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Submission No. 735

(Inq into better support for carers)

Committee Secretary

Inquiry into Better Support for Carers

House of Reps Standing Committee on Family, Community, Housing
and Youth

PO Box 6021

Parliament House

Canberra ACT 2600

I am a 24/7 carer caring for my wife Margaret. She has multi-faceted illnesses originating from untreatable Lyme Disease.

I feel that my role is largely misunderstood in the general community including friends and relatives.

I contribute to Australian society by caring for my wife at home providing quality of life rather than saving the Govt a lot of money. Otherwise she would need to be institutionalized - and these facilities do not exist.

Margaret has a full range of seizures, which have not responded to any medication. What she has a choking seizure at night I have to check her and if need be hold her on her side. She has a minimum of 3 seizures a night. We both (particularly me) suffer from acute sleep deprivation.

Basically we don't have any social life and are isolated. We try to get to a family exercise class, but that's a hard drive either way. Car headlights and reflective signs going over and bright sunlight coming home, all of which induce seizures.

Trying to drive with someone having a seizure when you can't pull over because of road conditions is very dangerous and stressful. I have to time all seizures and the recovery in case the situation becomes life threatening and I need to call an ambulance.

We are struggling financially because of the cost of food and petrol and medical visits. There is no public transport and we are 10km from the nearest village.

I consider what I do is worth even tho it pays around \$1.30 an hour.

We ran our own blacksmithing business. Joan home for nearly 20 years until the seizures worsened and she started wandering - and getting lost. The stress of trying to work, meet client deadlines and continually keeping an eye on Margaret, coupled with sleep deprivation proved too much and started impacting on my health.

Our local G.P. who had earlier put Margaret on a disability pension then recommended me for a carers pension.

I worry about our futures. Joan is 65 this year and suffers from several stress related illnesses, basically caused by our situation. Margaret is 9 years younger than me. What happens if Joan unable to continue my role (eg have a stroke) and when I die.

The things that stress me about being a carer:

- ① That any time I may have to deal with a life threatening situation - some seizures progress

others not

(2) As sense of completion of a task, you just go on, like heading water in a fast stream - you can't go forward or backward with a long term degenerative disease you slowly go down

(3) Very little respite care. I get 4 1/2 hours a fortnight and sometimes have to spend some of this shopping

(4) The general misconception that you are somehow "working a lark". You become - particularly in rural communities a second class citizen

(5) I don't get to talk to other carers, the nearest support group is 1/4 hour drive away and so I don't get to meetings

As we have no other income it would help if the home bonuses became permanent as it is very difficult to save. The bonuses generally get spent on vehicle maintenance and insurance and taxes. It is helpful to have them in one lump sum

24/7 carers really need more money per fortnight - is more than a full time job.

I need more respite care, just to have a break and survive

Maybe people living outside major centers, with no public transport need some form of petrol subsidy.

I am entitled to time off but can't take it - lack of funding for respite and therefore lack of respite carers.

For me the time frame for this submission was too short - so apologies for the small

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