

Nov 4/8/08

## Submission No. 1141

(Inq into better support for carers)

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

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 wife and I are primary carers for our son who has a regressive neurological disorder.

This 25 year old young man is mobile but requires 24 hour support. He has to have most things done for him ie showering, dressing, feeding and toileting. As he is non verbal and can wander off he has to have continual supervision.

To make life even harder for him he has little bladder control at night which generally requires one or more changes of bedding during the night. These changes generally occur anytime between 12.30 am and 5:30 am.

The other major concern with his condition is one of emotional highs and lows.

The disorder affects the brain's ability to control mental processes, much like someone on drugs of addiction. What this means is that some nights our son is so active he only sleeps for a short time usually until 12 am. From that point he is very boisterous and someone has to be with him until the normal day begins whereupon a mainly normal daily regime can return. From 5:30 pm to 8:am my wife and I are the carers.

It should be noted at this point that both of us are full time employees.

My wife is a senior primary teacher and myself a yard manager with staff responsibilities. Both jobs require large personal inputs.

We both are income earners because

(a) we have been able to access enough outside care to cover most of our needs

And

(b) we believe in the need to provide for our family's future both ourselves and our son's long term residential care.

My wife and I know we will be unable to forever care for our son at home.

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

As a carer, we feel that our role is to support our son but not necessarily provide the major part of his care as he grows older.

As we ourselves grow older it has become increasingly difficult to maintain our mental resilience and emotional wellbeing as we find that we are in a constant state of exhaustion.

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

As a carer, we face the following problems.

To care for our son we continually supplement his pension in order to provide for his needs. This is a considerable drain on our economic resources and means that we rarely go out for dinner or have a holiday. Certainly any type of extended holiday without our son has been impossible.

If we travel with our son we face the difficulty of finding suitable food for him as he has a range of food intolerances which can result in extremely violent outbursts. It doesn't require much imagination to be aware of the difficulties that this would cause in public places.

We also have two other sons and find that it is becoming increasingly difficult to maintain social and emotional contact with them as they grow and mature into adults. As an example of this one of our sons lives and works in Queensland and it is extremely difficult for us to visit him and his partner because of the difficulties associated with traveling that distance whilst maintaining our role as a primary carer.

Our other son is currently completing Year 12 and is anticipating being able to attend university which will create even more economic difficulties as the costs of providing for our disabled son seem to increase yearly as he grows older.

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

As a carer, we need help with being able to use the allocated hours of care for our son in a more creative way. We do understand that regulations are there to make sure that the money allocated for his care is used appropriately however sometimes it seems that these same regulations make it impossible to make the best use of these funds.

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

I think the Government can better help carers by actually listening to what is said at the planning sessions which we have with the care providers and government agencies so that funds allocated are used in the best possible way.

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

Les            and Anthea

Signature

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Print your name

Les            and Anthea

Date

3/7/2008

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