

ACC 4/8/08

Submission No. 1171

(Inq into better support for carers)

*House Stranding Committee on Family, Community, Housing & Youth
Committee activities (inquiries & reports)*

Inquiry into better support for carers

From Robert & Grace

- *our role & contribution as carers*
- *barriers to social & economic participation*
- *practical measures to support carers*
- *strategies to enable carers to have the same opportunities/choices as the wider community*
- *specific needs of older carers*

My husband and I have been looking after our disabled son all his life except for a brief period of 18 months when he first left school.

My husband, aged 66 yrs, owns and works his own farm and I am a school teacher at our local high school. I am 62 yrs. We are 21 kms from our nearest town. My husband and I juggle our jobs and caring for our son.

Our son Karl is 38 years old, has cerebral palsy and has never walked. He has some speech which is getting harder to understand. He has low muscle tone and an eyesight problem so can't write, and can read very little. He cannot use a knife or fork and drinks through a straw. He cannot prepare his own meals and needs help with showering and shaving.

He has a medical condition which requires monitoring and medication that costs us \$200 per month (not on the PBS). His GP is $\frac{3}{4}$ hour drive and his specialist is over 3 hours away.

Our son does receive 4 hours of respite twice a week and he attends the local aged care centre twice weekly. Both of these have costs.

A number of years ago we were told that for the government to provide care for our son would cost between \$600 to \$3000 per day. At the lowest rate that is approx \$200,000 per annum. Our son receives a disability pension and I, his mother, receive a carers pension – approx \$10,000. Surely there is a more equitable way to help carers. If we were to all dump our disabled people at hospitals it would create havoc.

Over the years we have spent a lot of money making our home wheelchair accessible as well as ongoing care costs. If we can obtain short term respite care there are more costs. My husband and I have had three short holidays on our own and to that we had to add the cost of care.

- If we'd been able to claim expenses (respite, pharmacy, fuel, house alterations etc) against our taxes it would have been a help.

- A voucher system with an upper limit of \$90,000 per year.

- A reimbursement scheme where we produce invoices as proof of payment.

There must be a fairer way of recognising the contribution we carers make.

Access to social participation is a big issue for us.

Accessible toilets – always have to be checked when going somewhere new

Accessible parking

Building accessibility

We cannot even visit or stay with many friends.

As we are nearing retirement the work issues aren't such a worry but over the years they have been very big issues. My husband has felt that because he is a farmer his work isn't considered as important as a 9 to 5 job. At one time when our son was very ill we talked of suicide as a way out/coping.

Practical measures

Much more respite time

More financial help

A database that includes people who need care and their carer/s.

A support network/caseworker who can supply information on what is of assistance eg aids, respite, financial

At the moment there seems to be many different organizations who have brokered for money to help but I'm sure a large amount of money goes on offices, wages, cars etc. Finding these organizations seems to be by word of mouth.

*# As carers we don't have the same range of opportunities/choices as others. This happens on a daily basis – we don't make **any** decisions without considering our son.*

For us also is the looming decision of the day we can no longer look after our son. Will we be able to obtain long term care when we make that decision? Will that care be available locally so he can still be a part of our lives and possibly spend day visits with us? What will happen when we can no longer drive? Being in our local country community will be important for our son's well being.

My husband and I would be happy to travel to Canberra to be interviewed by the committee if required.