

10 June 2008-06-10

Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

(Cc Hon Alex Somlyay MP Fairfax)

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.

My role as a carer commenced in December 1993 when my husband, [REDACTED], was diagnosed with a very large Brain Tumour and subsequently had surgery for its removal. These events left him paralysed from the waist down and unable to speak. He was hospitalised for 2 months after which he was discharged into my care, on the grounds that medical staff felt [REDACTED] was making better progress when I took him home on weekends. There was no consideration as to my capacity to cope.

Thus commenced a long rehabilitation process which saw us manage on our own with only limited family support for 9 years. After 5 years of my continuing to work full time and doing our own therapy at night which included taking [REDACTED] to a Hydrotherapy Pool for exercises, he had progressed to being able to walk and with intensive encouragement and effort he began to initiate conversation again. [REDACTED] balance continues to be affected, his recall of words can be difficult and his executive functioning is impaired. Motivation, initiation, problem solving, decision making and short term memory are some of the areas affected by this.

My role as a carer is to establish and maintain set routines and a stable environment which assist [REDACTED] to function at the reasonably high level that we have achieved. I also provide daily support in decision making, supporting and encouraging social interaction and all aspects of day to day financial and family matters.

We only started receiving Centrelink support a little over 5 years ago; however my health has progressively deteriorated due to ongoing stress and lack of time to devote to my own health, to the point where I had to reduce my working hours about 3 years ago, which has affected our financial future. The barrier in maintaining employment for me is mainly due to failing health.

My caring role has had a major impact on my life by changing it in many ways. Our relationship is not the same and as mentioned my health has been affected in a detrimental way. I find it difficult to have time and space for myself as we have had to move to a unit (as I could no longer maintain a home with a garden) and the TV is my husband's main interest at home with the consequence that it is never off. Due to [REDACTED] dependence on me it is difficult for me to have time away by myself as he does not cope if I go away. My energy levels have not allowed me to seek out interests or form new friendships for many years. It continues to be increasingly difficult to manage financially on a day to day basis and more so when our car and major household items are due for replacement. My medical expenses are now considerable and all this adds to the caring stresses.

I think the contribution I have made in not letting my husband remain mute and hospitalised and in the care of the government for the last 15 years should be recognised in a practical way:

- Substantially increasing the Carer Payment to better reflect the savings that the role has for society in general;
- Making the Carer Payment and Age Pension tax exempt;
- Removing the tax on the purchase of a cars and major household items for carers;
- Increasing ways that carers can receive support (In the last couple of years I have been fortunate in gaining some support through the Working Carer's Program via massages, swimming and gym passes to allow me to have regular short time out periods which have been beneficial and I could not have afforded these myself).
- Doing something to help carers with their health expenses.
- Early intervention support when people enter a caring role to avoid the health and relationship breakdowns that pressure causes.

These are some ways that support can recognise and make the role easier for carers in general, however, this type of support would assist me as an individual to make choices and have some quality of life for myself, which I have not had in a very long time, by mainly relieving financial stress, and giving appropriate recognition to the caring role.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Yours Sincerely

Judith