Submission No. 551
(Inq into better support for carers)
A.O.C. 7/7/08

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Committee Secretary
Standing Committee on Family, Community, Housing and Youth
P.O. 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.

Initially, may I say congratulations to the Committee for addressing the situation, and I trust a real improvement for the army of individual carers in this country will prevail.

Briefly, my position is that I am a carer of my husband, David. He had a stroke Nov.'99. Prior to the stroke we were independent citizens paying our taxes. Now we are both on a pension. David receives the aged pension and I the carer's payment and carer's allowance. Fortunately, we own our own home and have some savings, so our financial plight is not as dire as some struggling in rental accommodation with no savings. We live in rural area and are well plugged into the local support services and carer's community.

We must maintain a car as David is in a wheelchair and could not use public transport, which is generally very limited in regional Australia. I have to drive David to all medical appointments and therapies, often at some distance from Forster. The increasing cost of petrol is a problem looming on the horizon.

I am, along with fellow carers, struggling financially as a carer because of **Caring Costs** related to all the expenses over and above the normal living expenses of pensioners and retired people.

The only extra financial support available to a pension/carer couple is the carer's payment which is at present, $100.60 per fortnight. This amount plus, is paid out in costs involved for supporting the person the carer is caring for.

Though Federal, State and Local Governments provide the subsidised support services available, there are still additional costs to the carers. These add up, and far out weigh the living costs generally incurred by of an ordinary pensioner couple. No doubt some department in the bureaucracy will have figures to back up this claim.

As my caring situation is due to stroke, some four years ago I started a local Stroke Recovery Club. The club is affiliated with the Stroke Association of NSW. The Club has a dozen carers as members, including myself.

The club is structured as a self-help group to provide support and socialisation for those who are in the community, post stroke. We cover the full range of situations from recent strokes to the post stroke experience to seventeen years down the track.

I believe that one of the areas The Committee is particularly interested in hearing from Carers that have experienced difficulties accessing services due to the complex nature of the relationship between federal, state and locally funded services.

When I brought David home from the rehabilitation hospital, I required the services of the community health nurse (State Government funded). It was suggested that my husband should be in a nursing home (Federal Government funded).

David's needs were then, and remain "High Care" and hence an added financial burden to whichever Government funded body that put him on their books. I am not complaining about the support we received then or now. However, the 'user pay' system has pitfalls for the both the provider and the recipients of the service.

We receive support services from Federal Government (respite services) State Government (Home Care) and Local Government (HACC Services). From my experience and, I feel I can speak for my fellow carers it would seem that these services are always under funded, which ever government body is involved.

This situation put the carers in an ongoing advocacy role trying to get the best outcome for their loved one. It is a constant juggling act, which can be humiliating and akin to a begging role.

Each service has eligibility guidelines, which are a minefield to the ordinary citizen to confront. Currently, we are subsidised for Physiotherapy, Hydrotherapy, Lawn Mowing, fortnightly, and a Carer to give my husband lunch on Mondays, by a HACC service.

Recently, we were informed that our yearly assessment is due. This phone call engenders fear and uncertainty as to whether they will continue the subsidy or not. We still need it but can they justify the expense? Or worse still, who else in the community will be shunted off the service for us to be allowed too continue? This scenario equals a gratefulness/guilt trip.

We are clients of the Continence Aids Assistance Scheme, CAAS, they have a system where we are allotted so much a year and we order up to that much. It might not be enough, but at least one knows exactly where they stand and can budget accordingly.

We have a six hour Home Care (State Government) service on Tuesdays. This service allows me to play golf once a week and was contracted with Home Care eight years ago.

The gossip vine tells me that there is no way I would get that service now, as a new set of guidelines is operating. Apparently, maintaining my own health and sanity is not a government priority at any level of provision.

The carer's group I belong to, has been able to get funding to take 16 to 20 of us carers away overnight at least once a year, alas, this year we were told they did not get any funding, so our much looked forward to 'away time' is not to be. These 'away times' have been beneficial to all carers to recharge the batteries.

I have all but given up trying to avail myself Residential Respite services (Federal Government). We have our yearly ACAT assessment and my husband remains in the high care category.

First of all, the respite service presumes your life as a carer is completely organised. You have book ahead, and you can not take less than two weeks. Once again, I presume, this is governed by available finances, and related to fortnightly pensioner payments.

For me, a week's respite would be long enough, a fortnight is to long. Though desperately in need of a break, it is in the too hard basket for most carers to negotiate.

Emergency Respite service (Federal Government) is supposed to be available if you need it within that month, and if the service has sufficient funding left. Being aware of the funding situation, earlier this year, I rang to request some respite, so that I could attended a counselling training course.

I am a volunteer counsellor; I work at the Forster Neighbourhood Centre on Mondays, I am obliged to engage in so many hours of 'Ongoing Professional Development' annually. I applied for respite service to care for David in our home for three days.

The response was "We do not provide respite for training courses, only emergency service" Then, there was mention of the cost involved for someone to be there overnight and they were not sure their would be sufficient funds.

This was why I rang in advance, so they could factor into their monthly budget, the cost of my request. Not surprisingly, this was not enough as the goal posts keep moving, decisions tend to be made at the individuals discretion of the person responsible for granting the respite. I eventually got the respite I required through the HACC service.

This is where a life of juggling, akin to begging, can be so demeaning for the carer. One has to be aware of each of the services guidelines and engineer ones request to fit the criteria.

There has got to be a better way than having to negotiate the minefield of bureaucracy and the varied interpretations of the guidelines of those responsible for making the day to day decisions for carers.

I hope my document is of help, I could write you a novel but it would be basically, more of the same, constant juggling in all areas of life as a carer.

Sometimes I worry what will happen when I die, then, I think, oh well! At least I won't have to worry.

Yours faithfully,

Lesley