Submission No. 407
(Inq into better support for carers)
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FAMILY, COMMUNITY,
HOUSING & YOUTH

11th June 2008.

Toni

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.

I have been a carer for 16 years. My eldest son, 16, has severe athsma, ADD, ODD and OCD. My youngest son, now 8, was born with Down Syndrome, but also has many disabilities and serious health conditions. He has a degenerative lung condition, which in the near future will mean he will require a heart/lung transplant to live.

Because of my youngest son's condition I am unable to work, as I full time care for him, and home school him, as he is too ill to attend school. I contribute to our community with the full time care I give him, the schooling I provide him with, the nursing I do for him, and all the paperwork, running around and support I give him. I also run a playgroup for children with disabilities and so support many other families in our community. During my days, I also do 6 hours a month voluntary work at our local institution supporting adults with severe disabilities.

My caring role affects my life in all ways. I had to stop working. I only receive 6 hours per week respite to do all my shopping, bill paying and running around in. This means I am severely restricted in when and where I can go and how much time I have to get things done in. I have no social life, as my little one has a very low immune system and can't be exposed to germs, especially thru winter. Catching up with friends is done mainly over the phone. I am restricted in what I can be involved in for support. There are so many meetings we have to attend for his support to be upheld, continued and improved and this takes up a lot of our time.

It is difficult financially to survive. The pension barely covers our rent and private health cover. After food and petrol, there is barely enough to cover electricity, phone, and medicines. Anything outside of that just doesn't get paid. The bonus money which we receive at the end of the financial year is used to pay insurances and car registrations. Maintaining our home, the car and upgrading our appliances is beyond doing. We have not had a kettle or toaster for 3 months as we just can't afford to replace them. My son does receive a support plan from DSQ which does help to cover his medicinal and therapy requirements. He has warm clothes and schooling requirements. My other son and I make do with what we have. When we require surgery, we need to go privately so it can be done immediately, but the costs are so enormous, it puts us into extreme financial difficulty. I put my son on the public list for ENT 2 and a half years ago, and he is still on that waiting list. I ended up paying for him to have that surgery and a subsequent one during that time, as the wait was impeding his development and health.

To better support me and my family we need more money. That is just something that can't be avoided. We need to have more access to support and respite. We need more disability parking bays in our area. We need more health support, so there isn't such a long waiting list, and we need doctors who actually know what they are doing!!!!

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. I am happy to discuss any of these points with you.

Yours sincerely

Toni
Citizen of the Year 2008