

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

Acc 2.11.18

## Submission No. 976

(Inq into better support for carers)

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 submitting to the Inquiry because...

I have been caring for my 'high needs' care husband since 1996. He was left badly disabled after suffering a severe brain hemorrhage. At the time the only choice I had was to care for him at home or put him into a high level nursing home for care. He was 43 years old at the time.

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As you can imagine, this was a whole new world that we entered. Nearly 12 years on, while some things have improved, much has stayed the same. My choices of caring for my husband or finding out of home care for him are still as difficult and the options haven't changed.

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### 1. The role and contribution of carers in society

As a carer, I feel that my role is...

To do the best I can, not only for the person I care for, but the whole family. Everyone is affected in some way by what happens to a loved one. By becoming my husband's family carer my role as wife/mother/daughter/friend increased to become single-parent/main bread winner/therapist/accountant/taxi driver/spokesperson.

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Another aspect of being a family carer I believe is to let people know you exist. This means being willing to talk about your situation and taking the time to complete inquiries such as this.

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### 2. The barriers to social and economic participation for carers

As a carer, I face the following problems ...

On a personal level, the biggest barrier I have to participating on both a social and work perspective is the total reliance I have on relying on and having access to support services to help in the care of my husband.

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I initially cared for my husband alone for approximately 5 ½ years. With help from our ABI case manager, I accessed service provider funds through the then HomeFirst package. As the program bedded in and got up and running, it enabled me to have gain part-time employment as 'respite' from home, as well as motivating my husband a little more by having to deal with other people to help him.

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Unfortunately recently I had to give up my part-time job due to problems with finding suitable, reliable replacement attendant carers for the home program. Not only did it affect our finances, but the well-being of my husband who became very insecure with the whole process, due to his lack of understanding of what was happening due to his disability. This in turn, added to my stress levels.

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While things are settling down again, after about 3 months of trial and error, I do not feel safe in taking on part-time employment because of what happened previously. This subsequently affects certainly our financial situation. Families who rely on the carer and disability payments for their income as still on a rate of approximately \$0.70c per hour.

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Respite can also become a financial burden. On a very limited income, it is difficult to save to have a holiday for yourself AND pay approximately \$250 a week for a respite bed.

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### **3. The practical measures required to better support carers**

As a carer, I need help with ...

More stability and quality in the home support programs -

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Better choices for out of home care for high needs people – permanently and for respite.

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More financial security, e.g. superannuation funds

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More age appropriate/disability appropriate social programs for the disabled

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Help with education for children of disabled parents

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### **4. Strategies to assist carers to access opportunities and choices**

I think the Government can better help carers by ...

Helping long term carers have a more financially safe future for themselves, by looking at improving their income and introducing a superannuation scheme.

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Creating more 'respite' options – I currently live in city, with a population of over 65,000 that offers only TWO high needs respite beds. Not a great choice. It doesn't help carers when respite days are increased during elections, if the services aren't there to fill the needs.

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Create different programs to help the wide range of carers and their families. Some of us still have other members of the family to raise and educate to the best of our ability.

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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

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*Signature*

*Aileen*

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*Print your name*

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*Date*

4/7/2008

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*Postal Address*

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*Contact Telephone No:*