Submission No. 190

(Inq into better support for carers)

Inquiry into better support for carers.

My husband and I wish to make a submission to this inquiry based on our experiences as carers for his elderly parents in a rural community. His father suffered from Alzheimer's disease and his mother required care following a broken leg and hip and shoulder disintegration.

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

- Public recognition from the government of the importance of carers and of the amount they save the government by their unpaid caring.
- All carers eligible to receive a payment comparable to the Family Tax Benefit
- All carers eligible to receive a discount card similar to the current Seniors Card which would entitle them to travel, medications, incontinence and health aids and other goods at discounted rates. This card should not be means tested.
- Taxation incentives for those carers disadvantaged by tax implications because of changes caused by their caring role.
- Recognise and compensate carers for their increased financial costs in everyday living expenses because of their caring role.

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

Employment:

- It is very difficult for many carers to find or maintain employment unless their employment is home based and even then the time available for their business would be severely curtailed.
- Employment can only be maintained when the caring role is shared and when there is sufficient paid care available to supplement the carer. This is often not the case in rural/remote areas.
- There are also limited flexible employment opportunities available in rural/remote areas.
- There should be full tax deductibility for paid care, whether by a professional or non-professional, needed while the carer is at work.
- Carers should not be placed under pressure to find and/or maintain employment and should be eligible for full government support without having to look for work. The Carers Payment should be equal to the Newstart Allowance.
- It is very difficult for self-employed people to continue their employment because they often do not have others able to take over their job, or sufficient staff to cover necessary absences

We had been self employed but were fortunate that we had closed our business (for other reasons) just prior to our parents needing an increased level of care. We would not have been able to run our business and provide the level of care needed. Social:

- More provision of respite hours both daytime and overnight so that the carer can maintain his/her involvement in activities of choice for themselves. This is necessary to the emotional wellbeing of the carer.
- Encourage carers to maintain their social networks recognise the importance of this and provide financial assistance to enable the carer to meet any additional costs incurred.

Transport:

- It is more difficult for the carer and the person requiring care to access public transport or even to continue with private transport in some cases.
- There should be some reimbursement available where the carer has to upgrade their vehicle to meet the needs of transporting the person needing care.
- In rural/remote areas transport can be difficult if the person now requiring care was the primary driver as there are not many alternatives available
- Reimbursement needs to be available for the costs involved in travelling to all medical appointments, not just specialists, and this needs to be indexed to cover rising fuel costs etc. The paperwork for these claims also needs to be simplified a set amount could be given to all carers with opportunity to claim higher costs where necessary.

The practical measurers required to better support carers, including key priorities for action;

Priority 1 Financial Support

- An overhaul of the system of government benefits to give greater flexibility, recognising the hidden costs of caring.
- Discount card giving same benefits as Seniors Card
- Realistic compensation for travel to medical appointments, including medical tests and surgical procedures.
- Consider the specific differences in financial support needed depending on the circumstances whether the person receiving care is a child, young adult, frail elderly, dementia etc. and recognising that not "one size fits all"
- More flexibility in financial support during transition stages e.g. child to young adult, one to both partners needing care
- Investigate a way of paying the carer for dealing with the financial affairs of the person they are caring for, especially when these are complex such as for self-funded retirees. Some form of tax deductions should be available either for the carer or the person being cared for.
- If the person being cared for is in a financial position to pay the family member providing care, this be taxable income for the carer and a tax deduction for the person receiving the care.

Priority 2 Social Support

- More provision for respite care at all levels
- No financial penalty for carers who take a short break from their caring role
- Reimbursement of travel costs for non-residential carers
- Carers need a support person to talk to about the stresses and demands of their role, preferable in person, not just via a telephone link-up, and opportunity to meet together away from the caring environment

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.

- Assistance in planning for the future obtaining power of attorney etc. as early as possible
- Financial support including subsidies so the carer has funds for their own needs when their caring role ceases, especially if they have had to give up work, access superannuation and have used up their personal savings
- Assistance and support, both with information and emotional support, when moving between at home care and residential care options
- Continuing support for the carer once the person they care for is in residential care the caring role changes but does not stop. Residential care providers need to include the carer in their management plans recognising the knowledge and experience of the carer with the client.
- Counselling available for carers to help them cope with all aspects of the caring role, especially transitions from one level of care to another when the carer may be dealing with feelings of guilt, anger, inadequacy etc.

Summary

These comments are based on some of the experiences we have had as carers. We were probably in an unusual situation where the parents we cared for were financially independent and received no government pensions or allowances but it was difficult for us as carers, who were not in the same financial position, to receive compensation for our expenses and reduced employment opportunities.

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