

3 Arthritis, disability and quality of life

Arthritis is a significant cause of disability and has considerable impact on quality of life. It often limits a person's mobility and can cause them to have difficulties in carrying out daily tasks in the home or at work. Quality of life may be affected by chronic pain, limitations in physical functioning, and restrictions in the ability to work and interact socially. Functional limitations and disability associated with arthritis can also have a negative impact on emotional wellbeing by affecting self-esteem and self-image. Family members of people with arthritis-associated disability may also be affected—they are the most common sources of care for people with disability and are often burdened with high health care expenses as well as the physical and emotional strain of caring.

This chapter provides an overview of the types of functional limitations and disability experienced by people with arthritis. It describes the kinds of assistance people need to overcome these limitations, and explores some of the effects that arthritis has on the quality of life of people with arthritis-associated disability and those who care for them.

DESCRIBING DISABILITY

The term 'disability' encompasses a wide variety of physical and mental impairments, activity limitations, and participation restrictions (AIHW 2002). The type, extent and severity of disability is influenced by the health conditions a person has, as well as environmental and personal factors. Examining the interactions between disability, health conditions, wellbeing, and personal and environmental factors provides a picture of the burden of disability in the Australian community, and can help to identify some of the factors that influence people's experience of disability.

Data used in this chapter

The data used in this chapter were obtained from the 2003 Survey of Disability, Ageing and Carers (SDAC) and the 2004–05 National Health Survey (NHS), both conducted by the Australian Bureau of Statistics.

The NHS is designed to collect information about the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle (ABS 2006). To identify people with arthritis, respondents to the 2004–05 NHS were asked 'Do you have, or have you ever had, arthritis?'. Those who answered positively were then asked which type of arthritis they had, whether it was diagnosed by a doctor or nurse, and if they still had the condition. NHS data in this chapter relate to people who reported that they had doctor-diagnosed arthritis.

The SDAC aims to create a comprehensive picture of disability in Australia. It collects detailed information about three groups of Australians:

- people with disability
- older people
- those who provide care for older people or people with disability.

Items within the SDAC collect data on health conditions, physical and mental impairments, activity limitations, problems with body functions and structures, need for assistance, care received, and personal and environmental factors (ABS 2004).

The SDAC generates information that can be used to identify diseases and conditions that contribute to disability in the Australian population. Due to the survey sample size, it is not possible to separate out respondents with different types of arthritis (such as osteoarthritis and rheumatoid arthritis) or similar disorders such as gout. These conditions are grouped together as 'arthritis and related disorders'.

SDAC data in this chapter relate to people who reported that arthritis or a related disorder was their **main disabling condition**. Where survey respondents had more than one disabling health condition, the main disabling condition was the one identified as causing the most problems. If only one disabling condition was reported, this was recorded as the main disabling condition. For convenience, these people are referred to as having 'arthritis-associated disability'.

The SDAC collects information about the nature and severity of specific activity limitations or restrictions in 'core activities' (self-care, mobility and communication) and in schooling and employment. Severity of core activity limitation is classified as:

- profound—unable to do, or always needs help with, a core activity task
- severe—sometimes needs help with performing a core activity task
- moderate—does not need help, but has difficulty performing a core activity task
- mild—does not need help or have difficulty with core activities, but uses aids and has difficulty or needs help with using public transport, walking 200m, bending or climbing stairs.

Data limitations

Although the information from the SDAC presented in this chapter pertains only to respondents reporting arthritis and related disorders as their main disabling condition, the limitations and restrictions reported are not necessarily due to or only affected by arthritis. People may have had other health conditions that caused less severe problems than those caused by arthritis. Conversely, among people who reported conditions other than arthritis as their main disabling condition, some may have had limitations and restrictions due to arthritis. It is likely that the true impact of arthritis and related disorders on disability is underestimated by these data, particularly for those people who have less severe restrictions.

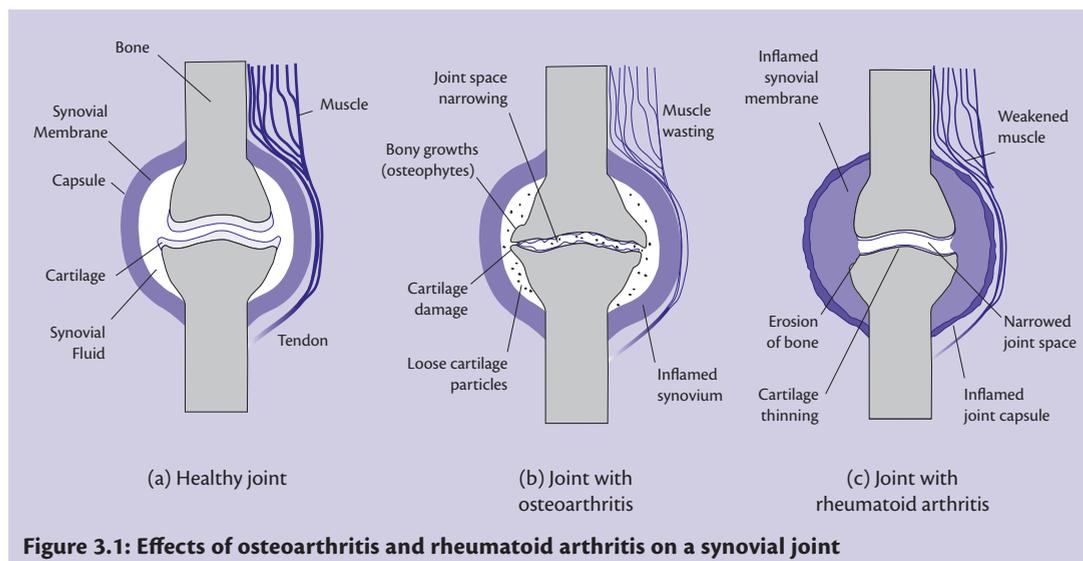
Similarly, the information from the NHS in this chapter pertains to respondents that reported a doctor's diagnosis of arthritis, but who may also have had other conditions that affected their physical and psychological health and health status. In both surveys, a large proportion of respondents (especially those in the older age groups) also had other long-term or chronic conditions that would have contributed to various aspects of disability and affected quality of life. It is not possible, based on these data, to tease out the individual contribution of arthritis or any other condition.

HOW ARTHRITIS LEADS TO DISABILITY

Arthritis is an inflammatory condition that affects the joints, causing damage to the joint structures and tissues. When this occurs, motion of the joint can become painful and/or restricted. This can lead to difficulties in performing the basic bodily movements necessary for daily activities, such as gripping, lifting, sitting down, standing up and walking. The structure of the joints and the effects that osteoarthritis and rheumatoid arthritis have on a joint's physical components and function are described below.

Joints

A joint is a point where two or more bones meet. Most moveable joints in the body are synovial joints, in which the bones are connected by ligaments, allowing a wide range of movement (for example, the hips, knees, shoulders and wrists). The ends of the bones within a synovial joint are covered by articular cartilage, which protects the bone ends, reduces friction and absorbs the shock of movement (Figure 3.1(a)). The joint is surrounded by a capsule of protective tissues, which is lined with a membrane (the synovial membrane, or synovium) that produces synovial fluid. This fluid nourishes the cartilage, removes waste, lubricates the joint and prevents friction. The joint is stabilised by the capsule and the surrounding muscles, tendons and ligaments. Damage to any of the joint structures can lead to problems with joint stability and motion.



The other type of moveable joint in the body is a cartilaginous joint. In this type of joint, the bones are connected by layers or pads of cartilage that allow flexibility, but a smaller range of movement than at the synovial joints. The spine is a column of cartilaginous joints, with each of the vertebrae connected by a disc of cartilage (see Figure 6.2 in Chapter 6). This arrangement enables the trunk and neck to bend and twist. A special pivot joint between the top two vertebrae allows the head to be turned from side to side independently of the spine.

Osteoarthritis

Osteoarthritis is the result of degradation of the cartilage within a joint. Both synovial and cartilaginous joints can be affected. Cartilage is a living tissue and undergoes a continual process of breakdown and renewal by the body. With ageing, this process may become out of balance, leading to a net loss of healthy cartilage tissue. The cartilage loses its elasticity and becomes more susceptible to damage. Over many years, it gradually degrades and roughens. It may split, and pieces may break off or break down, exposing the underlying bone (Figure 3.1(b)). The unprotected bone can thin out, lose shape and thicken at the edges of the joint, producing bony spurs called osteophytes. The soft tissues around the joint may become inflamed and swollen. Other bodily tissues, organs and structures are not directly affected.

Unlike cartilage, which does not have a blood supply or nerves, other tissues within the joints have many nerve endings. When affected by osteoarthritic degeneration and inflammation, these tissues are the likely causes of the pain of osteoarthritis. Different sites in and around the joint will contribute to different types of pain at different times, so the symptoms of osteoarthritis can vary considerably over time and from one person to another.

As osteoarthritic changes occur, the joint loses its smooth movement, becoming stiff and painful. Reduced use of the painful joint causes the muscles to weaken and lose bulk. This in turn increases the load on the joint and decreases its stability, resulting in increased damage to the cartilage, bone and soft tissues. In advanced stages of osteoarthritis the space between the bones is reduced and bones can be in direct contact during movement. This results in increased pain and further joint damage, leading to further reductions in joint function.

Rheumatoid arthritis

Rheumatoid arthritis is an autoimmune disease, in which the body's immune system attacks the synovial membranes, causing inflammation (known as synovitis). This leads to over-production of synovial fluid and swelling of the joint capsule (Figure 3.1(c)). The space between the bones is reduced and the cartilage and underlying bone may be damaged (or 'eroded'). This process results in joints that are swollen, stiff and painful.

In most cases, rheumatoid arthritis affects multiple joints, usually in symmetric fashion (that is, the same joints on each side of the body). This leads to widespread pain and stiffness. Usually the synovial joints only are affected, but the cartilaginous joints in the neck may also be involved. The main part of the spine is generally not affected. Muscles surrounding the inflamed joints may become weakened and lose bulk. Eventually the joints can lose shape and become deformed. Other tissues and organs throughout the body may also become inflamed, which can cause serious complications such as respiratory problems and heart disease.

Unlike osteoarthritis, where symptoms and associated changes in joint function occur gradually over many years, the symptoms of rheumatoid arthritis develop rapidly, often over a few weeks or months. In some cases, disease activity can cause severe damage to the joints in a relatively short period of time.

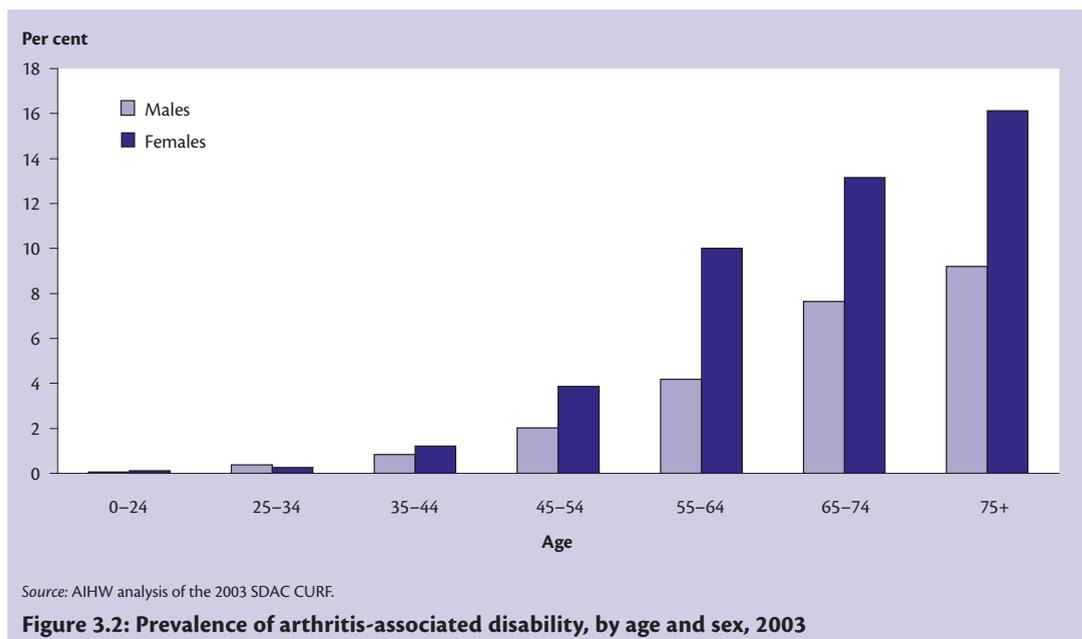
Different experiences of disability

As the symptoms and effects of arthritis vary between individuals and from one type of arthritis to another, so too do the resulting physical impairments and restrictions caused by reductions in joint function. There is, therefore, wide variation in the type and severity of disability experienced by people with arthritis. For example, a person with mild osteoarthritis in one knee might find it difficult to walk long distances or play vigorous sports, but be otherwise unaffected by the condition. In contrast, a person with severe and widespread rheumatoid arthritis may have difficulty with a range of activities, such as brushing teeth or hair, holding a knife and fork, or walking one block.

Personal and environmental factors also have a role in determining the effect that arthritis has on a person's life. For example, difficulty in climbing stairs would have a greater impact on a person who lived in a two-storey house than on a person whose house had few or no stairs. But people can overcome many of the limitations imposed by arthritis by learning new ways of doing everyday tasks, using assistive devices, modifying their environment and getting help from others. Through these adjustments, people with arthritis can participate in work and social activities, maintain their independence and maximise their quality of life.

PREVALENCE OF ARTHRITIS-ASSOCIATED DISABILITY

Arthritis-associated disability (that is, arthritis or a related disorder as the main disabling condition) affects an estimated 3% of the Australian population, or 561,000 people. It is more often reported by females (4%) than males (2%), and becomes more common with age (Figure 3.2). Among people aged 75 years or over, about 1 in 6 females and 1 in 11 males have disability caused mainly by arthritis or a related disorder.



PHYSICAL IMPAIRMENTS

A physical impairment is a problem with or loss of a body function or structure. Arthritis can cause a range of physical impairments, such as inability to use or difficulty in using certain body parts, chronic or recurrent pain, disfigurement, and deformity. The types of impairments experienced vary depending on the specific condition a person has, the area(s) of the body that are affected, and individual circumstances. The timing of onset, progression and severity of physical impairments are also affected by the type of arthritis a person has.

The most common physical impairments associated with arthritis and related disorders are restriction in physical activities or work and chronic or recurrent pain, with more than half of those with arthritis-associated disability in 2003 reporting these impairments (Table 3.1). More than 40% of all people with arthritis-associated disability in 2003 reported difficulty gripping or holding things, twice the proportion reporting this impairment among the general population of people with disability. Difficulty in gripping or holding was much more common among females than males, and females were also more likely than males to report incomplete use of arms and fingers. This may reflect the greater occurrence of rheumatoid arthritis and osteoarthritis of the hands in females than in males, or it might be associated with the lower natural grip strength in females, which makes females more susceptible to difficulty in gripping or holding things.

Table 3.1: Physical impairments/limitations associated with arthritis and related disorders, 2003

Impairment/limitation	People with arthritis as main disabling condition			All people with disability (N = 3,946,400)
	Males (N = 181,800)	Females (N = 379,500)	Persons (N = 561,300)	
	Per cent			
Restriction in physical activities or work	53	55	54	46
Chronic or recurrent pain or discomfort	52	53	53	34
Difficulty gripping or holding things	32	48	43	21
Incomplete use of feet or legs	26	24	25	16
Incomplete use of arms or fingers	13	17	16	11

Source: AIHW analysis of the 2003 SDAC CURF.

Rheumatoid arthritis and physical impairments

Physical impairments associated with rheumatoid arthritis include pain, reduced mobility, and fatigue. Pain can be ongoing and always present, or may be associated with certain activities; often both. Muscle weakness develops because of inactivity and as a side-effect of inflammation (Hakkinen et al. 2006).

Rheumatoid arthritis is a chronic and unpredictable disease. Deterioration in physical functioning can occur rapidly in the first couple of years following diagnosis (Eberhardt & Fex 1995). The disease course is variable, sometimes with rapid changes in disease severity and associated physical impairments, but generally there is increasing joint damage and functional disability over time (Simpson et al. 2005).

Osteoarthritis and physical impairments

Physical impairments associated with osteoarthritis result from pain, reduced mobility of joints, deformity or body stiffness. In osteoarthritis, pain is initially felt in the joints during and after activity, but as the disease progresses it may occur with minimal movement or even during rest (March 1997). Pain during rest can prevent a person from being able to sleep. In general, osteoarthritis symptoms and associated physical impairments have a gradual onset and worsen over time.

ACTIVITY LIMITATIONS

The ability to perform activities of daily living and to participate in work and social activities can be affected by the physical impairments associated with arthritis. Personal and environmental factors contribute to the extent and impact of activity limitations.

Many of the activities that become limited by arthritis are important for independent living. The activities considered to form the basis of daily living, referred to as 'core activities', are self-care, mobility and communication. Different areas of daily living are affected in different individuals. The extent and type of activity limitations experienced is dependent on the type of disease, the body parts affected, the severity of disease, age and other conditions present.

For example, loss or limitation of hand and arm function may result in difficulty with self-care activities such as household chores, cooking and dressing. Problems with hip or knee function may cause difficulty with bathing, dressing (especially dressing the lower half of the body), going up and down stairs, rising from a chair or bed, and walking. Devices or aids can help to resolve some of these difficulties; these are discussed later.

In some cases people have difficulty performing tasks but can still do them, whereas other people need assistance to undertake a task. Table 3.2 summarises the broad areas of activity where people with arthritis-associated disability reported either having difficulty or needing assistance.

Table 3.2: Broad activities where people have difficulty or need assistance due to disability, people aged 15 years or over living in households, 2003

Activity	People with arthritis as main disabling condition			All people with disability (N = 3,413,000)
	Males (N = 175,000)	Females (N = 361,000)	Persons (N = 536,000)	
	Per cent			
Health care	39	41	40	32
Home maintenance or gardening	40	39	39	37
Mobility	31	37	37	33
Household chores	18	38	34	31
Self-care	23	31	28	24
Cognitive or emotional tasks	19	24	21	40
Public transport	15	21	19	25
Private transport	11	17	15	24
Meal preparation	6	9	9	10
Paperwork	5	3	4	15
Oral communication	0**	0*	0*	4

* Estimate is subject to high standard errors (relative standard error of 25–50%) and should be used with caution.

** Estimate is subject to sampling variability too high for practical purposes (relative standard error greater than 50%).

Note: Excludes people with disability living in establishments.

Source: AIHW analysis of the 2003 SDAC CURF.

Health care, home maintenance and mobility were the most common areas that people with arthritis-associated disability in 2003 reported having difficulty or needing assistance with (Table 3.2). Females were more likely than males to report limitations in most areas of daily living, including mobility, household chores, self-care and transport. People with arthritis-associated disability were more likely than people with disability in general to report difficulty with activities involved with mobility, self-care and health care, but less likely to report difficulty with cognitive tasks, paperwork or transport.

Self-care tasks

Self-care tasks including showering, toileting and dressing are essential to maintain hygiene and wellbeing. Dressing was the most common self-care task that people with arthritis-associated disability reported needing assistance or having difficulty with (Table 3.3).

Table 3.3: Difficulty with self-care tasks associated with arthritis and related disorders, people living in households, 2003

Self-care task	Males		Females	
	Sometimes or always needs assistance	Has difficulty but does not need assistance	Sometimes or always needs assistance	Has difficulty but does not need assistance
	Per cent			
Showering/bathing	6	9	4	9
Dressing	9	13	7	13
Eating	1*	1**	—*	8
Toileting	2*	3*	1*	7*

— Less than 1%

* Estimate is subject to high standard errors (relative standard error of 25–50%) and should be used with caution.

** Estimate is subject to sampling variability too high for practical purposes (relative standard error greater than 50%).

Note: Excludes people with disability living in establishments.

Source: AIHW analysis of the 2003 SDAC CURF.

Mobility

Activities related to mobility include transferring from a bed to a chair, use of public transport and moving about within and outside the house. Difficulties with mobility can affect a person's ability to do other activities such as housework, shopping, preparing meals, managing medication and transportation.

About one-third of people with arthritis-associated disability in 2003 reported that they were unable to walk 200 metres or bend to pick up an object off the floor (Table 3.4). Almost half could not use stairs without a handrail. More than one-quarter reported having difficulty with transferring to and from a bed or chair. Females were more likely than males to report being unable to perform mobility tasks.

Table 3.4: Difficulty with mobility tasks associated with arthritis and related disorders, people aged 15 years or over living in households, 2003

Mobility task	Males		Females	
	Unable to do	Needs assistance or has difficulty	Unable to do	Needs assistance or has difficulty
	Per cent			
Walk 200 metres	24	19	16	25
Bend to pick up an object off the floor	24	..	20	..
Use stairs without a handrail	28	26	42	17
Mobility at place of residence	0	11	0	13
Transferring to and from bed or chair	..	28	..	31
Mobility away from place of residence	2**	10	—**	17
Use of public transport	7	10	9	12

— Less than 1%

** Estimate is subject to sampling variability too high for practical purposes (relative standard error greater than 50%).

Note: Excludes people with disability living in establishments.

Source: AIHW analysis of the 2003 SDAC CURF.

WORKFORCE PARTICIPATION

Because of the physical impairments and activity limitations caused by their condition, many people with arthritis have difficulty participating fully in the workforce. As arthritis progresses, the capacity to work can be affected. A person may need to change jobs or duties, reduce their hours, adapt to new circumstances or cease working altogether. For those with rheumatoid arthritis, employment restrictions may occur soon after disease onset, because of the rapid onset of symptoms and functional decline (Barrett et al. 2000). Employment restrictions due to osteoarthritis generally occur gradually, and mainly affect those aged 50 years or over (Arden & Nevitt 2006).

According to the 2003 SDAC, 71% of males and 64% of females with arthritis-associated disability reported having employment restrictions. Of these, approximately half were permanently unable to work because of their disability. People with arthritis-associated disability were less likely to be employed full-time compared with people with disability in general or people without disability, and more likely to not be in the labour force (Table 3.5).

Table 3.5: Labour force status by disability status, people aged 15–64 years living in households and not in full-time education, 2003

Labour force status	People with arthritis-associated disability	All people with disability	People without disability
	Per cent		
Employed full-time	23	31	54
Employed part-time	17	18	22
Looking for work	2	5	4
Not in the labour force	57	47	19

Note: People with a non-restricting disfigurement or deformity only are included in the group of people without disability.

Source: AIHW analysis of the 2003 SDAC CURF.

A diverse range of factors contribute to the development of employment restrictions (Table 3.6). These include employment factors, disease factors, and personal and environmental factors (de Croon et al. 2004; Frank & Chamberlain 2001). In many cases it is possible for the employer to make arrangements to help employees that have disability associated with arthritis to stay employed. This may include providing special equipment, training, allocation of different duties and altering the work environment. Work disability affects both the employee and the employer, and efforts to minimise the impact of arthritis on work participation benefit both parties.

Table 3.6: Factors associated with employment restrictions

Employment factors	Disease factors	Personal factors	Environmental factors
type of job	type of disease	age at disease onset	time needed for health care
amount and type of physical activity required	time since onset	education level	accessibility of workplace facilities
degree of autonomy	level of disability	motivation for work	transport needs
work environment	joints affected	economic considerations	
conditions of employment (e.g. flexible hours)	disease severity		
attitudes of employer and colleagues	symptoms		

Consultation with an occupational therapist can help people with disability to remain in the workforce. Occupational therapists are allied health professionals that can evaluate the needs of people with functional limitations. They can assist individuals to reach and maintain their highest level of functioning, and maximise their level of independence in all aspects of daily living, both in the workplace and at home.

SOCIAL PARTICIPATION

Social participation is another important component of life that is affected by arthritis (Wikstrom et al. 2006). Participation in social activities is a predictor of wellbeing (Zimmer et al. 1997). It enhances self-esteem and improves mental and physical competence. While undertaking leisure activities, wellbeing is improved by the sensations of losing the sense of time and enhanced awareness of the environment (Zimmer et al. 1997). Contact with a social network provides support and companionship that helps people to cope with stressful events. For people with arthritis, social participation improves perceptions of pain and the extent of disability, and improves psychological wellbeing (Ethgen et al. 2004).

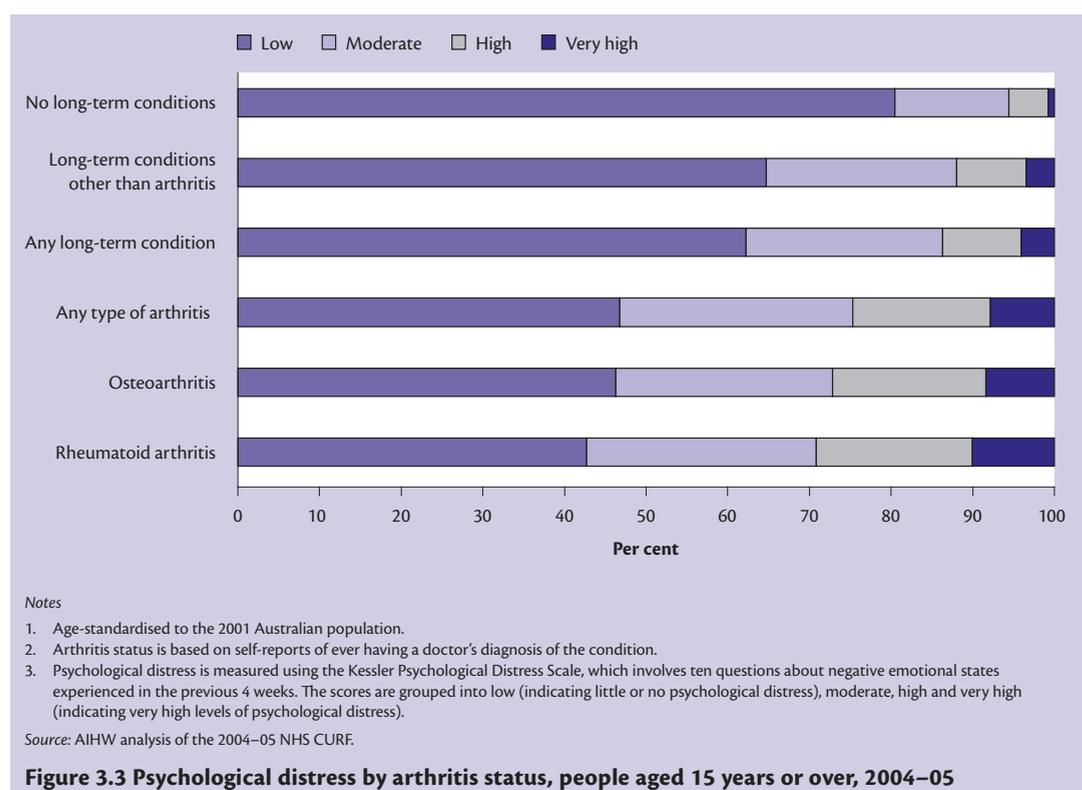
Physical impairments and disability associated with arthritis can pose a number of barriers that make participation in social activities difficult. Often people with arthritis need to change their activities to accommodate physical difficulties. Social participation may be reduced, and some people with arthritis cease social participation entirely. This can affect mental health and reduce the quality of life. According to the 2003 SDAC, more than 28% of people with disability associated with arthritis and related disorders could not go out as often as they would like because of their condition (AIHW: Rahman et al. 2005).

MENTAL HEALTH

The mental health of people with arthritis may be affected by chronic pain and other physical impairments. The limitations and restrictions imposed by arthritis can be detrimental to a person's self-esteem and self-image. Psychological distress can include negative emotional states, anxiety, depression and feelings of helplessness (Sheehy et al. 2006).

Among respondents to the 2004–05 NHS, psychological distress was much higher in people that reported having arthritis than among those with other types of long-term conditions (Figure 3.3).

About 10% of people with rheumatoid arthritis reported very high levels of psychological distress. For people with this type of arthritis, mental health may be further affected by the unpredictability of the disease and reactions to treatment (Simpson et al. 2005). New drug treatments can improve pain, mobility and fatigue, and they offer hope to people with rheumatoid arthritis. But each person reacts differently to the various types of medication. Treatments may fail to improve functioning or may be effective only for a short period of time (Plant et al. 2005). This causes anxiety and a high level of uncertainty when taking a new drug treatment (Simpson et al. 2005). All of these factors can cause depression and can make planning for the future difficult.



ENVIRONMENTAL AND PERSONAL FACTORS THAT AFFECT DISABILITY

Impairments and activity limitations are linked to, but don't always correlate with, clinical measurements of disease (such as progressive joint damage seen on an X-ray). This is because environmental and personal factors can also contribute to the impairments and activity limitations a person experiences. Environmental factors include the layout of the home and public buildings (such as access to ramps), transport availability, and workplace requirements (such as physical demands of the job and pace of work). Personal factors can include attitudes towards illness, fear of deformity and altered body image, and feelings about dependency and accepting help from others.

One personal factor which can greatly influence disability and quality of life is having other conditions in addition to arthritis. These are known as comorbid conditions. As arthritis mainly affects those aged 45 years or over, many people with arthritis also have other comorbid conditions. These may be other musculoskeletal conditions (for example, gout) or other chronic diseases such as heart disease or diabetes. In a Dutch population study, those with more than one type of musculoskeletal condition reported having a lower quality of life than those with a single condition (Picavet & Hoeymans 2004).

In the 2004–05 NHS, two-thirds of people with arthritis reported having four or more comorbid conditions. Self-rating of very good or excellent health was strongly related to the number of long-term conditions a person reported. One-quarter of people with four or more long-term conditions (in addition to arthritis) rated their general health as very good or excellent, compared with more than half of those with no other long-term conditions.

People with arthritis may also have coexisting mental health problems such as depression. Among people with rheumatoid arthritis, having a history of depression greatly impacts on the ability to cope with pain, and the mental health of those with a history of depression is poorer than those without a history of depression (Conner et al. 2006). In the 2004–05 NHS, about 16% of people reporting arthritis also reported that they had long-term depression, anxiety or other mood disorders. In comparison, 9% of people without arthritis reported these problems. Females with arthritis were around twice as likely as males with arthritis to report having depression, anxiety or mood disorders.

IMPACTS ON QUALITY OF LIFE

Health-related quality of life (HRQOL) is a measure of how a person's health affects what they are able to do and how they feel. It is used to describe an individual's perception of how a disease or condition affects their physical, psychological and social wellbeing. Arthritis has been found to significantly affect HRQOL (Carmona et al. 2001; Picavet & Hoeymans 2004; Woo et al. 2004).

An individual's perception of health is affected by environmental and personal factors such as their beliefs, experiences and expectations. These factors influence the extent to which a disease or condition affects an individual, and so impact upon HRQOL. Information about HRQOL can be used to describe and predict health outcomes, guide and assess clinical management, inform policy and direct the allocation of resources.

When the impact of arthritis on HRQOL was compared to other chronic diseases, such as allergies, chronic lung disease, congestive heart failure, diabetes, hypertension and ischaemic heart disease, arthritis was found to have the largest impact on physical components of HRQOL, and also to impact significantly on mental health components (Alonso et al. 2004; Woo et al. 2004).

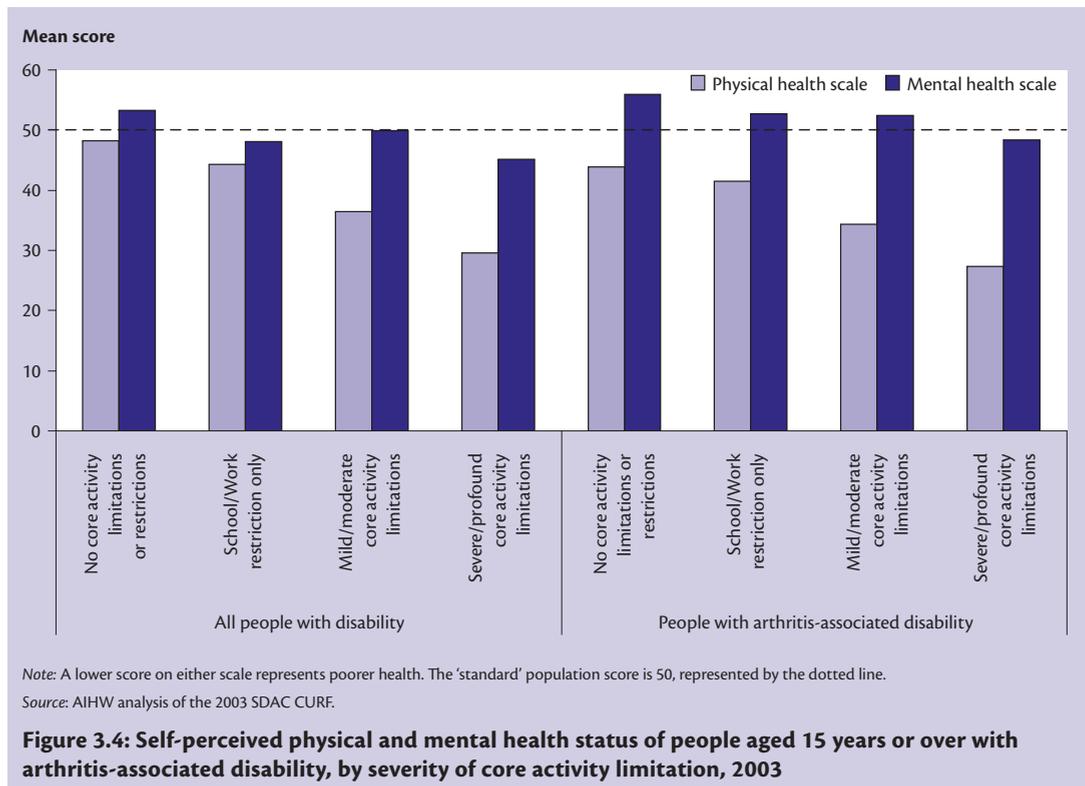
Box 3.1: Measuring health-related quality of life (HRQOL)

A large number of different sets of questions or measures have been developed to assess HRQOL. A measure of HRQOL can be specific and focus on the impacts of specific diseases—these are often used in clinical studies to measure variation within a study population. Alternatively, the measure can be general and collect information on the impacts relating to a broad range of health conditions—these are the HRQOL measures most commonly used in population health surveys. A general measure that is frequently used is the 12-item Medical Outcomes Short-Form (SF-12) (Ware et al. 1996).

The SF-12 consists of 12 questions (or 'items'), from which information about the respondent's physical and mental health status can be derived. The physical health status items focus on limitations in physical functioning, role limitations due to physical health problems, bodily pain and general health. The mental health status items focus on role limitations due to emotional problems, social functioning, mental health and vitality. The items relating to physical and mental health status are combined to form physical and mental health scales that can be compared between individuals or population groups. The scales are weighted such that the general population has an average score of 50 and a standard deviation of 10. A lower score on a scale indicates lower health-related quality of life in that area.

Among people with arthritis-associated disability in 2003, self-perceived physical health status decreased with increasing disability severity (Figure 3.4). This is to be expected as the physical health scale is a measure of physical functioning. Those with no limitations in core activities (self-care, mobility and communication) or restrictions in work or schooling only had an average physical health scale score of 42 (see Box 3.1). This is higher than that of people with profound or severe core activity limitations (average physical health scale score of 27), but less than the standardised Australian population average score of 50. People who reported no core activity limitations may still have limitations in other areas (such as home maintenance), which could account for their lower physical health score.

In comparison, self-perceived mental health status remained around the Australian population average score of 50 for all levels of arthritis-associated disability severity. Previous studies have shown a link between depression and disability in people with arthritis (Hill et al. 2006). In the 2003 SDAC around 5% of people with arthritis-associated disability also reported having depression; the mental health scale score among these people was 39.

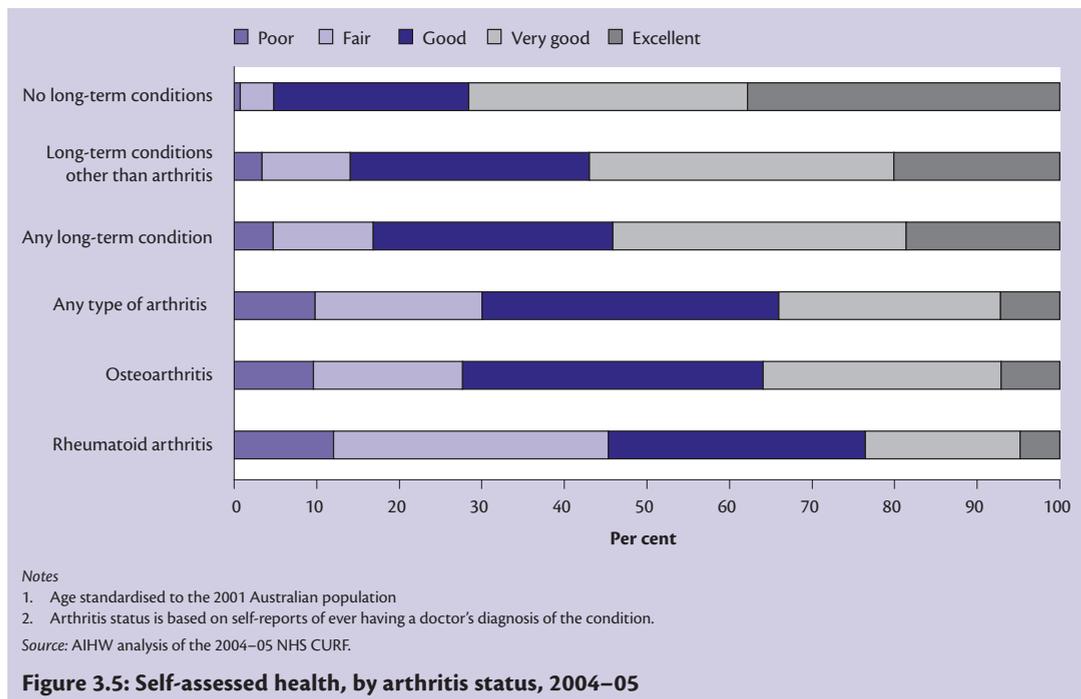


SELF-ASSESSED HEALTH

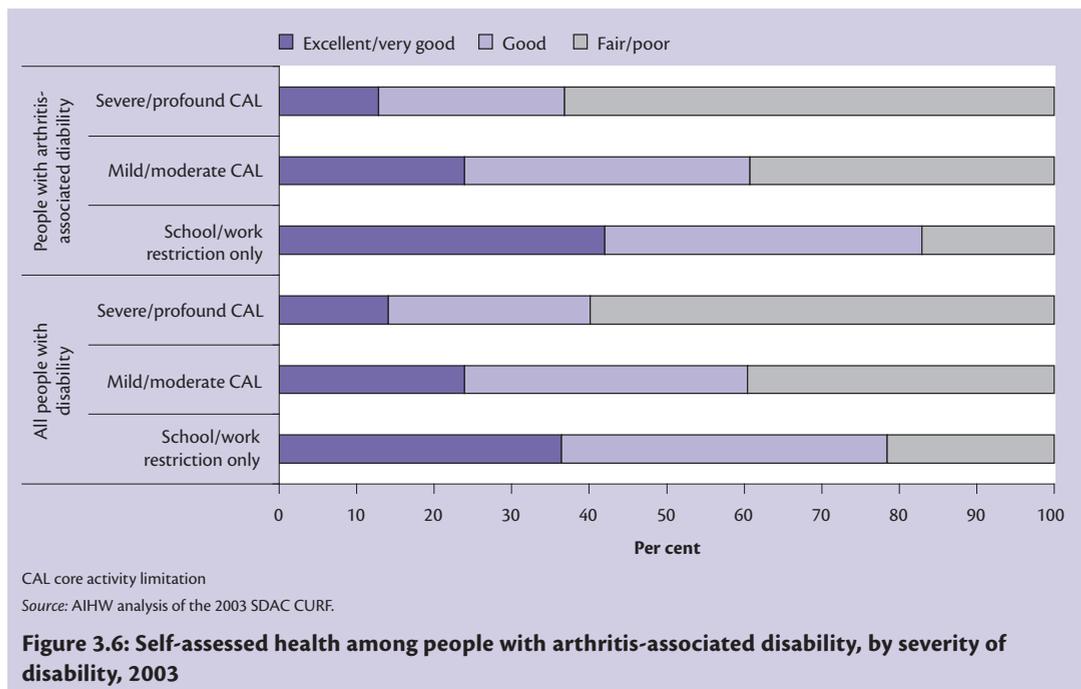
The chronic, pervasive nature of arthritis is likely to have a strong impact upon people’s perception of their own health. Self-assessed health status is therefore a powerful descriptor of psychosocial health.

Self-assessed health status is a brief and general measure that can be used to examine the effect of disease, disability or other factors on a person’s perception of their health. In the NHS, a person’s perception of their health status is assessed by the question: ‘In general would you say that your health is: excellent, very good, good, fair or poor?’.

Results from the 2004–05 NHS indicate that most people with arthritis perceive their health to be good, very good or excellent (Figure 3.5). However, self-assessed health among people with arthritis was considerably poorer than that reported by people with other types of long-term conditions. A large proportion (45%) of people with rheumatoid arthritis, in particular, perceived their health status to be poor or fair.



Self-assessed health is also affected by the severity of any existing disability. Among people with arthritis-associated disability in 2003, more than 60% of people with severe or profound core activity limitations rated their health as fair or poor, compared with 17% of those who had schooling or work restrictions only (Figure 3.6).



ASSISTANCE WITH EVERYDAY TASKS

Not everyone with arthritis will be affected in the same way by their condition. Some will experience little or no limitation of their daily activities, whereas others will be severely disabled. All along this continuum of abilities, people may require some form of assistance with the everyday tasks of life. This can range from something as simple as a device for opening jars, to mobility aids such as a walking stick or frame, personal assistance with household tasks, or high-level residential care.

Use of aids and home/office modifications

There are many specialised aids that can be used and modifications that can be made to the home and work environment to allow a person with arthritis-associated disability to successfully undertake personal, work or household tasks. Some aids that are available to help people with these tasks or other activities are outlined in Box 3.2.

Aids and modifications limit the impact of arthritis on daily activities and improve independence. In 2003, just over half of people with arthritis-associated disability reported using aids. They were used more commonly by people in older age groups and generally more often by females than males (Figure 3.7). The most common activities that people with arthritis and related disorders used aids for were mobility (outside the home 16%; within the home 12%), showering (13%), toileting (8%) and rising from a bed or chair (6%).

Box 3.2: Aids used to manage limitations associated with arthritis and related disorders

Dressing

button/ zipper aids
sock aid
shoe horn
long-handled comb or brush

Kitchen

jar / bottle opener
ergonomic utensils (e.g. vegetable peeler)
ergonomic cutlery

Garden

kneeling/sitting aid
tall seedling trays

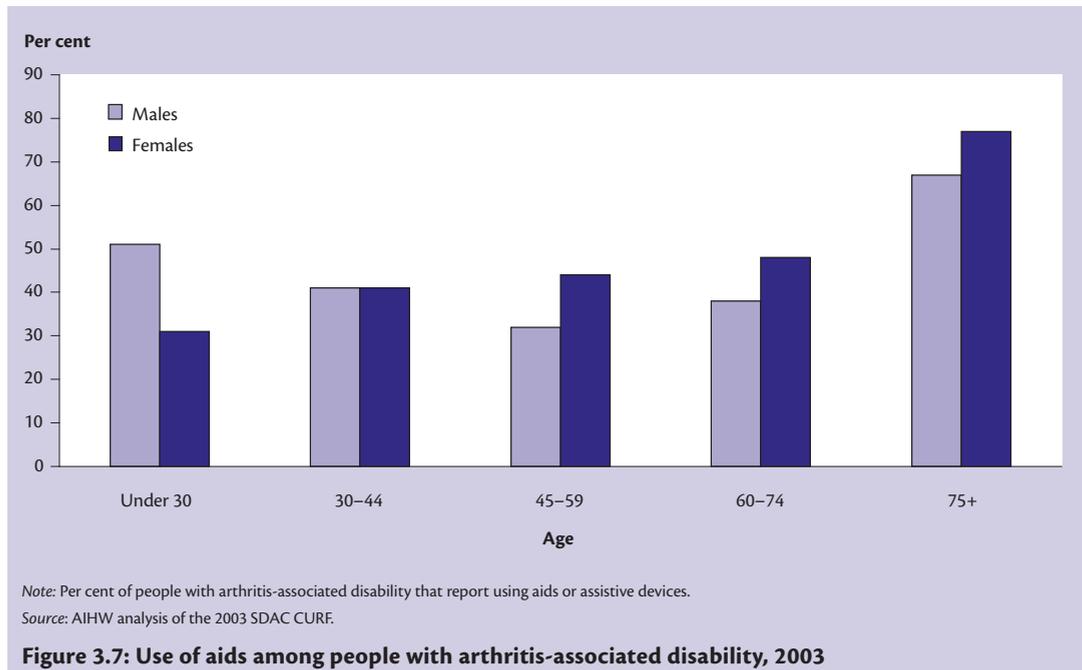
Bathroom

safety grips
seat for shower
long-handled scrub brush or loofah
tap and door handle turners
non-slip mats
raised toilet seat

Office/workplace

adjustable chairs and desks
document holders
ergonomic mouse and keyboard
special office supplies (e.g. pens, stapler, scissors)

Modifications to the home can help people with arthritis and related disorders to cope with common difficulties such as the use of stairs, sitting, standing, and reaching. The installation of hand rails (10%) and ramps (2%), and changes to toilets, baths and laundries (7%) are the most common modifications to the home reported by people with disability associated with arthritis and related disorders (AIHW: Rahman et al. 2005).



Care and assistance from others

To cope successfully with arthritis-associated disability, people often need assistance from family, friends, medical professionals and support services. Care and support is most commonly provided by unpaid (that is, non-professional) carers such as family members and friends (Carers Victoria 2005). Care for people in the home, in community settings and in residential care can also be provided by paid care workers and community support services. The frequency, type and duration of care or help needed by a person with disability will depend on the particular condition the person has, its severity, any comorbid conditions, and the type of physical and activity limitations experienced.

Carers

The Australian Bureau of Statistics defines a carer as '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 (that is, aged 60 years or over)' (ABS 2004). A person may have more than one carer. The carer who provides the most informal assistance with core activities (mobility, self-care and communication) is known as the primary carer. The 2003 SDAC collected information from primary carers aged 15 years or over.

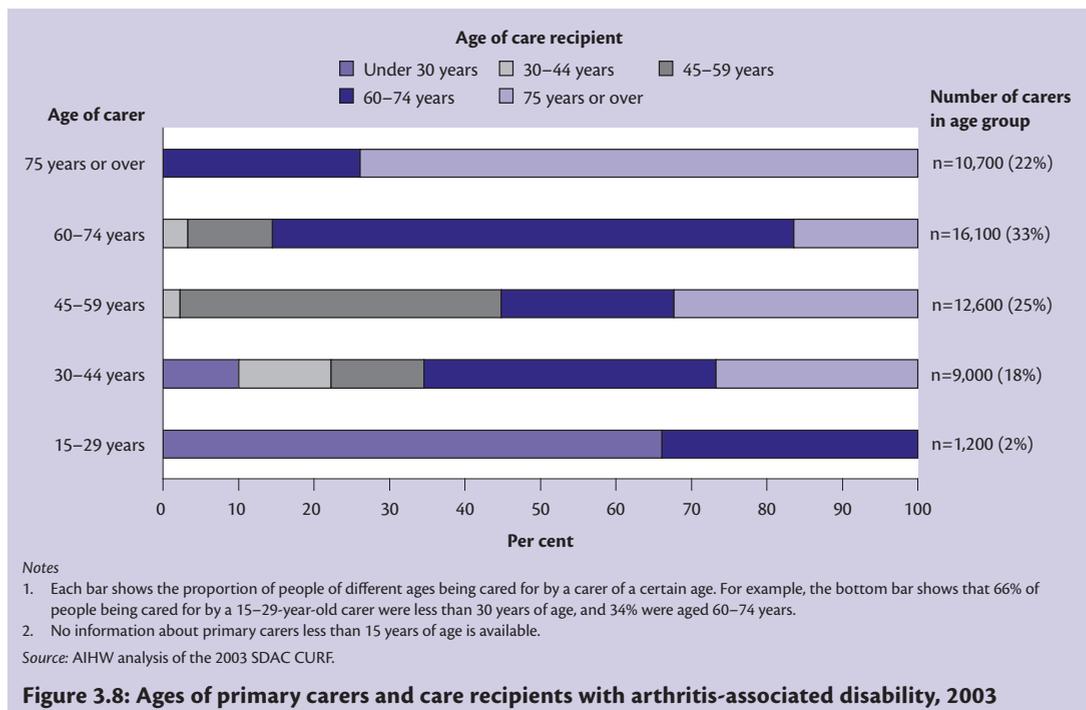
Of 475,000 primary carers identified by the 2003 SDAC, almost 50,000 provided care to people with arthritis-associated disability. Almost two-thirds of these carers were the spouse of the person with disability, and over half provided more than 20 hours of care each week. Almost 40% had spent at least 10 years in the caring role.

IMPACTS ON CARERS

Carers of a person with arthritis may also be affected by any functional limitations or disability that the person they are caring for experiences. Providing care comes with rewards and challenges for the carer. Rewards can include a sense of satisfaction with helping someone in need, strengthening relationships with family members, and receiving acknowledgment and appreciation (Carers Victoria 2005). Challenges can include the physical and emotional drain from caring, restrictions to social participation, a loss of freedom and spontaneity, and financial and legal implications.

The caring role places many physical and psychological demands on the carer. They may be required to assist with mobility, household tasks such as cleaning and cooking, and personal-care tasks such as dressing and bathing. In addition to these physical tasks, the carer provides psychological support to a person who may be anxious, depressed or fearful. The nature of the caring role and its impact on the carer will vary depending on a range of factors, including:

- the age of the care recipient(s)
- the age of the carer
- whether the carer lives in the same household as the care recipient(s)
- the extent of disability and the particular needs of the care recipient(s)
- the amount of support the carer receives from others (both other family members and paid care workers)
- the length of the caring role
- multiple caring roles
- the carer’s own health status (for example, any health conditions or disability that they have)
- the economic circumstances of both parties.



In 2003, more than half of primary carers of people with arthritis-associated disability were aged 60 years or over, and most (91%) of these carers were caring for a person also aged 60 years or over (Figure 3.8). Three-quarters of carers had at least one long-term condition, and more than half reported some degree of disability of their own. Common causes of disability among carers of people with arthritis-associated disability included arthritis (20% of carers with disability), heart disease (14%) and back problems (9%).

Carers of people with arthritis-associated disability report a range of positive and negative impacts that their caring role has on their life. For example, 32% reported that caring gave them a feeling of satisfaction, but 16% felt worried or depressed and 9% felt anger or resentment. For some, social and family relationships had suffered, with 19% reporting losing touch with friends and 8% reporting strained family relationships. Many also felt financial effects; although 45% of carers reported that their income had not been affected, 18% reported decreased income, 26% had extra expenses and 27% were having difficulty meeting everyday living costs.

These impacts can have substantial effects on the physical and mental health and quality of life of carers. Almost 20% of carers of people with arthritis-associated disability in 2003 reported that their physical or emotional wellbeing had changed due to their caring role, and almost 25% rated their general health as fair or poor. In turn, care recipients may feel like a burden, and become anxious or uncomfortable about asking for help. It is important that carers ask for assistance when they need it, and also take time out from the caring role (Carers Victoria 2005). This can provide relief from the duties and worries of caring, allow personal time for relaxation and recreational activities, and enhance mental health and wellbeing. About one-third of carers of people with arthritis-associated disability in 2003 desired more support or improvements to assist them in their caring role. The most common types of support desired were financial assistance and respite care. A variety of support services are available to help people with caring or provide respite, ranging from a couple of hours to a few weeks at a time. More information on these services can be obtained from Commonwealth Respite and Carelink Centres (freecall 1800 052 222).

Formal support services and residential care

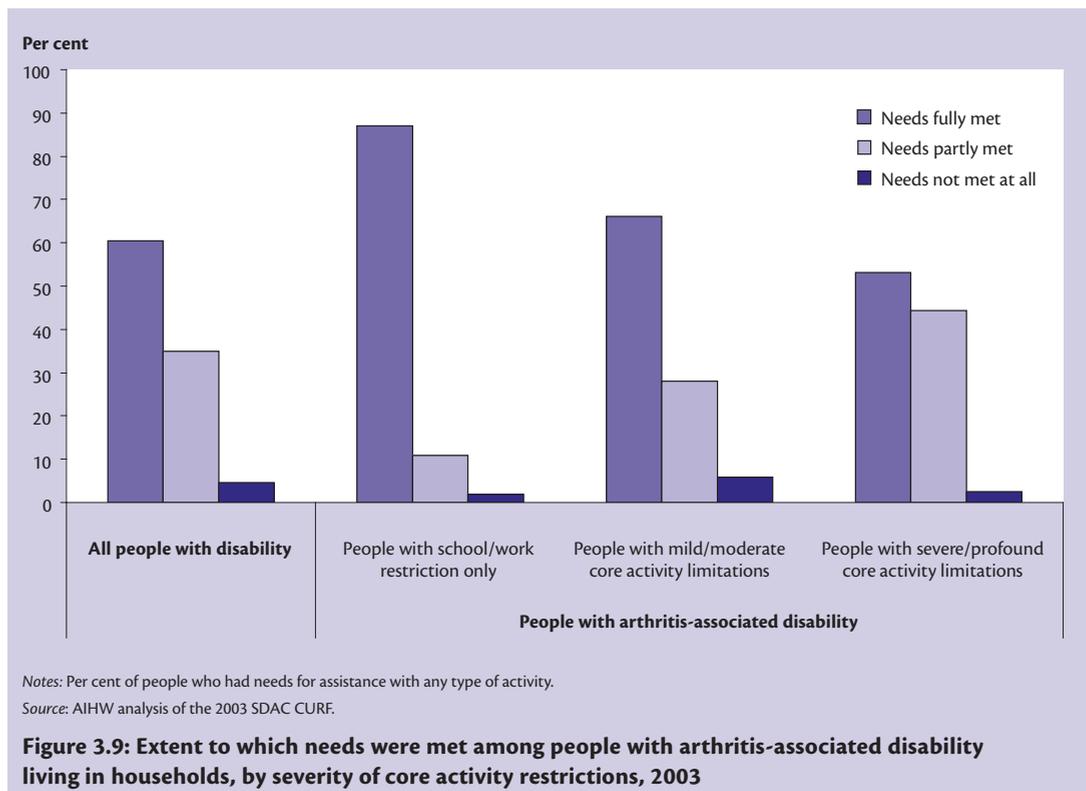
Support services and paid care workers can provide care in the home and in community settings. Services provided include home nursing, domestic assistance, delivered meals, respite care, garden and home maintenance, social support and transport. These services help people to maintain independence, and provide support for carers.

Around 3% (56,000) of people reporting arthritis in 2003 were living in residential care facilities; 30% of these people (almost 17,000) had arthritis-associated disability. People in residential care often have profound difficulties with mobility and/or other limitations, such as incontinence or memory and cognitive difficulties. Many carers continue to provide care for family members in residential care, but their caring role changes. Carers can supplement and complement the care provided by professional staff, and may be involved in activities such as feeding, personal care, and outings or holidays.

Unmet need

The aim of care is to meet the needs of people with disability. The severity of activity limitations experienced affects the ability of carers to meet those needs. In 2003, an estimated 345,000 people with arthritis-associated disability living in households needed assistance with one or more activities. More than 60% of these people had their needs for assistance fully met. Those with severe or profound limitations were the most likely to have unmet needs; 47% reported that their needs were only partly met or not met at all (Figure 3.9).

These data suggest that there are people with severe disability in the community that are only partly having their needs for assistance met. It is important that people with disability receive adequate support from carers, community services and paid care workers, so that they can participate in the wider community to the fullest extent possible and maximise their quality of life.



REFERENCES

- ABS (Australian Bureau of Statistics) 2004. 2003 Disability, ageing and carers: summary of findings, Australia. ABS cat. no. 4430.0. Canberra: ABS.
- ABS 2006. 2004–05 National health survey: summary of results, Australia. ABS cat. no. 4364.0. Canberra: ABS.
- AIHW (Australian Institute of Health and Welfare) 2002. The International Classification of Functioning, Disability and Health (ICF). Disability data briefing series no. 20. Canberra: AIHW.
- AIHW: Rahman N, Bhatia K & Penm E 2005. Arthritis and musculoskeletal conditions in Australia 2005: with a focus on osteoarthritis, rheumatoid arthritis and osteoporosis. Cat. no. PHE 67. Canberra: AIHW.
- Alonso J, Ferrer M, Gandek B, Ware JE, Jr., Aaronson NK, Mosconi P et al. 2004. Health-related quality of life associated with chronic conditions in eight countries: results from the International Quality of Life Assessment (IQOLA) Project. *Quality of Life Research* 13:283–98.
- Arden N & Nevitt MC 2006. Osteoarthritis: epidemiology. *Best Practice and Research: Clinical Rheumatology* 20:3–25.
- Barrett EM, Scott DG, Wiles NJ & Symmons DP 2000. The impact of rheumatoid arthritis on employment status in the early years of disease: a UK community-based study. *Rheumatology (Oxford)* 39:1403–9.
- Carers Victoria 2005. *Surviving the maze* (fact sheets series). Melbourne: Carers Victoria. Viewed 14 March 2007, <www.carersvic.org.au/BCFC/BCFC.htm>.
- Carmona L, Ballina J, Gabriel R & Laffon A 2001. The burden of musculoskeletal diseases in the general population of Spain: results from a national survey. *Annals of the Rheumatic Diseases* 60:1040–5.
- Conner TS, Tennen H, Zautra AJ, Affleck G, Armeli S & Fifield J 2006. Coping with rheumatoid arthritis pain in daily life: within-person analyses reveal hidden vulnerability for the formerly depressed. *Pain* 126:198–209.
- de Croon EM, Sluiter JK, Nijssen TF, Dijkmans BA, Lankhorst GJ & Frings-Dresen MH 2004. Predictive factors of work disability in rheumatoid arthritis: a systematic literature review. *Annals of the Rheumatic Diseases* 63:1362–7.
- Eberhardt KB & Fex E 1995. Functional impairment and disability in early rheumatoid arthritis—development over 5 years. *Journal of Rheumatology* 22:1037–42.
- Ethgen O, Vanparijs P, Delhalle S, Rosant S, Bruyere O & Reginster JY 2004. Social support and health-related quality of life in hip and knee osteoarthritis. *Quality of Life Research* 13:321–30.
- Frank AO & Chamberlain MA 2001. Keeping our patients at work: implications for the management of those with rheumatoid arthritis and musculoskeletal conditions. *Rheumatology (Oxford)* 40:1201–5.
- Hakkinen A, Kautiainen H, Hannonen P, Ylinen J, Makinen H & Sokka T 2006. Muscle strength, pain, and disease activity explain individual subdimensions of the Health Assessment Questionnaire disability index, especially in women with rheumatoid arthritis. *Annals of the Rheumatic Diseases* 65:30–4.

- Hill CL, Gill T, Taylor AW, Daly A, Grande ED & Adams RJ 2006. Psychological factors and quality of life in arthritis: a population-based study. *Clinical Rheumatology* 26:1049–54.
- March LM 1997. Osteoarthritis. *Medical Journal of Australia* 166:98–103.
- Picavet HS & Hoeymans N 2004. Health related quality of life in multiple musculoskeletal diseases: SF-36 and EQ-5D in the DMC3 study. *Annals of the Rheumatic Diseases* 63:723–9.
- Plant MJ, O’Sullivan MM, Lewis PA, Camilleri JP, Coles EC & Jessop JD 2005. What factors influence functional ability in patients with rheumatoid arthritis. Do they alter over time? *Rheumatology (Oxford)* 44:1181–5.
- Sheehy C, Murphy E & Barry M 2006. Depression in rheumatoid arthritis—underscoring the problem. *Rheumatology (Oxford)* 45:1325–7.
- Simpson C, Franks C, Morrison C & Lempp H 2005. The patient’s journey: rheumatoid arthritis. *British Medical Journal* 331:887–9.
- Ware JE, Kosinski M & Keller SD 1996. A 12-item short-form health survey: construction of scales and preliminary tests of reliability and validity. *Medical Care* 34:220–33.
- Wikstrom I, Book C & Jacobsson LT 2006. Difficulties in performing leisure activities among persons with newly diagnosed rheumatoid arthritis: A prospective, controlled study. *Rheumatology (Oxford)* 45:1162–6.
- Woo J, Lau E, Lee P, Kwok T, Lau WC, Chan C et al. 2004. Impact of osteoarthritis on quality of life in a Hong Kong Chinese population. *Journal of Rheumatology* 31:2433–8.
- Zimmer Z, Hickey T & Searle MS 1997. The pattern of change in leisure activity behavior among older adults with arthritis. *Gerontologist* 37:384–92.