The Honourable J. Elliott, MP, Minister for Ageing, House of Representatives.

Dear Minister Elliott,

Re: Submission to the **Productivity Commission into Aged Care**.

I am writing to express my concern regarding the cost of the care of my husband who at 57 years of age has early onset dementia.

We have been married for 27 years. Since August 2008 he has been unable to work and after several months we were given a diagnosis of dementia. The specific type is unknown.

Since this diagnosis I have been trying to find information that is accurate and concise regarding the cost of his institutional care when that becomes appropriate. After several phone calls Centrelink have informed me that our combined incomes are to be divided and that for the rest of his life I will subsidise my husband's care. If I try to arrange finances to provide for his care then this income is combined with mine and the cost goes up proportionately.

It is a common problem with this disease that for many years, prior to its diagnosis, the victim's mismanage their finances. My husband would not invest into his superannuation despite many pleads to do so. I am now left with this legacy and a possible life expectancy for him of 5-15 years at a cost of \$25,000-\$45,000 per year. The laws governing this disease and nursing home care are established with an aged couple in mind not a middle aged one.

The financial pressures upon me are great. Our two children are still at university and I need to provide for my own old age and his care. Initially I was advised that he was entitled to the disability pension when he entered into an institution. I have since been advised that this is not correct and that my income is above the threshold of \$50,000 for the disability pension. I have only just started to earn this level of income as I have worked part time for several years to raise our children. He had a small income protection plan which I have been using to contribute towards his superannuation to assist me with his care later on.

I am requesting that consideration during the Productivity Commission into Aging be given to people with early onset dementia and their families. Some financial assistance such as the disability pension needs to be given to assist their families through this

difficult time. Income thresholds are an inaccurate measure of financial security and the laws should provide for some special consideration of families in this situation.

May I also suggest that people in my position do not pay tax. I realise that this is a very novel idea but I am realising that I cannot provide for my husband, support my daughters through university and provide for my own old age. Should my husband live for 15 years it is impossible for me to shoulder this burden. We have inherited some money but this will deflate and his fees will inflate over time. I make this suggestion as I feel it would be simple to implement and the government is better off in the long run as I will have finances for my own old age and for my children to inherit. My husband's fees should not be elevated by this adjustment but should be worked out on the current manner ie on my income and our assets.

Yours truly,