

Submission No. 1067

(Inq into better support for carers)

Rec 28/1/08

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

Dear 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.

I have been the primary care for my husband who is a quadriplegic with very limited speech, for almost 16 years. During that time I have also cared for our two sons who at the time my husband became ill were 1 and 3 years of age. I cannot fully participate in a social life because my husband requires almost constant care. Even if I manage to organize some respite it is usually of a short period of time which necessitates me checking my watch all the time to make sure that I do not overstay my allocated time. Another problem is finding suitable people with appropriate skills to assist my husband when I am not there. Mostly it's just easier not to bother going out as the stress of organizing the respite often defeats the purpose. I also feel that while I can be depended on to make a commitment to go somewhere the support person I have organized to relieve me may decide that they are not available and only let me know at very short notice. I find it difficult to commit to anything because I have been let down so many times in the past.

I have struggled to continue working but with a tremendous amount of organization I have recently managed to return to full time work as our sons now assist much more with the caring responsibilities to facilitate this. Over the past 16 years we have suffered financially as we survived on one part time income and one pension to pay our mortgage and raise two children. It is difficult not to be envious of others, especially friends who haven't faced our challenges, who can have family holidays, follow their dreams, continue their careers uninterrupted, have investments, and be secure about their futures.

I worry about my future as I age because I struggle to find the time and energy to successfully look after myself physically, and emotionally and to maintain myself so I can continue my caring role. I worry what will happen if I became ill, and when I no longer have the help of my sons to share the caring role as they pursue their own lives and careers.

The things that stress me most about being a carer are never being able to relax as I never feel that I am in control but that other people and events shape my daily life for example, recently my husband went to University where he was studying believing that a support

worker would meet him there and assist him. My husband has limited speech and mobility and it would be extremely difficult for him to summons help from a stranger. The nursing agency left a message on my phone. They had been unable to find a support worker (they always leave things to the last minute) and my husband had caught his regular taxi to the university where he was left, unattended as he expected to be met by a support worker. My husband was at the university with no assistance, no knowledge that no one was coming, without any means of asking for help (he cannot ring on a phone and he has difficulty in making himself understood). I had to work out a solution from my position at work 40 minutes drive away, in my job where I have responsibilities and cannot just leave when an event like this occurs. These sorts of incidences are never far from my conscious thinking. I find it hard to relax and complete my work – I am forever checking my email as that's how my husband can communicate with me – to make sure that he the support worker has arrived to look after him.

Recently there were events in our suburb that had me worried about the safety and security of my husband in our home. Because of a lack of funding there are times when my husband is by himself. He enjoys this little bit of independence. However, if someone broke into the house he would not be able to defend himself and it would be difficult for him to get out of the house quickly if he was startled. We always have to find solutions to issues such as these ourselves and try to solve them. The issues we experience are probably experienced by other people in similar situations but there is no central body to coordinate this that we can ask for advice so we feel that we are always “re inventing the wheel” when there probably is already a solution that someone else has found.

If I give up work because of all the issues we face, then I too will become a prisoner from circumstance that we were not responsible for and our quality of life, such as it is, will suffer. I need to have some independence because before my husband became ill I worked and had a career. My career and life dreams have been largely put on hold in order to care for him. His career and life dreams came to a grinding halt because of a mystery virus, and his whole life changed overnight from being a fit, healthy family man with excellent career prospects to someone totally dependent on others for all his personal care and every day living.

The things that stress me most about being a Carer is never feeling that I am have control over any aspect of my life. I pride myself on being reliable but the people that I rely on to care for my husband often are not. I can never tell someone that I can do something because I am never certain that the respite or what ever help I can set up will eventuate. I can never make plans with any certainty, nor make plans in advance or ever be spontaneous. It is stressful to always have to depend on others. It is stressful having people in our home all the time to care for my husband, dealing with their many personalities and needs. It is stressful having someone in my bedroom first thing every morning and last thing at night as I share a bedroom with my husband. It is stressful having someone in my home who is able to move freely through every room in the house and look in every cupboard as they need access to everyday items. My home is not the sanctuary it was before my husband became ill, there are often people there because they

are caring for my husband. Most people can be themselves in their own homes but I always have to be ready to be polite and courteous, and have a clean and tidy house. I find it stressful asking for help from others all the time because without this help I would be unable to cope.

I need help with additional funding to purchase the hours of care that my husband needs to support him daily. I need the government to recognize the importance of people with a disability to live in their own homes but with sufficient support to meet their needs and not drain the emotional and physical resources of their families.

I think the Government can help support Carers by supporting them to live their lives as they would like to live it eg support them to be able to attend work, attend conferences, meetings etc.

I think the Government can better support Carers by asking Carers what they need – allocate funding to Carers that they can administer themselves within reason such as funding to buy support when they need it such as for work commitments, weekends away, time out to go for a walk or go to a movie, receive regular massages. It is never easy asking for help or requesting some respite time. It would be a huge relief to have some kind of system such as a voucher system where vouchers were issued for example, once a month. Carer's could elect to spend these each month or save then up to purchase something they really needed such as a weekend away once in a while. Each Carer is different from the other and have different needs at different times.

Another way the Government could support Carers is to increase the funded training positions so that people are trained properly before they work in the field. Maybe they could buddy up with an experienced support worker to learn the ropes and develop their skills. Support worker's rate of pay also needs to be increased to attract suitable people to the profession. We could relate many disastrous situations where we have been subjected to having someone in our home that not only does not have the appropriate skills, but are thieves, unprofessional, discuss private information about other clients, are chronic liars, and many have psychological issues.

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

Vicki
3 July 2008