

The Impact of caring for a person with Dementia

Dementia in Australia - Australian Institute of Health and Welfare 2012

Relationship of carer to care recipient

According to the 2009 Australian Bureau of Statistics' (ABS) *Survey of Disability, Ageing and Carers* (SDAC) data, the most common relationship between the co-resident primary carer and the person with dementia was a spouse or partner caring for the other (57%). Just over one-third (36%) of primary carers were the son or daughter of the person with dementia, and 7% were another relative, friend or neighbour. Female primary carers were more likely than male primary carers to be the spouse or partner of the care recipient (58% and 53% respectively).

Impact of the caring role on carers

Caring for a person with any type of disability or chronic condition can be physically, mentally, emotionally and economically demanding, but existing research suggests that the burden of caregiving is particularly high for those caring for a person with dementia (Kim & Schulz 2008, MetLife 2006). Many factors may affect the level of caregiving burden, including personal characteristics of carers and care recipients, living arrangements, employment and financial situation, and the level of support available from formal services and other family and friends (Kim & Schulz 2008).

Relationships

Being a primary carer can affect not only the relationship of the carer to the care recipient but also the carer's relationship to others. As shown in Table 1, primary carers of people with dementia were more likely than primary carers in general to report that the caring role had placed strain on their relationship with the care recipient (34% and 17% respectively), and less likely to say the caring role had brought them closer together (19% compared with 31%). A similar proportion indicated that there was no change in their relationship with the care recipient.

Primary carers of people with dementia were more likely than all primary carers to indicate they had lost touch (or were losing touch) with existing friends due to the caring role (39% and 23% respectively), and they were less likely to say there had been no change (37% and 54%).

Physical and emotional wellbeing

According to the SDAC, adverse physical or emotional effects of the caring role on the primary carer of a person with dementia included feeling weary or lacking in energy (reported by 34%), and frequently feeling worried or depressed (33%). Table 1 shows the range of physical and emotional impacts of caring for a person with dementia.

The data also indicate that a higher proportion of primary carers of people with dementia (57%) reported one or more of these adverse effects compared with primary carers in general (48%).

Primary carers were also asked about sleep disturbance due to the caring role. Among those caring for a person with dementia, about 66% of co-resident primary carers reported some extent of sleep disturbance. This was a higher proportion than reported by co-resident primary carers generally (49%). Not only were primary carers of people with dementia more likely to have their sleep interrupted, this also occurred more frequently than it did for primary carers generally. For example, 34% of primary carers of people with

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dementia reported having their sleep interrupted frequently compared with 24% of all primary carers.

Table 1 also provides information from the SDAC on how satisfied primary carers felt due to their caring role. About 19% felt satisfied, but 73% reported that they did not. Similarly, 21% of all primary carers felt satisfied due to the caring role, while 69% did not.

Table 1: Physical and emotional effect of caring role on primary carers of people with dementia and all primary carers of people living in the community, 2009 (per cent)

	Primary carers ^(a) of people with dementia	All primary carers ^(a)
Adverse effects due to caring role^(b)		
Feel weary or lack energy	34.3	32.9
Frequently feel worried or depressed	33.2	30.1
Diagnosed with stress-related illness	*10.3	11.3
Frequently feel angry or resentful	*14.7	12.1
Not stated	*7.9	10.0
<i>One or more of the above adverse effects</i>	57.2	48.2
Total	100.0	100.0
Sleep disturbance due to caring role		
Sleep interrupted frequently	34.0	24.2
Sleep interrupted occasionally	32.4	24.4
Sleep not interrupted	26.6	42.0
Other ^(c)	*7.0	9.4
Total	100.0	100.0
Satisfaction due to caring role		
Feels satisfied	18.7	20.9
Does not feel satisfied	73.4	69.1
Not stated	*7.9	10.0
Total	100.0	100.0
* Estimate has a relative standard error of 25% to 50% and should be used with caution.		
(a) These SDAC data pertain to <i>co-resident</i> primary carers and thus exclude those living in a different household.		
(b) The sum of the adverse effects may exceed the total since any one primary carer could report multiple adverse effects.		
(c) Included 'Not stated' and 'Sleep interrupted but frequency not stated'.		
Source: AIHW analysis of the ABS 2009 Survey of Disability, Ageing and Carers confidentialised unit record file.		

Primary carers of people with dementia provided assistance with at least one core activity of daily living. Specifically, 92% provided assistance to the care recipient with mobility, 85% with self-care and 79% with communication.