

The Secretary
Better Support for Carers Inquiry

Submission No. 639
(Inq into better support for carers)

Aec 25/8/08

Dear Secretary

Below is my personal submission to the inquiry.

(1) My Circumstances

(1.1) Caring for my son

I am a 60 year old man with vision impairment on a disability support pension. Over the last 5 years, I have had to look after my son who is now 31 and who developed schizophrenia about 10 years ago. He is now on a steady medication regime. The extremes of his illness occurred over about a 5 year period where he was in and out of psychiatric centres. He was living with me for about 2 years between 2004 – 2006, but has now got his own accommodation nearby. He still requires my support in terms of personal advice and emotional care and occasionally, some financial support.

(1.2) Caring for my mother

Between 2000 to 2007 I have had to provide caring for my mother when she was living in her own residence, and later, living with me. She is now nearly 87 years old. She was diagnosed with Alzheimers around mid 2006 and prior to her admission to a nursing home, she had two separate falls breaking her arm and later, her wrist. She lived with me in that period for about 4 months where I had some support workers coming in 3 times per week to shower her and to take her out one day a week. My brother, who lives near by would take her out also, but I was the primary carer as he was not well himself and has family commitments. Generally speaking, with both my son and mother, there were periods where intensive care was required.

(1.3) My Personal Experience

I am a single person, now with a girlfriend, but in the past, these pressures mentioned have made it very difficult to have a "normal" life. My situation has improved of late, but over a long and continuous period, the personal stresses are often over whelming. Due to life stress and my particular disability of hormonal imbalance problems, I have experienced some periods of depression. I acknowledge that my caring role has been far less than many others, but I have had my own experience that allows me to make some comments and suggestions that may be useful to this inquiry.

(2) Particular Problems Detailed

(2.1) Harsh Centrelink Requirements

At one stage, I applied for a Carer's Support Allowance to help me assist my mother. I found the compliance requirements totally unhelpful and out of touch with reality. What was defined as "personal care" was insulting to one's intelligence. For example, cutting up vegies was counted, but not the cooking time. Doing my mother's shopping, business or extra cleaning, taking her to doctors, etc was not considered as personal care and not to be counted as time of caring. My mother was incapable of doing these things for herself. As I considered that I could not meet the rigid provisions prescribed by Centrelink, I withdrew my application. I have discussed these matters re Centrelink with others in similar circumstances and they too reported the same difficulties and frustrations.

(2.2) Carer Gender Difficulties

Being a male means that looking after an older woman is not always appropriate. I have had to bathe my mother and take her to the toilet and dress her. That was ok by me, but this is not always the case for some people. Problems can arise in situations for carers where there are no daughters in the family to attend to very personal female needs in both a physical and emotional sense. Vice versa for women having to look after men where they may be large in body frame or even aggressive at times. Also, with my mother, it was only after a fair period and after receiving the advice of women support workers, that I came to realise my mother was experiencing depression, after which, she got the necessary treatment. Women were able to provide certain attentions and ways of relating that a male could not.

(2.3) Caring for the Mentall ill

My son is reasonably stable now, but he still experiences paranoia and voices at times. This requires a lot of attention and emotional support and occasionally he has to see his psychiatrist. An appointment for him requires an upfront fee of around \$180 of which he gets back about \$100. Often, I have to assist my son with his finances as he has not got the money to afford such medical costs. Not everyone is in a position to provide this financial assistance.

State health funding has been cut over the last few years, so that support services he regularly attended and relied upon, are now not available. Because of the nature of his illness, much demand falls back on me to keep him on track so to speak and provide social

company and activities for him. I understand this would be the experience of many other Carers in this situation.

(2.4) Access to Information for Carers

Information is not readily available. You have to go out and do all the research yourself. In my case, I have had previous work experience related to the social welfare field and have been able to find out what I needed to. This was not easy, but I imagine for others not experienced in dealing with the relevant agencies, it would be very difficult. A lot of assumptions are made by the various agencies that people know what to ask. Carers have to wade through all this and it can be a long and frustrating process. There are lots of pamphlets there, but not the people there to explain and work through with a Carer, the complexity of dealing with support agencies. I only found out by accident, where I could get further assistance for my mother through a nurse at my GP's surgery.

(3) General Comment

Caring for the aged and infirm has many levels of complex. No where near enough money or resources are being provided to assist Carers. The vast work, time and struggle of Carers goes mainly unrecognised by governments, the larger community and even in many instances, by other family members. In essence, we have a section of our community who are impoverished and compromised citizens, unable to secure the benefits of social infrastructure available to other fellow citizens. This is an area of grave need which requires the attention of our society. It raises serious questions such as - How do we care for our families and each other? Are the current working arrangements of government services able to provide adequate care?

With a rapidly growing ageing population, is it just, is it reasonable or sustainable to continue placing the burden of 'caring' responsibilities entirely on the few that take on these roles? Carers not only face the responsibilities of their particular tasks, but also have to struggle with the personal pressures, both physical and emotional affecting their lives. In many ways they are denied opportunities to work, socialise in the larger community and live a normal life. As well, their voices go unheard. Most Carers probably don't see things this way, but none the less, their lives are often significantly diminished and the flow on of this can be long term and is a loss to the community to which they belong.

(4) Recommendations

(4.1) Total rethinking and revaluing of the role and responsibilities of government health and welfare services and private support agencies is needed. A holistic approach is required that engages all the parties concerned. This must come from the community as a whole, The thinking has to extend beyond the service providers to involve people in an ongoing consultative process.

(4.2) A Community Charter could be developed which sets out certain community standards, and which is built on the concept of genuine "**Community Care**" for the whole community. Part of that Charter would apply to "Carers" and those in need of care, which would specify the support they receive and the level of that support. Such a Charter would of course require a great deal of research and planning and probably, changes to government legislation. The various levels of government, Federal, State and Local and private organisations/agencies would function within the standards set out in this Charter, which could be binding through "Memorandums of Understanding" signed by the various parties, or even by legislation. Governments of any persuasion would have to conform to this "**Community Charter**", hopefully preventing political intervention with changes of governments and bringing more stability and focus to social policy over time.

(4.3) More Comprehensive Consultation with Carers and their families is needed to thoroughly assess the precise nature of each Carer's circumstances and this should be ongoing on a regular basis.

(4.4) More Community Awareness and information should be engendered and made available, perhaps through Public Libraries, the internet, community nurses at GP surgeries and advertising through the media.

(4.5) Comprehensive Information specifically for Carers and their families should be made more accessible and simplified through a central co-ordinating body within a region.

(4.6) A Central Register should be established within a Local Government Area for Carers so that a more effective monitoring and delivery of support can be achieved.

(4.7) Centrelink should initiate changes to broaden their knowledge and understanding of the experience of Carers and work more closely and co-operatively with those agencies which are

providing services to Carers and families. They should not be applying so rigid and bureaucratic rules, which end up creating more problems than they solve for recipients and the process of effective service delivery itself.

(5) Foot Note: Some of the above ideas may may sound extreme, but I refer to the Disability Discrimination Act of 1992 as an example. This was implemented because of the great impetus for change back then. Like wise, the needs and social conditions exist there now for the support and protection of Carers and those being cared for.

Practical and informed social planning can result in a better and more rewarding society, and which, in the long run, can bring less hardship for people and more sustainable cost structures for the community.

John

27th June 2008