

Committee Secretary  
Standing Committee on Family, Community,  
Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

APC 4/8/08  
Submission No. 1197  
(Inq into better support for carers)

4/7/08

Dear Committee 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 husband and I were both born with a physical disability. As such we both care for each other. I use crutches to get around and my husband relies on a wheelchair for his mobility. As Carers, as well as husband and wife, our role is to support each other in all facets of life.

Neither of us feels we are considered as a Carer by society in general, and therefore entitled to Carer support. This seems an inequality on a number of fronts. At one level, we can be denied the support of formally meeting with other like minded Carers because it appears that we are both people with disabilities rather than in a supporting role we both assumed when we married. Granted we have our own support network through an Association which supports children and adults born with the same disability as we were, but this isn't quite the same as a Carer's support within the general community.

Due to our condition we face various mobility issues, amongst other things, and our health does fluctuate so we also face additional burdens on our finances which those living without a disability do not. As noted above, both of us use various forms of equipment, which necessitates meeting the cost of having a car modified so we may drive it to our places of employment, thereby contributing taxes, so we can access the community. We rely on our car to move around the community in general, although at times we also need to use multi purpose taxi transport, which is expensive and not always timely in turning up hence important appointments can be missed. We must also regularly pay for specific medicinal and continence requirements as part of our ongoing daily living.

Sometimes one of us takes on more of a caring role than the other, but there is no rhyme or reason as to when or where this may occur. As an example, should one of us have a specialist appointment or need surgery then we may require assistance, but it is not always possible for the other partner to get time off work for this. It is not always possible to anticipate when one of us may need someone accessible to look after or assist them. Even though we endeavour to live as independent lives as possible, we do acknowledge that we are often more prone to illness than others who do not have a physical disability.

I'm aware of Red Cross' short term emergency respite support available for 24 or 48 hour periods to provide short term care support in the home. This could come in useful and reduce stress for us at times since neither of us would be able to fully help the other with toileting, showering or other personal needs. Both of us are also employed full time and cannot always take time off due to work commitments, so extended periods of illness can pose a problem if a family member is not available to assist. To employ an agency person to assist could involve a large fee, although it would give piece of mind that the other person was ok.

On another level, although we do not need or have a formal regular able bodied carer, we do need help with various domestic tasks and rely on family to support us at various times. We endeavour to be as independent as possible so access the services of Silverchain's home help service. This involves us

paying someone to assist us by coming to our home on a fortnightly basis to help with tasks we are unable to do ourselves.

Contrary to our desire to be active and independent members of the community, we often feel that society can tend to view us as if we have an invisible disability. In a way it is a discrimination that assumptions are made that we both must require assistance, rather than that we equally assist each other.

Instituting a universal service which would enable people to gain access to the services they need, when and where they need them, is something we aspire to see the government support in the future. Had we been injured via an accident we could potentially have received support for our needs, but since our disabilities are congenital this is not the case. Something like a new levy service could be means tested and take into account the means and ability of the individuals in supplying the equitable supports they require to be active citizens in the community. We have heard of countries like Sweden using such schemes and would encourage the government to explore the suitability in setting up similar schemes in Australia, on a national basis.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely

Kerrie