

June 30, 2008

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

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 has been increasing over the last 20 years and until 2007, we had not accessed any services for assistance. I am the primary carer of my husband (age 55) who has a muscular condition which is deteriorating. As my husband's condition has worsened, my role as his carer has increased. My husband is now confined to a wheelchair; he has swallowing difficulties and is at risk of aspirating into his lungs - therefore his food has to be vitamised and fluids have to be thickened. He is also an insulin dependent diabetic and has sleep apnoea.

My husband requires assistance with every aspect of his daily life - getting in and out of bed, showering, dressing, getting on and off the toilet, medication, food preparation, etc.

My husband has been assessed as eligible to receive High Level Care Permanent and Respite. He has been placed on a waiting list for an EACH package - but there are none available. At present, he accesses HACC care for 4 hours a day 4 days a week (Monday, Tuesday, Wednesday and Friday) - total 16 hours.

The rest of his care is undertaken by myself, our son (who is 19 and attending university full-time as well as being a Member of the Army Reserves) and other members of our respective families.

I contribute to society by working part-time. My employer has been extremely flexible with my working arrangements. There have been times when I have been on the bus going to work and received a call from the care providers to say they are unable to get carers to attend to my husband. I then have to immediately either go home to look after

my husband or try and get a family member to go (sometimes the only one available is my husband's mother who is 85).

My caring role affects my life in that there is no support of a night. I get up a couple of times a night to check my husband's position and breathing. In the last ten months, I have had one night away and that took three months to organize.

I rang the Commonwealth Carer Respite Centre two weeks ago (on Monday 16 June) to try and access some respite for my husband so that I could have a rest. I am still waiting to hear back from them as to when there will be a place available.

I find it difficult financially because a lot of the necessities my husband requires (such as specially thickened fluids & special dressings to prevent pressure sores) are not covered by Medicare or our private health insurance. My husband had to have a hospital bed which had to be specified to a certain height and the head and feet had to be able to be raised by controls - \$5,000. You can access a wheelchair through the State Government Medical Aid Subsidy Scheme, but you have to pay for it to be modified - \$750. Of the over \$20,000, we have outlaid on medical expenses for 2007/08 – only \$1500 has been claimable through Medicare or our private health insurance (which we are struggling to maintain).

The payments of \$1,000 and \$600 made by the Government to Carers are a mere drop in the bucket compared the actual expenses outlaid to maintain a disabled person in the home.

The practical measures that would better support me are increased access to respite care so that I can have a break for a couple of weeks every 3-4 months or even one night or a weekend a month. This would alleviate the ingrained tiredness and stress that I suffer which in turn is affecting my health. My constant worry is that if my health fails, then there is no-one to look after my husband.

It is also very difficult to access information – you ring one Department and get passed to another Department or get told it is State or Federal or vice versa. In the end, you give up trying because, as a carer, you just don't have time to keep following things up or to do the amount of paperwork involved.

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



MICHELE