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Submission No. 890
(Inq into better support for carers)

Deborah :

Secretary

Standing Committee of Family, community, Housing and Youth

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House of Representatives

Parliament House

Canberra ACT 2600

Dear Secretary

I read that your Committee on Family, Community, Housing and Youth is interested in finding out how better to support Carers.

I am the primary carer for my daughter. So what, I hear you ask, shouldn't all mothers care for their children. I agree with you wholeheartedly on that point.

The difference being that most parents can see at some point their workload will begin to diminish to the point of redundancy as their child moves into adolescence and then adulthood. As it should be!

Not so in the case of parents of children with special needs. That certainly is an all encompassing phrase isn't it? 'All children have special needs' I was once told by the mother of a robustly healthy and intelligent five year old, to which I agreed, but also pointed out that a when a child cannot empty her bladder by herself that her need may not be more 'special', just a little more urgent.

The carer of a child with special needs starts out as a parent, but one with extra responsibilities. Often the care of this child is done with love and unselfishness, as would most parents meet the needs of their children. However, the demands of a child with a medical condition tend to increase rather than decrease with time and the personal toll can be greater than the parent ever imagined.

I have always felt that it was my choice to become a parent and that with the help offered by a close knit family would overcome all difficulties. It is a wonderful support, of course, and there is probably no better back stop for

young parents under pressure than to be able to let grandparents help with raising little children. But it is not always possible or practical.

At some point along the parenting route, you have to start to admit that your role is more of carer than parent. That is quite a startling fact to face in itself, but it also masks the underlying issue that one or the other of this child's parents will be forfeiting a career that they may have hoped to resume.

This is a personal cost with financial and emotional implications. It is just not possible to ask a stranger to do all the things that you have learnt to do in the roll of a carer. Perhaps some of what you do for the person you are for is akin to nursing- so do you call in a qualified nurse for that? Then there is the getting to medical appointments, hospital admissions, physiotherapy, occupational therapist, organiser of social activities for the person you care for, look after their intimate personal care, in fact the list goes on and on.

I am not unique in this situation, but I realized this year as my father's cancer needs more aggressive treatment that I am in the process of being 'pincer gripped' - being needed by both my aging parents and my daughter, sandwiched between two generations of people who need assistance.

Increasingly I am aware that I will not be young forever and so I worry about the future and who will take over the caring roll for my daughter when I am no longer capable.

We live in a society that honours its elderly and gives the best chance of a happy and productive life to people with all sorts of disabilities. The problem as I see it is that there are a group of people support by taking on a caring role but who in turn find it hard to navigate the system to have their own needs met.

This could be for time out or time to rebuild a career, or attend to their own medical issues.

In the last two years I have started to get assistance from Home Care who are very practical in helping to share the physical work of caring. It may be stating the obvious but there are not nearly enough people working in this area as we need and the need is growing as our population ages. There have been times when home care workers have not turned up either for reasons of illness or being short-staffed, and so reliability of back up is not as good as it should be.

What do carers need?

Recognition of the role they play in society. While a realistic wage for the work they perform seems out of the question it may help many carers to know that:

They have an entitlement to a period of leave from their caring role for a period of a week at least twice a year.

That when on leave the person/s they care for will be cared for in their preferred environment to the extent that they currently are cared for.

That the person they care for is also entitled to a holiday for 1 week a year which is in a supported and appropriate environment.

That as the carer ages or becomes incapable that there is a guaranteed support of paid carers to take on the caring role. The transition should give the carer the assurance that there is a continuity of the standard of care, preferably a consistent and steady pool of paid, well trained carers to draw from.

That if a carer wishes to resume employment there is an adequate pool of trained carers to take over the caring.

That those carers resuming work be supported by knowing their caring role is being performed at no cost to themselves, by a qualified person, who can be relied on to turn up when they are rostered on. This would have to be the biggest issue to the dilemma of returning to work or not- knowing that you have reliable back up carers.

That a carer is entitled to a number of hours per week- minimum 4 that can be taken as personal recreation or for social interaction.

That carers who face-long term caring roles also may need psychological counseling by a specialist with an understanding of the duties performed and the stresses they place on the carer.

Carers need to know what strategies the government has in place to deal with an ever increase of a small pool of paid carers. As the population ages we see much greater pressure on the same pool of people, who themselves are aging. There is bound to be a severe labour shortage which may mean that nursing homes are the most 'efficient' solution for anyone needing care regardless of their age.

Currently my need for respite is not being met. It would appear that there are numerous agencies who receive funding from either State or Federal to whom you have to apply to be considered for respite.

Each of these organisations employ social workers who are paid to spend inordinate amounts of time deciding which of their applicants will receive how much of the funding depending on their 'needs' What a waste of resources!

All carers should get the same entitlement to leave and support. If an annual allowance was allocated to each person who receives care, to be used to buy 'respite' then all the agencies need to do is employ the staff.

This submission has been written in great haste at the 11th hour. I am grateful that the committee wishes to improve life for carers and if I can be of further assistance in this endeavour, please feel free to ask.

Yours sincerely

Deborah

Carers play a vital role in sustaining Australia's current system of community-based person-centred care. However, they are often at increased risk of becoming socially isolated from their peers and disconnected from mainstream employment. Many carers also have significantly worse health outcomes than the general population (both in terms of physical health and psychological wellbeing) and endure problematic access to services and support. Carers also often face increased financial pressures, having limited opportunities to accrue savings, accumulate superannuation and save for retirement.

To obtain an improved understanding of the challenges facing carers and their support needs, the committee will inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- 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 examining each of these issues, the committee will also inquire into the specific needs of particular groups within the caring population including new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities.

For the purpose of this inquiry carers are defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'.