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(Inq into better support for carers)

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Committee Secretary
Standing Committee on Family, Community Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I feel that my role as carer of my 30 year old son Byron, is overriding everything else in my life. I have to manage his daily life, including his diet, clothing, supply of medication and financial affairs as he has not developed to a stage where he can manage as an independent person. Not only do I have these physical activities but also I have continuous concerns about where he is and what he is doing, not normal concerns with people of this age.

An example of the oversight required is on one windy, rainy mid-winter night when he did not come home as expected during the afternoon. I attempted to contact his mobile, but he had left it at home. We met several buses over three hours, called the bus operator, the police and the hospital all to no avail. Finally he walked in totally drenched and freezing cold after walking four kilometers from a shopping centre. He had caught the wrong bus which took him in the wrong direction. He eventually was dropped at our district shopping centre after the connecting busses home had ceased for the night. So he walked home. It had not occurred to him to call us from a public telephone.

I contribute to Australian Society by finding Byron productive employment and then ensuring that he continues in part-time work by liaising with his employers to ensure all is well in the workplace and that he is performing his duties to the required standard. I spent many hours in the past discussing his needs with educators and employers as he was unable to do this himself. He graduated from University with a Mathematics degree and if not for my involvement as described, he would be unemployed.

I face the following problems.

- Tiredness and short temper on a daily basis
- Always having to be available to sort out his problems
- Diminishing capacity to provide physical care as my husband and I age

- My concern for Byron's financial security, particularly when we are no longer able to manage his financial affairs.
- Subjugating my activities so that Byron's needs are not jeopardized.
- Taking Byron to social functions which are inappropriate for him, in turn causing irritation to us and the other people present, due to his having only one real friend who cannot entertain him all the time

I cannot fully participate in social life because I must consider Byron's needs. As a retired couple we would like to be able to take longer holidays together. This is very difficult as if I am away from home for more than one day I have to arrange for someone to watch over him and depend on the good will of neighbours. This is not fair on other people as Byron is my concern.

I am no longer able to work as I am too tired to be a mother, wife, and worker who is always on call. Even when working I had to be physically located so that I could attend to school calls within a few minutes and so that he could call into my workplace whenever he had a problem. This was regular enough to ruin my career.

I worry about my future because of my family genetics which include dementia of four immediate relatives, Coeliac Disease which often results in bowel cancer and hypertension. The stresses that I am under would increase my susceptibility to dementia. Also I would rather like to have a life of my own, selfish as that may be.

The thing that stresses me most about being a carer is that regardless of other people's involvement, I carry the ultimate responsibility for Byron while I am capable of doing so. Who will love Byron when I am not here and he is just another strange old man?

I need help with management of Byron's daily life and financial affairs into the future. Support from an external agency, such as the National Brain Injury Foundation, will be of great value in managing Byron's daily life and medication. The Public Trustee (or similar) would be important in managing Byron's financial affairs. Byron does not have siblings so we will depend on others, who we hope will be regular supporters and suitably caring. I am scared for his future without loving parents.

We would like the governments to ensure that sufficient funding is provided in the long term to the various agencies to enable them to provide the required levels of care and support and that they are regularly monitored to ensure that the required standards are maintained. If these services are provided, my quality of life and longevity will be significantly enhanced.

I need to receive practical advice, preferably in writing, about the services available eg Guardianship Boards, Public Trustees.

I would also like a central point for information and registration for services. In the past I have spoken to the ACT Government Disability people who have cheerfully and patiently given part of the story and advised that I contact a number of other funded private

providers. They all had different areas of interest and in the end I gave up through sheer exhaustion. I am articulate and well educated and if I find getting information difficult how do people with communication difficulties cope?

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

Merrelin