

MC 21/6/08

## **Inquiry into better support for carers**

**Summary:** A short introduction gives an outline of the symbolism of caring by myself, the carer, and my mother whom I cared for. I briefly describe the cause of her becoming dependant on me. In the section on 'the role of carers in society', I describe further how her rare condition was eventually diagnosed and some of the difficulties I faced when I first became a carer. In 'how the carer's role should be recognised', I underline some aims, including the idea for ongoing research and education in the area of care and disability. In 'barriers to social and economic participation by carers' I discuss issues affecting my caring role both privately and publicly. Finally in this section I talk about how the length of time of my caring role has affected me now that I am no longer my mother's carer. The next part is concerned with 'practical measures, as well as key priorities to better support carers'. I believe that publicity of what is available as a means of support for carers is crucial, particularly older carers who have spent half their lives looking after someone else. In 'strategies to assist carers to access the same range of opportunities as the wider community', I discuss the notion of education and public forums to enhance the light in which the carer is viewed. I point out the need for long term carers to have an advisory body to give appropriate guidance in ways of returning to the workforce. Finally, a look at statistics reveals a challenging future for the Government and society as a whole.

### **Introduction**

There is a single daffodil plant growing along side the pathway where I live. It is the only one remaining of many planted by my mother before her diverse, taken-for-granted skills became inadequate for her essential daily functioning. The deterioration in her health due mainly to Addison's disease was gradual, yet she became increasingly nauseous and at times her behaviour was aggressive – symptoms of her illness, I believe, and I was encouraged by members of the medical profession, as well as by family members to put her into an aged facility. The episodes of challenging behaviour were exhausting, but I did not foresee my mother being dispatched into corridors designed

specifically for superfluous geriatrics, besides on the whole she enjoyed helping endlessly with jobs around the house. These essential tasks: washing dishes, cooking, baking, ironing, sweeping are the 'menial' jobs traditionally undertaken by women, and not valued as they have no monetary worth in 'civilised', Western society. More recently I began to question notions of self-worth, work and ageing in a materialist driven society.

In 2006 my mother's health began to deteriorate markedly with increased episodes of stressful behaviour, angina attacks and other health complications, which meant she was in and out of hospital and when at home monitoring her through the night was the most difficult thing. I was very grateful to have an EACH package, but this did not solve the night problems.

Finally in 2007 there seemed little choice but for her to go into a nursing home – a decision not easily taken. As to the solitary daffodil plant, I believe it survived because of the care my mother had given it. She would take her little watering can and water it when she did her round of leaf-sweeping. Hence our daffodil has come to symbolise not only her ability, strength and love, but more recently for me it has taken on a range of new and conflicting meanings including - isolation, loneliness, perseverance, guilt and devotion.

These aspects of caring become an integral part of a carer's life, and no doubt will recur repeatedly in this submission. With regard to my own particular experience I will address issues relating to age and lack of confidence in searching for work both paid and voluntary, and the feeling of helplessness, inexperience and inadequacy despite having studied at tertiary level for most of the sixteen and a half years I looked after my mother: Embedded in a carer's life is the need for emotional support. This is not easy to articulate, but also needs to be addressed. Thus I will attempt to align my own experience as a carer with the terms of reference:

**\* Recognition of the role of carers in society:**

It seems that you have to be a carer to appreciate that carers of the physically and mentally disabled are the 'invisible' menders of society's inability to acknowledge, cope and satisfactorily address the idea that, firstly, the disabled are the responsibility of society as a whole, and secondly, their invisibility with regard to their contribution to the economy: We can safely say that successive governments' insensitivity to a proper commitment to carers, accounts embarrassingly for the misplaced pride in treasurers' budget surpluses. Research carried out in Western Australia reveals the extent to which Australia's 2.5million carers contribute to the economy:

Unpaid care for adult family members, friends or neighbours is imputed to be \$19.3 billion compared to the \$13.7 billion expenditure incurred mostly by governments and Non-government Community Service Organisations.

The Home and Community Program, worth over \$800 million nationally, meets only 9% of this need (Carer Australia, *Facts about Carers*).<sup>1</sup>

**\* How the role of carers should be recognized:**

**Aims:**

- Investigation and ultimately education in relation to the realistic nature of care in the home should be a priority.
- Publication of such findings, allowing the wider community to be made aware of the essential role of carers in society.

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<sup>1</sup> Kitty Delaney: *Overview of literature and research into Aged care Caregivers*, prepared on behalf of Carers WA, Delaney Woods and Associates, S Perth, WA, Jan. 2004

- Ongoing Research and Education in the area of disability and care are crucial.

A fair and civilised society pays attention to all members of its society, not only to the economically viable as measured by conventional standards. By attributing a just and proper reward – circumventing the need for means testing to those who work relentlessly, day and night with little or no rest for their love, devotion and commitment to the disabled members of their families; can a truly ethical society call itself developed and civilised.

An important facet in the role of a carer who receives benefits from the Government is that the carer can often be the object of disdainful treatment by some members of the Centrelink staff. It is possible that they are overworked and therefore forget salient points in their training manual reminding them that the view that carers are just another drain on the resources of the economy is wrong. Perhaps the whole sphere of caring needs to be viewed as an entity in its own right, with its own portfolio, which recognises the value of carers, and how much they actually contribute to the country's welfare ( see Delaney: *Overview of literature and research into Aged care Caregivers*, mentioned on previous page of this submission).

- \* **the barriers to social and economic participation for carers, with a particular focus on helping carers find employment:**

Time and commitment are crucial in the life of a carer:

Participation in life outside the home is limited: Attendance at uni lectures meant that only on days when my mother attended her day centre was I able to stay for a chat and a cup of coffee. On one such occasion I was delayed - I got a lift, but returned to find my mother sitting on the front step in the rain. Commitment, but also guilt therefore plays a

role in ensuring that social activities are kept to a bare minimum. The longing for friendship, someone to talk to, since one is not able to get out, is often overwhelming. Often one has to resort to impersonal telephone counselling.

Six years after I started caring for my mother I found out that I was eligible for a carer payment. This dependence on help from the Government, as well as the continuous indebtedness to others for favours is one important reason that the ability to earn a living and be independent is vital, but ironically impossible for a fulltime carer. At one stage I had to borrow money for my personal needs, such as dental treatment, physiotherapy, a haircut.

Now that I am no longer caring for my mother, issues relating to finding work are important. It only occurred to me on a visit to my doctor, in discussing the issue of what to do next, that in the more than sixteen years in which I was her carer, I must have been in an air of suspension somewhere, in a kind of carer-dream-world with regard to age and employment. Perhaps I thought that when things changed I could simply return to the workforce. It was the strange looks I got when I mentioned starting work again that affected me. I realised that despite having obtained recent tertiary qualifications, I was no longer the age I was when I started my caring role, for I am wanting to work, whilst traditionally this is a time when most people are thinking of retirement. My isolation was complete. I must have needed to go through this strange awakening...

**\* the practical measures required to better support carers, including key priorities for action:**

First of all, there are many carers in the community who have no idea of what services are available to them when they start caring. Services and the types of payment available should receive wider publicity.

The Each package is a much needed innovation. Its shortcomings are:

- it is currently only available on a very limited basis: when the carer's desperation for support becomes utterly hopeless.
- It needs implementation, therefore at a much earlier stage, in many cases before the carer her/himself becomes ill/ and/or simply fades away.
- Carers need a break at night sometimes – this could be arranged for a night or two on a monthly or fortnightly bases.

**A key priority** for carers is that they are recognized and treated as humans, not as commodities to be utilised at the discretion of the authorities. If a carer has a job and wants to retain it, every effort should be made to abide by the wishes of the carer and ensure independence is realistically maintained.

Carers need SUPPORT! Help and incentives to not feel worthless by retaining a foot in the community with ENCOURAGEMENT to pursue a leisure activity or take up a form of study/skill to ensure that when their caring role ends they will not feel isolated - this should be viewed as a priority, particularly for older carers who have spent half their lives looking after others.

**\* strategies to assist carers to access the same range of opportunities and choices as the wider community:**

- Carers should have the chance to participate in quarterly seminars, firstly, to debate personal issues, as well as how to best manage their isolation in society, followed by practical help and feedback .
- Public forums should be held where with their agreement, their work could be shown to the general public through talks, films, art, writing.

This type of education is essential for future generations of carers, and it can only enhance the light in which the role of the carer is seen, for with time the terminology within the caring paradigm will have to change to a more positive framework of expression - in order for the true value of carers to be appreciated by society.

**\* Transition into and out of caring:**

This is a problematic area in both aspects of care.

A comprehensive approach towards an understanding of difficulties facing

- (i) the new carer;
- (ii) the individual whose caring role ends early; or
- (iii) the individual whose caring role ends much later on, is paramount.

Older and long-term carers need access to an advisory body to receive appropriate guidance in ways of returning to the workforce, if living standards for the disabled and their carers are to improve.

Ongoing interviews with carers might be a means to understanding the role of the carer. However, instrumental to this inquiry is statistical evidence of the life expectancy for Australia's ageing population<sup>2</sup>, including projections for those with disabilities. Statistics published in *The Medical Journal of Australia*, indicates that severe disability levels for the next 25 years (2006-2031) will increase by 70%. "The main conditions associated with profound...core activity restriction in older Australians are musculoskeletal, nervous system, circulatory and respiratory conditions and stroke."<sup>3</sup> Therefore the question is what are the longterm implications for carers and their dependants, and how the Government will respond?

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<sup>2</sup>. Rebecca Kippen: *Demography and Sociology Program*, Research School of Social Sciences, The Australian National University, Canberra, in Joint Special Issue, *Journal of Population Research and NZ Population Review*, Sept. 2002.

<sup>3</sup>. [http://www.mja.com.au/public\\_issues/179\\_03\\_040803/gill0803\\_fm.html](http://www.mja.com.au/public_issues/179_03_040803/gill0803_fm.html), sighted 11/07/2008

It seems clear therefore that more carers will be needed whether sourced by formal or informal means, but overall there has to be a more thoughtful approach to the role of the carer.