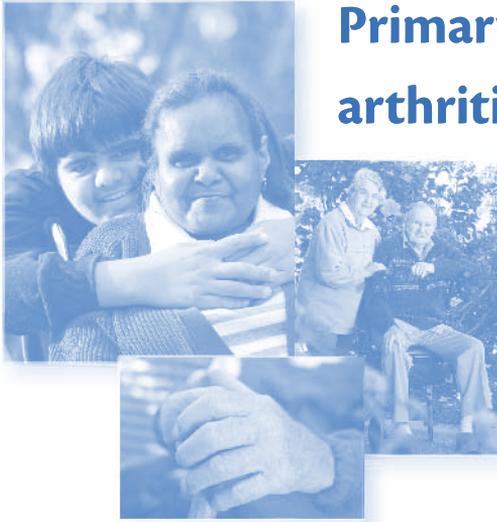




**Australian Government**  
**Australian Institute of  
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Arthritis series no. 12



## **Primary carers of people with arthritis and osteoporosis**

National Centre for Monitoring Arthritis  
and Musculoskeletal Conditions

May 2010

Australian Institute of Health and Welfare

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## Abbreviations and phrases

|   |   |
|---|---|
| <b>ABS</b>  | Australian Bureau of Statistics   |
| <b>ADL</b>  | activities of daily living  |
| <b>AIHW</b>   | Australian Institute of Health and Welfare  |
| <b>CURF</b>   | confidentialised unit record file   |
| <b>IADL</b>   | instrumental activities of daily living   |
| <b>SDAC</b>   | Survey of Disability, Ageing and Carers (ABS)   |
| <b>Primary carers of persons with arthritis or osteoporosis</b> | primary carers of persons with severe or profound disability due to arthritis or osteoporosis |
| <b>People with arthritis</b>                                    | people with arthritis associated disability   |
| <b>People with osteoporosis</b>                                 | people with osteoporosis associated disability  |

## Summary

This report provides statistical information on the primary carers of people with disability due to arthritis and osteoporosis, the nature of the support they provide, and the effect that this caring role has on their own health and wellbeing.

Arthritis and osteoporosis were the main reasons for severe or profound disability in an estimated 611,000 Australians in 2003. Of these, an estimated 50,000 Australians received help from primary carers for activities of daily living.

Family members were the largest source of primary care, mostly caring for a spouse or partner. Usually living with the care recipient, they provided assistance with a wide range of activities, and helped the recipient cope with their restrictions and maintain independent living.

A large proportion of primary carers (43%) of people with severe or profound disability due to arthritis were older adults (aged 65 years or over). More males (54%) than females took on this role.

The motivation of primary carers of people with arthritis or osteoporosis associated disability was admirable. They saw their caring role as a fact of life and a duty to the relationship. Many had quit their job early or reduced work hours to meet their caring responsibilities.

Many primary carers of people with arthritis and osteoporosis were older, and had their own physical problems and limitations of activities, which were sometimes exacerbated by the care-giving process. Often these carers themselves needed assistance with activities of daily living such as self-care, housework, transport and mobility.

The carers outlined a range of unmet needs, in particular respite care on a short-term or monthly basis. More than a quarter indicated their need for additional physical assistance.



# 1 Introduction

This report aims to quantify the role of primary carers in providing care, as well as to highlight the effects of this role on carers' own health and wellbeing. It brings together information about primary carers and the type of caring they provide for people with disability generated by arthritis and osteoporosis. The report also examines the motivation of carers and the support available to them for providing appropriate care.

The disability attributed to arthritis and osteoporosis is mostly classified as mild to moderate, except in the case of rheumatoid arthritis (AIHW: Mathers et al. 1999). Given the degenerative nature of some of these conditions, the extent of associated disability can become profound or severe in older age groups.

## The role of primary carers

The support provided by primary carers is diverse and can range from full-time assistance with daily activities to intermittent supervision. The tasks commonly performed include assistance with personal care, providing companionship and providing emotional support during a crisis (Box 1.1).

The type and frequency of tasks performed by a carer are usually bound by the nature of the recipient's needs and limitations. Help with personal care activities such as feeding, dressing, walking and assistance with toileting is more commonly provided to people with physical disability. Assistance with medications is also common in caring for spouses, older people and those suffering from both physical and mental disabilities. Assistance with lifting and moving things is more likely to be provided to older people with physical impairments.

## Disability associated with arthritis and osteoporosis

To assess the role and importance of a primary carer in the context of arthritis and osteoporosis, it is important to review the nature and extent of disability associated with these conditions. In addition to physical impairments such as chronic pain, joint stiffness and fatigue, which affect activities of daily living (ADL). The 2003 ABS Survey of Disability, Ageing and Carers (SDAC) shows that these conditions have a significant impact on employment or participation in social activities. The nature of the disability may vary with the type of condition (Box 1.2).

## Activity restrictions

Activity restrictions with arthritis occur mainly in the areas of self-care (showering, toileting and dressing) and mobility (transferring from beds or chairs, and walking around the house). Some people may have difficulty doing housework, shopping, preparing meals, or managing medication and transportation.

The level of activity restriction, however, depends on the nature and severity of the condition. Whereas some have considerable difficulty performing daily tasks, others may have only moderate difficulty. A large proportion may have no difficulty at all except for more intense mobility-related activities such as walking long distances, using public transport, going up and down stairs, or bending to pick up an object from the floor (ABS 2004).

The ability to function may change over time with the worsening of the condition. In the case of osteoarthritis, as the disease progresses the pain may become more severe and the body stiffer, and the capacity to perform activities is lessened. The type and number of joints involved also

### Box 1.1: Who is a primary carer?

The Australian Bureau of Statistics' (ABS) Survey of Disability, Ageing and Carers (SDAC) defines a primary carer as 'the person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities or long-term conditions or to older persons' (ABS 2004).

The assistance has to be ongoing, or likely to be ongoing, for at least 6 months and be provided for in one or more of the core activities (communication, mobility and self-care). Where the care recipient lives in the same household, the assistance may be for one or more of the following activities: cognition or emotion, communication, health care, housework, meal preparation, mobility, paperwork, property maintenance, self-care and transport.

Since the assistance provided by primary carers is mostly informal in nature, they are often referred to as 'informal carers'. Because the care is provided within the household setting, usually by a family member, the term 'family carer' is sometimes used. The role of a primary carer as described by the ABS is much more defined than the terms 'informal carer' and 'family carer' denote.

The informal support available from friends and neighbours serves to meet the person's needs that are relatively undemanding, readily reciprocated and not intensive. Support that requires more than this amount on a more frequent basis, such as going out, organising appointments, social services and managing money, and is provided informally by various family members, should be categorised as 'family assistance'. It is important to distinguish these largely supportive roles from that provided by a primary carer.

influence the severity of the problem, as is the case with rheumatoid arthritis. The limitations caused by osteoporosis mostly result from fractures or fracture-related complications; some people may lose their independence after multiple fractures (Cooper 1997). Almost 50% of people with hip fractures are likely to be permanently disabled and not regain their former independence (Johnell 1997).

### Box 1.2: Activity restrictions due to arthritis and osteoporosis

Arthritis or osteoporosis associated disability mostly arises from physical impairments that affect various activities of daily living. The type of limitation experienced varies with the nature and severity of the condition.

**Osteoarthritis:** The type of activity a person with osteoarthritis finds difficult to perform is determined by which joints are affected. Hand and arm problems may lead to a need for help with self-care tasks involving personal hygiene, dressing or household chores. When the hip or knee is affected, mobility can be restricted, making tasks such as going up and down stairs, rising from a chair or bed, and long-distance walking painful and difficult.

**Rheumatoid arthritis:** Deterioration in physical functioning can occur rapidly in the first couple of years after diagnosis. As with osteoarthritis, specific limitations are determined by the joint(s) affected. In rheumatoid arthritis, however, multiple joints are often involved, resulting in a greater range of activity restrictions. Being unable to perform common tasks can lead to high levels of anxiety and depression. Body image issues resulting from joint deformities can also reduce a person's wellbeing.

**Juvenile arthritis:** The condition can interrupt a child's daily activities, such as attending school and participating in play or exercise. Some children might find it difficult to sit on the floor, hold pens and pencils, carry books and open their lunch box. Pain and functional limitations can also prevent children with arthritis participating in sport, and the physical appearance of swollen and deformed joints can affect their wellbeing. These restrictions and psychological effects can in some cases result in social isolation and poor social development, which may in turn lead to problems with social interactions and personal relationships as well as with employment in adulthood.

**Osteoporosis:** Disability in osteoporosis is usually related to fractures, and may be short-term or ongoing. The site and severity of a fracture will determine how a person's functioning may be affected. Wrist and forearm fractures may affect the ability to write or type, prepare meals, perform personal care tasks and manage household chores. Fractures of the spine and hip usually affect mobility, making activities such as walking, bending, lifting, pulling or pushing difficult. Hip fractures, in particular, often lead to a marked loss of independence that affects overall wellbeing.

## Assistance required

People with profound or severe disability due to arthritis and osteoporosis mainly require assistance with self-care activities such as dressing, and showering or bathing. More than 30% of people with arthritis associated disability and almost half of those with osteoporosis associated disability have reported profound or severe restrictions in performing core activities, such as those related to self-care and mobility. They may also require assistance with mobility, using public transport, and moving around inside or outside the house.

Carers of children with arthritis, mostly parents, not only need to help with core activities of daily living but are also required to spend more time with the child (Britton & Moore 2002).

## Extent of the problem in Australia

Arthritis and osteoporosis were the main causes of disability in about 611,000 Australians in 2003. A brief overview of their physical impairments, activity restrictions, work participation and psychosocial issues, based on the 2003 Survey of Disability, Ageing and Carers (SDAC), is provided below. For a detailed description of arthritis and osteoporosis associated disability in Australia, see AIHW: Rahman & Bhatia (2007).

## Physical impairments

The most common impairment associated with arthritis and osteoporosis is chronic or recurrent pain. One in 2 respondents (2003 SDAC) with arthritis, and about 1 in 4 respondents with osteoporosis, reported difficulty in gripping or holding things (Table 1.1). Incomplete use of arms or fingers was also reported. Disfigurement or deformity was more commonly caused by osteoporosis than by arthritis.

**Table 1.1: Physical impairments associated with arthritis and osteoporosis, 2003**

| Impairment/limitation                   | Arthritis     |          | Osteoporosis  |          |
|---|---------------|----------|---------------|----------|
|   | Number ('000) | Per cent | Number ('000) | Per cent |
| Chronic or recurrent pain or discomfort | 304.8         | 55.9     | 32.6          | 65.5     |
| Difficulty gripping or holding things   | 272.7         | 50.0     | 14.3          | 28.7     |
| Incomplete use of feet or legs          | 135.5         | 24.8     | 12.4          | 24.9     |
| Incomplete use of arms or fingers       | 92.7          | 17.0     | 6.7           | 13.5*    |
| Disfigurement or deformity              | 15.6          | 2.9      | 4.4           | 8.8*     |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

Note: A person may report more than one impairment.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

## Activity restrictions

Most people with arthritis or osteoporosis associated disability reported restrictions in one or more core activities. However, other than those aged 80 years or over, most of the respondents did not need much assistance for undertaking these activities.

### *Self-care activities*

Respondents (2003 SDAC) with arthritis reported activity restrictions in showering, eating, toileting, and bladder or bowel control. A relatively small number needed assistance with these self-care activities, although dressing was one self-care activity where assistance was needed more often (Table 1.2). People with osteoporosis associated disability mainly required assistance with dressing, and showering or bathing.

**Table 1.2: Need for assistance with self-care activities, people with arthritis and osteoporosis associated disability, 2003**

| Activity requiring assistance | Arthritis     |          | Osteoporosis  |          |
|-------------------------------|---------------|----------|---------------|----------|
|                               | Number ('000) | Per cent | Number ('000) | Per cent |
| Showering/bathing             | 45.8          | 8.4      | 7.0           | 14.1*    |
| Dressing                      | 74.6          | 13.7     | 9.8           | 19.7*    |
| Eating                        | 25.1          | 4.6      | 3.9           | 7.8*     |
| Toileting                     | 16.8          | 3.1      | 4.6           | 9.2*     |
| Bladder/bowel control         | 15.0          | 2.7      | 4.6           | 9.2*     |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

Note: A person may need assistance with more than one activity.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

### *Daily activities*

A large proportion of people with arthritis associated disability were unable to perform property maintenance tasks without assistance (Table 1.3). This need for help increased with age. People with osteoporosis mainly required assistance with property maintenance and health care.

**Table 1.3: Need for assistance with daily activities, people with arthritis and osteoporosis associated disability, 2003**

| Activity requiring assistance | Arthritis     |          | Osteoporosis  |          |
|-------------------------------|---------------|----------|---------------|----------|
|                               | Number ('000) | Per cent | Number ('000) | Per cent |
| Health care                   | 300.2         | 55.0     | 35.2          | 70.7     |
| Housework                     | 228.1         | 41.8     | 32.0          | 64.3     |
| Property maintenance          | 292.9         | 53.7     | 36.4          | 73.1     |
| Paperwork                     | 56.6          | 10.4     | 9.8           | 19.7*    |
| Meal preparation              | 61.8          | 11.3     | 5.5           | 11.0*    |
| Transportation                | 194.0         | 35.6     | 20.6          | 41.4     |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

Note: A person may need assistance with more than one activity.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

#### *Mobility and transport*

People with arthritis mainly needed help with moving outside the house. Many people with osteoporosis needed help when using public transport, and moving around and outside the house (Table 1.4).

**Table 1.4: Need for assistance with mobility and transport, people with arthritis and osteoporosis associated disability, 2003**

| Activity requiring assistance         | Arthritis     |          | Osteoporosis  |          |
|---------------------------------------|---------------|----------|---------------|----------|
|                                       | Number ('000) | Per cent | Number ('000) | Per cent |
| Using public transport                | 32.7          | 6.0      | 32.7          | 65.7     |
| Mobility away from the home           | 111.7         | 20.5     | 20.1          | 40.4     |
| Moving about the house                | 53.1          | 9.7      | 6.7           | 13.5*    |
| Transferring to and from bed or chair | 61.3          | 11.2     | 9.4           | 18.9*    |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

Note: A person may need assistance with more than one activity.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

## Social participation

Arthritis and osteoporosis can have a considerable impact on participation in social activities. However, there is much variation in the extent to which people with arthritis or a specific musculoskeletal condition can participate socially. Those with rheumatoid arthritis are generally more restricted in their social activities. As the disease progresses, it may affect their ability to perform valued activities. Several studies have reported the negative influence that rheumatoid arthritis has on social participation within the first few years of its onset (van Jaarsveld et al. 1998).

Most people with arthritis associated disability, in responding to the 2003 SDAC, indicated that they were able to participate in social and cultural activities, and go out of their house as often as they wanted to (Table 1.5).

**Table 1.5: Participation in social activities, people with arthritis associated disability, 2003**

| Level of participation   | Males         |          | Females       |          | Persons       |          |
|--|---------------|----------|---------------|----------|---------------|----------|
|  | Number ('000) | Per cent | Number ('000) | Per cent | Number ('000) | Per cent |
| Can go out as often as would like                              | 117.0         | 72.0     | 253.1         | 66.1     | 370.1         | 67.8     |
| Can not go out as often as would like because of the condition | 40.6          | 25.0     | 116.7         | 30.5     | 157.3         | 28.8     |
| Does not leave home at all                                     | 2.9           | **       | 1.3           | **       | 4.2           | **       |
| Not applicable   | 2.2           | 1.4*     | 11.8          | 3.1      | 14.0          | 2.6      |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

\*\* Estimate unreliable for general use.

Note: The proportions are based on the estimated number of people, ages 35 years or over, with disability due to arthritis (N=545, 543).

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

Limitations in physical activity related to spinal deformity and hip fracture lead to activity restrictions and decreased participation in recreational activities, which can result in social isolation for people with osteoporosis (Geusens 2003).

## Assistance required

Of the estimated 611,000 Australians with arthritis or osteoporosis associated disability in 2003, only about 50,000 received assistance from a primary carer. These people all had profound or severe core activity restrictions related to their condition.

## 2 Carers of people with arthritis and osteoporosis associated disability

This chapter provides an overview of primary carers and a more detailed look at people with disability due to arthritis and osteoporosis in Australia. Assistance provided by the carers of people with arthritis and osteoporosis, the impact of the role on their physical and emotional health, relationships with other family members and friends, finances and employment is included.

### Primary carers

The majority of primary carers in Australia are middle-aged and caring for a parent or a partner. Most are female. While males care more often for their partners, females often provide care to partners and parents as well. Both sexes were equally likely to care for their children.

### Tasks performed by carers

A large majority of primary carers helped with transport and mobility (74%) and household chores (72%), including help with grocery and preparing meals (2003 SDAC).

- The assistance with mobility was mainly to help with travel away from home (64%) and moving around the house (27%).
- Assistance with self-care tasks including help with getting dressed (46%), bathing or showering (37%), and getting into and out of bed or a chair (30%).
- Almost one-quarter (23%) of carers helped feed their care recipients.

### Primary carers of people with arthritis or osteoporosis associated disability

The demographic profile of primary carers of people with arthritis is considerably different from that of primary carers overall. A larger proportion of males take on the task of caring for persons with arthritis (Table 2.1). Many carers of people with arthritis were aged 65 years or over (43%) or 45–64 years (37%), compared with 22% and 46% respectively among the primary carers of people with disability due to other causes.

**Table 2.1: Age and sex distribution of primary carers of people with arthritis and osteoporosis associated disability, 2003**

| Characteristic           | Carers of people with disability from: |              |               |              |               |              |
|--------------------------|--|--------------|---------------|--------------|---------------|--------------|
|                          | Arthritis                              |              | Osteoporosis  |              | Other causes  |              |
|                          | Number ('000)                          | Per cent     | Number ('000) | Per cent     | Number ('000) | Per cent     |
| <b>Sex</b>               |  |              |               |              |               |              |
| Males                    | 24.6                                   | 53.8         | 2.4           | 42.9*        | 108.4         | 25.7         |
| Females                  | 21.2                                   | 46.2         | 3.2           | 57.1*        | 312.6         | 74.3         |
| <b>Age group (years)</b> |  |              |               |              |               |              |
| 15–29                    | 0.4                                    | **           | 0.0           | 0.0          | 34.5          | 8.2          |
| 30–44                    | 8.4                                    | 18.3*        | 0.3           | **           | 101.1         | 24.0         |
| 45–64                    | 17.1                                   | 37.4         | 3.3           | 58.9*        | 194.2         | 46.1         |
| 65 and over              | 19.9                                   | 43.4         | 2.0           | **           | 91.2          | 21.7         |
| <b>Total</b>             | <b>45.8</b>                            | <b>100.0</b> | <b>5.6</b>    | <b>100.0</b> | <b>421.0</b>  | <b>100.0</b> |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

\*\* Estimate unreliable for general use.

Note: Primary carers, ages 15 years and over.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

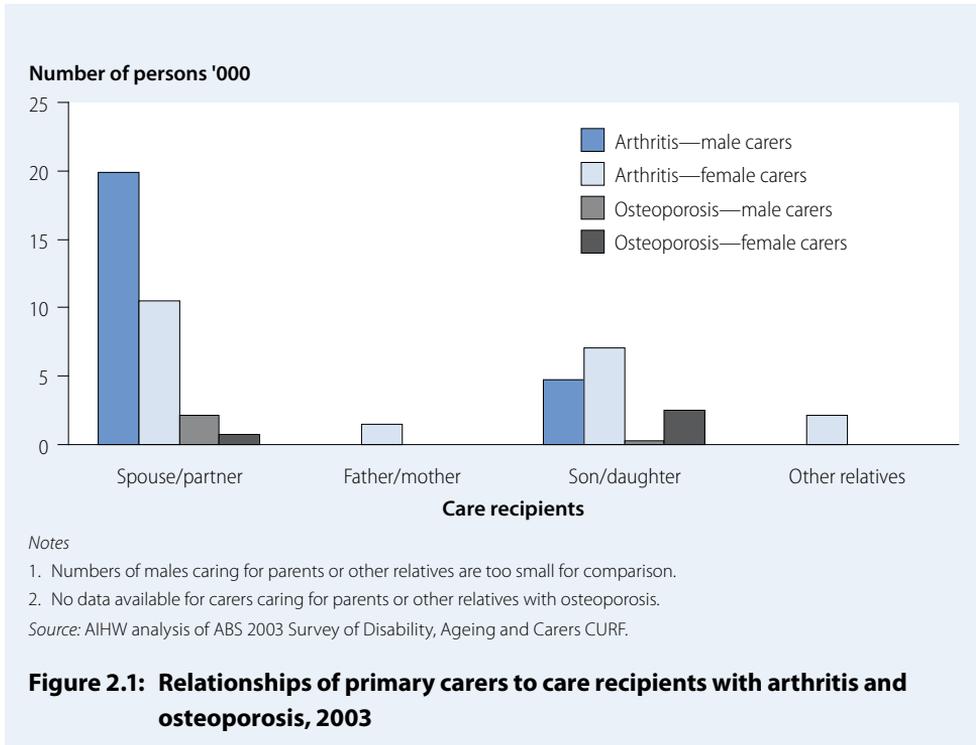
## Relationships of carers to care recipients

More than half of the primary carers of people with arthritis in 2003 cared for their spouse or partner. Around one-quarter took care of a son or daughter and a small proportion cared for their parents or other relatives (Figure 2.1). Male carers mostly provided care to their spouse, while more female carers looked after a son or daughter. Female carers were also more likely than male carers to be caring for their parents or other relatives with arthritis.

## Impairments of care recipients

Disability due to arthritis and osteoporosis mostly results from physical impairments, which can include chronic or recurrent pain, stiffness and reduced mobility of joints. Those with arthritis are mainly affected in the hands, spine, and weight-bearing joints such as hips, knees and feet (Cooper et al. 2000). For people with osteoporosis, the impairment usually arises after a fracture or due to fracture-related complications (Nosek et al. 1997).

The most common impairment of care recipients with arthritis was chronic or recurrent pain (Table 2.2). Many of these people also had problems with gripping or holding things. A large proportion reported problems using their feet or legs.



**Table 2.2: Impairments of care recipients with arthritis associated disability, 2003**

| Impairment/limitation                    | Number ('000) | Per cent |
|--|---------------|----------|
| Chronic or recurrent pain or discomfort  | 35.3          | 77.1     |
| Difficulty gripping or holding things    | 25.3          | 55.2     |
| Limited use of feet or legs              | 21.0          | 45.9     |
| Limited or restricted by hearing loss    | 15.4          | 33.6     |
| Limited use of arms or fingers           | 14.5          | 31.7     |
| Shortness of breath/difficulty breathing | 8.9           | 19.4*    |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

*Note:* Persons may report more than one impairment/limitation.

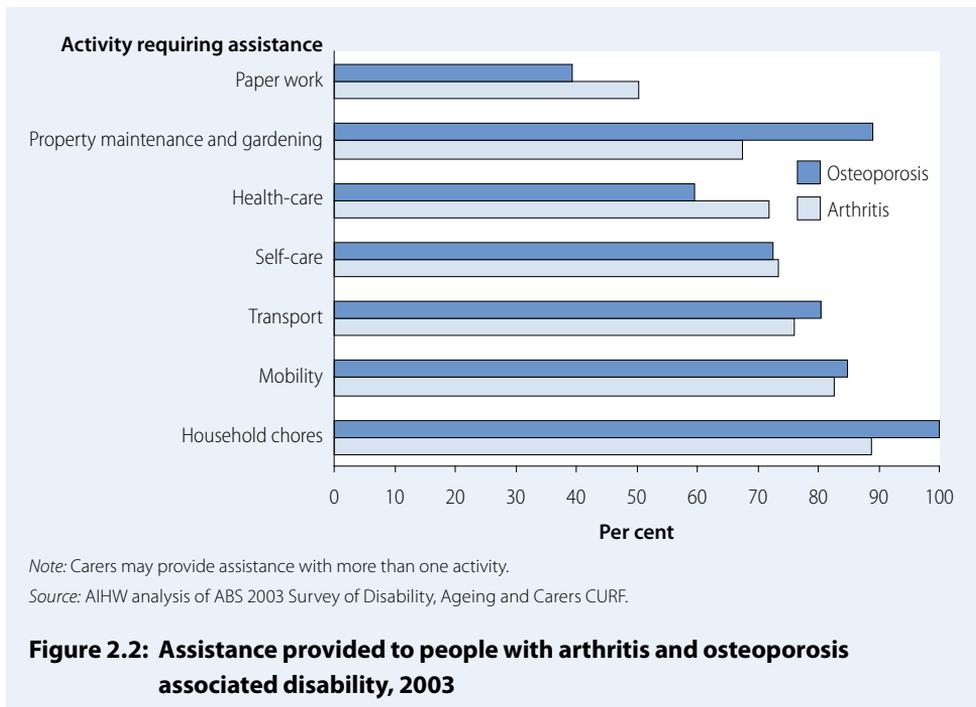
*Source:* AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

These impairments considerably affected the ability of people with arthritis or osteoporosis to care for themselves at home. More than half of those with arthritis were unable to manage alone for a day or more (Table A2.2). Those with osteoporosis were less likely to manage for more than an hour compared with those with arthritis.

## Types of assistance provided

Primary carers of people with arthritis and osteoporosis provided assistance with a range of activities including household chores, mobility and transport (Figure 2.2).

People with osteoporosis were more likely to receive assistance with common household chores, such as washing, vacuuming, dusting and meal preparation. People with arthritis were more likely to receive assistance with self-care and health-care tasks, as they may have difficulty using their arms or hands for bathing and grooming.



A large majority of carers helped with transportation activities, such as getting to the shops, medical or allied health appointments and recreational events. Carers of people with arthritis were more likely to provide assistance with dressing, getting into or out of bed or a chair, and moving away from home if using public transport. Carers of people with osteoporosis provided more assistance with moving around away from home (Table A2.3).

## Effects on carers

Although carers perform an important task for society and their relatives or friends, they do so at cost to themselves. Their role as carers can affect their physical and emotional health and their relationships (Stacey 2002). Employment can be affected when caring duties necessitate a reduction or cessation of paid work, with consequent reduction in income (Edwards et al. 2008).

## Physical and emotional health

Primary carers of people with arthritis reported a range of negative effects of caring. A large majority indicated that they were dissatisfied with their caring role and had suffered physical and mental health problems as a result of caregiving (Table 2.3).

**Table 2.3: Physical or emotional effects on carers of people with arthritis associated disability, 2003**

| Type of problem/effect                  | Number ('000) | Per cent |
|---|---------------|----------|
| Feeling of dissatisfaction              | 27.4          | 59.8     |
| Occasional sleep interruption           | 13.7          | 29.9     |
| Fatigue and weariness                   | 13.0          | 28.4     |
| Physical or emotional wellbeing changed | 8.9           | 19.4*    |
| Feeling of worry and depression         | 8.1           | 17.7*    |
| Feeling of anger and resentment         | 4.2           | 9.2*     |
| Diagnosed with stress-related illness   | 2.3           | 5.0*     |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

Note: Persons may report more than one problem/effect.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

Sleep interruptions were commonly reported by primary carers because they provided support for their care recipient during the night, and because the concern and emotional stress of caring disrupted their sleep.

## Relationships

The majority of primary carers lived with, and felt close to, their care recipient. However, 1 in 6 of primary carers admitted to tension in their relationship (Table A2.4), particularly when there was another person living in the house. Sources of stress included having less time for other family members, conflict between care-giving duties and the carer's as well as other household or family members' personal and social lives.

The majority of carers of people with arthritis felt that their relationship with friends was unaffected by the caring role. But those caring for someone with osteoporosis were more likely to have less time for friends or leisure activities. About 40% of carers of people with osteoporosis indicated that the care-giving has necessitated giving up contact with existing friends, and for almost a quarter of these carers their circle of friends changed.

## Financial hardship

The majority of carers, responding to the 2003 SDAC, felt little or no financial hardship as a result of providing care. Only a small proportion reported that caregiving is a financial hardship for them. About 14% of carers of people with arthritis and 18% of carers of people with osteoporosis stated that their income had decreased. Almost a quarter reported incurring extra expenses. Carers of people with arthritis reported more difficulty meeting everyday living costs in general than carers of people with osteoporosis.

## Employment

The employment potential and opportunities of some carers is affected by the constraint placed by the need to provide care. Many find difficulty in juggling the competing demands of caregiving and paid employment (Schofield et al. 1998).

The 2003 SDAC data broadly confirm these observations (Table A2.5) for many working-age carers (72%) of people with arthritis and osteoporosis. Around 28% of carers were currently employed. Of the carers not in the labour force, 51% did not work or were unable to work permanently. One-fifth worked before they began their care-giving activities.

According to the SDAC, the opportunity for full-time employment by many carers is also greatly affected by their caring role. For example, for carers of people with arthritis, the weekly hours of work reduced to 20–29 hours in 41% of cases, and to 1–19 hours in 47% of cases. Many carers had to quit their job early to begin the care (30%) or to increase the care (22%).

A small proportion of non-employed carers expressed the desire to be in paid employment while still caring for their relative (11% of carers of people with arthritis and 13% of carers of people with osteoporosis). A majority of these were male. They saw many barriers to finding employment. The main barrier to re-entering the workforce while caring was their age and no alternative care arrangements. The carers also reported difficulty in juggling work hours with care-giving commitments as one of the other problems.

### 3 Physical limitations of carers

The SDAC shows that a large proportion of carers, particularly those in older age groups, have had health problems that may affect or compromise their ability to provide support to those for whom they care. In many cases, both carers and their care recipients may have similar health problems as they are often in a similar age range.

This chapter examines the physical limitations of carers and notes that about 12% of Australian Carers' population suffers from arthritis and related conditions, and about 1% from osteoporosis.

#### Long-term health problems of primary carers

A large proportion of carers have long-term health conditions or problems. About 70% of primary carers in Australia, based on the 2003 SDAC, themselves had a long-term health condition, a disease or disorder that has lasted or was likely to last for at least 6 months.

The most common conditions reported in 2003 were musculoskeletal conditions (arthritis and related disorders, and back pain) reported by almost 1 in 4 primary carers, followed by hypertension, migraine and diabetes. Asthma, chronic bronchitis or emphysema and hearing problems were also commonly reported (Table 3.1). Many carers reported more than one condition concurrently.

**Table 3.1: Long-term health problems of primary carers, 2003**

| Condition                       | Primary carers |          |
|---------------------------------|----------------|----------|
|                                 | Number ('000)  | Per cent |
| Arthritis and related disorders | 55.5           | 11.7     |
| Back problems                   | 53.6           | 11.3     |
| Hypertension                    | 31.4           | 6.6      |
| Migraine                        | 17.4           | 3.7      |
| Diabetes                        | 15.3           | 3.2      |
| Asthma                          | 13.8           | 2.9      |
| Nervous tension/stress          | 12.7           | 2.7      |
| Depression                      | 11.7           | 2.5      |
| Heart disease                   | 7.7            | 1.6*     |
| Osteoporosis                    | 4.4            | 0.9*     |
| Other problem(s)                | 106.9          | 22.8     |
| No health problem(s)            | 142.1          | 30.1     |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

*Notes*

1. Primary carers aged 15 years or over.
2. Long-term health conditions of the carers, not disabilities.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

## Carers with arthritis and osteoporosis

More than 55,000 of Australian primary carers in 2003 had arthritis (Table 3.1). A large majority of them (61%) were in the age group 45–64 years, and more than one-third (35%) were 65 years or older. Three-quarters were female (Table 3.2).

The age distribution of carers with arthritis differed considerably from that noted for carers with other long-term health conditions. However, this age distribution is broadly in line with the prevalence of arthritis in the general population (AIHW 2008). The proportion of carers with osteoporosis was too small (0.9% of all carers) to make any useful comparisons.

**Table 3.2: Age and sex distribution of primary carers with arthritis, osteoporosis and other long-term conditions, 2003**

| Demographic characteristic | Carers with arthritis |              | Carers with osteoporosis |              | Carers with other long-term health conditions |              |
|----------------------------|-----------------------|--------------|--------------------------|--------------|---|--------------|
|                            | Number ('000)         | Per cent     | Number ('000)            | Per cent     | Number ('000)                                 | Per cent     |
| <b>Sex</b>                 |                       |              |                          |              |   |              |
| Males                      | 13.7                  | 24.8         | 0.0                      | 0.0          | 121.7   | 29.5         |
| Females                    | 41.5                  | 75.2         | 4.4                      | 100.0*       | 291.2   | 70.5         |
| <b>Age group (years)</b>   |                       |              |                          |              |   |              |
| 15–29                      | 0.2                   | **           | 0.0                      | 0.0          | 34.8  | 8.4          |
| 30–44                      | 2.2                   | 3.9*         | 0.0                      | 0.0          | 107.6   | 26.1         |
| 45–64                      | 33.5                  | 60.7         | 1.1                      | **           | 180.0   | 43.6         |
| 65 and over                | 19.3                  | 34.9         | 3.3                      | 75.5*        | 90.5  | 21.9         |
| <b>Total</b>               | <b>55.2</b>           | <b>100.0</b> | <b>4.4</b>               | <b>100.0</b> | <b>412.9</b>                                  | <b>100.0</b> |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

\*\* Estimate unreliable for general use

Note: Primary carers aged 15 years or over.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

## Physical health

Carers with arthritis or osteoporosis were more likely to report fair or poor health compared with those with other health conditions (Table 3.3). Variation in self-reported health status was greater in carers with osteoporosis than in those with arthritis or other conditions. Male carers were more likely to report fair or poor health than female carers.

Self-reports of health varied considerably with age. Older carers reported their health as fair or poor more often. Carers with other health conditions were more likely to report their health as excellent or very good in 2003.

**Table 3.3: Self-reported health status of primary carers, 2003**

| Health status       | Carers with arthritis |        |       | Carers with osteoporosis |        |       | Carers with other conditions <sup>(a)</sup> |        |       |
|---------------------|-----------------------|--------|-------|--------------------------|--------|-------|---|--------|-------|
|                     | Male                  | Female | Total | Male                     | Female | Total | Male  | Female | Total |
|                     | Per cent              |        |       |                          |        |       |   |        |       |
| Excellent/very good | 20.7*                 | 29.5   | 27.3  | 0.0                      | **     | **    | 31.2  | 45.3   | 41.2  |
| Good                | 38.9*                 | 35.1   | 36.1  | 0.0                      | 13.1*  | 13.1* | 36.6  | 33.7   | 34.5  |
| Fair                | 35.9*                 | 27.5   | 29.7  | 0.0                      | 74.0*  | 74.0* | 26.8  | 17.3   | 20.1  |
| Poor                | 4.5*                  | 7.9*   | 6.9*  | 0.0                      | 0.0    | 0.0   | 5.4   | 3.7    | 4.2   |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

\*\* Estimate unreliable for general use.

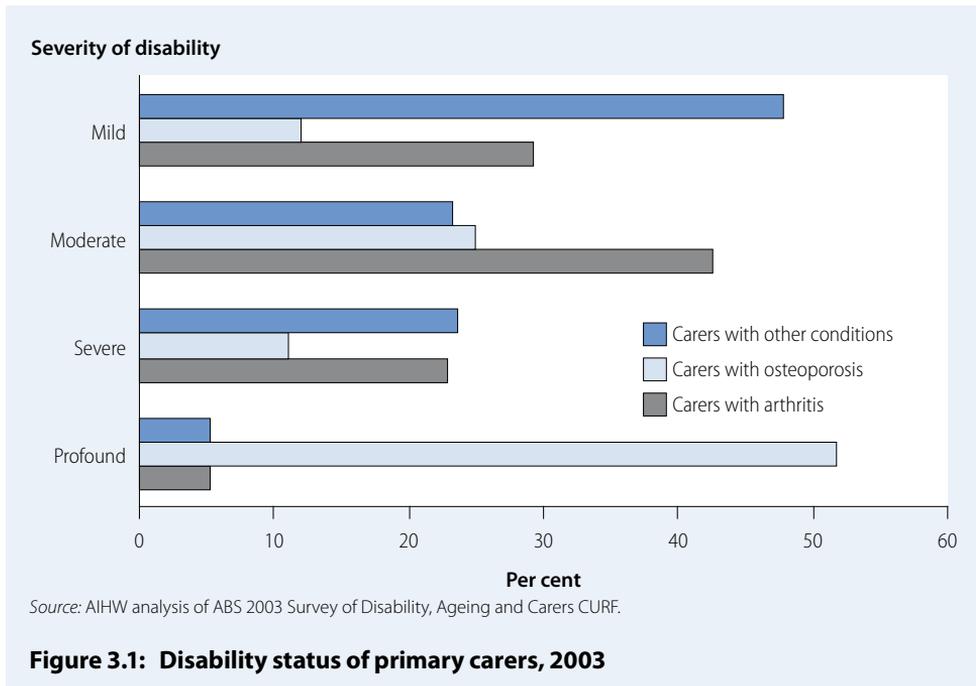
(a) Long-term conditions other than arthritis and osteoporosis.

Note: Primary carers aged 15 years or over.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

## Disability

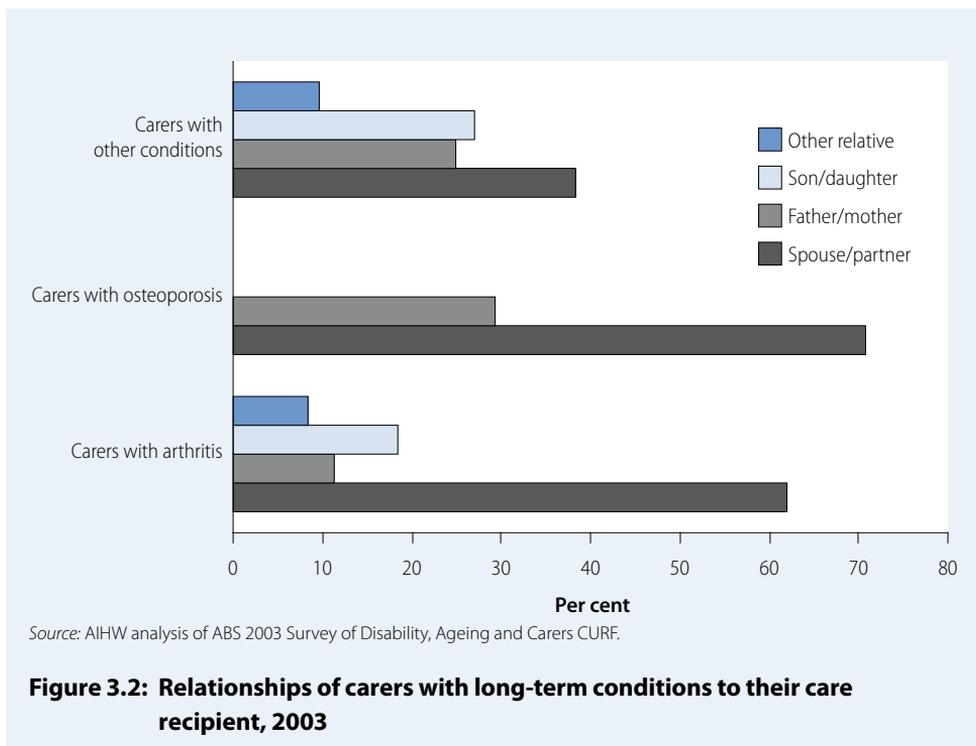
The disability reported by primary carers with arthritis in 2003 was usually moderate to mild (Figure 3.1). They did not require assistance with daily activities in general but often reported difficulties in mobility such as walking 200 metres, walking up and down the stairs without a handrail, picking up an object from the floor or using public transport. Many carers were limited in climbing stairs and carrying out other moderate activities.



Primary carers with arthritis also reported limitations in manual performance, difficulty gripping or holding things, limited use of arms or fingers, and limited use of feet or legs, mostly on account of stiffness or pain (Table A2.6). Pain was reported to interfere considerably with the carer's day-to-day work (general tasks). Female carers with arthritis were more likely to report pain as an issue than male carers.

### Who do they care for?

Most of the primary carers with arthritis and osteoporosis reported looking after their spouse or partner (Figure 3.2). This was more common among carers with osteoporosis than those with arthritis. By comparison, proportionately more carers with other conditions cared for a child (son or daughter). More than one-half (55%) of carers with arthritis were looking after someone aged 65 years or older.



The majority of carers with arthritis reported caring for a person of broadly similar age; around 41% of these carers were aged 65 years or over, caring in turn for a person about their own age (Table A2.7).

### **Work and employment**

Around 24% of carers with arthritis and 30% of carers with osteoporosis had to leave their jobs because of their caring role. More than one-third of carers with arthritis left their job as they preferred to provide full-time care but others did so because they had no option but to look after their relative.

About 5% of carers with arthritis and 16% of carers with osteoporosis, responding to the SDAC, expressed their willingness to work. However, a commonly reported barrier to re-entering the workforce was the carer's age. A lack of skills due to being out of the work force and no alternative care arrangements were the other concerns. Carers with osteoporosis were more likely to have trouble finding alternative care arrangements than those with arthritis.

### **Health and wellbeing**

Carers with arthritis and those with other conditions were more likely than those with osteoporosis to report changes in their overall physical and emotional wellbeing (2003 SDAC) (see Table A2.8). A large proportion of respondents to the survey felt dissatisfied with their caring role, felt weary or lacked energy. Almost 1 in 4 carers with arthritis, and 1 in 8 with osteoporosis, reported changes in physical or emotional wellbeing subsequent to their caring role. Sleep interruption, diagnosis of stress-related illness and feeling worried or depressed were some of the health and emotional effects reported as being due to their care-giving role.

There are several unintended consequences of these caring roles. Conditions such as back, neck and shoulder pain or injury may result from or be exacerbated by care-related activities (Independent Living Centre of Western Australia 2006).

## 4 Situation of and support for carers

Caring primarily for a person with disability can have significant effects on the physical, social and emotional health of the carer. Some of these effects may be lessened by additional support, both formal and informal. Carers with sufficient support are reported to have lower levels of depression and better satisfaction with their caring role (Edwards et al. 2008; Pinquart & Sorensen 2007).

### The motivation for caring

Carers take on their caring role for a variety of reasons. While some carers feel it is their duty and believe that they are in the best position to provide appropriate care, in many cases the role may have been taken on in the absence of an alternative.

Primary carers cited family responsibility as the major reason for taking on the role. A large proportion also surmised that they could provide better care than someone else. Many cited emotional obligation, or the opportunity to show loyalty or give back (Table 4.1).

**Table 4.1: Reasons for taking on the primary caring role, 2003**

| Reason                                      | Carers of people with disability from: |              |                |
|---|--|--------------|----------------|
|   | Arthritis                              | Osteoporosis | All conditions |
|   | Per cent                               |              |                |
| Family responsibility                       | 35.5                                   | 27.3*        | 58.4           |
| Could provide better care than someone else | 34.5                                   | 34.9*        | 39.1           |
| Emotional obligation                        | 14.8*                                  | **           | 34.5           |
| No other family or friends available        | 5.9*                                   | 5.6*         | 23.5           |
| No other care arrangements available        | 4.2*                                   | 4.6          | 11.9           |
| Alternative care too costly                 | 2.3                                    | 5.4          | 17.1           |
| Had no other choice                         | **                                     | 5.4          | 18.4           |
| No other family or friends willing          | 0.5*                                   | 11.1*        | 15.1           |
| Other reasons                               | 0.4                                    | 0.0          | 14.6           |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

\*\* Estimate unreliable for general use.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

### Formal and informal support

Primary carers are supported directly or indirectly by a range of formal services including financial assistance, respite care, counselling, care planning, and other coordinated services that provide in-home support and related assistance. Most of this support becomes available through the government-funded support services.

The financial assistance provided through the carer support allowance and carer payments (Box 4.1) can alleviate some of the financial problems encountered by the carers and their care recipients. Carers unable to combine paid work and caring, in particular, rely on government income support. This financial support partially compensates for lost earnings for carers while providing full-time care.

Much of the informal support is provided by family and friends (D'Abbs 1991). This support may often be transitory and vary with how the support providers are related to the carer or the care recipient. This informal support or assistance has been often cited as informal care, overlapping with the role of a primary carer. However, a distinction between an informal carer and a primary carer needs to be clearly made (see Box 1.1) and this distinction has been maintained in this report.

### **Box 4.1: Government payments for carers**

Carers are eligible for a range of payments and allowances grouped as income support payments and income supplements.

#### **Carer payment**

The carer payment is an income support payment, subject to the same income and assets tests and paid at the same rate as the age pension. This payment is targeted at people whose caring responsibilities limit their workforce participation (currently, a carer can work up to 25 hours per week without losing the carer payment).

#### **Carer allowance**

It is a non-income-tested, non-means-tested income supplement for people who provide daily care and attention in the person's home. The allowance can be paid to carers whether or not they receive a government pension or benefit, and in 2004 it was extended to those who do not live with the care recipient.

#### **Mobility allowance**

Mobility allowance assists people with disability to pay for transport costs when they are unable to use public transport without substantial assistance.

In 2007, 116,614 people received the carer payment. The majority of these were at the maximum rate, while 13% were receiving the reduced rate. Nearly three-quarters had been receiving the payment for fewer than 5 years, and less than 1% had received the payment for more than 15 years (Edwards et al. 2008). Around 400,000 and 52,000 people received the carer allowance and mobility allowance, respectively, in 2005–06 (AIHW 2007).

The use of formal services is an important form of assistance. Respite care, in particular, provides alternative care arrangements to allow carers short-term breaks from their everyday care commitments.

## Types of support needed by carers

Data from the SDAC shows that only a small proportion of primary carers of people with arthritis or osteoporosis needed general assistance with household chores. Most said that they had the necessary skills to look after their family member. The remainder indicated that they could use some help.

Carers most likely to identify need for assistance were those looking after an older spouse or parent (75 years or older) and providing care for extended periods of time. Help was more likely to be sought by female carers (62%, compared with 48% of males) and those who felt that they had no choice in taking on the caring role.

**Table 4.2: Support or improvement most desired by carers, 2003**

| Areas requiring support or improvement | Carers of people with arthritis associated disability |          | Carers of people with osteoporosis associated disability |          |
|--|---|----------|--|----------|
|  | Number ('000)   | Per cent | Number ('000)  | Per cent |
| Financial assistance                   | 6.6   | 14.3     | 0.5  | 8.9      |
| Respite care                           | 4.8   | 10.4     | 1.1  | 17.6     |
| Improvement in own health              | 1.7   | 3.7      | 0.5  | 8.9      |
| Emotional support                      | 1.2   | 2.7      | 0.3  | 5.6      |
| Other                                  | 4.7   | 10.2     | 0.0  | 0.0      |

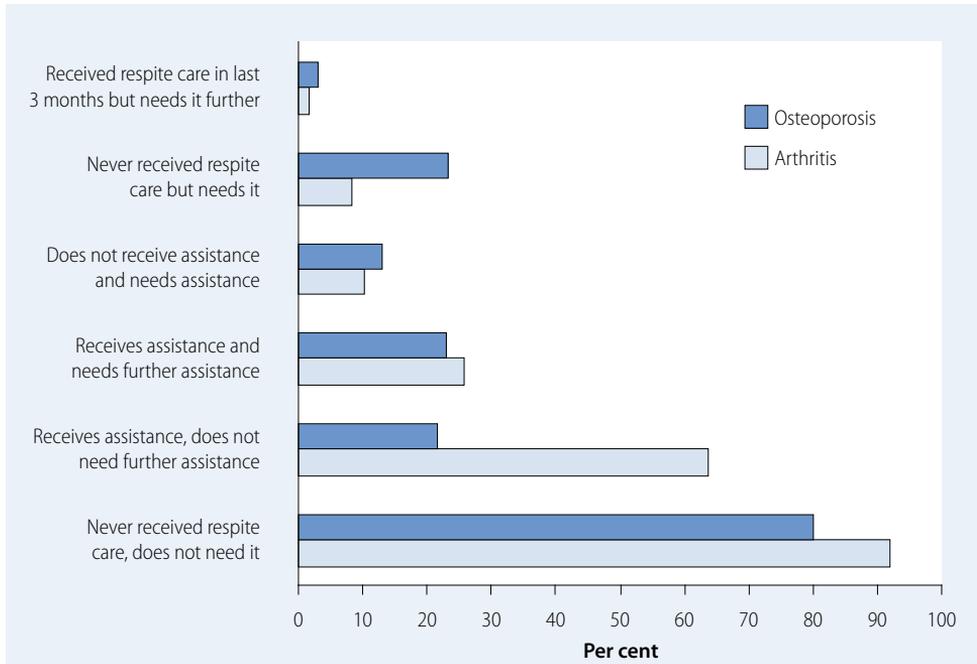
Source: AIHW analysis of 2003 ABS Survey of Disability, Ageing and Carers CURF.

Around 1 in 10 primary carers of people with arthritis desired respite care. About 1 in 5 carers of people with osteoporosis also wanted respite care (Table 4.2). Of these primary carers of people with osteoporosis, most indicated that they needed this support mostly on weekdays and nights; around one-third reported needing some support on weekends as well.

## Use of carer support services

About one-third of primary carers of people with arthritis or osteoporosis received assistance from other family members and friends. While many carers looking after their spouse or partner also received help from a co-resident child, other relative, friend or neighbour, those caring for a child were helped often by their spouse or partner. Assistance from formal providers is not commonly sought by primary carers of people with arthritis or osteoporosis (Figure 4.1). A large majority of primary carers of people with arthritis (92%) and osteoporosis (80%) had never used respite care.

Only a small proportion of carers (15% of those caring for people with arthritis and 22% of those caring for people with osteoporosis) were receiving the carer payment. Many of the primary carers not receiving any financial support did not consider themselves carers as such; others stated that they were not aware of the availability of this type of support.



Source: AIHW analysis of ABS 2003 Survey of Ageing, Disability and Carers CURF.

**Figure 4.1: Needs and receipt of assistance and respite care by carers of people with arthritis and osteoporosis, 2003**

## 5 Conclusions

This report on primary carers of people with arthritis and osteoporosis associated disability raises several important issues. In view of the ageing of the Australian population, the ageing of primary carers themselves may become a significant issue. The health and wellbeing of carers also remains a concern.

### Ageing of care recipients and their carers

Arthritis and osteoporosis were the main reasons for disability in about 611,000 Australians in 2003, with about one-third (about 200,000) of them with profound or severe core activity restrictions. Most of these people were older adults, with the proportion of those with profound or severe disability rising with age. With the ageing of the Australian population, the number of people with profound or severe disability from these conditions is likely to rise further.

There is also the likelihood of concomitant ageing of the carers. Most of the primary carers in 2003 were looking after their spouse or partner, and were mainly in the older age groups. The ability of these carers to take on this added responsibility for long is likely to be low. As it is, only a quarter of Australians with profound or severe disability arising from arthritis or osteoporosis (about 50,000) were being looked after by a primary carer in 2003. This proportion may reduce further with the ageing of both care recipients and their carers.

### Condition-specific caring roles

Females generally take on the caring role more often than males. This pattern reverses among carers of people with arthritis. Two different factors contribute to this reversal: the greater prevalence of arthritis in females and its characteristic age distribution. Both osteoarthritis and rheumatoid arthritis are much more common in females than in males, with a large proportion in the older age groups.

### Health and wellbeing of carers

The demands of caring have significant effects on the health and wellbeing of carers. They often report lack of sleep, feelings of fatigue and weariness, and anxiety and depression. Caring can also affect their relationship with the care recipient, other family members and friends. The potential for employment and the opportunities of carers can be affected, often resulting in financial hardship.

## Relationship between formal and informal support

During the entire process of caring there is strong interdependence between the formal and informal care sectors. A great many carers benefit from the government allowances and support, in particular respite care. Additional physical support not only provides some relief to the carers but also has a positive effect on their wellbeing.

## Contributions to health sector

Primary carers not only help the person in need but also contribute to the health sector by providing indirect economic support and service delivery (Access Economics 2005). This form of caring is, however, often invisible in society (Adams & Tovey 2007). Due to recent sociodemographic changes, as well as health system and community care policy and practices, many carers are now likely to take on the tasks and activities that were formerly the domain of professionals (Edwards et al. 2008).

## Appendix 1: ABS Survey of Disability, Ageing and Carers: primary carers

The SDAC, conducted by the ABS, collects information about disability in Australia, including the provision of care. The survey collects information on disability-related topics, such as health conditions, impairments, activity restrictions, body functions and structures; information on a range of environmental and personal factors; and information about care providers. Five consecutive SDAC surveys have been conducted since 1981. The latest, conducted in 2003, collected this information from 41,200 respondents.

### Box A1.1: Terms and definitions: Survey of Disability, Ageing and Carers, 2003

#### Carer

A carer is a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons (aged 60 years or over). The assistance must be ongoing, or likely to be ongoing, for at least 6 months. Assistance to a person in a different household relates to 'everyday types of activities', without specific information on the activities.

Where the care recipient lives in the same household, the assistance for one or more of the following activities is covered by this definition: communication, health care, housework, meal preparation, mobility, paperwork, property maintenance, self-care and transport.

#### Primary carer

A primary carer is a person of any age who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance must be ongoing, or likely to be ongoing, for at least 6 months and be provided for one or more of the core activities (communication, mobility and self-care).

#### Informal assistance

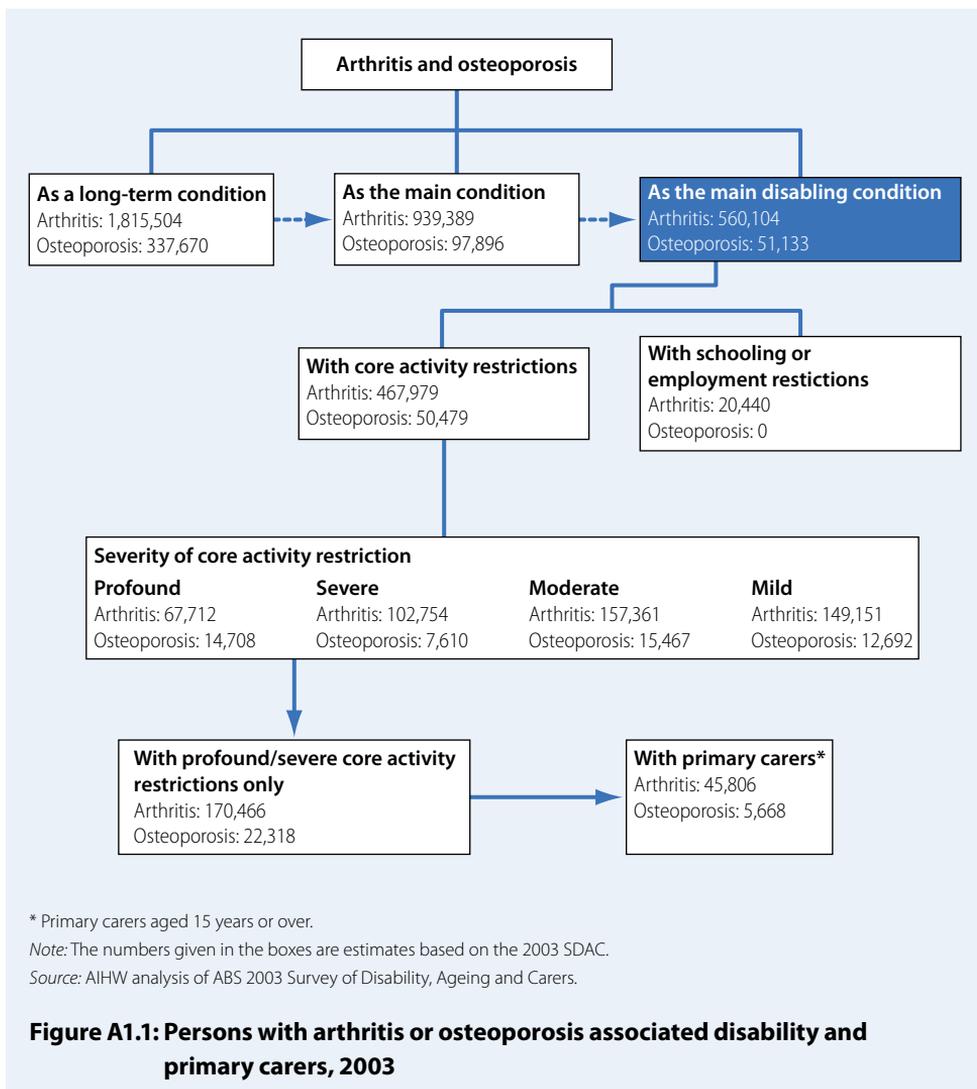
Informal assistance is unpaid help or supervision that is provided to a person with one or more disabilities or persons aged 60 years or over living in households. It covers only the assistance provided for one or more of the specified tasks for an activity.

'Tasks' pertain to a particular type of activity. For example, self-care comprises the tasks of showering and bathing, dressing, eating, toileting and managing incontinence. Housework, identified as a single task, includes household chores such as washing, vacuuming and dusting.

*Source:* ABS 2004

Using specific definitions (Box A1.1), the 2003 SDAC collected information about the type of care provided by primary carers (aged 15 years and over), the support available to them, their sociodemographic characteristics and the effect the caring role has had on their lives. Only people with a main disabling condition and a profound or severe core activity restriction were asked to provide information about their primary carers. A self-enumeration form was also completed by carers, which included information about their attitudes to, and experience of, the caring role. Information on their long-term health conditions was also collected.

Figure A1.1 shows the 2003 SDAC sampling strategy, the manner in which arthritis and osteoporosis are reported, and how a particular group of respondents with disability are linked to the primary carers.



\* Primary carers aged 15 years or over.

Note: The numbers given in the boxes are estimates based on the 2003 SDAC.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers.

**Figure A1.1: Persons with arthritis or osteoporosis associated disability and primary carers, 2003**

## Conditions and disability

Information about arthritis and osteoporosis can be generated in three different ways: as a long-term condition, as the main condition and as the main disabling condition. The three terms are defined as:

- **long-term health condition:** a disease or disorder that has lasted or is likely to last for at least 6 months. A person may report more than one long-term condition.
- **main condition:** the most prominent condition amongst the list of long-term conditions reported by a person. The main condition may cause some amount of discomfort, but is not associated with any impairment or restriction. No disability may be associated with this condition.
- **main disabling condition:** the condition that is responsible for the most disability. People with a disabling condition are restricted in their activities, and most of them need some form of assistance with the core activities of daily living.

## Core activities

There are four levels of core activity restriction, based on whether a person needs personal assistance with, has difficulty with, or uses aids or equipment for any of the core activities:

- self-care—bathing or showering, dressing, eating, using the toilet and managing incontinence
- mobility—moving around at home and away from home, getting into or out of a bed or chair, and using public transport
- communication—understanding and being understood by others (strangers, family and friends)
- schooling or employment.

## Severity of disability

A person's overall level of core activity restriction or the severity of disability is determined by the highest level of restriction the person experiences in any of the core activity areas. Four different categories are identified:

- **profound:** unable to perform, or always needs help with, one or more core activity
- **severe:** sometimes needing assistance to perform a core activity
- **moderate:** not needing assistance, but having difficulty performing a core activity
- **mild:** having no difficulty performing a core activity but using aids or equipment.

The number of Australians with arthritis and osteoporosis as long-term conditions or as the main condition as estimated using 2003 SDAC is quite large. Many of these people are likely to have severe activity restrictions and require assistance with daily activities.

However, the SDAC does not allow the linkage of data on long-term conditions and main conditions to that on primary carers. For this reason, the information provided in this report is based on carers of people with arthritis or osteoporosis as their main disabling condition and where they have profound or severe core activity restrictions (arthritis associated—45,000 carers; osteoporosis associated—5,000 carers).

### **Activities requiring assistance**

The SDAC also collects information on various types of activities, both activities of daily living (ADL) and instrumental activities of daily living (IADL), for which assistance from a carer is required. The ADL are a person's basic daily living activities, also known as core activities (such as self-care, mobility and communication). The IADL are generally more difficult and complex tasks necessary for independent living that may be managed with the help of various aids or appliances.

## Appendix 2: Statistical tables

**Table A2.1: Sociodemographic characteristics of primary carers, 2003**

| Characteristic                   | Primary carers |          | General population |          |
|----------------------------------|----------------|----------|--------------------|----------|
|                                  | Number ('000)  | Per cent | Number ('000)      | Per cent |
| <b>Marital status</b>            |                |          |                    |          |
| Married                          | 333.2          | 70.5     | 7,943.9            | 51.6     |
| Separated/divorced               | 63.9           | 13.5     | 1,537.6            | 9.9      |
| Widowed                          | 11.9           | 2.5      | 904.9              | 5.9      |
| Never married                    | 63.5           | 13.5     | 5,005.6            | 32.6     |
| Not applicable                   | 0.0            | 0.0      | 4.1                | 0.0*     |
| <b>Educational level</b>         |                |          |                    |          |
| Year 8 or less                   | 75.6           | 16.0     | 1,428.2            | 9.3      |
| Secondary                        | 200.6          | 42.5     | 6,777.3            | 44.0     |
| Vocational/university            | 188.2          | 39.8     | 6,883.0            | 44.8     |
| Not applicable                   | 8.1            | 1.7      | 307.6              | 1.9      |
| <b>Total weekly cash income</b>  |                |          |                    |          |
| < \$130                          | 32.3           | 6.8      | 1,206.2            | 7.8      |
| \$130–\$224                      | 143.4          | 30.3     | 2,328.7            | 15.1     |
| \$225–\$449                      | 121.1          | 25.7     | 2,363.2            | 15.3     |
| \$450–\$701                      | 52.0           | 11.0     | 2,553.1            | 16.6     |
| \$702–\$1,150                    | 40.8           | 8.6      | 2,354.4            | 15.4     |
| > \$1,150                        | 16.5           | 3.6      | 1,370.8            | 8.9      |
| Not applicable                   | 66.4           | 14.0     | 3,219.7            | 20.9     |
| <b>Dwelling type</b>             |                |          |                    |          |
| Private                          | 464.7          | 98.3     | 15,010.5           | 97.5     |
| Special                          | 7.8            | 1.7*     | 203.5              | 1.3      |
| Not applicable                   | 0.0            | 0.0      | 182.1              | 1.2      |
| <b>Country of birth</b>          |                |          |                    |          |
| Australia                        | 351.4          | 74.3     | 11,173.1           | 72.6     |
| Other English-speaking countries | 45.2           | 9.6      | 1,623.4            | 10.5     |
| Other countries                  | 75.9           | 16.1     | 2,599.6            | 16.9     |
| <b>Area of residence</b>         |                |          |                    |          |
| Major cities                     | 293.3          | 62.1     | 1,0261.7           | 66.7     |
| Inner regional                   | 116.9          | 24.7     | 3,315.4            | 21.5     |
| Other areas                      | 62.3           | 13.2     | 1,819.1            | 11.8     |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

*Notes*

1. Primary carers aged 15 years or over.
2. Special dwelling type includes a hospital, home for the aged, hotel, motel, hostel for the homeless, and retired or aged accommodation (self-care).

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

**Table A2.2: Care recipients' ability to care for themselves at home, 2003**

| Managing ability                               | Arthritis associated disability |          | Osteoporosis associated disability |          |
|--|---------------------------------|----------|------------------------------------|----------|
|  | Number ('000)                   | Per cent | Number ('000)                      | Per cent |
| <b>Unable to manage alone</b>                  |                                 |          |                                    |          |
| For a few days                                 | 29.2                            | 68.7     | 3.9                                | 72.2*    |
| For one day                                    | 25.1                            | 54.7     | 2.9                                | 51.2*    |
| For a few hours                                | 9.3                             | 21.9     | 1.2                                | 24.1     |
| For less than an hour                          | 3.9                             | 8.9*     | 1.1                                | 18.7     |
| <b>Able to manage alone with difficulty</b>    |                                 |          |                                    |          |
| For a few days                                 | 5.1                             | 19.2*    | 1.5                                | 27.8     |
| For one day                                    | 4.6                             | 10.0*    | 2.4                                | 43.2*    |
| For a few hours                                | 4.1                             | 8.9*     | 3.2                                | 59.2*    |
| For less than an hour                          | 0.9                             | 2.4*     | 4.3                                | 75.4*    |
| <b>Able to manage alone without difficulty</b> |                                 |          |                                    |          |
| For a few days                                 | 3.6                             | 7.8*     | 0.0                                | 0.0      |
| For one day                                    | 4.5                             | 0.9*     | 0.3                                | 5.6      |
| For a few hours                                | 27.1                            | 59.2     | 0.9                                | 16.7     |
| For less than an hour                          | 37.7                            | 88.7     | 0.3                                | 5.9      |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

Note: Persons may provide more than one response.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

**Table A2.3: Specific activities with which carers provide assistance, 2003**

| Type of assistance                  | Carers of people with arthritis associated disability |          | Carers of people with osteoporosis associated disability |          |
|-------------------------------------|---|----------|--|----------|
|                                     | Number ('000)   | Per cent | Number ('000)  | Per cent |
| <b>Self-care</b>                    |   |          |  |          |
| Dressing                            | 27.8  | 60.7     | 2.9  | 51.8     |
| Getting into or out of bed or chair | 26.4  | 57.6     | 2.1  | 37.5     |
| Bathing or showering                | 15.9  | 34.9     | 2.2  | 39.3     |
| Eating or feeding                   | 11.5  | 25.2     | 1.2  | 21.3*    |
| Toileting                           | 4.4   | 9.6*     | 1.4  | 25.3*    |
| <b>Mobility</b>                     |   |          |  |          |
| Moving around away from home        | 27.9  | 60.9     | 4.5  | 80.4     |
| Moving about the house              | 19.2  | 41.9     | 2.1  | 37.5     |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution..

Note: Carers may provide assistance with more than one activity.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

**Table A2.4: Effects on relationships of carers with care recipients and friends, 2003**

| Nature of relationship                  | Carers of people with arthritis associated disability |              | Carers of people with osteoporosis associated disability |              |
|---|---|--------------|--|--------------|
|   | Number ('000)   | Per cent     | Number ('000)  | Per cent     |
| <b>With care recipient</b>              |   |              |  |              |
| Unaffected                              | 22.2  | 48.5         | 2.2  | 38.5         |
| Brought closer together                 | 11.8  | 25.8         | 3.2  | 56.1         |
| Strained                                | 7.7   | 16.6         | 0.3  | 5.4          |
| Less time to spend with them            | 4.1   | 9.1          | 0.0  | 0.0          |
| <b>Total</b>                            | <b>45.8</b>   | <b>100.0</b> | <b>5.7</b>   | <b>100.0</b> |
| <b>With friends</b>                     |   |              |  |              |
| Unaffected                              | 29.5  | 64.4         | 2.1  | 36.8         |
| Lost/losing touch with existing friends | 12.9  | 28.2         | 2.3  | 40.3         |
| Circle of friends has changed           | 3.4   | 7.4          | 1.3  | 22.9         |
| <b>Total</b>                            | <b>45.8</b>   | <b>100.0</b> | <b>5.7</b>   | <b>100.0</b> |

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

**Table A2.5: Employment status of carers of people with arthritis and osteoporosis disability, 2003**

| Employment status                       | Carers of people with arthritis associated disability |             |                 | Carers of people with osteoporosis associated disability |             |              |
|---|---|-------------|-----------------|--|-------------|--------------|
|   | Males   | Females     | Persons         | Males  | Females     | Persons      |
|   |   |             | <b>Per cent</b> |  |             |              |
| Employed                                | 28.8  | 27.5        | 28.2            | 0.0  | 49.6        | 28.5         |
| Worked prior to caring role             | 20.6  | 20.3        | 20.4            | 8.4  | 27.5        | 19.3         |
| Did not work/permanently unable to work | 50.6  | 52.2        | 51.4            | 91.6   | 22.9        | 52.2         |
| <b>Total</b>                            | <b>53.8</b>   | <b>46.2</b> | <b>100.0</b>    | <b>42.7</b>  | <b>57.3</b> | <b>100.0</b> |

Note: Carers aged 15–64 years only.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

**Table A2.6: Physical impairments of carers, 2003**

| Impairment/limitation   | Carers with arthritis | Carers with osteoporosis | Carers with other conditions <sup>(a)</sup> |
|---|-----------------------|--------------------------|---|
|   |                       |                          |   |
| Limited/restricted in physical activities or in doing physical work | 39.4                  | 32.7*                    | 13.2  |
| Chronic or recurrent pain or discomfort                             | 36.5                  | 16.5*                    | 10.9  |
| Difficulty gripping holding things                                  | 33.6                  | 34.0                     | 6.9   |
| Partial loss of hearing   | 20.3                  | 0.0                      | 10.9  |
| Limited use of feet or legs   | 9.2*                  | 0.0                      | 2.9   |
| Limited use of arms or fingers                                      | 6.0*                  | 0.0                      | 2.0*  |
| Disfigurement or deformity  | 2.3*                  | 0.0                      | 0.7*  |
| Other long-term condition that limits or restricts                  | 2.5*                  | 0.0                      | 1.3*  |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

(a) Condition other than arthritis or osteoporosis.

Note: Primary carers aged 15 years or over.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

**Table A2.7: Age distribution of carers and their recipients, 2003**

| Age group of care recipient | Carers with arthritis |             |             |                   | Carers with osteoporosis |             |             |                   |
|-----------------------------|-----------------------|-------------|-------------|-------------------|--------------------------|-------------|-------------|-------------------|
|                             | 15–29 years           | 30–44 years | 45–64 years | 65 years and over | 15–29 years              | 30–44 years | 45–64 years | 65 years and over |
|                             | Per cent              |             |             |                   |                          |             |             |                   |
| Less than 15 years          | 0.0                   | 80.1        | 1.7         | 0.0               | 0.0                      | 0.0         | 0.0         | 0.0               |
| 15–29 years                 | 0.0                   | 19.9*       | 9.4*        | 3.2*              | 0.0                      | 0.0         | 0.0         | 0.0               |
| 30–44 years                 | 0.0                   | 0.0         | 2.1*        | 0.0               | 0.0                      | 0.0         | 0.0         | 0.0               |
| 45–64 years                 | 0.0                   | 0.0         | 51.9        | 9.2*              | 0.0                      | 0.0         | 0.0         | 21.8              |
| 65 years and over           | 0.0                   | 0.0         | 34.9*       | 87.6              | 0.0                      | 0.0         | 100.0*      | 78.2*             |

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

**Table A2.8: Physical and emotional effects of caregiving on carers, 2003**

| Effect on carer                                   | Carer's condition |                 |                      |
|---|-------------------|-----------------|----------------------|
|   | Arthritis         | Osteoporosis    | Other <sup>(a)</sup> |
|   |                   | <b>Per cent</b> |                      |
| Does not feel satisfied due to caring role        | 71.4              | 80.0            | 66.5                 |
| Feels weary or lacks energy                       | 46.3              | 63.1            | 31.7                 |
| Frequently feels worried or depressed             | 28.6              | 29.4            | 13.1                 |
| Change in physical or emotional wellbeing         | 25.8              | 12.1            | 29.4                 |
| Sleep interrupted occasionally due to caring role | 25.7              | 46.1            | 19.6                 |
| Frequently feels angry or resentful               | 17.1              | 16.8            | 14.2                 |
| Diagnosed with stress-related illness             | 12.1              | 28.6            | 9.7                  |

(a) Condition other than arthritis or osteoporosis.

*Notes*

1. Primary carers aged 15 years or over.
2. Persons may report more than one effect.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers CURF.

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