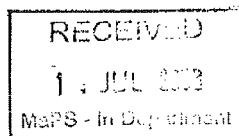


AOE 4/8/08
Submission No. 1131
(Inq into better support for carers)

9 July 2008

Mr. W. Shorten MP
Member for Maribyrnong
Parliament House
CANBERRA ACT



Dear Mr Shorten

I am writing in response to the Federal Government's 2008 budget and to tell you a bit about my family situation.

My husband Dave and I are the proud parents of three beautiful girls 14, 12 and 11. My husband works full time averaging 55 hours per week. He earns approximately \$78,000. Our youngest daughter Tara has severe spastic quadriplegic cerebral palsy and intractable (uncontrolled) epilepsy which makes our lives unpredictable and at times very stressful.

We receive just over \$100 per fortnight for the Carers Allowance to help care for Tara. Dave earns over the income threshold to apply for the Carers Pension. Our financial position has deteriorated rapidly over the years since Tara's diagnosis. When Tara came into our lives we owned our home outright - due to a lot of hard work from us both. We also could afford a new car, which we updated regularly - also due to Dave and myself working hard and saving well. Since Tara's diagnosis we have had to sell our home as it was no longer suitable for our family, and build an accessible home for us all. We can no longer afford new cars. In fact we had to purchase a second hand vehicle with hydraulic lift to take Tara's electric wheelchair. This cost \$45,000 which we now owe a family member for and somehow will have to pay back. We also owe over \$125,000 on our home loan and our home is still not entirely finished - even though we have been here for nearly 5 years. We used to have savings - we now live week to week. I can no longer work due to Tara's fluctuating medical needs and appointments and Dave is forced to work long hours to support us all - which means I get little support at home. We also have no family in the area.

I regularly drive to Sydney Children's Hospital Randwick for medical appointments (a round trip of 420km) and John Hunter Hospital (a round trip of 186km). Unfortunately we cannot use a small fuel efficient vehicle to drive to these appointments so along with the cost of fuel we also have consultation fees as well. This could mean that a day trip to Sydney for a medical appointment can cost over \$200. Our chemist costs for prescription medication average about \$150 per month - this is with a Health Care Card.

Tara's current electric wheelchair was knocked back for funding through PADP and cost \$11,000. This amount is also on our mortgage. With the rising interest rates and increased costs in caring for Tara we are becoming increasingly worried about how we will cope financially in the coming years. Tara has now outgrown her current electric wheelchair and we have been sourcing quotes for a new one in the last few months. A new electric wheelchair will cost just under \$15,000. If this vital piece of equipment is not funded this time, this too will be added to our mortgage. A family member has been very generous with our financial situation many times in the last few years and 'bailed' us out with equipment that could not be funded except by us. I hate to think what would happen if we had

not had this help. While this financial help is very much appreciated by my husband and myself, we also resent the fact that we cannot afford to fund these things ourselves and the fact that not so long ago we owned everything we had and had money to invest.

With the change in Government we were hoping that Carers would finally get some more recognition. It's great that the Government has increased the child care threshold and subsidies to go with it for working families, but as a parent who would love to rejoin the workforce, but is unable to, I find it hard to understand why we as carers are continually being penalised because we can't work. My husband works extra hours to help pay for our many additional expenses which then puts us over the threshold to claim any sort of pension. The income threshold for a Carers Payment does not take into consideration the income that is required the care for someone with high support needs. In our case we pay extra for the following (and alot more)

- Vehicle - wheelchair modifications, extra large vehicle means higher fuel costs, registration and then insurance to also cover the modifications.
- Electricity - extra electricity costs. A person with a brain injury cannot control their body temperature like most people. Air conditioning is used to keep the house at an even temperature summer and winter. Extra for hot water costs. Showering takes longer and often more frequent showering is required. For example my daughter had a gastric bug earlier this year and I had to shower her 11 times in one day.
- Telephone - Telephone calls cannot be made to specialists and therapists in the economy time frame. Calls are always made in peak times and are often lengthy. Mobile phone costs are also alot higher.
- Equipment - Lifting equipment, handrails, walkers, wheelchairs etc etc.....
- Medical - As mentioned before the cost of travelling to appointments is crippling. Visits to GP's are frequent and chemist costs are prohibitive.
- Technology - We had to purchase a laptop for my daughter Tara to use last year at school. We then had to purchase a specialised maths programme and then a read/write aloud English programme. The cost of this was over \$3,000.

The above is only a quick rundown of the extra costs we face every day. Not to mention the emotional and physical cost to all our family. We are more than prepared to continue our caring role for as long as we are able, but at the same time we are saving the Government alot of money and resources. I would think it would be reasonable to expect that a caring Government would see the benefits of looking after their carers in the community and make our lives a whole lot easier – which would save the system in the long run.

Yours faithfully

Dianne

PS. Sorry if this letter is late for the submission for carers. I have been in hospital with my daughter and did not get time to complete this.