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Submission No. 1189

(Inq into better support for carers)

REC 4/8/08

Committee Secretary on Family, Community, Housing and Youth
PO 6021
House of Representatives
Parliament House
Canberra ACT 2600

July 6, 2008

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's enquiry into better help for carers.

I feel that my role as a carer is to meet the physical and cognitive therapy goals of my 16 year old son as set by his therapists and teachers and to give Alex every opportunity to live a fulfilled, independent and happy life.

The problems I face are, in part, physical, as I am 52 years old mother of a 16yo boy who suffers spastic cerebral palsy and requires help with all of his activities of daily living. I am beginning to feel the consequences of years of manual handling in my shoulder and back mainly by manipulating Alex in and out of vehicles and with transfers around the home.

Because of Alex's high physical needs and his lack of emotional independence it is difficult for me to have a social life. To get out to work is often difficult enough.

I have had to purchase a specially modified vehicle (on which I was required to pay duties), managed to purchase a second hand hoist and had to travel to Canberra from the Central Coast to get it and had to pay \$1500 to have it installed without any assistance (paid duties/taxes on petrol etc for this necessary mission and I am on the pension!!). This was just to simply enable me to take Alex swimming after school, to the library and to access his community in general which any other child would take for granted without having to rely on the erratic timetable of the community bus or to rely on special taxis. The time it takes for Alex to be loaded into a taxi negates any benefit from the half price mobility vouchers! The taxis are generally not available when I need them after school because they are driving other school children home and we risk missing out on the outing altogether. Alex's wheelchair, his only form of independent mobility requires repairs, and he

requires a walking frame at the cost of nearly \$800. Alex's physical, therapy and equipment needs will continue into his adulthood.

On the Carers' Pension if I choose to work I am means tested and my working hours are restricted to 25hrs/week *including* traveling time and *even any study hours!* How can I possibly continue to meet all of Alex's needs on the pension under these restrictions or to advance in my career and/or work opportunities? There are times when I have had the opportunity of work when I needed the funds to provide the necessary gear and have had offers of assistance to cover Alex for one or two hours after school but I would be at risk of losing the pension and the benefits if this happens on too many days of the year!

So, under the current system, my choices are

1. Forfeit the pension/benefits and go to work full time/overtime and neglect the duties and responsibilities I have to Alex so he can have the necessary equipment, and rely on respite to allow me to do this (so far I have been unsuccessful in my applications for respite care due to demand) or
2. Stay on the pension, work part time and be there for Alex but deprive him of the equipment he needs for therapy and access his community (which others take for granted) because I could no longer afford to run the VW Transporter required to accommodate his wheelchair or to meet the cost of therapy and the cost of living.

Not that great a choice! It is hard enough for someone living on the pension with a normal child let alone adding the unavoidable and necessary extra costs and dedication of time vital to offer the best potential for living as independently as possible to the disabled child. Part time work on the pension does not cover the basic cost of living and we are faced with extra costs yet we are being held back by a system that is meant to support us. If the Blind Pension is not means tested then why is the Carers' Pension? After all please consider that it is not as if we are trying to get the sofa recovered, or mag wheels for the car. It is walking frames, mobility aids, continence aids and equity and access – our priorities are sound, we only want what is best for our kids and help in order to achieve this. "Better Together" (DADHC initiative) would be more effective without the means test for carers.

The only other option is to have Alex made a ward of the state and have the Department deal with the therapy, costs, time and equipment. I am not prepared for that and would like the Minister to consider that carers like myself are prepared to give all it takes to keep their loved ones out of state care, that carers are relieved of the means test on their earnings if they choose to work and that their work and study hours are not restricted. We cannot live on part time work and the pension alone and still continue to do all that we do. I believe that by reconsidering the means test for the Carers' Pension there would be more options for carers, as carers, in meeting their responsibilities and reduce the load on the State by encouraging carers to continue to care for the frail and disabled in their communities and with their families. Carers would benefit by having more

choices in planning for the future rather than waiting for any available "handouts" at the end of the day. There will be less pressure on PADP and charity services in providing equipment as carers would be able to bypass waiting and purchase themselves (hopefully subsidized and tax exempt equipment and aids). Dropping the means test would encourage many carers happily back into the work force, to pursue careers, encourage them away from the welfare system towards independence rather than dependence on the system and to make good life choices for themselves and for those in their care.

As an ageing carer I also have concerns about my ability to continue to look after Alex into my 60s and beyond. As mentioned earlier I have some injuries and have so far been unsuccessful in my application for respite care for Alex. I believe this is an issue the Department is looking into and aiming to improve. So far I have been able to cope physically but I am concerned that should my health fail respite or some alternative suitable for Alex will be available, as I have not been demanding of it so far. Hopefully you will be there when I, myself, need care.

In the meantime if Kevin Rudd should shout me just ½ day in a health spa I would be totally powered up for the next 6 months of caring!!

Thank you for asking
Regards

Linda