

SUBMISSION TO PARLIAMENTARY ENQUIRY INTO BETTER SUPPORT FOR CARERS

Carer Details: Patricia

**Caring Experience: Son with MH issues – 20 years
Aged Mother (87) – 10 years
4 Grandchildren - 7 years
(profoundly deaf)
Ageing spouse - 2 years
(pain management)**

Role and Contribution of carers in Society: If you look at my own contributions, I think these are considerable to society, and in addition I have held volunteer and paid positions all with a carer focus, while juggling my caring roles. I am not unique as I have met many carers who work as well as have multiple caring roles, but mostly we compare the certificates of thanks that we receive, as we all volunteer for committees or do extra hours in our jobs due to our commitment to carers. I think the government could do a lot more to validate the caring role and the contribution that carers make to society in a monetary sense that would reduce the stress many of us have to make ends meet. For many years I was a single parent, and my children without a disability had prices that they paid to, as there was very little extras in our household in the years when my youngest son started to suffer from his mental health issues. Just the fares to get everywhere was a huge financial burden.

The Barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment:

My experience: This has not been easy, and there is almost no support for carers to work or study, unless they can successfully negotiate this with a supportive manager. I have found the most support when a manager has had a caring role also, but I have also had other managers who have been very unsupportive, and have no real understanding of what the caring role entails, especially multiple caring roles.

I was once able to claim Carer Leave, but no one in the organisation had told me about this, I discovered I could ask through the Working Carers Website. It was handled like they were doing me a huge favour, and it was actually my sick leave, so I had to use annual leave when I had to have an operation myself, so it was really a bit of a joke really and had just meant a lot of extra paperwork and a second rate worker.

When studying for my tertiary qualifications, I had to ask for one extension for an assignment, but I had to make sure I attended 90% of my classes. This is very difficult at times with a caring role, and I know other carers who have had to give up due to TAFE and other educational facilities not understanding the responsibilities.

Educational Facility Support: There is support for people with disabilities, but nothing for carers, and I think this should be addressed. This is particularly relevant for class attendance when it is not our choice that we have to miss a class, and in fact, makes extra work to try to catch up.

Respite: If there was respite available, and not just for people caring for aged as I am aware of one pilot offering this, this would be a real support to carers who are wanting to either return to the work force, or have a balance in their caring role that provides mental stimulation and creative opportunities.

Educate Employers and give some employer incentives to employ carers, as well as some financial rewards for working carers, as there are often extra expenses to be able to work – respite is not free or easily accessible.

Educate Centrelink: I was once asked how I could be a carer and work, which completely invalidated the roles I had. I said that I definitely qualified as a carer. When my son became unwell, he was 14. I had no idea I could have had mobility allowance or could claim any assistance. Over the years, and even as recently as last week, other carers told me that they had gone through the whole school system without knowing they could apply for assistance.

More promotion in schools about Young Carers and the availability of supports to assist families who have someone with a disability, including mobility allowances. Many disabilities, especially MH issues, are starting to occur and there should be more education for families during this critical period, where early intervention can better support the young person and their families.

Young Carers: this is particularly significant for young carers. Some initiatives have been offered here, but young carers often don't want to (stigma) or don't realise (not promoted well enough) that help is available. My other sons did not do as well as they could of at school, because I was a single mum then (husband suicided) and had to ask the boys to help with my youngest son. At that time, had no idea what was available to help us, and it has taken nearly 20 years to acquire the knowledge. If only I had known then what I know now.

Major Breadwinner and Juggler of my many roles: (Stress and Self Care)

I also have the major breadwinning role in my family, and am often bridging the gaps that a disability pension does not cover, if I am to give my son the opportunity to reach his quality of life goals. In the last 5 years, since he has lived independently, he has had 5 major episodes in hospital. In one instance, it was code red across the state, I was working in a hospital in Liverpool, my son was in Sutherland Hospital, and his flat was at Matraville,

where I had to visit at least every second day to walk and care for his dog. He was in hospital for 10 weeks.

I save the government a considerable amount each year by providing support to my family. I receive one carer allowance for my mother, as my son does not acknowledge that he needs a carer, even though I provide a lot of support when he is unwell. He has bipolar disorder, and there has not been a time during the last 5 years that he has been well, either recovering from a manic episode, which then has him go through a depressive episode, and then a manic episode. He is compliant with his medication, and has insight into his disability, but life stresses (trying to study, or trying to work, or sometimes just maintaining himself) contributes to an episode.

I know many carers who have similar issues, and are hard pressed to maintain their physical and emotional wellbeing. I have learned to care for myself through education & training.

Funding for Education & Training for Carers: Any paid roles expect qualifications and an expectation that education is available. This is not the case for carers, even though they save the government billions of dollars every year. There is no ongoing funding available to support this area for carers. Mental Health has received some funding, but it is 3 year projects, that create some hope for carers, and then it disappears with the stroke of a pen.

I know the education and training I have received has sustained me in my caring role, and taught me more effective ways to care. I have learned not to "over care" by not doing for my son what he is capable of doing for himself. This applies to my other caring roles as well, and I continue to empower all the people I care for, rather than disempowering them by doing things that they can do. My elderly Mum still does what she can do, although it can be easier and quicker when I am in a hurry to do it for her, I have learned that this is not in her best interest or my own long term.

It has also taught me to care for myself, as if I become sick, either physically or psychologically, I cannot provide the care or I reduce the quality of the care if I am depressed, stressed or overwhelmed. I have processed the grief and have become very effective at managing change, as my life has to cope with a much higher degree of change than an average person. I have learned to model behaviour that has assisted my family and the people I care for profoundly.

CHOICES: Working is good for me, even when I am told on occasions that I think more of my work than I do of them. This is untrue, but it hard for me to manage the "guilt" I sometimes feel, but without what I earn it would be harder for all of us.

Even though I have worked, I have not a lot of superannuation, and many carers have none at all. As we are living longer, and the people we care are living longer, our caring roles are also longer, and we are also living longer

which is a double edged sword for carers. How do we provide adequately for our own retirement? How do we have or even look forward to a holiday?

Strategies to assist carers make choices:

1. **Reduced TAFE fees and resource costs for carers, so they can access personal interest courses to revitalise themselves, and assist them to sustain themselves in their caring role**
2. **Respite and Support to work or study as well as flexible course material coverage (attendance requirements/on line opportunities)**
3. **Increased carer allowance and carer payments to better bridge the costs of caring, including fees for service. A working carer often has increased costs, as people judge that they can afford to pay without also looking at costs or outgoings. They often have to make up shortfalls to assist people requiring services on pensions**
4. **Ongoing funding to train carers in their caring roles, ie, manual handling, understanding the person they care for (grief and impact of grief for carer and care recipient) and impact on the whole family**
5. **Having a strategic framework of support, rather than just doing it haphazardly. Some areas of Sydney are more disadvantaged than others, so carers living in these areas are more disadvantaged.**
6. **Extra challenges for CALD and Aboriginal carers**
 - **more education so that they understand they fit the criteria of a carer.**
 - **Funding to make education & training opportunities available in cultural languages, or are culturally appropriate.**
 - **More funds available to train and support bilingual workers.**
7. **Recurrent funding to raise awareness of carers of the need to Plan and make arrangements for the Future for themselves and the person they care for. Assistance with legal subsidies as it costs money to set up a disability trust and consult to find out the best ways of doing this planning**
8. **A superannuation plan for carers**
9. **A reward system for long time carers, and multiple caring roles – a long service plan, like other workers are entitled for....10 years etc. There has been a bonus, but that is being challenged by the current government.**
10. **A Holiday fund system for carers.....very few carers get to have a holiday as there is usually not enough money, and the respite has been used up during the year to survive.**

I hope this has been useful, as I have given up a Sunday afternoon to prepare this, and hope that you will keep me advised of what decisions are made.

Yours sincerely,

PATRICIA |
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