

A.O.C. 30/6/08

SUBMISSION TO :

'Better Care for our Carers' Parliamentary Inquiry.

From:

Alan ~

Background

To better understand the difficulties I face as a carer and to assist me in my role, it is best that the Committee understands the circumstances of the person whom I care for.

Can I say however that I love my wife and I would continue to care for her regardless of the external support structures or financial assistance that might be available now or in the future.

Any support and assistance however, makes my efforts to improve the quality of my wife's life somewhat easier and helps my personal circumstances to be understood and appreciated by the wider community which then makes my role somewhat less stressful and it enables me to do more of what I want to do for my wife.

The caring role is not something I have freely chosen but it is something we all have to acknowledge may be 'just around the corner.' I have had to deal with a number of personal issues to do with the loss of choice, freedom, independence, career opportunities, resentment, family disbelief, financial stress, substance abuse, anger from my only son because of my inability to see him and so on.

My wife is a chronic invalid, essentially bedridden with a hypersensitive nervous system that is very fragile to environmental and emotional stress. There is no medical label for her condition but we have three pathology reports to prove that her nerves are or have been under attack from her own body. She has an auto immune illness and other problems.

She has had the occasional home visit from her GP but never from a specialist who might be able to assist us the most. To the latter time is money and they don't have the time to see us at home. Essentially the person who needs the most help often falls through the cracks in the system.

Carers cope they do not necessarily have the means, time, energy or will power to agitate for change. They are too busy or focused on getting through the task at hand and facing the next day's challenges and demands.

My wife also has a chemical sensitivity to Volatile Organic Compounds which means that she cannot tolerate new carpets, glues and solvents, the smells of products found in chemists,

hospitals, supermarkets and public toilets. Deodorants, plastics, shiny magazines , new electronic gadgets are also dangerous.

Due to her condition she cannot travel by 'train, plane and sometimes automobile' as the noise, pollution, smells, road bumps and surrounding movement and activity of personnel and machines can rapidly overload her nervous system's capacity to dampen or filter the amount of sensory input. as we do on a daily basis.

This makes a visit to a doctor, dentist, specialist, hospital etc problematic and potentially dangerous as her presence in these environments may mean she gets worse rather than better. It is all too hard to try to explain this over and over again to those in 'authority,'

If we can and must travel we take a portable air filter which we can plug into a mains electric outlet to provide clean air and lessen the risk of her becoming 'overloaded' with the smells she will encounter.

The Difficulties I face as a carer

1) Living with the knowledge that if I become mentally incapacitated or die my wife will not cope due to the nature of her special needs. Needs that only I truly understand. If the worst happens she wants the option of ending her life with dignity but religion dictates that she may need to suffer. She may survive but it is the option to end her life that she wants.

Hence I feel very alone, vulnerable and scared for her should something happen to me. What the worst aspect of the above is that there is no solution that I can see. My wife has no relatives to call on and my family do not believe she is as ill as she is and have never offered any assistance. They believe she should "get over it or push through it or she is putting it on or..." They do not want to know how ill she is because it might impose some sense of obligation to help me that they do not want to accept.

2) Not been able to access any carer 'respite' because of her special needs.

From long experience I can read her body language and I know what needs to be done. To entrust others to care for her may lead to actions which precipitate a sudden deterioration in her well being. I have to be extremely careful whom I ask to care for her even if it is for a short time. The assumption that respite is vital for carers may be true for some but not for me. Respite is a risk and furthermore there is no way the physical and emotional support my wife needs could be replicated in a strange respite environment by strangers no matter how compassionate.

3) Even I was able to find someone to care for her, the financial costs involved in paying carers from private agencies and the likelihood that there will be any consistency in carers over a reasonable period of time poses a huge problem. Every new carer has to be 'trained' and every carer has to be able to meet or be willing to adapt to my wife's emotional and physical needs. I had one agency carer who lasted 2 hours at our home because she objected to the fact that we had asked her not to wear perfume as it made my wife feel ill! Another agency person rejected the position because the home (she said) "smelled like death!"

4) Having to pay to save my sanity. Fortunately our neighbour has a good understanding of my wife's needs and if I can manage to get away she will care for my wife as well as I could expect someone to do so. But I have to pay a local person on top of all the other costs associated with having a 'holiday.' The point I am making is that it is unfair that the only

financial assistance you can receive is if the carer belongs to an agency. Why can't I get some support if the only person available is a trusted friend or neighbour?

5) The unspoken assumption by the medical profession and the various Depts of Health that my wife can travel at will to obtain medical attention and to meet their requirements for her to receive further assistance. There is also the costs in both waiting time and money if scheduled appointments are missed. For example one specialist my wife recently saw, charges \$390 if you do not provide 24 hours notice. I cannot tell how she will be from hour to hour, let alone day to day. The Dept of Health said it was not their problem!

6) The extra costs involved if my wife requires a home visit or if I see our local GP for **repeat** prescriptions on her behalf. For example the RACGP will not cover their members if they prescribe without seeing the patient or the patients representative. This means that when I see my local GP we are ineligible to get the Medicare rebate and I must pay \$50 per visit just to get a prescription because my wife cannot make it.

7) The costs of caring e.g. increased water and electricity bills, special bedding, laptop computers for the bedridden, mobility aids, wear and tear on the carer (e.g. chiropractic treatment for back strain.) An increase in the Carer's Allowance. The \$50/week pays for one Doctors visit to get a prescription.

8) The need for us to have top private health care as if I need to have something done I need to have it done quickly so I can return to care again a.s.a.p. If Private Health Cover continues to rise I may not be able to afford to care for myself and take preventative measures e.g a colonoscope to check for bowel cancer. Something will have to give.

9) The attitude among many so called friends that if my wife does not do what that person recommends (e.g. follow a certain diet, perform meditation, repeat affirmations, see this or that person for advice etc) then she has rejected the person who gave that advice and therefore she is now responsible for her current predicament and will not get any help from that person again. From my discussions with others, this is a common experience the chronically ill encounter. People with the best intentions actually cause more distress because they think they know what long suffering patients need when in fact they have little if any understanding of the circumstances.

What would I like from the State and Federal Government.

1) An increase in the financial assistance given to carers to reduce the stress associated with establishing and managing special environments and the unique needs of the chronically ill.

2) An understanding that not all carers want or can have 'respite' but would prefer support at home if they are to "get a break." This will mean State Governments will need to put more resources into home assistance because currently priority goes to those on government pensions.

3) An acceptance by the Government and the medical profession that some chronically ill people cannot travel and hence need to be seen by GP's and Specialists at home. Otherwise the people who need the most help just fall through the cracks and suffer unnecessarily. Could there not be a mobile specialist service for registered special needs patients?

4) That pressure be put on the AMA and the RACGP's and other specialist Medical Colleges to educate their members to really listen to what the chronically ill have to say. As a carer I

have all too often faced specialists and doctors who have this arrogant, 'know it all attitude' and who cannot 'look outside the square.' They are right!!!!

I have experienced those professionals who do not believe what my wife has to say even though it is she who lives with her illness '24/7'. Too many doctors get personally offended if they are contradicted about something they have said or believe even if it clearly contradicts the experience of the carer and the patient.

5) An Ombudsman for Carers established in Legislation to ensure that our needs as carers are acknowledged and met.

Thank you,

Alan