

Committee Secretary
24/08/2008
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.

Self Management of EACH Package

We have been caring for our mother at home successfully, for seventeen years.

Over the years we have had different care packages, the first commencing in 1995 with Linkages (Vic State) & now EACH (Federal). Over the years we have experienced a great deal of stress, bordering on the extreme, relating to the service provider component of our care package. Because of this stress on our family, our sleep becomes affected and my stomach condition, (gastric reflux), flairs up due to the stress from these issues. Self-management would stop the stress caused to us from overzealous service providers with a 'tell you what to do' approach, instead of considering the individual family's needs, listening and compromising where possible, etc!

The Care Package needs to be tailored to each individual person's requirements, as the generalised guidelines simply don't always work, especially in our situation. We know exactly what we need care wise. We are a very private family who simply wish to care for our dear mother, in our own home of 57 years, with the respect and dignity of our family home protected, as it is our home and not an institution! The approach and attitude of some service providers terrifies our mother and us. The care recipient and primary carer need to be the focus of the care, but somehow service providers have lost their primary objective.

Self-management would allow significant cost saving in our case as the following shows:

- • Approximately five hours extra care, this is extremely significant as we are always struggling with ONLY fourteen hours and these saving would alleviate all of that cost pressure;
- • The care dollar would be used more efficiently, gaining our family the maximum hours of care possible;
- • Thus the government would gain though better value for the care package dollar;

- • Eliminating a high percentage of the precious care funding being paid out in management fees!

We need to draw attention to the hardships many carers go through each and every day simply caring for their loved ones.

All carer's stories are moving and powerful in their own way, as they are varied in the type of disabilities. All types of care packages can have their difficulties in maintaining hours of paid care assistance for basic human needs, such as shower services and respite care. We believe self-management of care packages, should be made available to all caring families who would wish to avail themselves of this option.

We all deserve care packages that can alleviate stress on carers and be personalised to suit each individual case and their specific care requirements, with minimal supervision.

Long Term Carer Needs

As a carer of seventeen years I feel socially isolated, due to a total lack of respite hours of care, as we have no funding for in home respite care at all! I feel I work for my income support (carer payment) 24 hours 7 days a week I do this by choice. I am now 46 years of age; I started caring when I was 29 years old. Why are carers not recognised for their work as workers are? For seventeen years I have not earned a wage, I have had no superannuation contributions for the entire duration of my caring roll, I am unable to save any money, in fact I have to draw down on what little superannuation I have to keep us financial. What will happen to Carers like me when we retire? I have not worked in the mainstream sense for so long, no allowance is made for Carers who have to re-enter the work force & many find this adjustment extremely difficult. Centrelink need to have a Carer adjustment policy, to help people like myself to work mainstream, once they are ready to cope with normal working conditions!

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Terry