

Submission No. 1019

(Inq into better support for carers)

ABC 28/7/08

The Secretary,
Family and Community Committee,
The House of Representatives,
Parliament House,
Canberra
ACT 2600

30th June 2008

To The Secretary,

I would like to lodge a written submission to the inquiry into the needs of people who look after those with chronic illness, disability or frailty.

The terms of reference are;

- **The role and contribution of carers in society and how this should be recognized**

The role of carers in society is huge, they take on the responsibility of loved ones 24hrs a day 7 days a week 365 days a year, and if they are lucky might receive a carers allowance (which is means tested) or carers payment, they don't do it for the money, they do it because they have unconditional love for the person they are caring for. They look after all their physical, medical, transport and daily needs. Without carers all these people no matter what age would have to be looked after in facilities with nursing staff paid to care for them, this would place a huge financial and resource burden on the Australian health system.

- **The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment**

Carers are consumed by the person they are caring for and as there is insufficient help out there to assist, they are unable to hold down a job, as they have to put the person they are caring for first and without the reliable back up support the responsibility of holding a job is not an option. This forced state of unemployment is a huge number of people out of the workforce, again creating financial stress for employers.

- **The practical measures required to better support carers, including key priorities for action:**

If a carer is prepared to care for a loved one the support given should be without limits, the amount of money saved on these people being looked after at home as oppose to being in facilities (government provided) its not much to ask for. Any carer would be happy in my opinion with part time work; they wouldn't want to be away from the person they are caring for, for too long. If someone could assist during these hours it would give the carer some normality. There is some government funded help between 7am and 8pm but any night nurse caring has to be self funded and my research has shown they can charge anything from \$280 a night to \$41 an hour. Having given up work to care for someone it isn't affordable. Respite care is another sore point, as they are not enough facilities to give carers a break when required. This insufficiency of respite care to cope with the load of patients defeats the point of respite care in the first place. Without respite, the full time carers end up leaving the loved one in nursing homes and other care facilities as the load of caring becomes to great a burden.

- **Strategies to assist carers to access the same range of opportunities and choices as the wider community, Including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.**

To provide facilities offered in the wider community to accommodate for people bringing the person they are caring for with them, or providing qualified staff to look after the person you are caring for so the carer can socialize and have timeout. Once you become a carer you are isolated from society and contact is restricted to doctors, therapists, chemists, hospitals and people who are involved with the person you care for.

What is needed is a balance of providing home care hours around the clock if needed, respite care places within a reasonable distance of the people requiring them. Look at each case individually and provide the funding required to make the person being cared for and the carer as comfortable as possible. Provide more facilities for people under the age of 65 and of non aboriginal background. Nursing homes for people under 65 are unsuitable.

My current situation

On the 12th Novemeber 2007 my then 17year old daughter Laura suffered her second stroke, this one a lot more severe and debilitating, she nearly died. After 2mths in Wollongong intensive care and 2mths on the ward Laura was transferred closer to home, Shoalhaven Hospital it has now been 8mths since her stroke and she is currently in Hospital in a Rehab ward. I have given up work, where I had been permanent part time for the last 7yrs to look after and help assist Laura in her recovery. I want to bring her home to care for her but she requires more care than is allowed through home care, and I am but one person. I can be her 1 fulltime carer during the day, but can't get the help or care to change her during the day, or after we pay (if we can afford it) for a night nurse get up twice a night to assist in positioning and changing, I am nearly 44yrs old but still feel I would be unable to sustain this for an indefinite period of time. I do not have a choice, my choice would be to bring Laura home with her family, she has 2 younger brothers, Laura will have to be placed in a nursing home, which is classed as unsuitable placement as there are no positions available through DADHC group homes in this area, Where is the choice, is a nursing home the place for an 18 yr old girl who is locked in a body that doesn't work, Laura fully understands what is being said, she laughs and smiles and if that is all I can get for now, I'm happy to still have her.

We need help these situations are stressful enough with Dept doors, funding and help being closed on you. We just want to be as much of a family as we can, and give Laura the best quality of life we can, and a nursing home isn't the answer-----but because of lack of funding and insufficient facilities there are no other options.

Yours faithfully

Cathy