

16th June, 2008

The Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing and Youth,
PO BOX 6021
House of Representatives
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 was married in 1987, my first child was born in 1988 and my second in 1992. In 1994 my husband was put on a Disability Support Pension for mental and physical health problems. I went on a Wife Pension (now obsolete), and we have remained recipients of these pensions right up to the present date. So in a 21 year marriage my husband has been on Disability for 14 years. The reality is however, our family would not have survived without welfare.

During these 14 years my roles as carer have been many and varied. I managed the entire household. All the finances, shopping, washing, cooking, house maintenance, car and mower repairs, dealing with tradesmen, mowing the lawn, house work; care of the children right up to involvement with schools, homework and their education. In all of this I had a husband who was or appeared to be powerless, too fatigued to do anything, locked up in his own world, afraid to venture out the front door, oblivious to what was going on around him. He just sat in the kitchen reading books!

In 1999 I decided that I could not balance the budget anymore and so I returned to nursing. My husband was not in favour of this, but knew we had no choice. I worked two shifts a week which meant my income was able to carry the mortgage. My husband's aggression increased the more I worked, and his focus on being involved with the children remained unchanged. In 2003 my husband began working 13 hours a fortnight in a labour intensive job which was not suited to his health.

One difficult aspect of this carer role was dealing with health problems. Not only did my husband require numerous medical appointments to specialists, I had acute migraine episodes on a regular basis, which left me in pain and vomiting for up to 12 hours. As I have no family in Australia, and my husband's phobias meant that we were socially isolated I and my children had no support. And when I got sick my husband "fell apart" and often became verbally abusive.

Two years ago I had a complete nervous breakdown. I couldn't give another drop, I couldn't take any more of anything, and I couldn't handle one more word of put down! All I wanted was to go to a place where I could sleep, be looked after and stop crying.

For many years we had seen counsellors, together and separately. They kept on telling me that it wasn't right to put up with constant verbal abuse. I eventually believed them. I eventually realised that I deserved respect. I knew that for as long as I had been married I often felt unsafe with my husband. I lived in fear of his outbursts, his sexual demands, his abuse. So two years ago I asked him to move out. It was a terrifying discussion, but I knew I had to do it. I told him I needed space and that he had to learn to stand on his own two feet. He was absolutely shocked and had no idea what so ever of how his lifestyle as husband and father had been so destructive. It took him three months to finally move out and find a place to live (in the same town). To this day he does not understand how he impacts on his family.

Over the years I have been lucky to find various ways of gaining support for myself and wished I could share these with other carers, especially those who are burnt out or still living in denial. I have been particularly blessed to have free respite holiday accommodation for one week the last 2 years and will be using this again this year thanks to Carers Queensland. I find it appalling that many carers do not look after themselves and try and get help and how little doctors know when it comes to supporting carers and telling them how to get personal and financial help.

One practical measure which I think your committee could look into is the way in which wages affect pension payments. My husband relies totally on his disability pension and would rather receive that than go through the personal pain of looking for work. At 58 years of age that is understandable. He is trying study at present. I on the other hand I like the benefits of a pension, but would prefer to earn as much as I can from work. This year I regained my registration as a Registered Nurse, thanks to a scholarship, and so my wages have increased dramatically. All the same the more I earn the less pension we get. I really do think that the threshold should be reviewed. As a couple we can earn about \$220 a fortnight, and then our pensions are reduced at 20c in the dollar. Because carers are caring 24/7, they are actually working, so this should be recognised such that if they get paid work they should be entitled to keep a larger amount of their pension.

In summary, my 14 year experience of caring highlights 3 main points. Firstly, there is a culture in Australia that says it is a very noble and worthy thing to care for a relative 24/7 year in and year out. This culture is supported by an expectation that parents, wives, children will care for a relative who is sick and in need. This perception needs to change dramatically. Carers as people need to care for themselves first and foremost, then care for others. Otherwise they will end up like me, broken down and worn out, while the one they care for thrives and grows into old age. Carers have to avoid the trap of rescuing and doing for others what they can do for themselves. There needs to be a campaign in the print media, radio and television to highlight the abusive aspects of caring and the need for carers to take time out and get help.

Secondly, information on what carers can obtain in terms of personal and financial help is very scant. Unless a person actually belongs to a carers' organization, it is difficult to know where to get help. Doctors and Centrelink staff need to improve their knowledge of what is available in the community, and how important it is for carers to have a break and where to get respite.

Thirdly, for any carer who goes back to work to either gain sanity or income or both, it would be good if the wages earned did not impact so greatly on their pension payments. Incidentally I don't know how women cope on Job Start when their husbands go on Disability Pension. The payment is less than my Wife Pension and their ability to earn is greatly reduced. They also lose the benefits of rebates on car registration, electricity, phone. This is a matter of grave injustice to me and I think should be reviewed. If my husband and I were to formally separate I would lose my Wife Pension and all the benefits. Given my precarious health this is not an option. So I have no choice, but to remain married, but living apart. All the same, the more I earn the less pension he gets and the possibility arises that I will be paying his rent as he seems incapable of looking for work because he has too much study!

Thank you for considering my experiences as a carer at your Committee's Inquiry. I look forward to hearing what recommendations are made.

Yours sincerely

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