

AOO 17/7/08

Submission No. 853
(Inq into better support for carers)

3 July 2008

Committee Secretary
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.

The Committee is seeking a better understanding of the situation for Carers in Australia. Use any or all of the following starting points to help you write your letter:

I feel that my role is a very complex one.

History: My husband was diagnosed with a Neurological degenerative condition in 1979, just two years after we were married. It meant a huge adjustment to our lives as two spouses. It hit us hard with dealing with the onset of lack of lower motor skills eg Patrick's inability to walk meant he became totally wheelchair reliant within two years. His disease process has meant the loss of many other skills and abilities, it has limited our social ability for example access to many public and private venues even now with the building codes Australia the access issue is still far from fair and equal. Financially it was difficult as we became a one person income couple, and Patrick had 5 children of his first marriage with all the financial responsibilities of a first then second mortgage, child maintenance and health costs plus the costs of home renovation as his disease process made him wheelchair reliant and a range of facilities needed to be incorporated into our home.

Over the past 29 years I have become my husband's physiotherapist as necessary to keep his muscles from total atrophy, podiatrist and manicurist as due to poor balance he cannot manage such tasks, his wound nurse, as wheelchair living is an occupational hazard for tissue tearing; pressure care specialist, as the body loses muscle the pressure areas on the bottom and the feet become susceptible to pressure sores; case manager for keeping track of care workers who come to the home to carry out personal care routines and this means filling in when they don't arrive, educating a continual stream of new workers and also those who have been before on the new or re instituted treatments; negotiator for access to care or respite care. Overnight care includes re positioning due to pain in my husband's legs, assisting with bladder/bowel functions as necessary.

The range of tasks spans 24 hours, frequently a number of days in

sequence meaning broken nights sleep. It also means I am on call 24 hours per day and night; 365 days per year each and every year.

As with many people my husband does not like to leave his home for respite. His home is familiar, well arranged to meet his needs, comfortable and comforting with his music and telephones, his TV in his bedroom etc. Going into respite diminishes his daily experience of life hence his reluctance and my weariness with the relentless volume and range of tasks.

I contribute to Australian society by providing:

For a person to live in their own home when they need access to 24 hour on call care, means that the carer in the family must be willing to be available and accessible to them at any time. Not only for the routine tasks and supports but also for the unforeseen, sudden illnesses, such as Asthma attacks, outbreak of skin problems that my husband has due to Exccema and Psoriasis; ordinary days when fatigue sets in to a greater degree and the need for assistance is higher. Throughtout the day he requires considerable support and physical care plus management of his daily matters. This translates to be available to transfer him from the wheelchair to a: bed or toilet or shower chair and back again.

Hence my contribution is to be the 24 hour carer each and every day, to add value to his life by being a loving support person willing to give any assistance at any time and to draw on my own lateral thinking, expertise, skills and abilities to find solutions and ways around difficult matters without the assistance of professionals.

I act therefore as a para-professional, with a wider range of skills than they, as I have to act in such a wide variety of roles where as their skills are compartmentised.

The obvious conclusion is that my skills are worth in economic terms significant amounts of money. More essentially I provide the opportunity to aid someone to live in the community and participate in a number of ways which provides the added advantage of their ability and opportunity to contribute to the community and create work and employment to members of society. For example my husband does Awareness training on living with disability for a wide number and range of people in varying roles, disability care workers, train drivers, bus and taxi drivers. We have both contributed to training people with his condition; public servants. Participated in the development of Disability access plans. Secondly his disease and long slow degeneration provides work for many people in society as care workers, allied health workers, specialist medical officers, decision makers and policy developers on so many levels of public life.

The reality is that his contribution to society has been of value to many people by his spirit, initiative, energy to give and contribute to others understanding of living in a different way.

So together we have added value to society by showing that to live with a disease process is not one totally of deficits but one that adds to the human experience.

I face the following problems:

Diminishing health and strength to keep going due to repetitive tasks that have damaged my back and neck ...

I can't fully participate in social life because:

I do work in a very part time capacity as of the past five years and have had a satisfying career up until recent times. I developed my own business which allowed me to be flexible in the volume and range of work that I would choose to do. However the last few years have meant I

have almost withdrawn from work.

With my social life it is restrained by my husband's ability to access many places, his needs for care, the lack of suitable holiday venues and facilities and ignorance in the tourist industry; poor planning on behalf of developers and local governments commitment to full access by wheelchair users. I do manage to keep some contact with my own friends but often cannot match their expectations of being available and certainly cannot participate fully in the wide range of activities like weekends away. ...

I am financially struggling because of:

We have now become self managing in terms of finances but only because in the earlier years I worked six days a week over the 168 hours of the week to manage to earn a reasonable living. ...

I would like to work (full-time or part-time) but have the following issues to deal with:

My career has been satisfying though not of my choice. Consistently there have been opportunities that I would have pursued if the disease process had not been a part of our lives ...

I worry about my future because:

My greatest fear is if I pre decease my husband. Whilst this may be regarded to be within the normal realm of concerns for people in mature years my anxiety lies with the knowledge that my husband could not stay in our home if I am not able through death or illness to be his carer. He would have to be taken into residential care and this would cost him dearly in terms of his spirit and wellbeing. ...

The things that stress me the most about being a Carer are:

The total and individual sense of responsibility for my husband's well being and care. Due to the range of services that one has to work with no one else shares the responsibility for all aspects of his care.

The lack of recognition as having skills expertise and abilities that are of merit by the health and allied health professionals. The lack of valuing of the caring role by the wider community. For example I reject the mantle of martyr, saint, poor thing, person to be pitied. I have a role to play that adds to the well being of someone in society. I therefore add to the human capital of society. I also add to the economic processes by carrying out tasks that reduces the drain on the public purse.

In this state we have the 'Carer Recognition Act' 2004 which seeks to acknowledge the valuable role of carers and bring them into the decision making processes via consultation with them on both service provision and strategic direction of health and disability services. This is a useful first stage of valuing carers and one that the Federal government could follow to ensure that across all sections of government, attention was paid to make relevant decisions considering people with disabilities chronic illness and frailty and the needs of their carers. Federal legislation could bring parity across the states.

Federal legislation could set the stage for national leadership on a wide range of decision making levels and policies such as: planning infrastructure of public resources and venues which address access issues, this equates to adequate Australian building codes provisions.

Income support could be streamlined to meet in a flexible manner different life stages and needs of people through illness and low ability periods; carers able to access income support at specific periods when paid work is not an option such as during one of those critical periods.

Appropriate housing planning so that people with disabilities and their carers can live in a range of places and differing kinds of buildings relevant to different life stages; an increase in the supported accommodation for people with disabilities to live independently in the community. Hence increases under the CSTDA for accommodation support.

Health care and care support in the community. A broad policy initiative on increasing the numbers of people coming into the workforce of the care industry and appropriate levels of funds directed to service provision for care workers to be paid realistically for the responsibilities they take on in supporting carers to keep someone in the home; skills upgrading meaning incremental earnings. In addition mobile health teams, locums service of medical officers to attend home rather than people having to attend emergency departments of hospitals.

Ongoing support to carers health. This could be via extension of the medicare rebate system for physiotherapy for people with chronic conditions. Carers of people with a mobility disability frequently have physical damage to themselves due to long term repetitive tasks. Training in moving the care recipient, access to free physiotherapy on an as needed basis, access to specialist counseling for emotional and stress management would assist carers in self care.

Remember that it will help the Committee to understand your point if you can support it with examples from your own experience.

The Committee would also like to hear of any ideas, solutions or strategies that will support you in providing care. Use any or all of the following suggestions for getting started:

I need help with a flexible, appropriate to his needs, Respite care. The notion that the out of home day centre care is appropriate respite does not apply in our case and is refused by my husband. So also is residential care to which he is loath to go but has on rare occasions. The resolution is in home care worker support to allow me a regular break from my incessant tasks and a break away from home.

I need to have [insert a practical help or support here] and this would help me because it would enable me to: as above ...

I think the Government can better help Carers by = see above ...

Remember that it will help the Committee to understand your idea if you can support it with reasons that it will work or examples of things it will help you to achieve.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely

I do not wish my initials or state to be used or transcribed. Thank you
[Sign your name here]

[Type or clearly print your name here]