

2<sup>nd</sup> July, 2008

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.

The role of carer is usually thrust upon people with no warning or preparation. In my own case, my husband suffered a stroke on the 20<sup>th</sup> August 2001, at the age of 50. It was discovered that he was suffering from cardiomyopathy and was possibly in need of a heart transplant. Our local hospital did not have the necessary medical staff and facilities to treat him, so he was transferred from Katoomba to Westmead. As we had private health insurance, the specialist who accepted my husband was only able to locate a bed in a private hospital. While this was acceptable to us we had no knowledge of the complexities of the services offered by private versus public hospitals. As a result the following issues became obvious to us over the next few months:

- **the cost of the inter-hospital ambulance transfer** was our responsibility. We did not "request" the transfer to a private hospital – we accepted it as we were told it was the only bed available to us. By "nominating" to go private we became responsible for the transfer cost of some \$800.00. The health fund's responsibility only extends to "emergency" transfer to a hospital and as my husband was already in a hospital it was deemed to be a transfer of "choice". After much argument, a number of hours of discussions and buck passing, the health fund finally agreed to pay as the local hospital was not able to provide the services required, so therefore it could still be classified as a medical emergency.
- **Physiotherapy services.** In Katoomba Hospital, as a stroke patient, my husband would have received physiotherapy. As a "heart patient" in a private hospital, he was discharged home with only a follow up appointment with the cardiologist, and no access to the normal support

services normally available to stroke patients. When we finally accessed these services, we had to wait a further nine months for our initial assessment for hydrotherapy.

- **Occupational Therapy.** The public hospital had advised us there would be a home assessment to look at what aids/modifications would be required before he would be coming home. Also he would be assessed by an OT and given exercises to do to improve his daily living. As a patient in a private hospital, none of these services were available. After a couple of months, our GP arranged a 30 minute appointment with an OT at Katoomba Hospital to try to teach/encourage my husband to learn to write again. She resented our "queue jumping", said she had seen patients in worse shape than my husband and didn't see what we were complaining about. Yes, my husband had improved, but only after daily activities like crossword puzzles and physical tasks that we had done ourselves. Initially my husband had suffered total right sided paralysis and loss of speech! Seeking assistance to teach him to learn to write, seemed little to ask for.
- **Discharge Planning.** On his initial and subsequent discharges from hospital, the best I can say is discharge planning comprises a form that needs to be completed so we can go home. Tick the boxes, sign on the bottom line and a bed has been freed up for the next patient.
- Last October, Graham was in Westmead Private Hospital. At every possible place on the admission forms, and on his admission, I made it known that he had a carer. The morning he was discharged, I said I would sign the discharge form but they insisted that he sign himself, which he did. They then queried his scrawl, and said that that it was not a signature, so that I had better sign for him after all! The form showed him as a person who was being taken home by his wife – and that he needed no assistance with any activities – even though I had assisted him with his shower less than 30 minutes beforehand.
- **Access to Services.** Access to any service is difficult, because like the discharge planning forms, you have to be able to tick the right box. The Respite/Support Services all have criteria that must be met. What happens if you can't tick the boxes because you don't fit the exact mould? **Nothing.**

As a result of the stroke, my husband suffered from frontal lobe damage – personality changes and short term memory loss (symptoms similar to dementia). Alzheimer's Australia runs a course for families caring for family members with dementia. Entry requirement is a

diagnosis of dementia. Without this, no matter how similar the symptoms are, you don't qualify.

Other services that I have enquired about have age requirements – but we aren't old enough. Also some services are available through the public hospital system, but not from private hospitals.

- **Finances.** We receive a superannuation pension, topped up by the disability/carers pension. We travel by car between 400 to 500 km per week, to attend appointments (GP, nurse, pathology, hydrotherapy, physiotherapy, podiatrist, occasional x-rays, and specialists. Needless to say petrol consumes a considerable portion of our available funds.
- **Medical.** Thank God for the health care card – our out of pocket expenses for the 2006/2007 financial year were \$3,804. This is roughly equivalent to 3 of our fortnightly superannuation payments or 12.6% of our annual income; this does not take into account the private health insurance premiums which we are still paying.

#### **Who looks after the carers?**

I am drafting this sitting up in bed with bronchitis/pneumonia? Thank God for Blue Mountains Frozen Food Services, as I know there is food in the house. My husband is trying to "care" for me. I am still checking on all that he is doing to make sure that he is safe – but who looks after me?

I have my own medical problems. I had Non-hodgkin's lymphoma in 1991 and a second primary in 2000. In 2006 I was diagnosed with choroiditis, a degenerative eye condition which is fortunately in remission. We have no children, I contact my ageing mother daily. She, at times, feels neglected and resentful as I do not spend much time with her.

We need a local support service (community based) to support us. This should comprise a service that all carers registered with Centrelink are eligible to access – no other eligibility requirements needed. This local service, supported by the backbone of most communities – volunteers – , would exist to support carers. When a crisis occurs, such as a carer being ill, the carer could ring the co-ordinator, who could arrange assistance for the carer. This might just be a lift to the doctor's, coming in and cooking a meal - simple basic services to allow the carer to recuperate without undue stress and worry. Perhaps an *Adopt a Carer* Scheme, on the same principles as the *Adopt a Pensioner* Scheme (recently advertised scheme proposed on Channel 7 Sydney) should be investigated.

Carers are invisible! We are seen as the proverbial pain in the backside. We are the people who are there full time. We are undervalued, rarely listened to, and inevitably placed in an untenable situation.

We have to stand up for the person we are caring for at all times, but be prepared to be ignored. We still have to convince so many practitioners to "talk to us" so we know what is going on to best care for our family members. We need support, not ignorance; compassion not indifference; recognition not invisibility; pride not guilt!

Thank you for listening!

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