

Submission No. 59

(Inq into better support for carers)

A.O.C. 16/6/08

Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing and Youth

12th June 2008

Dear Secretary,

We 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.

We have thought a great deal about how to give you a better picture of our situation living with a young adult, [REDACTED] with many disabilities who is deteriorating in front of our eyes. It's become rather long as both my husband, [REDACTED], and I have written from different angles.

Our son, [REDACTED] now 18 years, is severely intellectually and Physically disabled. He has an extra tag on Chromosome 15q so he was born with his disabilities. In brief he cannot talk is incontinent, suffers epilepsy, spends most of his day in a wheel chair and has to be watched at all times.

We both work very long hours running and maintaining our own small business with 3 employees. Also living with us are [REDACTED] younger brother and older sister. Between work, running a household of 5 and caring for [REDACTED] we have little time to ourselves. Lack of time, disheartened and exhaustion probably best describes us on most days.

Ever since [REDACTED] was born all our decisions have been made with [REDACTED] needs foremost.

This includes where we live, where we work, where we go or don't go. These decisions made all the more challenging by the lack of support services we have been able/ unable to tap into over time.

For instance we would not normally choose to operate our business with employees from our house. However we feel we have no option but to do so to ensure when [REDACTED] comes home from school there is one of us here. We cannot rely on the current services available to give us the help hours required or on their reliability. This whole working from home situation is far from ideal for [REDACTED] safety or for our financial well being. We cannot have an eye on [REDACTED] every minute he is home while we are working which means [REDACTED] is often left unattended, a dangerous situation with his epilepsy. It is quite stressful every afternoon from when [REDACTED] comes home to when we finish work at 6.00pm.

[REDACTED] brother or sisters if home during this period are often asked to put their homework/study requirements aside to care for their brother.

Their needs and requirements always come second to [REDACTED]. You tend to brush aside their individual problems and they don't want to bother us with their problems so it all festers until something drastic happens. [REDACTED] sister went through a dark period at 16-17 years of age, always at the doctors to get on top of her problems. We still have on going issues here.

We have rarely, over the years, all been able to attend functions such as sports carnivals, speech nights, plays, Art shows etc. Someone has had to remain behind to look after [REDACTED]. Finding appropriate 'baby-sitting' or services to care for [REDACTED] on these

or other occasions is a difficult process to the stage where you give up trying and rather choose not to go out. There are a couple of services in our area, Redlands respite and BayCare but they won't even put [REDACTED] on their waiting list as the waiting lists are so long. This indicates a huge demand and the current services are not able to meet the need.

The end of school for [REDACTED] is this year and a frightening prospect for all of us. We know we will be faced with more days and hours in every week to care for [REDACTED] and I don't know how long we can maintain this before one of us falls apart. This wouldn't be so daunting if we had adequate reliable support to help us.

What would assist us in our caring role and allow us to continue to care for Joel at home:

1. Reliable care for [REDACTED] during the day and right up till we finish work at 6.00pm
2. 4 – 6 week-end respite per year
3. A block of respite each year. 2-4 weeks

[REDACTED] Life

[REDACTED] has a severe level of intellectual disability that requires constant monitoring and assistance caused by both his genetic malfunction and his constant fitting. Unfortunately no medicine has stopped his fits, only subdued them so the deterioration is continuing to happen. Fortunately, he is a gentle giant who does not exhibit any forms of violence or rage and never complains. We do our best to ensure his needs are met and has a relatively trouble free life.

He sleeps in a room devoid of all furniture except a mattress on the heavily carpeted floor and, in winter, a heater in the corner of his room. The heater keeps his room at a reasonably warm temperature because he is incapable of covering himself on a cold night.

If he fits during the night, we get up and check on him and try and get him back to a peaceful sleep.

Each day, at 7:30am, we wake him up (if he is not already awake) to get him ready for the day, which often consists of physically lifting him off the floor (his form of teenage rebellion). We cannot let him sleep in because he has a strict medicine regime, which is fairly inflexible.

Once up, he needs to be showered to remove the smell of stale urine and make him smell nice for his teachers. [REDACTED] is incapable of doing anything for himself, in the shower; we must do everything for him including soap, rinse and dry him. One consolation is that he does enjoy water and therefore enjoys being in the shower.

After showering we dress him then sit him up for breakfast, at which time we give him his medicine, (generally not too difficult because if he's hungry and it's in his mouth he eats it) then encourage him to spoon feed himself the rest of his breakfast (about the only thing [REDACTED] can do by himself ~ though, as a result of his epilepsy, this too is deteriorating rapidly).

Whilst he is feeding himself his sheets and clothes can be put in the washing machine to remove last night's urine, if required. The washing machine is basically run seven days a week to keep up with the demand and has the effect of increasing our water consumption above the average.

After breakfast is finished, it is time to get [redacted] toileted and dressed ~ again we have to do everything ~ then strapped into his wheelchair and off to school. Finally we have about 20 minutes to ourselves before we have to be at work.

Once [redacted] comes home, he needs constant monitoring & assistance (something that we find extremely difficult whilst we have to be at work) then the entire process begins again, this time in reverse until he gets to bed around 8:30pm when we can collapse as well so we are fresh for another excitingly interesting day. Even with the constant monitoring and assistance potentially dangerous accidents occur, like the time he was being sat down for his dinner and whilst his chair was being pulled out (care's attention diverted), so he could sit down, he blacked out and dropped to the floor. As he fell his head went straight through a glass panel in a French door and ended up with his head half in half out of the glass panel with daggers of glass each side of his head. I perish the thought of what might have happened had he not been wearing his solid cricketers helmet.

Our house has a lovely background smell (called "hint of stale urine"), which is ingrained into the carpets and furniture because of all the accidents that [redacted] unfortunately has. We have learnt to live with this but anyone visiting is generally too polite to mention anything but notice almost immediately. We also have holes in the walls caused by [redacted] going into a severe epileptic fits and his muscles convulsing uncontrollably. If he happens to be lying down near a wall when this happens his spasms can put a hole through the plaster board wall either by his feet kicking or arms flailing.

Our social life consists of sitting at home and watching over [redacted] (thank goodness for alcohol). It is generally too difficult to take [redacted] anywhere and [redacted] stance is if we take [redacted] we will end up watching him the entire night and probably will not have a good time so why bother going in the first place. Because of this we usually have said no to invitations in the past and now the people who used to invite us don't bother anymore.

And at the end of it all, it is not us with the pathetic life, it's [redacted] and he never complains ~ an inspiration to us all. Further he is happiest with the simplest of things, like me sitting on the couch with him in the evenings or feeling the freedom of being able to walk around (assisted of course); an ability that he is slowly loosing and I fear he knows this. He has no desire for the latest mobile phone or ipod or any other gadgets that teenagers of his age usually "need". He loves music, the wiggles & play school, provided he has heard it many times before. He loves to go for drives and he loves to have his grandpa sing "this old man" to him.

As his condition deteriorates we need to increase the amount of support and assistance that we provide him to ensure that he maintains a quality of life and some form of dignity. Further, as we steadily get worn out we are not going to be able to continue to offer our current level of support and will need to out source this to other professional organizations.

Your Sincerely,

Michael and Jenny