

Submission No. 1063

(Inq into better support for carers)

Glenda

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

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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.

As a Carer, I feel that my role is undervalued. Caring involves heavy physical lifting, psychological and emotional distress. I feel that my whole life is consumed with my carer responsibilities and have limited to no time for friends and family.

The role of a carer in the home is a very isolating existence.

I face the following problems of juggling full time employment and carer duties. This results in a constant feeling of fatigue and pushing myself to fulfil my responsibility in my job. All day at the back of my mind I am thinking and worrying about my husband. Sometimes I call on neighbours or friends to call in to the house to assist when I am at work.

Although my employer is very considerate to my situation I feel very guilty about the time I take off from work to take my husband to appointments and stay home with him if he is very unwell and cannot be left.

Financial hurdles seem to be the main problem. My husband and I are under retirement age so do not qualify for any pension. We have worked very hard in full time employment all our working life at time holding down more than one job to get ahead and make provisions for our retirement.

This work ethic has proven to be our downfall because our assets and income are deemed to be above the cut off for a carer pension and my husband is not eligible for a disability pension.

Access to another form of income instead of going away to work full time would provide me with the ability to care for my husband every day and remove a great deal of the stress that I experience from juggling two roles.

One of the major problems I face from juggling working full time and primary carer for my husband is detriment to my own health. I am battling with heart problems but there is no assistance to give me a break.

I need help with heavy lifting of the boxes of dialysis fluids and my husband is a double lower limb amputee. Also I need help in finding someone to provide me with respite who has technical knowledge of the dialysis machine. I also need help in finding time to look after my health with exercise and rest.

I have discovered a severe shortage of nursing staff trained in the use of dialysis machines. I set up my husband on the dialysis machine every night. Last year he was in hospital for five months and none of the staff were able to set up the dialysis machine. I was responsible for keeping him alive with the dialysis every night.

Career campaigns need to be targeting high schools to encourage students to take up nursing. In particular promoting the rewarding career of an enrolled nurse as opposed to a registered nurse. In my extensive experience of the hospital system I found the registered nurses who only went through University do not have any common sense or ability to do hands on nursing. Either older registered nurses who were hospital trained or enrolled hands on nurses are the people you can rely on.

By targeting high school students to seek a rewarding career in nursing may boost nurse numbers and result in more nurses taking an interest in specialising in dialysis.

I desperately need respite, but it is not possible to find anyone who can set up the dialysis machine for me every night and clear the machine every morning.

The National Respite for Carers project in 1996/1997 did not take into account the problem for carers when a patient needs particular medical intervention and there is nobody trained in the use of the dialysis machine for example, so respite is out of the question.

If it is possible to locate a private nurse who has the skills and knowledge to provide the specific care then the cost is out of the question.

I would like to suggest that the Government give consideration to the situation where there is a requirement to use a private nurse who has the necessary skills to care for the patient and provide short term respite, that the hourly cost is subsidised by the Commonwealth and not means tested.

My concern is I am older, but not retirement age, my heart is not performing at the optimum level and who will look after my husband if anything happens to me.

If I cease to be able to care for my husband I do not believe Nursing Homes are equipped to carry out nightly dialysis when there were no staff at two hospitals who could provide that service while he was an inpatient.

Physically and emotionally patients are better off staying in their own home and it is a financially beneficial option for the Government.

Practical ways to support carers could be to provide funding for a couple of hours a week for someone to tidy the garden, assist with cleaning in the house, do some shopping, ironing. This funding not to be means tested. These ongoing tasks add to the pressure of the caring role and working full time. Providing non means tested funding assistance with duties around the home would be another form of respite for the carer.

Nobody prepares you for becoming a carer and there is no duty statement for the role. It is a rollercoaster ride of emotion and physical exhaustion. Any assistance of respite would be gratefully accepted.

Yours sincerely

Glenda