

AOC 4/8/08

Submission No. 1134

(Inq into better support for carers)

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To: Committee, FCHY (REPS)
Subject: FW: Inquiry into better support for carers

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My name is Catherine , I am aged 50 and I care for my profoundly disabled, medically frail 24 year old son. Jonathon suffers cerebral palsy, severe scoliosis, profound intellectual disability and life threatening epilepsy. If he was assessed for an aged care facility he would be classed as requiring the highest level of care – constant seizures, unable to turn or move in bed (subject to pressure sores) and is, of course incontinent and totally unable to sit or walk. I really do object when it is stated that I do not 'work'. I personally have saved governments millions over two and a half decades and for 99% of this care I have received approximately \$50 per week. Do I feel undervalued – "yes!"

The level of care that my son requires is around the clock – I have been on 'night duty' for decades and as he has grown and his physical disabilities have become more apparent the physical demands combined with broken sleep must take their toll on the 'long term' carer. I am grateful to receive 14 hours of personal care assistance from Home Care - to move Jonathon is a 2-person job – I am the second person. 2 local lads with a physical disability (not intellectual) are in receipt of Attendant Care packages – this gives their families 36 hours x 2 (2 care workers) = 72 hours. I mention this so you can appreciate the savings that my care makes possible.

It would have been impossible to work 'outside the home' during Jonathon's childhood. His very high level of disability requires experienced staff to care for him – aged grandparents were totally unable to help in any way. My husband was always self-employed and worked from home; I assisted him in the day to day running of this business and played an integral role in the growth and direction of our business. The company was only able to pay me after many years of watching costs and putting all available resources back into the company. My own superannuation is therefore limited. Looking back over Jonathon's childhood years it would have been possible for me to work outside the home only if Jonathon attended a residential school or was the beneficiary of a share care arrangement. Jonathon is now physically frailer, more prone to chest infections and suffers many stomach and gastric upsets. His epileptic seizures are unpredictable and constant. My workload is massive and requires my total commitment – it is indeed a full time job. If anyone considered why I am not in paid employment it shows that they have little comprehension of the care demands of the profoundly disabled.

My husband suffered a severe stroke 5 years ago, a second stroke followed and he has since developed epilepsy. He required extensive rehabilitation and speech therapy, all speech was lost and this required much of my time and was, as you would imagine, devastating. I never applied for 'carer allowance' for his early care despite Centrelink insisting that he would qualify. He was unable to return to work and financial stress is a constant reality. I do find my multiple care demands stressful. This stress is unrelenting physically, emotionally, financially and socially and this takes its toll on my health and wellbeing. If I had confidence in the future care of my son my stress would be much reduced, I would then believe that my contribution was valued by government and society. In NSW my son would receive supported accommodation only if I had placed him in care as a child or if I walked away from his care he would then be deemed 'homeless' and the NSW government's hand would be forced. There is no provision in "Stronger Together" for accommodation for those disabled adults who reside at home. Death of either my son or me is the only way out – I am perplexed that it is deemed necessary to hold an inquiry to discover why we are stressed, have poor health, meager superannuation and limited retirement options! This is unconscionable when Australia currently enjoys such surpluses. France, UK and Canada are able to treat their profoundly disabled citizens and their carers with greater respect and innovation. Walk a mile in my shoes and you may benefit from greater wisdom and insight. Empathy and compassion would be appreciated optional extras.

Recently there has been much publicity of neglect of children and the discovery of elderly people who had died unnoticed by their neighbours. It was stated that 'we have lost our sense of community'. Government can not have it both ways – I have no wish to draw attention to my role in the community for the past few decades but I have no choice as I feel that the term 'carer' has become so generic therefore diluting its

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definition and the value that government and society places on the person who performs this role that bad luck, happenstance or God has placed upon their lives. It is stated that I have nursed my son for decades, worked – both unpaid and paid in our family business and cared for my husband when he suffered a stroke but I have always felt the need to contribute wherever possible and to give expression to my own interests and passions. I love to read, longed for travel is only possible between the pages of a good book; I volunteered as a reading tutor at my daughter's school for her entire primary education and continued this many years after she left the school. I have sat on the Management Committee of Community Options as the community representative, community representative on the then Docs School Age Therapy Review and cook and shop for elderly neighbours when I know they are unwell. To hear repeatedly "oh you don't work!" is an insult and shows very little appreciation of the real value of our work and its inherent hardships. This may give you some insight as to why long term carers' health, wealth and self esteem are compromised.

Key Priorities - Please desist with policy formation that uses as its bedrock "one size fits all". The Carer Allowance should recognize the more demanding caring roles. Our society values and recompenses higher demands in the workplace – should carers be exempt from this same recognition. Working outside the home should be possible with government help and innovation when the care recipient is mild, moderate or even severely disabled. Please understand that when the care recipient is profoundly disabled and medically frail and the carer is providing high level nursing care from anywhere between 60-100 hours per week it is highly insensitive to insinuate that 'they don't work'. Study should be encouraged for any carer when the care required could span decades. Meaningful tax deduction that reflects the real cost burden on families should be prioritized. I should not have to worry about electricity costs that are incurred as a consequence of moving to a mountain region to be close to a care facility (since closed) and the necessity of open plan home design to facilitate the movement of a very large wheelchair and hoist. The home needs to be warm – my son is stick thin, immobile and has poor circulation. It would be neglect on my part not to run up massive winter heating bills. I would imagine that I am now in the final stages of my caring role and I think it only fair after my contribution government should act on my valid concerns and give me some reassurance that a seamless transition to supported accommodation would be appropriate. Ideally this would take the form of a bed becoming available in our local area (4 group homes that provide for the profoundly disabled are located in my village) and Jonathon gradually staying longer. This would ease the separation pain for all concerned. I have no memory of not being responsible for Jonathon and this responsibility permeates my entire being – I do fear that ceasing this care will be akin to losing a limb.

Catherine