Submission No. 767
(Inq into better support for carers)
Acc 15/7/08

Graeme

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Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee
On Family Community Housing and Youth
P O Box 6021
Parliament House
Canberra ACT 2600

Dear Secretary

Submission regarding Better Support for Multiple Sclerosis (MS) Carers

No doubt you will receive many varied submissions on the problems of Carers and suggestions on the ways assistance could be provided by the Government.

I am a full time Carer for my wife who has had MS for some 16 years and is now at the stage where she is unable to do anything for herself and is fully dependent on care being provided to her. She is confined to a wheelchair unable to walk or do anything with her hands. Cannot even wipe her eyes or nose etc.

I retired from full time work in 1994 at the age of 57 and since then have been her full time carer.

Rather than submit lengthy details on our problems I will outline below the two major areas which worry a lot of carers like myself:

1. What assistance am I entitled to or can I obtain to assist in the caring role.

Caring for someone is usually not a role that you apply for or aspire to take on.
You do not receive any training for this role and at first you are reluctant to look for assistance.
When the need for assistance develops this is the most frustrating time.
There are supposed to be many organizations who can assist but no one area to look for guidance or assistance. Local Council can provide limited help. Others can arrange for a Case Manager but we have found no help here. (large fees and a 2 year wait.)
District nurses can provide limited assistance.
In the MS Carers Group I attend each month the other carers have at least 8 different types of assistance and care being provided and all by different organizations and levels of assistance.
These vary from 5 hours assistance per week to over 25 hours per week.
This assistance does not vary because of the level of care needed.

My suggestion is to do away with the dozens of small organizations providing care (mostly government funded) and centralize this role with a new organization or through Centrelink. This would eliminate the duplication of administration costs.

For example: Centrelink (or ?) could be the contact point for all carers seeking assistance and they (Centrelink) would have guidelines as to the care which could be arranged for each situation. They may determine that we need two nurses three times a week for showering assistance and then another ten hours a week respite care to allow for shopping and an outside interest for the Carer.
The actual provision of these services could then be outsourced by Centrelink.

2. What will happen when the Carer is no longer a Carer

Unfortunately, there is no cure for MS and many other diseases and the Carer is usually too occupied in providing the care to think of when the loved one has gone. People receiving a Carers Pension and Allowance do not usually have the financial resources to provide for their future after Caring.
Therefore, the Carer could be faced with the problem of being too young to receive the aged pension but not having any work skills to return to full time employment. Because of the toll of the caring roll they could also be unable or unsuitable to return to a full time occupation.

My suggestion is that some provision through Centrelink be made for persons in this situation.

This submission has been compiled quickly to give you what I consider are two important ways in which the government could help Carers.

Obviously there are many other problems Carers face and I am hopeful that your Committee will make suitable recommendations to the Government with a view to assisting Carers to continue there role and enable their loved ones to remain in their own homes.