

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

5 June, 2008

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 am a carer for my mother, who is 92 years old and has Alzheimer's. I have been looking after her full time for the last eight years, since she was diagnosed, and for some time before she was actually diagnosed because of other health issues. I have no family assistance.

Her condition is considered 'high care'. I wash and dress her, make all her meals, and do all household chores. She cannot be left alone at all as she would wander off or could hurt herself. It is a very stressful situation as she is easily upset and agitated, has no idea where she lives, or often who I am. She paces around most of the day, cannot sit still, and is always in a state of anxiety. She looks for her parents and brothers and sister who all died years ago. Often my day consists of her crying and begging me to take her 'home' to her mother and father because they will be worried about her. Nothing I say will pacify her. Sometimes, we have to drive around the streets in the hope that she will settle. It's hugely frustrating as this will often go on for hours and hours. Tonight, for example, I am into the fifteenth hour of her non-stop trying to leave the house to go to her parent's house.

She often puts on the cooker, or puts on the kettle with no water in it (has fused eight kettles in one year), puts off the oven when I'm baking, hides things, accuses people of stealing, leaves taps running – the list is endless. Looking after her is a full-time occupation every day all day, into the night, and sometimes during the night.

At one time, when she was very ill, I had no sleep for six weeks because she was hallucinating and shouting all night, and I couldn't leave her alone. I felt so exhausted I thought I'd die of a stroke or heart attack. I have often felt so exhausted and stressed that I've felt as if I was going to collapse. It is very difficult to live a life

where I have no normal conversation, and instead listen to nonsensical chatter all of the time. This is my life and has been for years.

My caring role affects my life drastically. I have no social life at all. I am divorced and feel that I have no chance to remarry or even make friends as I have no opportunities of ever meeting anyone. I feel doomed to spend the rest of my life alone. I am now 57 years old and was in my early forties when I began my full-time caring role. I worry constantly about my own future, or what is left of it. I feel isolated and alone. My life is constantly stressful. I have no time for any hobbies of my own, ((I used to paint pictures) can't watch a film on television without constant interruption, can't read a book, can't play my music in peace, can't concentrate on anything. I have no time for myself at all except for about three hours per week when I have a carer come so that I can go and do my shopping, pay bills etc. Three hours per week isn't even enough time to go and watch a movie. It feels as if I rush to the supermarket and rush back home. This can hardly be called time for myself, or time for a hobby or relaxation, and there is no time to make friends.

Living on a carer's pension is virtually impossible. The only way that I have survived is by handouts from family. I have borrowed money that I can never pay back. My whole pension merely pays the rent for my house. We live off my mother's aged pension and handouts. My car, which I need desperately, is very old, and now needs another engine, which I simply can't afford. Therefore, I will have to get rid of the car. I have no way of buying another car. I have no idea how I will do my shopping now, or take my mother to the doctor's, for example. Things just get worse and worse. The cost of petrol and running a car is now extortionate. Food prices and rents have escalated so much that it's impossible to cope.

I think it is utterly ridiculous that carers are expected to survive below poverty level when they are often working 24 hours a day, for years, with no weekends off, no holidays, and under extremely stressful circumstances. I do believe that we should be getting paid a proper wage with superannuation. I have no superannuation and no savings. What on earth is going to happen to me? How can I save money? It's impossible. At the moment, I can't fix my car, my fridge has been broken for months, my DVD player is broken, and I can't afford to replace any of them. My vacuum cleaner was also broken and my food mixer, but someone gave me theirs as they were buying new ones. So, when something breaks or needs repaired, I have no means of paying to replace it. I often feel suicidal because I can't see any future for myself, and am so frightened of the reality of ending up penniless and homeless, and all of this because I loved and cared for my mother instead of dumping her in a nursing home.

As we save the government billions of dollars each year, it's a disgrace that carers are expected to look after their loved ones while suffering such extreme isolation and poverty. What does the government do with the money we save them? I think they should all be given our income for six months and forced to live off it, including running a car and renting a house.

I have been on the housing list for almost nine years! I have virtually been told that I have no hope of ever getting a house. Newcomers are regularly put at the top of the list before my application. They are deemed more needy than me! I'd like to know

why? As I'm doing a service that saves the government such a huge amount of money, I feel that I should be a priority on the housing list. It's an unfair system.

When my mother dies, how on earth will I be able to live alone on \$270 per week and rent a house? The rent is more than my income. It's impossible. I will have to leave the home that I'm living in now, and have no idea where I'll go. I don't even have any money for a removal. I could not even describe the amount of stress that I suffer through worrying about my future. And that stress on top of the regular constant stress of looking after someone with Alzheimer's. I have not had a full night's sleep for years because of all of the worry. I get no exercise, can't even get out to walk, so also worry about my health. Many carers die before the person they care for and it's hardly surprising.

As soon as my mother dies I will have to find a job. Who will employ me at age 57, and after being out of the workforce for years? Before my mother was diagnosed with Alzheimer's, I was studying at the University of Queensland. I was hoping to upgrade my skills so that I could acquire a decent, professional job. I've lost that opportunity now, and could never afford to go back to studying.

I have to keep moving further out into the country because of the high rents in the areas where jobs are more available. Even if someone does employ me, how am I going to get to work without a car? There's no proper public transport here and few jobs. There is one bus twice a day, which is going to be cancelled. No-one will give someone like me a loan to buy a car. I have no credit rating.

The nursing homes and respite centres are also under-funded, and don't have enough staff. I have had a total of 15 days to myself in the past eight years, consisting of three breaks of five days each time. However, I don't intend doing it again. I was persuaded to put my mother into respite for five days recently, which was my third break, for my own health, and she came home covered in cuts, bruises, with infected and swollen legs, and a fracture in her back. It was absolutely shocking, and sheer negligence of their duty of care. I can't even trust the respite centre to look after her.

What would help all of the above? A lot of money needs poured into nursing homes and respite centres.

Carers should earn a decent wage for the work that they do under such stressful circumstances, especially considering the billions of dollars that they save the government.

Carers should be paid superannuation, and compensated for the years of superannuation and wages that they have already lost.

Carers should be given a decent amount of time for themselves. Three or four hours once a week are not enough. We should have a full day to ourselves regularly so that we can actually have some free time to de-stress, do something relaxing, and have an opportunity to make friends and enjoy some company. Surely we deserve to have a little of the things that makes life bearable and that others take for granted?

We also need help to find work when our caring role is over. We need to continue to be given an income while we retrain for work, and to be given training without having to pay for courses. And I don't mean those meaningless courses on how to write a resume, for example. Believe it or not but many of us are actually intelligent people! We need useful courses on updating computer skills, for example, or learning new ones, or depending on the carer's qualifications, given training for proper careers, perhaps within the government itself. What we definitely need is hope for the future.

I don't want to go to bed and think about ways and means of ending my own life because I can't see any hope of surviving after my mother has died – that is if I haven't died first.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Yours sincerely,

Faye