

Submission of recommendations to the Productivity Commission Inquiry

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The document acknowledges the importance of the support informal carers provide both to the care recipient and to formal care networks. It advocates the need to provide more support to informal carers so they can maintain their role! However there is no direction in how the system will achieve this much needed support.

The following recommendations are based on findings from our research involving the investigation of caregiving in the context of frailty in older persons.

Trial Registration: Australian New Zealand Clinical Trials Registry: ACTRN12608000565347

Carer Assessment

The challenge is to identify carers who may be at risk of negative caregiving reactions and provide timely and appropriate support services. However, in order to provide caregiving support, carer assessment is vital. Assessment of the caregiving situation and the needs of individual carers will ensure they receive flexible and quality support services. Currently, carers of frail older people in Australia are not routinely or individually assessed (Carers Australia, 2008). Rather, their well-being may be taken into consideration when their care recipient is assessed by an Aged Care Assessment Team (ACAT) for eligibility for aged care services. The recent State legislation entitled the "Carers Recognition Bill" is a step forward for all carers. This legislation provides carers with a right to an individual assessment.

Regular home based respite

We also recommend that the provision of regular home based respite for carers be more readily available, rather than the current intermittent residential respite care. This home respite will allow carers to maintain or pursue their usual activities, such as caring for their immediate family,

employment, social commitments and relaxation. Currently, residential respite care and financial assistance are the main government initiative to support carers. However, only 27% of carers eligible to receive respite (i.e. their care recipient has been assessed by an ACAT) have taken up the support of the service (Australian Institute of Health and Welfare, 2009) with only small numbers of carers satisfied with the service (Parker, Mills, & Abbey, 2008). Our experience suggests that respite is usually offered or taken up when a caregiving situation has reached crisis and one common reason for not utilising the service a second time is that the older person returns home confused and often incontinent, the carer is physically exhausted from visiting (usually daily, especially by a spouse) and mentally drained from feelings of guilt. It would appear that respite in the form that it currently exists (residential respite) does not improve or relieve negative reactions to caregiving for most carers.

Targeted health care initiatives

Regular carer support services and targeted health care initiatives, particularly those that focus on carers' health status and the promotion of positive health behaviours, may improve carer energy levels and their physical ability to provide care and they may alleviate or lessen negative reactions associated with caregiving such as depression.

Carer support services after placement in a residential aged care facility and in bereavement

Even when a carer can no longer care for a loved one at home their caregiving experience is not over, and carer support services may still be required. However, the carer is often forgotten by the government and health care professionals who relied upon their support to maintain the frail older person's independence in the community. For example, an older woman caring for her husband informed us that her husband had been admitted to a residential aged care facility, following a stroke. She was very distraught, they had known each other for 72 odd years, and had been married for 60 years. She was now alone in the family home, with a big dog, on a single pension; her carer allowance had also been terminated. She continued to visit her husband every day, travelling there by bus; she washed his clothes and fed him most meals. Her visits would often end in tears because due to his stroke, her husband had become abusive.

As a result of our ageing society, the profile of carers of community living frail older people is greater than ever. In terms of keeping older people independent and in the community, the health and well-being of carers is just as important as care recipient health status. In order to keep carers healthy and well supported they require assessment of their caregiving reactions, regular carer support services and targeted health care initiatives.

Australian Institute of Health and Welfare (2009) Dementia and the take-up of residential respite care. Bulletin no. 78. Cat. no. AUS 124. Canberra: AIHW.

Carers Australia (2008) Submission to the House of Representatives. Inquiry into Better Support for Carers. Canberra

Parker D, Mills S & Abbey J (2008) Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review, *International Journal of Evidence Based Health*, 6:137-172.