We can never eat out, or even buy a cup of coffee (unless someone else foots the bill) and we can't afford take away, so I never get a night off from cooking. Fast food for us is baked beans or an egg on toast. (Probably more healthy anyway)

I worry about my future because my own health is suffering due to the stress of day to day living. My husband's illness means a decline in mental and physical activity. He is also in need of a knee replacement which will have to be soon because we will also have to drop out of our Health Fund due to rising costs. The entire financial burden falls on me. With my family history I am at risk for heart disease, but my own health concerns have to take a back seat to those of my 'carees'.

My computer is my window on the world. My faith is my sanity saver. I don't know how I would cope without my spiritual family. My children live fairly close to us and these are at risk for their father's illness too. That is an added pressure for us and them as they have families of their own to be concerned about. They help out when they can and are a great support for us emotionally.

I am also suffering the effects of menopause with its inherent sleep debt and mental fogginess. It's just another thing that blights my life and makes the carer role all the more difficult. I am a little short on patience when I am so tired.

The things that stress me the most about being a Carer are...what will happen to those I care for if anything happens to me?

Neither of them is disabled enough to be placed in care, but I still cannot leave either of them for any length of time because of concerns that they will injure themselves. Neither of my children could cope with the responsibility of caring for their father. Walking will become increasingly difficult for my husband as his illness progresses. The decline in his abilities is very frustrating for him. He loves to surf, and this passion is now threatened as he struggles to stay in the sport he has loved all his life.

He has just passed a second driving test with a restricted license and only drives locally now. I have no idea what we will do when he can no longer drive.

I need help financially at this stage and I think that capping the GST for pensioners would be one good solution for many in our situation. As mentioned, to have a pensioner rebate cancelled out by the GST is very frustrating. We all need to pay our share of tax, but hitting those who can afford it least is not fair. Capping the GST to a \$10 maximum for pensioners in the current economic situation for any goods or services would be fairer.

A pension rebate on fuel tax at the bowser would also be good, especially in areas like ours that have no public transport to speak of. On production of a pension card and a photo license indicating a local address, the tax cut could be rebated at the service station.

I have always felt that the whole Carer Pension set up is a little unfair.

There are categories of carers from the occasional to the 24/7. This should be reflected in the payment structure and the amount of help available. Those full time carers of totally disabled people whose everyday needs are met by their carers 24/7, with those who cannot care for themselves in any way, should be recognized and compensated for. These are the ones who need more financial help and recognition for their sacrifice. No one would choose this life. Respite and other services need to be more available to these ones. The carer role is one of little time for self, resulting in stress related illnesses. If you don't look after carers, illness will force them to give up! Then who will take care of their charges? Full time Carers need a break way more often than they are getting at the moment.

My physical role at present is achievable in my current circumstances. This will change in the future as my husband and mother continue to decline in health, as they must. My concerns for now are mostly financial, but it would be reassuring to know that when I need the extra help later on, it will be readily accessible.

I also need to know that when it is time for my husband to go into full time care that I will still be able to survive. The main problem then will be losing his pension and then trying to live on a single pension when the cost of living is not reduced by half. It still costs as much to heat your home with one or a dozen people in it. Rates, insurances and other expenses don't get cut because your income is reduced. The single pension needs to reflect what it costs to live, not merely exist.

How can politicians possibly understand what it is like to struggle financially when it is not in the realms of their experience?

I think the Government can better help Carers by recognizing the contribution they make and the money they save the government every year. Those who have contributed to their country all their lives should expect that their country can give them something better in return when they need it.

Nursing homes for the elderly should not be the only option for young ones with disabilities such as Juvenile Huntington's Disease. There should be facilities available for the younger disabled people to be cared for without being placed in "God's waiting room". (Way too depressing!)

I know that the government is not a bottomless money pit, but it rattles me that money is often wasted on frivolous things and grants of various descriptions and sports related things as if these were even on par with what carers do.

Priority should dictate where money is spent, and carers should be a big priority. To look after the carers is to look after

yourselves. Prevention is better than cure in more ways than one.
Most would not give up their caring role, they just need help to carry out the assignment.

Thank you for taking my views into consideration as part of the Committee's Inquiry.
I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely, Jenny