

# Caring for families caring for a person with a disability

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“When you’re a carer, you need to realise that you’ve got to take care of yourself.” Naomi Judd (2004)

In Australia, it is estimated that there were 474,600 primary carers for people because of disability or age in 2003 (Australian Bureau of Statistics [ABS], 2003). The issue is of particular importance given the growing number of Australians who have caring responsibilities because of the ageing of the population. The number of people receiving government payments that support carers is substantial. In June 2007, there were 116,614 people receiving Carer Payment and 393,263 receiving Carer Allowance,<sup>1</sup> representing a 145% and 102% increase (respectively) since June 2000 (Department of Family and Community Services [FaCS], 2000; Department of Families, Community Services and Indigenous Affairs [FaCSIA], 2007).

While a great deal is known about the impact and contribution of carers in society, much less is known about how the carer and other family members work together to care for a relative with a disability. For practitioners working in the family relationships sector, assisting carers and their families to care for the person with a disability and themselves can be a difficult task, as caring can impact on many aspects of the lives of carers and their families.

In this article, I highlight some key findings from new research conducted by the Australian Institute of Family Studies (AIFS) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) about the nature and impact of caring on the carer and their family in order to broaden practitioners understanding of these issues (for details, see Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008).<sup>2</sup> Although I draw on findings from the study’s report, the views expressed in this paper should not be attributed to either FaHCSIA or AIFS. In the final section of this article, I provide a range of resources for practitioners to draw upon to support carers and their families.

The Families Caring for a Person with a Disability Study (FCPDS) investigated the impact of caring for a person with a disability<sup>3</sup> on carers who received government payments to care, and on their families. In late 2006, AIFS conducted a telephone survey on a representative sample of 1,002 carers from among carers receiving federal government payments. This is the first detailed, nationally representative analysis looking into the lives of families providing care.

## Emotional, physical, relational and economic costs of caring

The major findings from the study suggest that, while caring for a person with a disability is very important, there are significant emotional, physical, social and economic costs to carers and their families. Some key findings from the study are highlighted below.

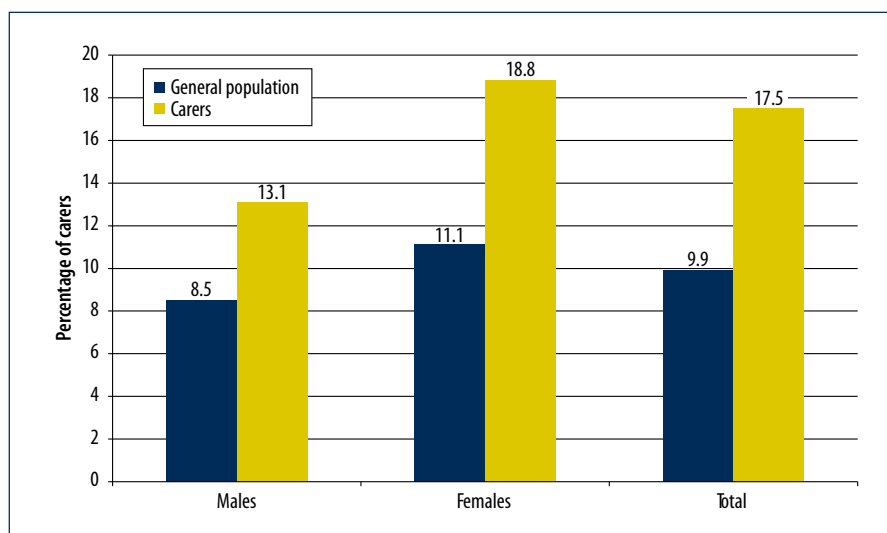
### 1. Carers had significantly worse mental health and vitality and higher rates of depression than the general population.

Differences between carers and the general population on these variables were evident for carers of all age groups, except when carers were 65 years or older. The rates of clinical levels of depression were 19% for female carers and 13% for male carers, while for females and males in the general population they were 11% and 8% respectively (see Figure 1). Fifty-one per cent of female carers and 30.7% of males also reported that they had been depressed for 6 months or more since they started caring. Family members also experienced high levels of depression, with 27.3% of partners, 12.1% of parents and 10.6% of offspring of carers experiencing a depressive episode of 6 months or more since caring began (see Figure 2).

1 *Carer Payment* is an income support payment available to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation. Like other income support payments, Carer Payment is targeted at those most in need. It is subject to income and assets tests and is paid at the same rate as other social security pensions. At 20 March 2008, the maximum single rate of Carer Payment was \$546.80 and the maximum partnered rate was \$456.80 per fortnight. Income testing arrangements mean that carers who participate in the workforce may have their Carer Payment reduced when their income level reaches a prescribed level, and the payment can stop altogether if the carer earns more than the upper level of the income test. *Carer Allowance* is a supplementary payment available to people who provide daily care and attention in a private home to a person who has a disability, severe medical condition or who is frail aged. Carer Allowance is not taxable or subject to an income and assets test. It can be paid in addition to Carer Payment or other social security income support payment. At 20 March 2008, the rate of payment was \$100.60 per fortnight.

2 This report is available online at [www.aifs.gov.au/institute/pubs/resreport16/main.html](http://www.aifs.gov.au/institute/pubs/resreport16/main.html)

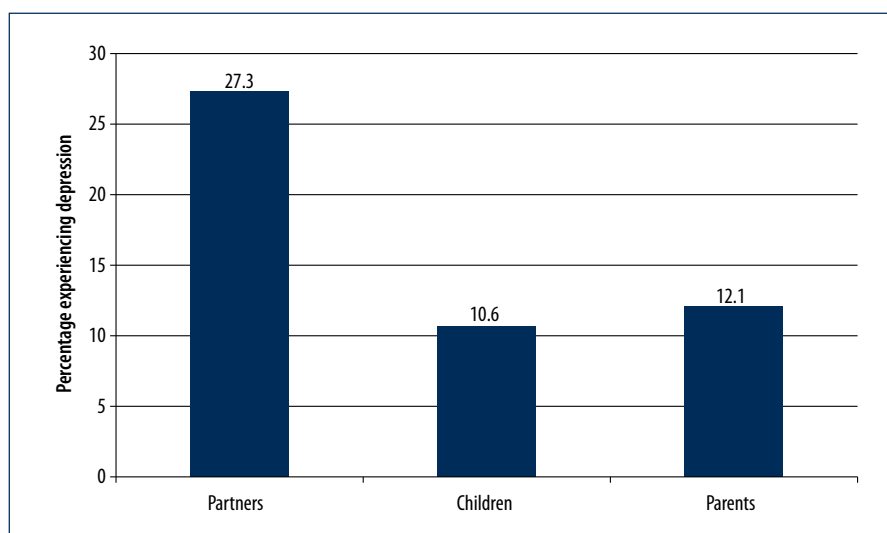
3 In the FCPDS, close to half of the people with a disability had some form of physical disability (47.4%), and 14.5% were in the multiple disability category. Sixteen per cent of people with a disability had an intellectual/learning disability, while 11.2% had a psychiatric disability. Only 4.9% of people with a disability had a sensory or speech impairment, and 2.8% had acquired brain injury.



Notes: The incidence of clinical levels of depression in the past 4 weeks was also significantly higher for male and female carers than males and females with no caring responsibilities (males:  $\chi^2(1) = 5.84, p < .05$ ; females:  $\chi^2(1) = 39.18, p < .001$ ).

Source: FCPDS 2006; Household, Income and Labour Dynamics in Australia (HILDA) survey, Wave 4.1

**Figure 1: Clinical levels of depression over last 4 weeks, by gender and caring status**



Note: More partners experienced a depressive episode than children and parents of the primary carer ( $\chi^2(2) = 93.67, p < .001$ ).

Source: FCPDS 2006

**Figure 2: Family members' experience of depression**

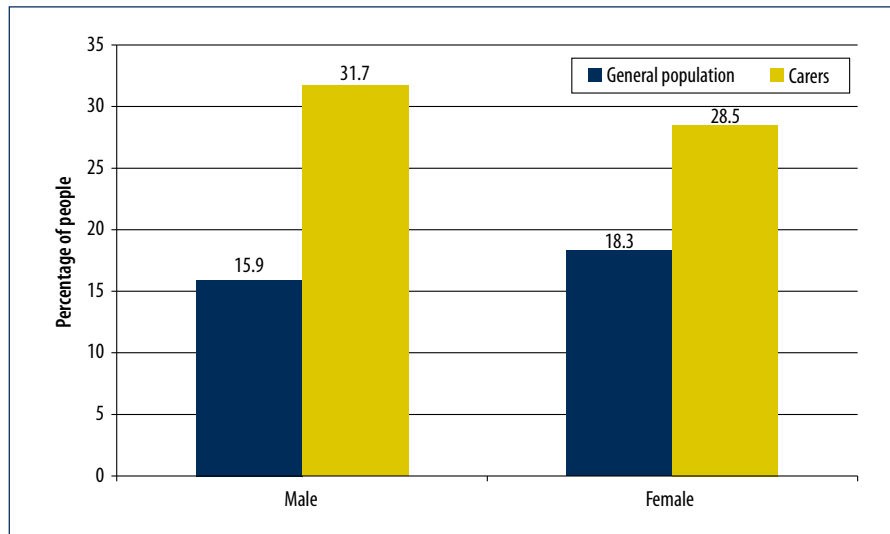
## 2. The risk of carers and family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring.

The risk of carers experiencing a first depressive episode of at least a 6-month duration was greatest in the first year of caring (over 13% of carers), but over the next 20 years the risk was fairly stable at about 3%.<sup>4</sup> Carers were also asked about the experience of depressive episodes of other family members. For other family members, the first year of caring accounted for 41.6% of all the first depressive episodes experienced by people with a disability and 17.9% of first depressive episodes of other household members. In this context, early intervention is important in the first year of caring, and thereafter a less intensive but easily accessible intervention may be more appropriate. The early intervention may need to be intensive, given our data on the interconnections between carers and other family members' mental health. It probably would need to address relationship issues such as poor family functioning, for instance, as this variable had moderate associations with higher rates of depression within the family.

<sup>4</sup> In the FCPDS, 26% of carers had been caring for 13 years or more, and 6% for 20 years or more. Carers' experiences of a depressive episode were asked about retrospectively over the entire period of care.

### 3. Almost twice as many carers were in poor physical health than the general population (see Figure 3).

The finding that almost twice as many carers were in poor physical health was not the result of carers being older than the general population. As many of the risk factors for poor physical health were the same as for poor mental health of carers, a coordinated bio-psychosocial intervention may best meet the needs of carers and their families.



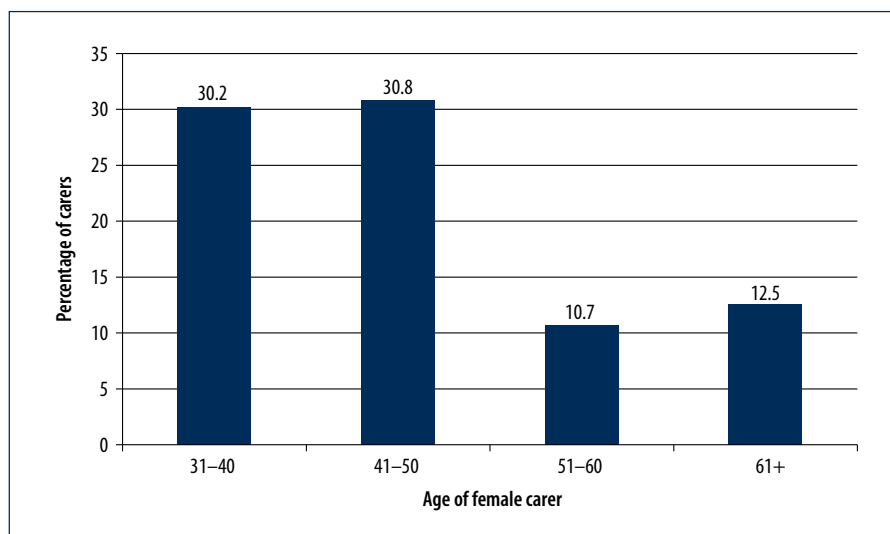
Notes: A greater proportion of female carers were in poor physical health than females from the general population ( $\chi^2(1) = 45.30, p < .001$ ). A greater proportion of male carers were in poor physical health than males from the general population ( $\chi^2(1) = 38.66, p < .001$ ).

Sources: FCPDS 2006; HILDA Wave 4.1

**Figure 3: Incidence of poor physical health, by gender and caring status**

### 4. Almost one in three female carers aged 50 or less had separated or divorced since they started caring, while one in seven over the age of 50 had separated or divorced since they started caring (see Figure 4).

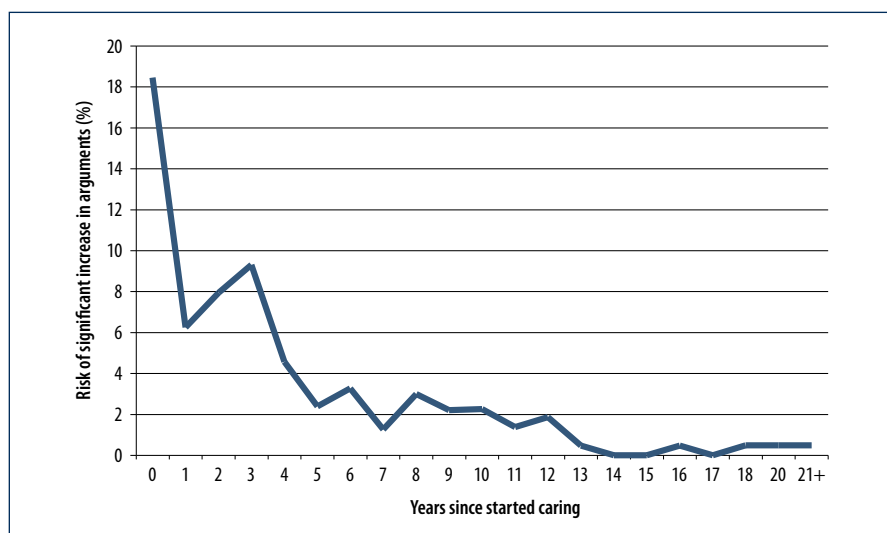
The study also provides new information on the timing and risk of increased arguments and relationship breakdown between carers and their partners since caring began. There was a heightened risk of arguments between carers and their partners shortly after commencement of caring (see Figure 5), but an even distribution of the risk of relationship separation over time. The first year of caring seems to be the critical period when additional support may reduce arguments between spouses. The provision of care for a person with a disability did not affect carers' satisfaction with their relationships with other family members. However, carers' children did not get along as well with one another when compared to the general population.



Note: Female carers of a person with a disability who was not their partner ( $n = 396$ ). Although there was a very high rate of separation for carers aged 18 to 30 (55.6%), this should be regarded with caution, due to the small sample size ( $n = 18$ ); however, the other rates were robust.

Source: FCPDS 2006

**Figure 4: Relationship separation of female carers, by age group**

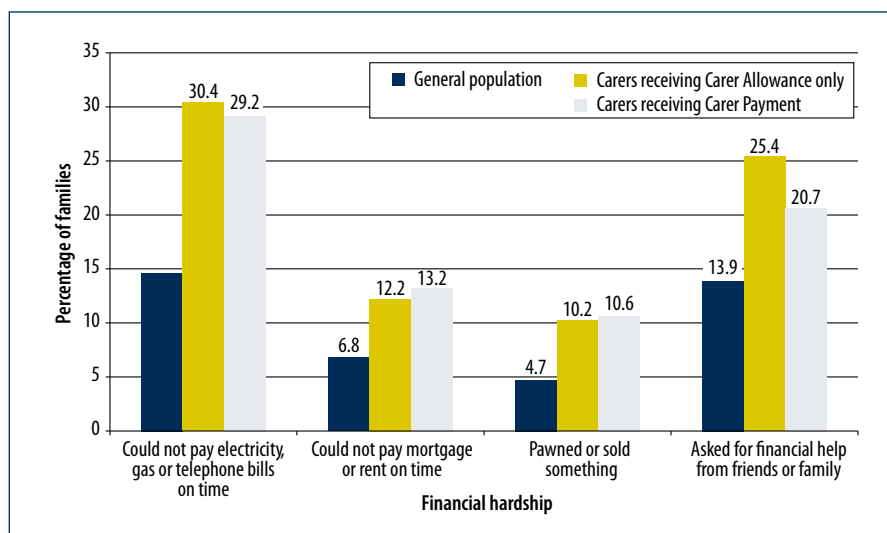


Note: The data presented are based on 431 carers who (a) were not caring for a partner with a disability; and (b) had at any stage had a spouse/partner.  
 Source: FCPDS 2006

**Figure 5: Reports by carers not caring for a partner of significant increase in arguments, by years since started caring**

**5. Compared to families from the general population, a higher proportion of families of carers suffered from greater financial hardship (see Figure 6).**

Irrespective of which payment carers received (Carer Payment or Carer Allowance only), families who cared for a person with a disability experienced a higher level of financial hardship than the general population. Higher levels of financial hardship are a key factor in the higher rates of depression and lower levels of face-to-face social contact that carers experience (see Edwards & Higgins, 2008; Edwards, Higgins, & Zmijewski, 2007). For practitioners, this presents a challenge, as carers and their families may require intensive support and further referral to additional services. Balancing the welfare of carers and their families with the family budget is a key concern.



Notes: In this instance, the data for carers from the FCPDS have been weighted by gender and age to match the gender and age characteristics of the general population in HILDA Wave 4.1. Statistical tests suggested that, compared to the general population, significantly higher percentages of households caring for a person with a disability “could not pay electricity, gas or telephone bills on time” ( $\chi^2(2) = 161.40, p < .001$ ), “could not pay the rent or mortgage on time” ( $\chi^2(2) = 43.38, p < .001$ ), “pawned or sold something” ( $\chi^2(2) = 59.60, p < .001$ ) and “asked for financial help from friends or family” ( $\chi^2(2) = 80.01, p < .001$ ).

Sources: FCPDS 2006; HILDA Wave 4.1

**Figure 6: Financial hardships in carers' families, by type of hardship and caring responsibilities**

**6. Carers who had multiple care responsibilities or who were also caring for children had worse mental health outcomes.**

Thirteen per cent of primary carers cared for two or three people with a disability. In addition, one in three (34.7%) cared for at least one child along with the person with a disability (who could also be a child). Caring for more than

one person with a disability and/or caring for a person or child with a disability while caring for other children were associated with carers having significantly worse mental health outcomes.

## Caring and social isolation

Social isolation is another key issue for carers. In this section, we report on the social lives of carers and the barriers to face-to-face social contact (see Edwards et al., 2007, for details). The key findings are outlined below.

### 1. Eighteen per cent of carers have face-to-face social contact with friends or relatives outside of the household once or twice every 3 months, or less often than this.

In the general population, significantly fewer people (10.2%) have similarly low levels of face-to-face social contact with friends or relatives not living with them. One of the limitations of making this comparison is that carers may be systematically different to the general population on a range of other variables, which may, in turn, be associated with their level of face-to-face social contact. However, even after controlling for many demographic variables, carers from the FCPDS were still 1.46 times more likely than the general population to have low face-to-face social contact with friends or relatives outside of the household.

### 2. Almost half of interviewed carers wanted more face-to-face social contact when asked whether they would like to get together with friends or relatives outside of the household.

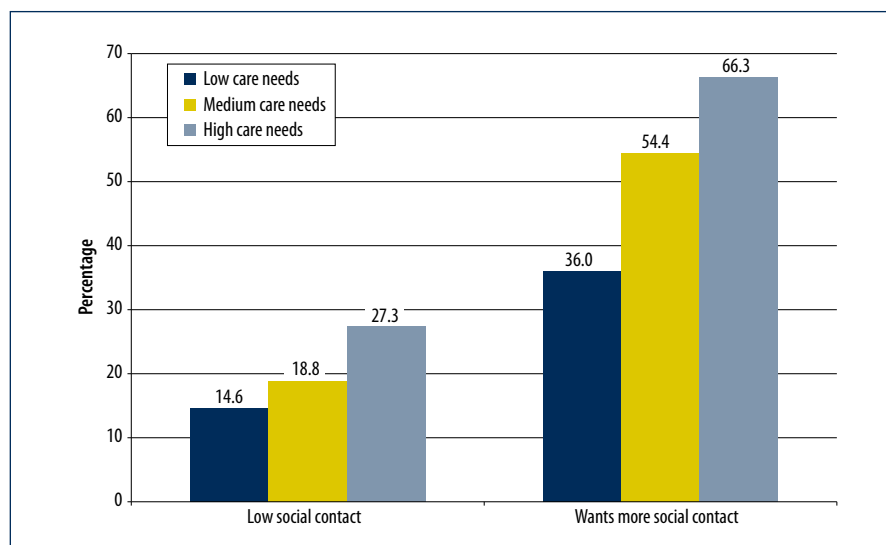
While almost half of the carers wanted more, half were satisfied with the level of face-to-face social contact. Only 2% wanted less social contact.

### 3. There were two main factors associated with carers who had low levels of face-to-face social contact and those who wanted more face-to-face social contact: the care needs of the person with the disability and financial hardship.

Carers who were caring for a person with a disability with high care needs were 1.9 times more likely to have low face-to-face social contact and 2.7 times more likely to want more face-to-face social contact than carers of a person with low care needs (see Figure 7). Compared to carers who did not experience any financial hardship events, carers who experienced two or more financial hardship events were 2.5 times more likely to have low face-to-face social contact and 1.9 times more likely to want more face-to-face social contact (see Figure 8).

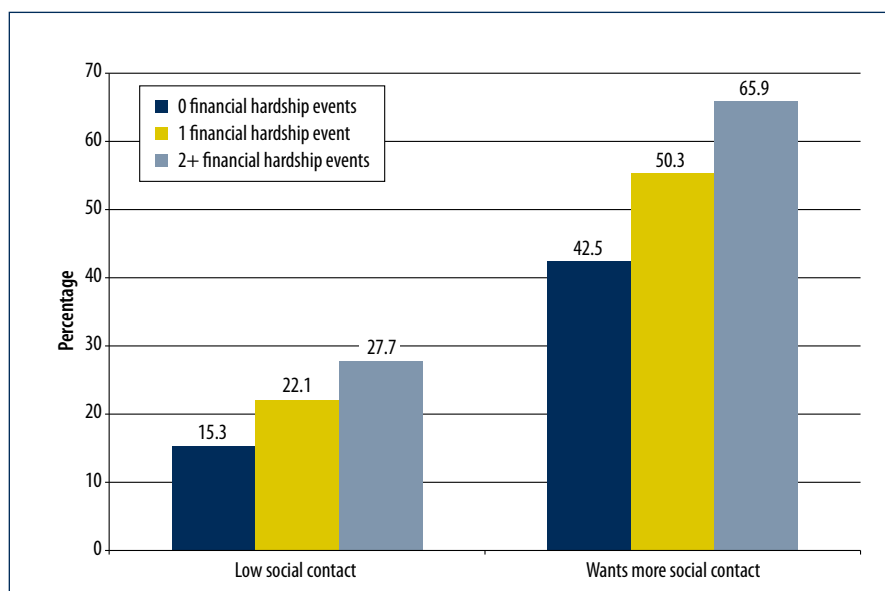
**Carers who provide care for people with more complex and difficult disabilities struggle to find suitable alternative care arrangements to allow them to get out and socialise.**

These findings suggest that carers who provide care for people with more complex and difficult disabilities struggle to find suitable alternative care arrangements to allow them to get out and socialise. On the basis of these results, it also seems reasonable to suggest that the experience of financial hardship may limit the ability of carers to see friends or relatives outside of the household, as socialising may require carers to be able to meet the costs of either catering for visitors or the costs of going out (transport, a meal or other social activity, and the potential costs of providing alternative care in their absence). Saunders (2006) has documented the higher levels of financial hardship experienced by Australian households in which there is a person with a disability, and one interpretation of our results suggests that carers could be responding to such financial hardship by limiting social outings in order to reduce costs.



Source: FCPDS 2006

**Figure 7: Carers' face-to-face social contact with friends and relatives outside of the household and the care needs of the person with the disability**



Source: FCPDS 2006

**Figure 8: Carers' face-to-face social contact and the experience of financial hardship**

## Supporting carers

In our study, 47.9% of carers indicated that they, the person they cared for and other family members did not use any disability service (Edwards et al., 2008). The study did not provide information about why this group of families did not use any services and highlights the need for practitioners to find ways of engaging with some of these families. However, one in ten carers reported their families used some form of psychological service, such

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as counselling, a psychiatrist or a psychologist. Respite services (13%) and consulting a general practitioner (11%) were the other commonly used services by these families. Given the challenges facing some carers and their families, the use of these three services highlights that it is unlikely that family relationship practitioners are appropriate support providers for all issues. A coordinated effort from medical practitioners, specialist support providers and services may be indicated in some instances. One of the key issues for family relationship practitioners is referral to appropriate support services or providers for problems outside the scope of their role and expertise. Carers Association Victoria (2005) recommends many things that family relationship

practitioners can do, such as:

- Provide support in a way that acknowledges that a carer has first-hand knowledge of the person being cared for.
- Consider the needs of the carer as well as those of the person being cared for.
- Consider cultural and language differences, especially in relation to assessment, treatment and information.
- Try to maintain open and honest communication.
- Don't assume a person may automatically provide care without any back-up support or resources.
- Consider the impact of the disability or illness on all the family members and their relationships with each other.
- Keep well-informed of appropriate services and other helpful resources that may be of benefit to the care.
- Respect the privacy of a carer's home.
- Try to let the carer and their family know in advance about changes in your service, such as staff leaving or roster changes.

## Conclusion

In this article, I have drawn attention to research that highlights that caring can have a negative impact on carers' physical and mental health, relationships, social contacts and financial wellbeing. Understanding the extent and impact of caring and how families structure themselves around the care needs of individuals provides an important insight into the future needs of families. It can also inform the ways in which family relationship practitioners can continue to address these issues to improve the wellbeing of all families and individuals who are giving care, and those who are needing care.

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### Resources for carers and their families and family relationship practitioners

- **Carers Australia** ([www.carersaustralia.com.au](http://www.carersaustralia.com.au)). The carers associations in each state and territory provide carers with referrals to services and practical written information to support them in their caring role. There is a wide range of information and resources available and carers can contact their nearest carers association on 1800 242 636 to obtain free information on a range of topics.
- The **National Carers Counselling** service offers short-term counselling for carers, contact 1800 242 636 ([www.carersaustralia.com.au](http://www.carersaustralia.com.au)).
- **Family Relationship Services for Carers** provide mediation and counselling to assist families who are concerned about the future care of their family member with disability, are thinking about making arrangements for the future care of their family member with disability, or experiencing disagreement around the future care needs of a family member with disability. Services are tailored to family circumstances and may be delivered in individual, couple or family settings ([www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/carers-family\\_mediation.htm](http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/carers-family_mediation.htm)).
- The **Mental Health Respite Program** (MHRP) provides a range of flexible respite options for carers of people with severe mental illness/psychiatric disability and carers of people with intellectual disability ([www.fahcsia.gov.au/internet/facsinternet.nsf/mentalhealth/nav.htm](http://www.fahcsia.gov.au/internet/facsinternet.nsf/mentalhealth/nav.htm)).
- A number of resources are also available on the **Australian Family Relationships Clearinghouse** website: [www.aifs.gov.au/afrc/links/disability.html](http://www.aifs.gov.au/afrc/links/disability.html)

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