

A.O.C. 30/6/08

## House Standing Committee on Family, Community, Housing and Youth Inquiry into better support for carers

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### Context of this submission

- I am a 47 year old single woman with a young son, working full time as a professional. I have post-graduate management qualifications and would like to continue my studies beyond my current Masters level.
- I try to contribute as a volunteer at Carers NT as a Carers Ambassador and a board member, as well as participate in my own professional member organisations in order to maintain and enhance my knowledge and skills, and have some 'outside' interests.
- I am healthy, fit, financially independent and receive a reasonable income from my work and my investments. I am able to provide for my son and myself. I am generally satisfied with my lot in life. I have much to be grateful for, satisfied with - and I am!
- I care for my frail aged mother who is in her mid-eighties, with physical disabilities, some cognitive impairment, multiple cancer-related ailments; yet who also has a stoic attitude and a determination to manage her challenges and not be diminished by them.
- At the same time, I am very busy, possibly *too* busy and feel balanced on a knife edge. I live with a sense of 'one slip and I'm gone'. If I become ill and can't continue to care for my son and my mother, even for a short time, I have no backups as I live in Darwin away from any family and long-term friends. I live in dread of any event that will either impact on my own capacity to care and earn income, or increase my caring responsibilities beyond what they are at present.

### The role and contribution of carers in society and how this should be recognised

- Review of all legislation to ensure recognition of the role of caring, in terms of inclusion of carers in decision-making about the care recipient, access by carers to information about the care recipient, national consistency across mechanisms such as power of attorney / guardianship / advocate.
- Review of all publicly funded health providers, especially hospitals, to ensure that carers are recognized in the process of service delivery, particularly with respect to admissions, informed consent to procedures / medications, discharge planning, lengths of stay, training of staff, availability of staff to inform / advise carers, scope for carers to remain with the care recipient in hospital where necessary.

### The barriers to social and economic participation for carers, with a particular focus on helping carers to find and / or retain employment

- Carer insurance that is covered by superannuation funds through an additional tax free contribution or some other mechanism, so that there is sufficient additional income for the carer who may be incapacitated and who needs to 'replace herself' in the home until he / she is recovered and able to resume caring duties (either fully or partly). This is particularly for the working carer who may also have other non-carer family responsibilities such as parent of dependent child/ren. A bit like workers'

compensation, for the carer! As a carer, I'm able and prepared to pay for this myself but not all carers are and this should somehow be recognized.

- Greater freedom to salary sacrifice across all sectors, without FBT implications, for additional leave / insurance premiums / superannuation (particularly those making up lost time in super due to extended periods out of the workforce due to caring responsibilities).
- Assistance to set up 'work from home' options so that when needed, carers can continue to work without leaving the home or the care recipient's residence.

### **The practical measures required to better support carers, including key priorities for action**

- Free flu and Hep immunizations to carers and immediate family to minimize risk to the care recipient.
- Bulk billed medical services at general practices for the carer when the matter relates to the care recipient, such as seeking explanation for complex medical problems, medication side effects etc.
- Recognition of the additional costs of housing and utilities arising from the care of a person within the carer's home, possibly through scope to claim tax rebate in a manner similar to that available to working / operating a business from home. These costs are not easily covered by contribution from the care recipient, whose own costs of living can be affected by medical and transport expenses.

### **Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future**

- Protection of a carer's job when there is a need to take extended leave (such as for palliative care purposes, or during the acute and sub-acute stages of an illness of a care recipient e.g. post-stroke) - being able to go back to the same job without discrimination (refer carer insurance above). Provisions similar to those for maternity / parental leave could work.
- Care recipient ownership of aged care packages or places so that the carer does not have to locate in a particular geographical area where the care recipient (especially frail aged) has been allocated a community aged care package / residential care placement. These packages are 'owned' by the providers, and as such, are controlled by other interests that may be in conflict with the best outcomes for the recipient and the carer.
  - For example, fees paid by care recipients are set by the providers and if there is more demand for care packages than there is available in supply, providers can charge the maximum amounts irrespective of the care recipient's capacity to pay. I understand very well the provision of the Act and regulations pertaining to this; however I know that many providers have unwritten policies in place to optimize income and can cream the demand to ensure those with capacity to pay have a priority.
  - This also applies to care recipients with higher needs; these people demand more servicing from a provider, which reduces the provider's profit margins. It is more

attractive for a provider to allocate a package to someone whose needs are low, than it is to someone whose needs are greater. The gap between service capacity (determined by the provider, to include profit margin and other 'indirect costs') and care recipient need is provided by the carer in many cases.

- The type of care services offered by community aged care package providers can be limited to the more traditional 'personal cares' and 'socialisation' that often fail to reflect the individuality of the care recipient and the carer's input. Trying to change a provider when one has a package and can't get the service needed is impossible, if there are no available packages with the alternative provider and if the current provider is not prepared to sub-contract the care.
- Allocating a package in a way so that the care recipient owns it and then chooses, in collaboration with the carer, an appropriate range of services and supports with the assistance of a case manager and funded by the package, could in some cases result in more support being available, and greater flexibility in type of support and scope to relocate to alternative geographical locations. Providers would need to become more competitive in terms of charges and service flexibility, rather than the current arrangement where providers have substantial control. This control impacts significantly on carers. For example, if a carer wanted to relocate to Brisbane or Adelaide in order to pursue a work opportunity or different educational opportunities for a child, she / he would be limited by the availability of aged care services for the care recipient; they would lose the current package, and given waiting lists for packages in those other locations, the option of moving is diminished if not removed altogether.

JANE  
Carer