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# Impact of home based long term care on informal carers

## Background

Well coordinated and integrated home based care is an efficient and cost effective model for providing long term care. There is, however, emerging evidence to suggest that family members pay a price for taking on long term care responsibilities at home.

## Objective

This article draws on published literature to provide an overview of the health, economic, and social issues faced by informal carers. The objective is to contribute to the knowledge base of clinicians about the impact of chronic disease and disability on families taking on the care responsibility in a home environment, thereby informing the delivery of best practice.

## Discussion

In 2006, there were approximately 632 694 primary carers aged 15 years or more in Australia. These carers collectively have the lowest level of wellbeing scored by any group, and compared to the general population have a significantly higher level of depression, were more likely to experience physical pain, and more likely to experience financial stress. Failure by clinicians to recognise the burden on informal carers may result in long term adverse outcomes for this group that may outweigh the benefits of managing people with disability and chronic illness in the community.

■ **As providers of health care to the frail, elderly and the sick, clinicians need to be aware of the issues faced by families affected by chronic disease and disability. Well coordinated and integrated home based care has been recognised to be an efficient and cost effective model for providing long term care.<sup>1,2</sup> While caring for a loved one in the home environment can be a rewarding experience, this model places heavy reliance on family members to coordinate, provide and ensure access to required care. It is now becoming evident that the benefits of such home based care are achieved at a cost to the informal carer.**

## The profile of carers

In 2006, there were an estimated 632 694 primary carers in Australia aged 15 years or more. A primary carer is considered to be someone who is primarily responsible for the home based care of an elderly person, or a person with a long term health condition or disability.<sup>3</sup> While the majority of these primary carers were between 30–64 years of age, the elderly were over-represented in the carer population, with over a quarter of primary carers being 65 years of age or more. Over 60% of primary carers were women.<sup>3</sup>

The most frequent relationship of the care recipient was a partner/spouse, while a quarter of those with primary carer responsibilities cared for a child with a disability.<sup>3</sup> Assuming an hourly wage of \$25.01, the cost of replacing the care provided by all informal carers for the year 2005 was conservatively estimated at approximately \$30.5 billion.<sup>4</sup>

## Their health and wellbeing

A recent Australian study has identified that carers have the lowest level of collective wellbeing of any group studied, with female carers experiencing lower level of wellbeing compared to their male counterparts.<sup>5</sup> Using the Personal Wellbeing Index (PWI), which was developed by a partnership between Deakin University and Australian Unity, carers were compared with other groups who report wellbeing levels below the normal range of 73.4–76.4, such as unemployed people and people on very low incomes living alone. On a score ranging from

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0–100, carers collectively scored the lowest score recorded at 58.5. Carers who were sole parents caring for a child with special needs fared the worst, as did carers who were not in the labour force.<sup>5</sup> Lower levels of wellbeing among carers compared to the general population were observed among all age groups (18 years of age or more).

These findings, reported by Cummings et al,<sup>5</sup> add a quantitative aspect to earlier reports of the negative effects experienced by carers. In a national survey of carers conducted in 1999, 67% of all carers reported that the caring role had directly impacted on their mental and emotional wellbeing.<sup>6</sup> Analysis of the 2003 Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics<sup>7</sup> shows that a significantly higher proportion of primary carers rate their health as being fair or poor compared to other people of the same age in the Australian population (*Table 1*). The higher proportion of primary carers reporting fair or poor health is seen across all income gradients.<sup>3</sup>

Carers have a significantly higher level of depression compared to the general population. A survey using the Depression Anxiety Stress Scale (DASS) of over 4000 carers determined that carers had a mean score of 38.3 (indicative of moderate depression) and that over half (56%) were at least moderately depressed; only 35% of respondents were not depressed. In contrast, just 6% of the Australian population is depressed.<sup>5</sup>

A higher proportion of carers compared to the general population report experiencing physical pain; on a pain scale of 0–10, only 25% of carers report being pain free or experiencing no more than mild pain (scoring  $\leq 1$ ), compared to 50% of the general population. The 12 point difference in wellbeing between carers and the general population at the low end of the pain scale ( $\leq 1$ ) gradually increases to become a 20 point difference at the high level of the pain scale,<sup>8</sup> suggesting that carers are less resilient in responding to additional stresses such as pain compared to the general population.<sup>5</sup>

Experiencing a physical and mental health condition was associated with lower levels of wellbeing for carers compared to the general population. Lack of time and not being able to afford the care were identified as the main reasons for carers not accessing health care for themselves.

### Their financial status

According to Cummins et al,<sup>5</sup> 'carers are twice as likely as is normal to worry that their income will not be sufficient to meet their expenses'. Around 30% of families receiving carer benefits experience difficulty in paying utility bills compared to 15% of the general population.<sup>8</sup> This is not unexpected, given that the average household income of a carer is much less than that of the general population.<sup>5</sup>

Recognised causes of lower income in households where there are

Table 1. Proportion of primary carers reporting fair or poor health, by age group

Age (years)	Primary carers (%)	Australian population (%)	p value
15–49	19.7	2.9	<0.001
50–64	30.1	11.9	<0.001
65+	32.1	18.4	<0.001

Source: Australian Bureau of Statistics, 2003 Survey of Disability, Ageing and Carers

informal carers include loss of earning capacity of the person affected by chronic illness or disability, increased medical expenditure, and the cost of home modifications and/or disability equipment.<sup>9</sup> A less recognised but significant cause is that primary carers in general have lower rates of full time employment participation rates, with just 19% in full time employment compared to an age and gender standardised Australian average of 42%.<sup>4</sup> Carers who are in the paid workforce are more likely to work part time, with 22.8% of primary carers working part time compared to the Australian average of 17.2%.<sup>4</sup> Female primary carers aged 30–64 years work about 11 hours per week on average, compared to about 20 hours per week for age matched women who are not carers.<sup>3</sup>

Under current Australian government policy, primary carers not in paid employment can receive a means tested carer payment of up to \$537.70 per fortnight for a single person (or up to \$449.10 for each person in a couple). An additional non-means tested carer allowance amount of \$100.60 per fortnight is available to primary carers of people with special needs. Given that these payments are less than the current minimum wage of \$1044.24 per fortnight,<sup>10</sup> it is not surprising that carers are experiencing high levels of financial stress.

Equally significant is the fact that due to their reduced ability to participate in the paid workforce, carers are less able to invest toward their retirement, resulting in long term reliance on the government to meet their needs in retirement. Advances in medical management have resulted in longer life expectancies for people affected by chronic disease or disability. Consequently, primary carers of high care needs children in particular, may never have the opportunity to return to the workforce and/or participate in further education opportunities. This is clearly evident from a recent modelling exercise which identified that, on average, single parent mothers aged 30 years who do not have postsecondary level education and care for a child with disability will, at the age of 65 years, have a superannuation fund of no more than \$25 000.<sup>3</sup> These mothers are likely to be dependent on government benefits to support them through the increased health problems that they are likely to experience in their senior years.

### Social isolation and impact on family

Individuals and families caring for someone with high care needs at home often feel isolated as a result of not having the time to socialise and restrictions on their ability to go out; in the case of caring for a partner/spouse, carers often feel isolated because of the loss of their companion and the relationship.<sup>11</sup> Family are also likely to miss out on

the usual family experiences due to the increased demands associated with being a primary carer.<sup>8</sup>

### Other issues

Confounding the measurable effects of caring is the fact that carers are frustrated with government bureaucracy.<sup>11,12</sup> There is anecdotal evidence – such as that presented in 2008 to ACT Legislative Assembly candidates, and the 7.30 Report aired on ABC on 1 October 2008<sup>13</sup> – that carers have to deal with an inflexible, inefficient, bureaucratic system that has lost touch with the issues faced by families affected by disability. Carers have no choice but comply with these requirements to ensure continuing support, adding to the demands of being an informal carer.

### Conclusion

An aging population, together with increasing levels of chronic illness and disability among the Australian population, mean that considerable health care resources are being spent on managing people with long term care needs in the home environment. In managing such patients, clinicians must take into consideration the significant impact that the care responsibility has on families. Without such consideration, there is the potential that the poor health and high levels of ongoing financial stress experienced by carers will not only result in greater health needs as the carers move into their senior years, but also leave them with little resources to buy the health care that they may themselves need in the future. Consequently, the benefits gained by shifting long term high care to the community can potentially be counteracted by the high cost to the government of supporting the carers for the rest of their lives. Ensuring the wellbeing of carers also means that the care recipients continue to receive the best possible care, thereby ensuring better outcomes all around.

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