

A.O.C. 2/7/08

Submission No. 448

(Inq into better support for carers)

Secretary  
 Inquiry into Better Support for Carers  
 Standing Committee on Family, Community, Housing & Youth  
 POB 6021  
 House of Reps  
 Parliament Hse  
 Canberra ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing & Youth's Inquiry into Better Support for Carers.

My role as a carer is 24/7. I became a carer at age 41 when my husband suffered a diabetic coma and became an acquired brain injury statistic at age 39. At the time I was a practising lawyer and my husband a documentary film producer. Our lives changed drastically. I cared for my husband for the following 10 yrs without seeking government assistance because:-

- I was fiercely independent & we were overseas at the time;
- I loved him and had great compassion for what he had suffered
- I did not want to institutionalise him

In 2005, exhausted financially, unwell and highly stressed saw us return to Australia.

Contribution to Society - extraordinary financial savings to

government ie my assumption [and other carers] of the responsibility to provide total care privately for one of its citizens for which it otherwise would have had responsibility for. My husband is ACAT's assessed as "high level permanent & respite dementia specific." He is medically assessed for the disabilities pension & myself or the carer's pension.

### Challenges I Faced

a) lack of real assistance from the visible organisations funded by Govt. to provide assistance and support to Carers by :-

(i) games of referral onwards and back and forth by one organisation to another [A.B.I.O.S.]

(ii) refusal of assistance on grounds my husband was a citizen of another country despite the Act I [the carer] was a citizen. [Old Disability Service].

b) time it took [18 months] to obtain residential respite.

I had to have a "melt-down" in order for various organisations to pull out their finger and organise appropriate help. Each organisation always cites a reason why they cannot help in my case.

c) lack of age and disability appropriate residential respite homes ie. aside from Multicap which offered us limited residential respite owing to funding issues, all other residential respite is inappropriate eg 1 respite bed in a secure dementia unit of an aged care facility which often refuses said respite on account of my husband's younger age, diabetic needs etc etc.

d) need to seek counselling to maintain sanity dealing with these agencies, although funded by Govt to assist Carers, were not assisting at all.

e) Failure of all services to refer me on to Carer's Qld.

Recognition of My Role [et al] as a Carer

- a) financial recompense - in the form & expression of a "gift" from Govt by way of a permanent annual bonus payment for eligible carers. This is the only time a carer may choose to use finances in a frivolous & fun manner
- b) T.V. spots highlighting the roles carers play in society; the statistics on carers in the state or Australia; and the fact it could happen to anyone. These short segments could show true stories of lives before and after; how a carer contributes to society and recognition of this with a simple thank-you.

Affect of Caring Role on My Life:

- a) life as a once young professionally driven financially independent yuppie couple - gone.
- b) heightened and sustained stress levels especially in public
- c) affect on mental and physical health
- d) development of abusive behaviour and the need to seek counselling complicated by love, by suicidal thoughts, by tiredness, by unwellness
- e) feelings of guilt committing my husband to inappropriate residential aged care facilities and therefore not enjoying true respite myself
- f) despair, depression where verbally attacked by members of the public if I am unable to control/manage my husband's social behaviour eg my husband is an acquired brain injury, a wanderer with short term memory loss and is an ~~IBD~~ diabetic ie unstable diabetes. He looks normal. He does not wear a sign saying he is brain damaged. He is ~~obs~~ obsessive compulsive and has socially unacceptable behaviours. He cannot exist safely alone and has no memory if he wanders off. I am like a mother with a disobedient child who never grows up so I can be free.

On The Positive Side - I believe my husband's mind now is a beautiful mind and he has taught me to be a better person - a much less selfish person.

### Financial Difficulties

- a) I sometimes find it difficult financially because we live on Mackay Is [for cheaper rental reasons] but all cover respite services are on the mainland, hence increased financial costs.
- b) I have been refused cover respite at home because of:-
  - (i) fact of our location
  - (ii) fact of finding a male carer
  - (iii) expense of providing a carer to Mackay Is
  - (iv) because my husband is an IDDM diabetic - agencies use the excuse they need to provide a nurse to oversee injections when this is & should not be true ie my husband administers his own injections but needs supervision because of memory loss.
  - (v) although Blue Care cover Moreton Bay Islands, their hours of in-home respite are limited to 4hrs/week. This is inadequate when you take in travelling time to the mainland by ferry & back to take a break.
  - (vi) I will be a hospital admission in July at Redlands Hospital. It is better if a professional carer service provides in-home respite but I have been refused on grounds of financial cost [Commonwealth Respite & Carelink]. Instead they will look to place my husband in secure residential care on the mainland.

### Barriers in Finding/Retaining Employment:

- a) I haven't tried since returning to Australia but know

That adequate in-home respite care by professionals would be necessary to allow me the freedom to return to the work force, preferably on a casual / part-time basis.

b) My husband does better if he remains in his familiar background where he has learnt some memory.

### Practical Measures For Better Support.

a) immediate allocation of State + Federal funds to acquire eg 4 or 6 bedroom suburban homes; make their doors and yards secure; staff them with professional carers and make them easily available for residential respite for carers for maximum 1 week in every month if so required by a carer.

b) if a carer is in the private rental market, ensure that the Centrelink rental assistance grant is increased at an appropriate ratio to any increase in rent by a landlord. At present it is capped at a maximum that is insufficient to stop a carer sliding into poverty with the current housing / rental increase problem.

c) immediate emergency at-home respite care [no excuses] when the carer is the subject of a hospital admission eg extra funding to Blue Care to initiate / provide this service in the Moreton Bay Islands

d) longer day respite hours by Blue Care on the islands to enable the carer to travel to the mainland for a day's respite once / week at least, or to work.

e) training for professional carers [not nurses] in diabetic care supervision for diabetics with memory loss so

This cannot be used as an excuse to refuse residential respite or at home respite. Remember family members are not nurses and yet the world happily allows them to manage / supervise diabetic medications / injections!

f) priority for listing for carers for public housing

The above support would greatly assist me to:

- a) continue healthily caring for my husband
- b) enable me to have some quality of life of my own
- c) not to be resentful
- d) maybe work; continue study; take up an interest.

Thank you for taking my views into consideration as part of the Committee's enquiry. I look forward to reviewing the recommendations you make in order to improve support for Carers.

Yours sincerely

Kathleen

PS Without my great faith in God, His Son & His Holy Spirit I would not have been able to do this.