

Submission No. 1127

(Inq into better support for carers)

Acc. 30/7/08

29th June, 2008-06-29

Committee Secretary,
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 feel that my role of a carer is to care for my disabled family members to the best of my ability. My late husband and I married and had 5 lovely children, two of which were born with an intellectual disability and condition deteriorated and both suffer from epilepsy. I have cared for these two disabled family members and still care for them for the last 36+ years and do not received any help and have just been knocked for respite care package. On top of that my husband suffered from a genetic condition called myotonic dystrophy and this is what took his life almost three years ago. At the time of his death I received a bare 4 hours per week respite for him, I was working part-time to supplement a part pension and caring for the two above mentioned family members. The above caring roles is taking its toll on my health and I would love to have a small slice of time for myself which I never have had, in other words I have been a carer for some 36 years at times caring for 3 family members and receiving little or no help. I have never had a social life, my family is my life but I feel my other family members suffer because of my heavy caring role.

My son's epilepsy is not controlled by medication and I am unable to leave him without supervision. He suffers from drop seizures and would not tell me if he has had a "fall" as he calls them. He doesn't like any fuss and gets aggressive with me when I go to his aid. Part of his trouble is he won't ever initiate going and having a drink and therefore I think he dehydrates and in summer my life, even more so, is on edge whenever the weather is hot. The winter hasn't been any better so my life is literally on edge at all times particularly late afternoons and I transport him to and from his work situation because the public transport system is so poor he would have to leave home at 6.50 to start at 8.30 and get home at 5.00 when work finishes at 3.30. He wants to be independent but with his epilepsy uncontrollable he needs as much sleep as possible and needs to be picked up as afternoons are his worst time. So you can see my life is not my own. I can only work part time so I can be his taxi and his lifeline for his safety and for my sanity. Yes I have

just been refused respite???? Is this fair? I can not access any such service as Coastlink or Life without Barriers because I can not depend on the carers to effectively care for his needs. He has medication of a morning and late afternoon (one tablet at approx 5.00 and the rest at tea time. Tea time has to be at a reasonable hour as I can't administer his medication without his tea as it is too potent for his body and then that will trigger seizures. So you can see that my life evolves around making sure medication and meals are on times and sufficient for his body's needs.

I have no social life or never have had and I would have been married 37 years last March as I have been caring literally all my married life. My friends are practically all in the same position as me, as we help each other the best way we can by supporting and helping each other through mutual support.

I am really worried about the future. What is going to happen to my son and daughter when I can no longer look after or care for them? I am involved and have been involved in looking for suitable accommodation to cover my son/daughters needs. I don't like what I see offered by the government at the moment as my son needs almost 24 hours supervision and this is pretty well nonexistent. I shouldn't have to rely on my family taking over the caring role as they have their own families and yet what alternatives are there??? My eldest son doesn't want any thing to do with the family and I feel the reason is that he feels that he has never had any quality family time as his disabled brother and sister always took away from his time and this is extremely hard for me to cope with as I feel that I have failed him as a mother and as you can imagine this is extremely stressful.

I need help with a little bit of respite e.g. pick my son up from work, work with his financial side of his affairs and then come home, maybe with a male worker to do some male things together as my son has no male contact within the family at present. A person to help my daughter prepare a meal and cook dinner once a week would be just lovely as at times I am just too tired to care and just cook the easiest meal possible – not always the best nutritious meal.

When I go to work it is as a Community Carer working with aged clients who suffer from dementia. Although I enjoy this work I also are still caring and providing for the aged. I can see from this job that the 7 1/2hours a week is not sufficient in a lot of cases and if this amount of time was adjusted to each clients needs and wants. These clients in most cases are dependant on the Community Care Workers as many have not got family close by or the families lives are so busy they have little or no time for their mum or dad or both. The aged are far better if they remain in their own homes and receive as much help or as little help as they require as their dementia progresses. This therefore should then apply to the disabled, some require a small amount and some require a large amount of help. I feel that if enough support was given more would be able to remain in their own home longer. There again if government help to families was greater maybe families would be more able to share the load of caring either for the aged or the disabled.

I also feel that governments in particular Centrelink should have Caseworkers to assessed the requirements of each individual depending on the circumstances. There is a lot of

paperwork to be filled in a person with dementia or a person with an intellectual disability cannot do all this themselves. A person with a disability in most cases are not going to all of a sudden be cured e.g. a Downs syndrome person is never going to become normal and yet they are constantly receiving forms to be filled in a job they just can't do. Doctors become cranky as paperwork takes up valuable time, which could be better spent on another person's health requirements hence freeing up doctors time to be spent on more deserving cases. Yes I know that there are some people who receive the Disability Pension who with correct treatment or retraining may be able to return to the workforce, so therefore these kind of people should be required to go for regularly checkups and therefore in time return to the workforce and they should be required to fill in and report regularly to say Centrelink while some should not have to go through the trouble of filling in forms constantly.

Another suggestion I have is that there be a website formed to make sure services are effectively spread to the needy and that the needy should only be able to access help through one agency and this agency look after all the needs of that client e.g. home help, respite, holidays, vacation care etc and this should be monitored. I know that several families get help from several sources and when filling in a form that say "do you receive any help from anywhere else" it is easy to write "no" and this is never checked. It should be and hence services could be more evenly spread instead of some families receiving lots of services and some families receiving none. Families should be visited regularly to see that the correct services are going in and they are receiving as much help as they can. Services should also be accountable – I know of several services that have just recently been spending up big to use up money e.g. a small group went to Qld for a holiday, they flew up, stayed at first class accommodation, ate all meals out – wouldn't be all like to do that? This was open to some 4 or 6 people and yet there are hundreds on the books, this doesn't seem fair to me. Another group went to Sydney, stayed at Starcity, ate a meal at the Centrepont tower Revolving Restaurant and saw Billy Elliott and yet again it was a select few. These last two were to use up money and this money was spent on just a few? This is not fair to me or anyone else who is desperately waiting on a respite package. I wonder how many other places used up money for the sake of using up money, when there are many others waiting and can't get basic help????? I bet these were not isolated incidences!!!!

I have said time and time again that yes the Government is trying to help but help is only getting to a select group. There needs to be better resources governing and watching who, where, how people use the money the government is providing. Just because one gets a package last year, it shouldn't mean that they automatically carry it on forever.

I hope that I have answered some of the questions you wanted answered and my taking the time to answer is beneficial to the general aged/disabled persons in our community. Looking forward to being of assistance to you in the future. I see the role of carers as a very valuable role who are saving the government mega bucks. Yes the governments are paying out mega bucks but it is not evenly been distributed and this is the greatest need. The people who deserve the help receive the help to continue the vital role they are performing in the community and in their families.

Thank you for giving me the opportunity of taking part in the Committee's Inquiry

Yours faithfully,

Carmel