

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family, Community Housing
And Youth

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.

My reason for submitting this report is that my experience and that of friends I have met through respite carers, Consumer Reference Groups, and the odd carer get-together organized by Carer Links North, or Northern Community Options (who provide my case management) should be of value to you in understanding the various predicaments, problems, frustrations, and even hopelessness that is an ongoing part of our lives.

1. THE ROLE OF THE CARER.

In my experience, carers do what they do for a number of reasons:

- a. simply love for the person they care for;
- b. a perception of a debt owed to a parent;
- c. responsibility to a child; or
- d. any combination of the above.

That becoming a carer saves the community an enormous tax debt is probably the least of considerations to the carer but should be obvious to and appreciated by your committee.

In my own case, my wife, who now suffers from Fronto Temporal Dementia, almost single-handedly raised our five children because during their developmental period I was a member of the Royal Australian Air Force and, because of frequent postings, was often unwillingly separated from the family. At the same time she was employed as a primary teacher except for when the children were very young. She was loyal, loving, hardworking and I still adore her.

For fifty-one years she cared for me and my children - all of whom are professional people thanks to her example and nurture - I certainly don't begrudge her the care I give now - I owe it to her.

2. PROBLEMS FACED BY A CARER.

I think it would be fair to say that in many instances a carer has more restrictions placed on him/her than any prisoner being punished for a crime. In most cases caring is a one-on-one situation (particularly in the case of the elderly caring for a spouse or single parents). If the condition of the person being cared for is of

such a nature that he or she cannot be left alone, then the carer is forced to be housebound. There is no time for recreation. You can't drop everything and go to the shopping centre to get that item you forgot at the last shopping break. If, as is the case with my wife, the "caree" is unable to speak the carer experiences such loneliness that he/she is reluctant to take the respite available because the council or agency carer has become a friend and one enjoys their company because, as often happens, old friends don't want to share your predicament and drop off.

Of course the carer can get or renew "a life" by placing the loved one in a "facility". In my experience these come in four categories:

a. modern mansions, built to pass accreditation, with everything that opens and shuts. They can be recognized by the solid brass door handles and door furniture and usually the lack of sufficient staff to do the job;

b. a few examples of the above with sufficient staff, but a surcharge for "extras";

c. some well-established (usually run by religious organizations) facilities which provide adequate care but are difficult to gain access to;

d. the old, well-staffed, very caring establishments of another age, which are being phased out of existence because they are unable to meet current safety standards (my wife was in one such place - it provided the best occupational therapy and personal care I have experienced to date but suffered from age and being something of a fire-trap and has since been closed).

The problem here is that dedicated carers don't want any of these options on a permanent basis and only options b and c (or d at a pinch) when things become too much and some respite is needed.

3. PRACTICAL MEASURES TO SUPPORT CARERS.

Full-time carers and to a lesser extent, part-time carers, are in a unique financial situation:

Those of us who became carers after retirement, who planned for an active and fulfilling retirement after many years of preparing for it, only to be thrust into this role by the unexpected illness or disability of a spouse, suddenly found that the nest-egg put away to finance this idyllic future was required to finance such items as bathroom renovations, installation of hoist points and purchase of hoists, installation of ramps, purchase of wheelchair, lifting armchair, stair chair lift, commode chair, modifications to motor vehicle to facilitate transport, etc. These add up to many thousands of dollars. Ongoing costs such as incontinence aids (the current allowance for such covers about six weeks of the fifty-two week year), contribution towards in-home respite and residential respite reduce what superannuation and pension are left considerably.

Part-time carers may be able to earn a living but they still have to meet the expenses listed above and often with a very small income base to start with.

Single parents looking after an autistic or otherwise disabled child are in a similar situation to the retiree. Little income and no prospect of improving it.

Solutions? This is the hard part. Adapting my home to accommodate my wife with her disability has cost in excess of fifty-six thousand dollars. The government contribution to this was approximately four thousand dollars plus whatever rebate was allowed on my income tax for these items. I think that a more realistic approach could be made in the level of assistance granted for this type of expense.

Why is it that such a small fraction of incontinence aid cost is allowed? If the patient was in care the whole cost would be met!

In-home respite is probably the greatest boon to carers. There doesn't seem to be much rhyme or reason to the amount available to each carer. I guess the case managers decide cases on their merits and try to allocate the resources they have in the most efficient manner possible. But consider this: the average worker on 40 hours a week has 128 hours to use as he wishes. He can sleep, exercise, play sport, visit his doctor, go shopping, meet friends, read a book, go to the cinema or a show, go to the football, indulge a hobby or whatever. A carer on the other hand- apart from what limited sleep he enjoys- might have 14 hours to do the same things (that is my allocation) others may have more or less. I suspect that very few have more. Before any recreation can be contemplated the essentials have to be covered, shopping for food, etc.; medical appointments; car services; the odd haircut; perhaps nine holes of golf - I'd never have time for a full round! I can't remember the last time I saw a movie, went to a symphony concert or a stage show - things which I enjoyed regularly before my wife's dementia. Perhaps our case managers could be given a little more largess to spread around in this area - just enough for a few more hours each would be greatly appreciated

The costs of caring are large, financially, emotionally and in time. For me money is not the answer. I have sufficient to live day-to-day, but then I have two small super pensions and a part aged pension. (There are worrying periods, e.g. I am in need of neurosurgery in the lumbar region - it will cost a lot - the money I have is in fixed deposit to assist with income and can't be accessed except at time of maturity each year so I'll have to put it on the plastic and pay interest until that time). Others are not so fortunate and have very limited incomes - life for them must be an unending battle to survive they need all the financial assistance possible!

4. STRATEGIES TO ASSIST CARERS TO ACCESS OPPORTUNITIES AND CHOICES

Whatever changes/improvements your committee makes to support for carers it is essential that all carers, and in particular new carers, are aware of what help is available. That help, even now, is considerable but many people flounder around, unaware of what is available. This may be the fault of the medicos who make the diagnoses not being au fait with the system - but I believe that it is at that point that the carer should be allocated a case manager, introduced to Carers Australia and any other source of information necessary to their efficient functioning as a carer. This could save a lot of heartache.

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Thank you for taking the trouble to read my opinions and observations. I hope that they will be of use to you in your deliberations. Please don't hesitate to contact me if you wish to clarify a point or wish to seek more information. I would welcome any information concerning outcomes of your work.

Yours sincerely,

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