

Submission No. 975

(Inq into better support for carers)

From: tony&jane
Sent: Friday, 4 July 2008 1:33 PM
To: Committee, FCHY (REPS)
Subject: Inquiry into better support for carers - Younger Carers

To - Standing Committee on Family, Community, Housing and Youth
 Re - Inquiry into better support for carers Subject Younger Carers

From Tony

Personal Background. I am a carer for my wife who was diagnosed with dementia five years ago at age 54. Due to my wife's situation I gave up full time work immediately, did part time work for around one year and have been a full time carer since then.

I am chairman of the WA and a member of the National Consumer Advisory Committee of Alzheimer's. A consumer being a user of Alzheimer's services; normally a person with dementia or carer. Our life would have been immeasurably worse without the service to Alzheimer's Australia so I am just trying to repay in some way for the help received.

Focus of this submission is on Younger Carers (less than 65) who have special needs but being in a minority are generally less well supported.

- the role and contribution of carers in society and how this should be recognised;

If I were not able to care for my wife she would be in a full time care. As a result her quality of life is better and the economic burden on the state is much less. However, this is not without cost to the carer, emotionally, physically and financially.

I am not sure there is an easy answer to recognising the carers contribution but anything to publicise their role and encourage the general public to understand and help would certainly be of significant benefit.

- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;

I gave up work at the peak of my earning capacity, at a time when I was making voluntary super contributions to plan for the future. I have lost at least 5 years income and used savings to survive. Working part time is very difficult as the needs of the person you are caring for vary daily and as things progress they need constant care.

For a person who cannot be left, to work requires full time care facilities, where the care person effectively replaces their carer and this could include things like showering and dressing. These are not available within current arrangements.

As an experienced practitioner with the Resources sector desperately short of labour, I suspect my removal from the workforce has had a negative economic impact in spite of my caring role. I could have paid for care support had it been available.

Having to make the choice between caring and working is not a pleasant one, especially if that involves putting your loved one prematurely into full time residential care.

- the practical measures required to better support carers, including key priorities for action; and

Younger people with dementia are generally physically very capable, often have more limited mental capacity but can be extremely emotionally aware. This usually means they need different type of activities to the normal residents who are typically 75+ and largely inactive. As a result nearly all of the types of respite and residential care are not set up to cater for younger people. Imagine a young person with dementia going into a hostel where the residents are 75+ all confined to chairs and playing bingo. I think you would be distressed. Therefore, the carer does not get many breaks as they do not want to subject their loved one to these sorts of facilities, which can be extremely depressing. Also they may well put off a move into full time residential care,

not wanting to subject their loved one to that situation but as a result increasing the pressure on themselves. I would like to see recognition of this problem and the setting up of facilities which specifically cater for younger people. With the lower numbers, this would probably mean that one service provider would need to be selected and that there would be a limited number of centres. Still I would be much happier to travel to an appropriate facility rather than go to a local less appropriate one.

The diagnosis of younger people with dementia is often significantly delayed (a few years) during which time there is great uncertainty and distress. In extreme cases people may get into financial difficulties due to inappropriate action by the person with dementia. This is rarely treated sympathetically by groups like the Legal professional and the ATO. Improved education of the medical profession so that they can recognise dementia in younger people and other groups such that they treat the condition as a genuine problem and act accordingly would help significantly. The development of a National symbol which could be associated with persons' with dementia would also help the general public in recognising the issue and thereby supporting their carers.

- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

In general as a carer if the person you are caring for is happy your life is much better, so there is an inextricable link.

To be able to make choices you need information, opportunity and a real choice.

Information is a real problem. There are many Federal and State programmes, some of which are jointly funded. It is extremely difficult to find out what is available and how they may help you. I have not been able to find anyone who seems to properly understand how they all work. Trying to find help at a time you are already stressed means you miss out on help or find out much too late. Simplification in the programmes would greatly help carers. Some sort of "Care Manager" would also be useful.

Consumer directed care would also be of great benefit as sometimes there are programmes but they don't match what is needed. For me I don't need home help e.g. for shopping as I can do it myself but need more respite time so I can go shopping. Respite time is also very beneficial for my wife as she gets more social interaction so it is a win-win for me.

Finding what residential care facilities are available, what they can actually offer and how they relate to your needs is a major task. I am in this process at present and it is incredibly time consuming, again at a time when you don't have time and the whole process is very distressing. I have been using a significant part of my regular respite time to do this. It is compounded by multiple service providers (not necessarily a bad thing). This process makes you think about a role beyond full time caring but very limited help is available (Alzheimer's counsellors are the only one I know of). This on top of looking at residential care just compounds the stress on a carer. Hence some agency who can help an individual through the process of residential care selection and if possible "life after full time" care would be extremely helpful.

As always additional money would also help. Clearly for me I have lost a great deal of my future security and my carers allowance only pays a small proportion of the respite care my wife has (which thankfully is government subsidised).

Paying an accommodation bond of \$300k+ is a frightening prospect and having to look at the possibility of selling the family home to raise the bond is a very tough call and would certainly make the future very different and less palatable. Again all at a time when you are already making very stressful decisions. Some assistance e.g. zero interest government loan, could be the answer.