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Submission No. 1045

(Inq into better support for carers)

4 July 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
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.

Background

I am a 40-year-old carer who cares for my 44-year-old husband, who is disabled through chronic disease. His health is very up and down. I've been a carer for nearly four years. I work part-time as a Commonwealth public servant, and my husband gets a part disability pension. We rent publicly – though we have a house deposit – as we can't afford the repayments on current real estate prices. I am involved with Carers ACT, and would not have made it this far without their support.

Situation of carers in Australia

I feel that my role as a carer is to ensure that my husband has the best possible quality of life. My role as a carer concerns nearly every aspect of my husband's life, from assisting with or providing personal grooming to being his advocate when he's in hospital. Being a carer has affected my whole life, from how I sleep to how much I can work.

I contribute to Australian society by saving taxpayers a great deal of money. If I wasn't my husband's carer he would need a lot more paid support services, as much as a frail elderly person, or would possibly need to be in full-time care. He would also be sick in hospital more often, which also costs money.

I face the following problems:

- Lack of affordable, suitable housing. We rent privately, as in the ACT if you work at all you make too much money to be eligible for public housing. We'd love to buy our own place - a one or two bedroom flat on a single level with no steps would be suitable, but affordable housing seems to be all about 3 or 4 bedroom houses.
- Continuing to work, even part-time, is challenging as it requires constant juggling of needs and priorities, as well as a great deal of stress and anxiety. Working and being a carer can sometimes seem overwhelming, but I persevere for the respite work provides from caring, as well as the money. We have experienced how dire it is surviving solely on benefits.

Financially we are OK at the moment, but I am not sure if I will be able to continue to work the whole time that I am a carer. I have already reduced my work hours from full-time to 25 hours per week, then to 20 hours a week as my husband's health has deteriorated. I worry a lot about being solely on benefits in the future, and being unable to manage financially.

I worry about my future because our situation is so uncertain. My husband does not have a prognosis for his condition, so we are unsure what to expect. My main concerns are about work, finances, the emotional wear and tear of watching my husband suffer, and dread of being a widow.

- Work: can I continue to work; would I be able to reduce my hours if I thought it was necessary as a carer; how do I decide if I can no longer work.
- Finances: not being able to manage solely on benefits; being poor for the rest of my life as I have little superannuation and no assets.
- Emotional wear and tear: constant anxiety; burnout; and isolation.
- Widowhood: how will I carry on?

The thing that stresses me the most about being a carer is the daily uncertainty. Is my husband going to have a good day? Is he going to be in extra pain, will he be able to eat at all, will he have any energy? Will I need to take him to hospital? Is he OK while I'm at work (he has been known to fib on the phone so as not to worry me)? How many problems will I have to solve? Will I be able to solve them all? Will I be able to cope?

Ideas, solutions, strategies

I think the Government can better help Carers by:

- Increasing the amount of the carers pension. It is great that the government provides income support to carers, but the amount needs to be reasonable for carers to live on.
- Providing some sort of superannuation scheme for carers, either to top their part-time superannuation up to the equivalent full-time level, or for carers who are unable to work. This would alleviate the fear of future poverty for carers.
- Providing access to low cost loans for essential items eg car to transport cared for person to appointments/hospital/errands, home loans for affordable housing, loans for funerals, loans for essential equipment. Carers would more easily be able to obtain and pay for the necessities of life and caring.
- Guaranteeing the right of carers to flexible working arrangements as a basic employment condition. The Commonwealth Public Service and some organisations guarantee that women returning to work from maternity leave have access to flexible working arrangements, in recognition of the importance of work/family balance. Carers need at least the same rights as working parents.
- Developing and implementing a national carers code to replace the various existing State and Territory codes. A national code would make resolve any differences in rights and recognition across jurisdictions. It would be great if this code was enforceable, especially on doctors who work in hospitals, who I've found to be the worst offenders in terms of providing information.
- Continuing to provide funds for respite services and carer support services. Increasing the funding would mean that more people are eligible for respite services eg in NSW most councils only provide respite services for frail elderly people and young people with severe intellectual disabilities – this means my husband is not eligible, even for community transport. It is not right that there are differences between the States/Territories in eligibility for respite services.
- Continuing to adequately fund the Pharmaceutical Benefits Scheme (PBS), as the cost of medications can be incredibly high and a huge burden to carers. Before my husband's disability pension was granted it was not unusual for us to spend \$200 a week at the chemist.
- Developing and implementing a mechanism that ensures patients with health care cards and pensioner concession cards are bulk-billed by doctors and other medical practitioners

such as radiologists. Sometimes it is not the amount of the gap that matters, but it can be difficult to find the \$50 to go to the GP, the couple of hundred dollars for the ultrasound, or the \$500-odd for the CT scan.

- Increasing the funding for Interstate Patient Travel Assistance Scheme (IPTAS). This scheme reimburses patients and their carers for transport and accommodation costs when it is necessary that medical treatment be provided interstate. These are State/Territory-run schemes, but I assume the funding is provided by the Commonwealth. My husband has been sent to Sydney for treatment many times, as the specific medical expertise is not available in the ACT. Travelling interstate for medical treatment imposes quite a financial burden on carers, as there are extra expenses for train or air fares, or petrol costs, as well as accommodation.
- Improving the relatives' accommodation at major hospitals. My husband spent ten weeks at Royal Prince Alfred Hospital (RPA) in 2004-05, and I had to live part of that time in a backpacker hostel and part of the time in a pub. When my husband was sent back to RPA in 2006, relatives' accommodation was organised differently: this time I had to share a bedsit with another woman. There was no privacy as the two beds were only an arm's width apart. Apparently I was lucky to even get that, as they turn away so many relatives seeking accommodation. The relatives' accommodation at the Concord General Repatriation Hospital is an old Nissan hut, and is right next to the morgue. Life is tough enough as a carer with a cared for person in hospital, without having to put up with less than ideal accommodation.

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.

Your sincerely,

Jo-Anne