

2008-06-04

A.O.C. 12/6/08

Committee Secretary  
Standing Committee on Family, Community, Housing and Youth

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry for Carers.

I face the following problems:

- lack of appreciation by my husband as well as friends and the community as a whole of the work involved in caring
- lack of emotional as well as physical support for me as a carer
- difficulty in retaining my own quality of life while making sure my husband's needs are met.

My husband is angry and resentful about having to be in Residential Home. He has Parkinson's disease for 21 years and following several hip replacement operations and dislocations has been wheelchair dependent for 7 years during which time he has required high level care.

Seven years ago I decided to put [redacted] into care because I became depressed and exhausted. Seeing to [redacted] needs meant compromising my own. In order for [redacted] to continue his interests and retain some quality of life I had no time or energy for myself. My husband had difficulty communicating because of his illness and gradually withdrew into his shell. I became a slave in my own home. Friends and family kept away as they found the situation unpleasant and unrewarding. The path became lonely. Who cares for the carer?

Although we now live apart I spend many hours each week seeing to my husband's care. This includes advocacy with Centrelink, financial advisors, solicitors, Residential Home staff, doctors, dentists, and optometrists, support group and the art group I founded for people with Parkinson's 14 years ago. I take him for swimming therapy each week to the AIS and read to him. With secretarial help I am putting his family history and autobiography on a website. I do these things partly to assuage guilt and partly to find creative solutions to a tragic situation. But it is hard to keep going where there is no encouragement or gratitude.

My experience has shown how me how badly educated we are as a community about the work and needs of carers. I hope the present government can reverse this situation.

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.

Nancy