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Submission No. 1155

(Inq into better support for carers)

**PARLIAMENT OF AUSTRALIA**

**HOUSE STANDING COMMITTEE ON FAMILY, COMMUNITY,  
HOUSING AND YOUTH**

**INQUIRY INTO BETTER SUPPORT FOR CARERS**

**Submission by**

**Margaret**

1. My dad is an 87 years old. He receives the Carers Allowance because his 85-year-old wife, my mum, is now pretty much incapable of physically doing anything much without assistance. She has a wheeled walker chair. Because my dad is a veteran of World War 2 they receive some in home support from the Department of Veterans Affairs, but not much, two hours a fortnight. They receive the aged pension – so of course my dad doesn't get any carer bonus. My mother has had a stroke and has some help for personal care a couple of times a week.

2. My parents will not complain about the home help – except to immediate family – but they don't want us to do anything. I am inclined to think they are fearful that if they rock the boat, the boat will sink. As well, they get stroppy when we suggest things. "Don't treat us like children," they say.

3. A recurring theme seems to be workers who come late and leave early. Also, there seem to be issues associated with occupational health and safety as to what workers will or will not do, or can or can not do. The one which strikes me as kind of defeating the purpose of the service is not being allowed to get down to wash the legs and feet of a person on a seat in the shower.

4. I am familiar with the "no lift" policy in home care, flowing it would seem from the 'no lift' policy in hospitals, but the emergence of a 'no bend' policy and the other one, the 'no stand' policy – apparently the length of time spent standing to iron is restricted to about 10 minutes – these I find a bit mind-boggling. As is not being allowed to use a cobweb broom to get down cobwebs near the ceiling, as this could crick the neck.

6. My dad has had enough of the paperwork too. He reckons they want too much of old people. I am not sure who the 'they' is he is referring to, but surely to goodness once a person gets to be 80 or 85 the government could do away with a fair bit if not all of the bureaucracy. My parents have a very good financial adviser, who is authorized to deal with Centrelink, but I believe this is another instance of what my dad feels is his independence being taken away from him.

### **Practical measures for carers**

7. Overall, my parents do not get a satisfactory service. I do wonder what kind of accreditation and monitoring there is in place for people getting help in their homes, old or otherwise. I would like the Committee to inquire into and report on this.

8. I would also like the committee to report on occupational health and safety issues which diminish the services being provided, including the necessity to do away with third party liability.

### **Practical measures for carers over the life-expectancy age**

9. I would like committee to inquire into and report on streamlining the bureaucracy for people aged in their 80s or over whatever the life expectancy age is. Also, anyone who gets the Carer Allowance and any other kind of pension/benefit should get anything which is made available to a person on Carer Payment.

### **Parent carers**

10. I would like to suggest to the Committee that parent carers are a particular group within the caring population who have specific needs which must be identified and responded to. Particularly, parents who have a child born with profound life-long disabilities.

### **The four pillars of the system of support**

11. My experience with the support for parent carers is that the four pillars of the system of support are:

- Cruelty
- Stupidity
- Senselessness
- Arrogance

12. Replacing these four pillars with

- Kindness
- Wisdom
- Sense
- Responsibility

has to be the key priority for action.

13. Just on 18 ½ years ago my youngest sister looked like she wasn't really coping with having two children, a two year old and a new baby. Because I was then working part-time I was able to find the time to help out. When it emerged that there was something wrong with my sister's second child, I continued to help out, mainly spending hours pushing a pram, but also taking my nephew to playgroup and therapy sessions.

15. I was also there when Victoria's Department of Human Services for all intents and purposes took a cricket bat to my sister, slammed her around the head, whacked her in the guts, wiped their hands and left. This was when those in charge in Victoria's DHS rang my sister and told her two other children could get services if her child didn't, her services were finished, bye.

16. Watching my sister slumped on the floor, physically overwhelmed by the news given her, the survival fight mechanism kicked in – that emotional drive which makes you act. I had a responsibility to protect my younger sister. We went into battle. Eventually the services were reinstated.

17. That battle took place 15 years ago, when there was the Coalition Kennett government in Victoria. The battle for support for a person with multiple and profound disabilities has continued throughout the intervening years, unchanged by the coming to power nine years ago of the Labor Bracks now Brumby government.

### **Making public policy and legislation**

18. Since the early 1990s I have been active in disability issues, and have written and spoken fairly extensively. My horror of the system is unabated. There is something really amiss when families must make their private lives public as 'evidence' of the need for support. Reforming public policy only in response to pressure generated by the media is unacceptable.

19. I well remember a few years ago when my sister and a friend were front page on the Herald Sun with their plight at the costs being heaped onto their families to fund their children's artificial feeding food supplies. Going public was a huge dilemma for both families, but with their backs to the wall they felt they no other choice. The four pillars – cruelty, stupidity, senselessness, arrogance – were readily obvious in the change to funding the feeds.

20. The public had no problem in recognizing the four pillars. Subject to intense public scrutiny, within 12 hours the Minister reversed the situation. Months and months later other families were still thanking my sister and her friend for being public.

21. The review of the Carer Allowance (Child) was brought about by the Fyshlock family being very public in the media.

22. Of course there are too the bloody minded politics, when governments use their numbers to push through what is obviously flawed. A good example of this is Victoria's Disability Act 2006, which the government pushed through while it still had the numbers in the Upper House. Notably, the Minister responsible refused to attend the upper House Legislation Committee where she would have been questioned on the Bill, which did not have bi-partisan support. Having conducted the reform of the legislation internally, the Minister released the Exposure Draft on the Bill in November 2005, then presented the Bill to Parliament February 2006. It received assent May 2006. I suggest this is a record not to be emulated.

### **50 cents a day**

23. Back in 2006 the then Victorian Ministers for mental health, disability and ageing released new carer policy and at the same time extolled the virtues of the Victorian government's \$130 million contribution to carers across the three sectors. Using ABS numbers, this equates to 50 cents per day for a carer – not an amount which might demonstrate kindness, wisdom, sense and humility.

### **Co-operative Federalism to make the provision of care a first order issue**

24. I hope that the spirit of Co-operative Federalism means that the provision of care, to both carers and the people they care for, become an issue of the first order in the nation.

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I would appreciate the opportunity to speak personally with the Committee.

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