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Submission No. 1137

(Inq into better support for carers)

Committee Secretary  
Inquiry into Better Support for Carers  
House of Representatives Standing Committee on Family,  
Community, Housing and Youth  
PO Box 6021  
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 care for my 79 year old Mother who suffers Alzheimers Disease and have been doing so for 4 years. We rebuilt our family home to accommodate Mum long term and she is very happy living with us. At this point in time she is aware enough to know that she can not care for herself and is incapable of doing anything unsupervised. She is completely reliant on us for her food, clothing, bathing, social and emotional needs. For example I cannot ask her to go and brush her teeth as she no longer knows what a tooth brush is. I have to put tooth paste on her brush and hand it to her and wait for her to finish. This is the same with any process whether it be dressing, eating or bathing. I have to oversee everything she does and meet all her needs. I am prepared to do this for her – she is my Mother. I am aware that the time will come when I will have to put her into a nursing home but at this stage of the disease her confusion level is such that she needs one primary carer. Unlike a person with a physical disability who has a sound mind, Mum is unable to express her needs. When Mum does go into the Nursing home in order for us to have respite (63days a year), her level of confusion increases. There are no cases more important than others though it should be recognised that the needs of an Alzheimer's sufferer are different from a person with a physical disability who can still communicate their needs. Mum can't even recognise when she is thirsty let alone get herself a drink of water. She can still walk and insists on helping around the house which involves constant supervision on my part as she does not cope with inactivity. This in turn leaves me with virtually no time to achieve anything of significance. She gets very depressed and cries as she feels useless. It is a constant juggle to engage her only in manageable tasks in order to avoid the depression and frustration that comes from her failing. This is a full time job requiring full time commitment.

I do receive fabulous support from Blue Care - Dementia Services in the form of daytime respite. This is very necessary for Mum to be involved in social interaction. They are a fantastic group of individuals who fully understand the stresses involved in caring for a dementia patient. I have also tapped into the Community Options Program and Mum enjoys a day of interaction with one of their staff as well. I am

very happy with the support I am able to access and know that there are further services I can tap into as this ghastly disease progresses. More funding is necessary to keep competent staff and attract new staff. The main issue I have is the way I am 'paid' to do the job required of me. We as a family – and it is a family commitment – are prepared to put our lives on hold to do this for our Mum and Grandma and as a result are penalised financially. We can not improve our financial situation (we are not destitute) but at this stage in our lives with young and older children we should be starting to consolidate for our future. We do not need financial stress on top of emotional stress.

I believe the following suggestions may assist to support and improve the lives of individual carers and the various organisations in place for respite, counselling etc.

1. The payment for a full-time carer should not be means tested in relation to their partner's income. Working partners are paid to do a job and carers should be paid accordingly for theirs. Full time carers save the government billions per annum. Currently it seems there are barriers to progressing financially for carers and their partners. Carers lose all payments and benefits once their partner earns over a specific amount. A partner's income should have no impact on the carer's payment.

2. In order to stop the welfare system being abused, a process of verification from an outside support individual or group (e.g. doctor, respite support, etc.) should be required in order to identify genuine cases. There are certain criteria that need to be met to ensure the continuation of unemployment benefits. Similar evidence needs to be provided in order for carer's payments to continue. The money saved from payments to non-genuine cases could be contributed funds towards genuine carer cases.

3. Nursing homes appear to be lacking in quality staff for several reasons. One of the primary reasons is that the wages paid are not in line with the huge work load and responsibility that is required of these people. Consequently staff members are transient because of this and therefore little familiarity can develop between the nursing staff and residents. Additionally the groups that support in- house carers and clients are not paid appropriately for the commitment and caring required in order to carry out their jobs as professionally as possible. Offering 24 hour care and supporting the financial, emotional and practical needs of carers is an area that requires far more financial support that is currently offered.

I am also including a copy of the letter that I sent to James Bidgood – Member for Dawson regarding Carers payments through Centerlink. I have had no response from his office only to be told that our place of residence is not in his electorate. However it may give a little more insight into our situation.

Please feel free to contact me regarding this submission as I would be happy to discuss and issues with you. Thank you for this opportunity.

Regards,

Cathryn