

ABC 17/7/08

**Submission No. 892**  
(Inq into better support for carers)

Ms Annette Ellis MP  
Committee Chair  
Inquiry into Better Care for Our Carers  
House of Representatives Standing Committee on Family, Community, Housing and Youth  
Parliament House  
CANBERRA  
ACT 2600

Dear Ms Ellis

As a Carer I wish to make the following submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's inquiry into Better Care for Our Carers.

**My role as a Carer**

My husband Piet has disabilities due to a brain injury following a collapse whilst working in our garden and striking his head five years ago.

Piet is not safe to cross roads alone, cannot drive a car or catch a bus, make himself a cup of tea, or remember to go to a toilet. He is unable to plan or initiate many tasks, has low motivation and has attention deficit/poor concentration.

He has a range of health problems that have arisen as a result of the damage his body suffered following the injury. These include hearing loss, diabetes, vascular disease in his leg, incontinent bladder and bowel, aortic aneurysm, recurrent lung emboli (clots), renal failure, seizures, periods of confusion and episodes of challenging behaviour.

My role as the primary carer for Piet is to assist him to undertake personal care, social, spiritual and cultural tasks that he is no able to undertake alone due to his cognitive impairment. My priorities are that he is safe and has a good quality of life.

I assist my husband

with his personal hygiene, dressing and grooming with support from Parkside Working Carers support program,

take care of his dietary restrictions,

give him his medications,

monitor his blood glucose levels and blood pressure,

take him for regular pathology and medical tests,

take him to appointments,

cut his hair and attend to manicures and pedicures,

attend to shopping for clothing & prescriptions,

launder and iron his clothing,

undertake all shopping, cooking and cleaning, household maintenance and gardening

take him for walks,

take him to church,

negotiate with service providers and advocate for him;

protect him from exploitation (such as cold calls soliciting business, religious organisations recruiting membership etc), and

protect him from physical harm which basically means ensuring that Piet is accompanied or supervised at all times.

My husband cannot perform most household tasks although he can dry dishes and vacuum with prompting and encouragement

To cover the costs of our living expenses as well as Piet's disability I work full time.

**Problems of the Carer Role**

**Financial:**

At the time of Piet's accident we were debt free – we owned our house in a rural area of Tasmania and we had savings. Unfortunately we needed to relocate following Piet's injury in order to access rehabilitation and support services as well as flexible employment for me that would fit around Piet's needs.

All of our savings were exhausted in the two years following the accident due to the need to pay for services, equipment, and renovations which I continue to strive to complete. I was not able to undertake adequate levels of employment at this time and this caused us significant financial strain from which we cannot recover.

It is essential that I sustain employment to pay for our mortgage and all other household expenses, and to provide for Piet's medications, continence aids, weekly hydrotherapy, day centre attendances x 3 per week, support worker programs x 8 sessions per week, medical and health costs (physio, podiatry, optometry, dental, medical practitioners/specialists) as well as equipment needs such as embolic stockings and exercise equipment to maintain mobility.

We have had further expenses related to Piet's disability such as the need to alter our bathroom, and alterations to the rear entrance of the house to enable safe access. We also face the upgrade to the front entrance of the house which it is not possible for Piet to use.

It is very difficult to meet all of the obligations on my earnings, even though each of the care services we access is subsidised.

### **We struggle financially because**

Our incomes (my wages and Piet's aged pension of \$39 per fortnight) are considered separately for taxation, and yet treated as a single income for the purposes of determining support or assistance.

In the care situation where a spouse has an acquired permanent disability my experience is that there is no hope of change, no chance of improvement, a carer's financial and personal resources continue to be depleted, there is no partner with whom to share the load, and the carer experiences the loss of their life partner

### **Considering the combined income of couples in the carer/care provider situation where one partner is incapable of contributing in any way to the household (income or function) thus the entire financial burden falls to the carer:**

1. completely disregards the reality that a carer is '*living two lives*'. The carer must represent, advocate, protect, make and act upon decisions for another person.
2. generates poverty and an underclass in terms of standards of living. There is clearly an expectation that as the carer I am not only required to ensure the safety and quality of life of Piet with only remuneration of less than \$50 per week allowance. But also I am entirely responsible for the total financial needs for my husband's life (apart from his \$39 per fortnight). We have both consistently contributed to the economy and have not ever inappropriately used services. We both were hard-working people and who have opposed welfare dependence where-ever independence is possible.  
I believe that the government is very dependent upon me to support my husband as well as me and is dependent upon me as an unpaid carer for the remaining hours of my life to ensure the wellbeing of Piet.  
I am aware that if we were no longer legal partners government agencies would essentially have to come to the party in the provision of his support and that in fact he is likely to be better off in terms of an adequate personal income and access to services than if he remains in my care as my spouse.
3. is a significant disincentive to carers' re-entering the workforce. I am aware that renting a property would have enabled us some rental assistance and that had I not re-entered the workforce I would have been eligible for welfare support.

For example

- To go to work we must pay for the extra support needed for Piet from day centres and support programs. <sup>1</sup> These services are subsidised however the cost to us for use of these services is \$132.50 per week (equivalent to about 22% of our income, with the mortgage consuming a further 35% of our income).
  - Disability is costly. In Piet's case he is on many medications and has physical problems that require support. His disability also incurs additional costs due to its impact on the household (for example carpet cleaning, car cleaning, breakages, the need for ramps, rails, and improvements such as steps, shower access).
4. During my first year as a primary carer I had to relinquish health insurance due to cost. This is a tremendous loss to us and is irretrievable due to the penalties associated with age entry into health insurance funds.
- Piet's teeth have deteriorated due to cracking from minor seizures and it is not possible to access public dental care as this means waiting for longer than five years. Consequently we have had to use private dentists at substantial cost.
  - Piet has needed several hospitalisations where he is subjected to the indignities of an overstretched public health system that has no tolerance for people who are ageing nor for people with disabilities.

#### **Respite and employed carers:**

I have only ever sought to use respite to enable me to continue earning wages by fulfilling the requirements of my job. (I have not sought respite for any other reason and take my responsibilities as a carer seriously).

Respite for me to travel to perform my job would entail one to three nights respite every one or two months. However it is **not possible** to access respite in residential aged care for such sort periods as in Hobart aged care homes will only provide respite for a minimum of two weeks. I am aware that most aged care homes would prefer not to provide respite at all as they do not see it as a core business activity.

The result is either that Piet must remain in residential aged care for the full two weeks or leave after the shorter period but I am required to pay for the entire time in any event. If we were to use residential respite in this way it would add a burden of stress for both of us due to unnecessary length of separation, untenable costs, and the impact on Piet's cognition and ability to cope. He invariably deteriorates in this environment and much work is necessary to restore his pre-respite functionality.

In home respite for short periods (such as three nights per month) is far more suitable, less disruptive and a more humanitarian approach for someone such as Piet who becomes lost and does not receive adequate care in these facilities. Unfortunately in-home respite is not available to people who are aged disabled.

#### **Accessible services:**

1. I relinquished my employment at the time of Piet's accident to assume the carer role because there was not any community rehabilitation service available in the north of the state and only two hours care support per week could be provided. As Piet needs constant supervision I had no choice but to remain at home with him for all except those two hours per week. Six months after Piet's accident we relocated to Hobart from our rural home in the north of the state away from our families to gain improved access to medical and support services. This move has enabled me to return to work to earn enough income to pay for our mortgage and for Piets attendance at rehab and support programs.

---

<sup>1</sup> Weekly: HACC \$10; Monday Banksia= \$12 plus \$20 transport, plus lunch usually about \$15; Tuesday = CACPS \$12.50; hydrotherapy \$7.50; Wednesday Headway \$7 plus \$20 transport; Thursday CACPs \$12.50, Friday Migrant Centre \$16 including transport.

2. There are no support services (eg day centres, training programs, social programs, respite centres) for aged disabled people in the city of Hobart itself. Most services are located in the far northern suburbs of Glenorchy and Chigwell, resulting in ghetto-like service development encouraged by state and commonwealth government agencies.

Access to these services is further hampered by the cost of transport for all except those who live in those suburbs.

### **I worry about our future**

3. I have reason to be concerned that Piet will not receive good care should I pre-decease him. Many health care workers do not understand the limitations of someone with an acquired brain injury (ABI) and this has been very evident during respite in aged care homes where Piet has suffered neglect. This has included him not being washed or shaved, not having his teeth cleaned, not receiving help with continence aids. He is not allowed to attend his regular programs while in respite due to the daily schedules and he is excluded from in-house programs because he cannot understand the programs and he is not assisted to find his way to the venues. People with ABI often present as 'normal' and the deficits only become apparent when a problem arises, or when they are in the company of another person for a period of time.
4. Systemic problems and limitations in the provision of care to aged and disabled in the community give me cause for concern as far as the future is concerned. Advocacy and a system of accountability is even more important I believe in the community sector where the care recipient (who is vulnerable) and the care provider are generally the only people present for the care provision. There is not a system of accountability for the delivery of services in the community care sector.
  - Whilst we receive good quality services much of the time we have had instances of carers not arriving, or not staying for the requisite time, carers not prompting or assisting Piet with his tasks so that he has not been appropriately dressed, has not been shaved, has not had his teeth cleaned.

On one occasion he spent most of the day outside in a state of undress in near freezing temperatures when a support worker did not arrive as arranged. I was at work and found Piet in this state upon my return.

We have had one instance of a carer bullying Piet such that he became fearful and anxious about her presence and I was thus alerted to the problem.
  - Although service agencies have responded to problems efficiently and effectively, I am very aware of the importance of my advocacy role and the consequences of the potential problems where there is no advocate.
  - In my experience funders (usually the Commonwealth government), service providers, brokers, case managers, and care agencies do not ever check on the standard of care being delivered in the community sector.
  - I am aware of others who have been promised services but never received them. I believe the provider was funded to deliver the service, however there is no mechanism used to check that funding is applied to service provision, nor is there an avenue for recipients to take if there are problems with community care. I believe the opportunity and incidence of exploitation in community settings is probably very high. There are many people who do not and will not speak out because they are 1) afraid of losing even a second rate service; or 2) due to their cognitive impairment they may not be aware that standards are not being met.
  - I have been told that Tasmania has the highest proportion of population of people living alone and receiving community based services,
  - It is interesting to note that there is a compliance and complaints mechanism (albeit limited to a retributory approach without any move toward a system of self disclosure or quality improvement) for the residential aged care sector, but no similar system exists for community care.

As a consumer I must say that there are many risks and limitations in residential care, however because the aged care accreditation agency has a performance target of accrediting 98% of aged care homes, complaints and compliance requirements are ultimately rather irrelevant (see budget papers). Clearly the minimum standard for accreditation is to be among those 98% of aged care homes. This is an approach that should be avoided in developing quality improvement and safety systems in the community sector as it clearly is designed to obscure or conceal problems in the sector.

Where aged care providers have been investigated for several complaints and/or compliance issues there are no real penalties. For example there have been instances where facilities with very poor compliance records have received accreditation and/or has received significant funding for further service development – including community service developments without accountability requirement.

### **The things that cause me stress are**

Whether or not I will be able to continue to work. This is a health and ageing issue for me and it is a fact that my lifestyle as a working carer certainly has taken a toll on my capacity and capabilities.

Only temporary jobs were available to me during my first four years as Piet's primary carer and so I held a series of short term positions throughout this period. I gradually increased my hours of work as I located support services.

I have now secured a permanent position but even in this role my probation period was extended beyond the norm because my employer (a government department) needed to be assured that my carer responsibilities would not impinge upon my job responsibilities. I have worked in the job for 11 months now and have not taken any carer leave, and fortunately have not been ill so have not required any sick leave. I have consistently met or exceeded my performance targets. However because of the terms of my employment I am constantly concerned that I will fail and be penalised.

I am on a waiting list for surgery (and have been for 3.5 years) but although I wish to have this matter resolved I also dread the call to have the surgery as I am concerned that I may not be able to secure care for Piet at the time.

Affordability for health care is an issue and as Piet is vulnerable and has many health problems his needs are the priority. I am pleased to have located a GP who bulk bills both Piet and myself, however the associated costs such as prescriptions are prohibitive for me. Piet has an aged persons concession so we can meet his medical care needs.

### **I think the government can better help carers by**

1. Enabling people needing care to receive a pension entitlement that is an adequate living income, despite their carer's earnings.
2. Treat the incomes separately for all purposes, or treat the incomes as combined for all purposes. But please remove the double standard, which seems only designed to further disadvantage an already disadvantaged group, so as to advantage government treasury.
3. Provide working carers with a health care card. As a working carer we assume the cost of living of our dependent partner, however unless the carer is in a high income bracket

**the costs of disability + a couple living on a single income + no means of earning additional income = financial stress.**

A health care card could be a recognition acknowledging the contribution of people who work for no remuneration as a carer and for wages to support themselves and their care recipient. It is also a way of addressing the declining health status of carers.

4. Service access criteria should acknowledge Working Carers as a legitimate criterion for support services to care recipients.
5. Provide a form of affordable/accessible health insurance to enable hospitalisation with some associated choices for people with disabilities who are excluded access to health insurance due to cost.
6. Introduce a system of compliance, quality and safety within the commonwealth government-funded community care sector, taking some lessons from the aged care homes compliance systems and limitations. This should include the introduction of a system of funding monitoring, complaints, quality monitoring and quality improvement.

7. Work toward developing cottage, stand-alone, and in-home respite options in place of residential aged care homes as venues for respite (which cannot be flexible and can only be provided on their terms due to their business and profit priorities).
8. Develop some rehabilitative training options for aged, cognitively disabled people to maximise their potential, retain/develop skills, and delay the onset of dementing illnesses. (For example 'disability –relevant' computer courses and programs that will help maintain cognitive agility; enable support to aged disabled to participate in community groups - for example Piet was involved in electronics and a radio museum prior to his accident. He would like to attend meetings and to participate in a club environment around this hobby. This is not possible due to costs and his need for support).
9. Find ways of improving security and the standard of living that
  - do not penalise carers and their care recipients who are paying mortgages instead of rent, and
  - do not penalise care recipients who are receiving care from working carers.
10. Reduce the 'ghetto-isation' of service development by requiring service development to occur where people with needs are located. Requires service development to take into account epidemiology and demography; funding criteria should reflect this. Topography should not be accepted as a primary driver.
11. Review the criteria that enables the development of community based services by organisations with poor records of legislated compliance, complaints or quality.

Yours faithfully

Annette

03/07/2008.