

Submission No. 1186

(Inq into better support for carers)

AOC 4/8/08

4th July 2008

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 son, Benjamin , had Duchenne's Muscular Dystrophy, which is a muscle wasting disease and, at the final 4 - 8 years, leaves the sufferers with as much strength and mobility as a quadriplegic - that is virtually none. Benjamin could do nothing for himself, except talk & laugh (!) and drive his electric wheelchair. He could not eat, get dressed, toilet or shower, move his hand, use a computer nothing without another person's assistance. However, Benjamin had his full mental capacities and completed his Year 12 studies and also Certificate IV in Multi-Media at TAFE.

You may notice that I am using *past tense* when talking about my son. Sadly Benjamin passed away at the age of 22 years in June 2007.

And that is why I am writing to you: I am 56 years old now. My 21 year marriage broke up 4 years ago (*stress of a disability in the family?*). After years of devoting my energy, love and time to caring for my son - I now have to try to support myself - get back into the workforce, with few skills and a lack of confidence after being removed from mainstream society for so long.

If you can please take my story into account. I live in a minor Australian capitol city and I know of 3 - 5 other mothers, also single mums, caring for their adult boys with Muscular Dystrophy, who also face the same loneliness and desolation after this horrible disease will take away their young men. What will happen to them then?

I think the Government can better help Carers by giving valuable, quality day options* for disabled adults and thereby giving their carers a chance to continue to be participants in society (by working & retaining their skills) and have some real chance of meaningful re-entry, when and if their carer role finishes.

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

Esther

Inquiry into Better Support for Carers
*House of Representatives Standing Committee on Family,
Community, Housing and Youth*

* Permanent homes on the cluster model would be even better, as carers of Muscular Dystrophy sufferers routinely get up 2-4 times each night to turn their 'caree' and hence are nearly continuously sleep-deprived, making day work difficult. This model works well in Europe. However - given probable lack of funding - the day options would be GREAT.