

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

STAND  
Submission No. 322  
2 (Inq into better support for carers)  
FAMILY A.O.C. 30/6/05  
HOUSING & YOUTH

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...

My son has Duchenne Muscular Dystrophy, he is 30 and completely dependant, I am his full time carer 24/7.

More information is attached on a separate sheet

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

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

Full time care of my son, there is no time for anything else. I dress him, wash him, toilet him, provide everything he needs and literally do everything for him. It is very very time consuming, to shower and toilet

More information is attached on a separate sheet

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

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

Geographical and social isolation. We live near Warrnambal - 3½ hours away from Melb. No public transport - if my son wanted to catch a train to Melbourne he has to sit in the baggage car with no carer as he has an electric wheelchair. This is not possible for him.

More information is attached on a separate sheet

3. The practical measures required to better support carers

As a carer, I need help with ...

As my son is around 90kg it is very difficult,  
It would be ideal if my husband could be here  
full time as well but he has to work so  
that we can eat and pay the bills. We want  
to care for our son ourselves as his condition

More information is attached on a separate sheet

4. Strategies to assist carers to access opportunities and choices

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

I have cared full time for my son for 30  
years - so have no superannuation.  
The carer bonus allows me to go to an  
optometrist and replace my glasses as my  
eyesight worsens, to go to the dentist

More information is attached on a separate sheet

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

Print your name

SUSAN

Date

19-6-2008

1. Continued

him takes  $2\frac{1}{2}$  to 3 hours. To get him out of bed dressed around 1 hour.

2. Continued.

We have little support and no help from family. Holidays just don't happen, if we were to take my son we would need hoists, toilet chair, his wheelchair and charger and traveling for him is not comfortable, just too hard!!

Power bills!!! The internet is my communication, and also my sons only outlet. Everything he has needs to plug in - his bed, charging hoist battery, charging wheelchair, heating. There is always something plugged in and turned on.

### 3. Continued.

is terminal and he doesn't want strangers coming in and showering and toileting him. We do have a carer from an agency that comes in on a Friday for 4 hours allowing me to go to town and pay bills, buy groceries etc. If my husband works overtime my allowance from Centrelink sometimes disappears. This worker for 4 hours a week will earn more than I do in a fortnight. Surely I am not worthless!! What I do for my son must be worth something all the time. We moved out of town to be able to afford to buy a home. If we didn't own our home we would not be able to cope financially at all.

Providing a wheelchair accessible car is much more expensive and we have had to get a loan for this as there is no public transport.

More money needs to be provided to the aids and equipment program. Any equipment a disabled person needs is so expensive. There needs to be a lending service in the event of break downs eg no hoist - person has to remain in bed for days until it is fixed. This is also much more difficult because we live in the country.

4 Continued

and have treatment without having to wait 3 years for public dentist. Prior to carer bonus was unable to go to dentist when needed. My back also gives me a lot of problems from years of lifting and transferring so require chiropractor every couple of months.

The carer bonus needs to stay, we all have different needs and can put this extra money to where it is required the most.

I worry what will happen to me in years to come, no superannuation and no skills as it seems that carers just aren't worth much. I hope this will change. If I did not care for my son he would have to move into somewhere full time, this would cost a fortune. Carers should be worthy of payment in their own right.