

A.O.C. 7/7/08

**Sent:** Thursday, 26 June 2008  
**To:** Committee, FCHY (REPS)

**Subject:** Submission: Inquiry into Better Support for Carers

26 June 2008

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.

Carers, often unacknowledged, make a substantial contribution to the economic and social fabric of Australian life. Society often places a disproportionate burden of caring on women, who supposedly are the nurturers and natural carers. Consequently, they terminate or defer their studies or careers to shoulder the responsibility of caring for a loved one. This has significant impact on their future financial security and job prospects.

Thus, I will take you through a journey of my lived experience as a carer and the challenges I daily face in my caring role. I am just one of a plethora of Australians caring for a child, young person or adult with a disability or chronic illness or a frail older person or a person requiring palliative care in the home.

I am a 54-year old female who struggles to work full-time and study part-time at university to keep abreast of changes in my field of work while being a carer. Mortgages, credit cards and other bills still have to be paid. Should I choose to relinquish my paid role, the Carer Payment would be insufficient to cover all my family's expenses, including substantial medications and service provider supports. However, work and study have provided some respite from my caring role and validation of me, as a person of some worth.

For 10 years now, I have been forced into the role of breadwinner and informal guardian and financial administrator. All domestic and maintenance jobs around the home are my responsibility. Social activities, apart from family gatherings, are few and far between and mostly, at my instigation. So much of our family activities are hidden behind the 'white picket fence' because of the turmoil the family regularly experiences and the stigma attached to my loved ones' especial illness.

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As a working carer, I have experienced discrimination in my past three workplaces. When employers became aware of my caring commitments, opportunities for advancement were limited or overt statements were made about my capacity to balance my work, caring and personal life. Other staff determined this as a personal weakness and used that knowledge to gain advantage over me. In my most recent, past position in a well-respected human rights-based organisation, I approached my employer about the possibility of part-time or job share work but was told that the workplace could only accommodate full-time staff. This statement was made, despite the Queensland Government's Carer Recognition Policy.[1]

"The Carer Recognition Policy illustrates to the community and to all tiers of government how the needs of carers can be recognised, respected and better accommodated. These needs include a range of issues from the delivery of care to the impact caring may have on carers' employment, their family life and general well-being. Raising the status and profile of those who give care in the Queensland community will enrich the quality of life not only of carers but also of those being cared for.

The Carer Recognition Policy provides Queensland Government departments and agencies with a framework to identify and recognise the important role of carers. It provides a clear set of principles and guidelines for Queensland Government agencies to adopt in recognising the role of carers in the design and delivery of relevant policies, programs and services, now and in the future."[2]

Until just under two years ago, I was a carer for three generations of family members – my mother, husband and adult son. On my mother's death, one would have expected that my load had lightened a little. However, my 67-year old husband's physical, psychological and psychiatric health has deteriorated dramatically. He spends most of his days in bed due to chronic depression and acute anxiety, apart from an ongoing diagnosis of schizophrenia and alcoholism.

About every two to three months, he has day surgery to correct the ravages of his alcohol addiction. At other times, he needs to attend the hospital clinic for follow-up post-surgery. He also needs to have regular blood tests and visits to his general practitioner and public psychiatrist. This means I have to take time off work or pay a local non-government organisation (NGO) to take him to, then bring him home from these interventions. The NGO has recently raised its fees 100 per cent, having a substantial impact on our budget.

Because I was seconded from one employer to another to work on a special project, I was paid at a higher wage level. Therefore, Centrelink deemed that I earned too much and my husband had his little bit of aged pension withdrawn along with most concessions. Luckily, he qualified for a Commonwealth Seniors Card and can still access cheaper prescription medications. Before turning 65 years of age, he had been a disability support pension recipient for over five years with a degree of financial autonomy. Unfortunately, Centrelink makes no concession for the additional costs that ill-health, respite care and community services cost a working carer whose real income is substantially reduced compared with another worker at the same income level with a retired, well spouse.

Apart from the financial aspect, I am more concerned about the other negative implications of this Government policy. My husband was born into a generation where the man went out to work to support his wife and family while his wife kept the 'home fires burning'. He was and still is a very proud man. This attack on his identity, dignity and self-esteem has further eroded his mental health. All too often, I am the recipient of his violent, verbal and physical outbursts as I am perceived to have succeeded where he failed.

I pay for centre-based respite and community access respite for him. I pay someone to do a small amount of housework and to mow and tidy the yard. However, after I go to work, my husband often rings and cancels the services. Now, I feel uneasy all day long at work, not knowing if my husband had the care and support he needs. It is amazing how organisations' policies of 'confidentiality' preclude carers from knowing what is going on in their care recipients' lives.

Late last year, I managed to convince my husband that I needed a break and with his consent, booked him into residential respite. While the break was wonderful, the emotional blackmail that I experienced on my return made me wonder if the break had been worthwhile. My husband told me in no uncertain terms that he hated the respite, the facility, the staff and that he would never go to respite again. Every opportunity he got, he told family and friends about the dreadful experience he had, inferring that it was my fault because I had abandoned him.

I now believe the time is fast approaching when I will have to make more decisions about his interim and long-term care. Having worked with many carers over the years in my human service roles, I acknowledge that the decision is not easy but one that has to be made, sooner or later. I feel it is no longer safe for my husband to be at home, especially when my adult son who lives with us, is away from home. I am starting to feel that I am failing in my duty of care to him. I know though, he is probably going to hate me for that decision and that I am already going through the five stages of grief....no longer a wife in essence.

I carry a deep sense of loss in my heart for my co-resident adult son too. He is the third of my four sons and also has schizophrenia and chronically misuses alcohol and non-prescription drugs. He has previously self-harmed and threatens more self-harm and harm to me, on occasion when I try to reason with him about his activities. He is on a disability support pension and has no regular job. He does occasionally pick up some lowly paid work but is often taken advantage of by unscrupulous employers. He is very vulnerable to exploitation by shady characters, drug dealers and pawnshop operators.

Many times I have had to stand up to these exploiters and tell them to leave my son alone. Often, I have fronted up to pawnshops, paid to retrieve my possessions and advised them that my son lacked the capacity to understand the nature and consequences of his actions and that he owned nothing and therefore, had nothing to pawn unless it belonged to family. I have pleaded with them to place an alert on their records of these circumstances to no avail.

While I am the primary carer of my husband, my son certainly is the secondary carer. I don't think I could continue to work if it was not for him. However, the situation is far from ideal as there is a co-dependency happening between my husband and son and certainly at times collusion to exclude me from what they actually get up to during my working days. Coming home in the evening to find them both 'under the weather' and the house in disarray is very disturbing. No amount of pleading by me will make them cease their destructive behaviours. I have even tried restricting the amount of money they have access to at any one time. However, they always seem to be able to find the money for a six-pack of beer or rum or a cask of cheap wine.

On many occasions, my son has resorted to 'hocking' our possessions or trading items for drugs. My wedding and engagement rings and other family jewellery disappeared without a trace or explanation. I was too afraid to report the losses to police for fear that my son would be arrested. Therefore, no insurance claims were ever made. Too, coming home to

find suspicious characters in my home while my husband was in bed have alarmed me... were they casing out the place for a future robbery? The phone ringing at all times of the night is another disturbing happening. When I answer the phone, there is mostly no response or if my son answers, not long afterwards he finds some excuse to go out.

However, there is some hope on the horizon. My son's mental health is stable with a new psychiatrist and a new medication regime. When he is reasonably sober, we have a good relationship and he tries to help, where he can. Too, just today, I accompanied my son to a Government alcohol and drug clinic for an assessment for a possible detoxification program. He said he wants to 'get off' the alcohol and drugs, but I am afraid his motivation may not last. I will give him all the encouragement and support that I can, though.

As a result of my caring experiences, I would like to suggest a number of strategies that may assist carers to access the same range of opportunities and choices as the wider community. They include:

- relaxing 'confidentiality provisions' to enable carers to engage in care assessment and planning and constructive dialogue with their loved ones' treating health care, allied care and community care staff – recognition as an integral and knowledgeable part of the treatment program
- developing national carer legislation to reduce discrimination in the workplace, centers of learning, financial institutions and wider society
- ensuring financial institutions accept carers' roles as substitute decision makers for financial matters where their loved one/s lack the capacity
- ensuring hospital treating teams and general practitioners accept carers' roles as substitute decision makers for health and lifestyle matters where their loved one/s lack the capacity
- developing legislation and employment conditions for carer leave similar to current maternity leave provisions
- more emergency, transition and permanent respite beds
- a national carer identification card with access to concessions and other benefits
- substantially increased carer payments and allowances
- amendments to eligibility criteria for care recipients' aged care pensions where the caring spouse (usually much younger) is still working but paying out a substantial proportion of her/his income to balance her/his continuing involvement in the workforce and caring role
- amending pawnbrokers and second-hand dealers legislation to provide substantial punishment for dealers knowingly accepting 'stolen' goods (from family members) after being warned by family members; making provision for the recording of family members' concerns on relevant client records; tightening up criteria for lines of credit etc.

I believe these are economically and socially viable alternatives to the very high costs of unwell, frail or disabled family members being prematurely or inappropriately placed in permanent residential care because carers are at the end of their tether or missing out on opportunities and choices available to members of the wider community.

Thank you for reading my family's story and taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Yours sincerely

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[1] Queensland Government. (2007). *Carer Recognition Policy*. Brisbane: Author.

[2] Queensland Government. (February 2007). *Message from the Premier and Minister: Carer Recognition Policy*. Brisbane: Author.