

Submission No. 470
(Inq into better support for carers)
A.o.c. 2/7/08

Lynnette

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

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Dear Secretary

I wish to make a submission to the Committee's Inquiry into Better Support for Carers.

I am the carer for my partially paralysed husband who suffered a C5 spinal injury 36 years ago as a National Service Conscript. After rehabilitation he was able to work for 30 years as a communications technician and retired because of his health 7 years ago. He uses a wheelchair and requires assistance in many areas.

One of the things that stresses me most about being a carer is dealing with Centrelink. The attitude of this organization appears to be anti-carers; that we are trying to "rip off the system". I was made to feel that, because we are being financially supported by Centrelink, we are bludgers. The staff are rude and often unhelpful; the queues almost impossible and the office we have visited has poor disabled access. Every communication contains implied threats of penalties. I did not know that there was Carer Allowance until a social worker at my husband's workplace told me of it weeks before his retirement. When I did apply for this token payment I found that my form stating what I did my for husband was not weighted the same as the one completed by his doctor even though my form "ticked the same boxes" as that of the doctor. This is unfair; it could mean that a carer, because she/he did not get the required number of points, would miss out on this token payment. The amount of the Carer Allowance, \$100.60 per fortnight, is an insult considering what I do for my husband. A professional carer would not work for that amount.

Under Centrelink rules when a carer requires hospitalisation that time must be taken from the allowed respite days. I feel this is unfair as an ill carer would require both sick leave and respite days to regain health.

When I asked Centrelink about my taking a university course I was told I could not as I would not be caring for my husband. No questions were asked about the type of course, whether it was full time or part time or an external study. The answer was an emphatic NO. Women with small children are not treated this way when they wish to take tertiary study.

I have been extremely disappointed with the Commonwealth Care Link service. I was given obsolete information and told to call places that had already referred me to Commonwealth Care Link. What is needed is a "one stop

shop” that has up to date information and links to service providers to avoid the trial and error method that I have been using. A Google search for carers would be ideal.

When I could no longer lift my husband I enquired about hoists at the Independent Living Centre. The occupational therapist there gave me information on various hoists but recommended that rather than save up and purchase one myself I contact the occupational therapist at my local public hospital who would assess my husband’s needs. I did this and waited 12 months for someone to come and do the assessment. Frustrated at having to call the ambulance service for help when things were urgent, I phoned the hospital again and found that they had me on a waiting list for the wrong type of service. After explaining the situation in great detail again I was visited by a very overworked occupational therapist and the supplier of the hoist that the Independent Living Centre had recommended. I was ready to use our credit card to purchase the hoist immediately but was told to wait and it would be supplied by the Program of Appliances for Disabled People. Nothing was heard for a further 18 months and then only when a specialist treating my husband at the same hospital asked what assistance I was getting and what appliances I needed. The resulting enquiry by the specialist found that the occupational therapist had been so busy the day she assessed my husband that she forgot to transfer his notes from her diary to his file and had forgotten to send the required forms to his doctor. The forms were duly completed and we waited another 8 months for the hoist. The Program of Appliances for Disabled People urgently requires more funding and more occupational therapists are urgently needed in Western Sydney.

Another frustration I encounter is health care professionals whose consulting and treatment rooms do not cater for wheelchair patients who cannot physically move themselves from chair to bed. As the carer I am expected to do this and any request for assistance is denied “as it might hurt my back”. It hurts mine and I am made to feel that as a carer I am expendable. I have found waiting rooms that are so crowded with chairs that there is no space for a wheelchair and doors that are almost too narrow to get the chair through. Designers of consulting rooms should be advised that the rooms may be used by people in wheelchairs.

Another frustration as a carer comes from the physical environment. These include kerb crossovers that are not smooth and not wide enough for a wheelchair; signed disabled parking spaces not wide enough for both a wheelchair and a car; signed disabled parking spaces with no adjacent kerb crossover; and wide wheelchair disabled parking spaces taken by people who can walk well. My local railway station has no access for people in wheelchairs. Are there any low floor buses west of Parramatta?

I experience difficulty in accessing assistance, knowledge and training to assist my husband. He was initially treated at the Austin Hospital in Melbourne and while we lived in Victoria we could access services there. However when his job transferred him to New South Wales that back up disappeared and he is now in the total care of a GP. The spinal unit at Royal North Shore hospital did not want to know about him. I find most of the aids I need using the trial and error method. So far these have included the Independent Living Centre by phone, talking to the local pharmacy, the New Inventors television program (the car boot slider for the wheelchair) and by using the internet. I recommend that the Commonwealth Care Link have this type of information on a website or in a newsletter/magazine that could be issued regularly to carers.

The work that carers do should be rewarded by an increase in allowance and not a token one. \$100.60 per fortnight is probably less than one day's pay for professional carers. Surely we can share some of the millions of dollars that we are saving the government. A culture change is needed in Centrelink so that carers are not treated as potential criminals who are out to rip off money from the government. Centrelink staff need to know the work that we do is very important. They also need courses in basic good manners.

Thank you for taking the time to read this letter.

Yours sincerely

Lynnette