

Arthritis and osteoporosis  
in Australia 2008

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# Arthritis and osteoporosis in Australia 2008

National Centre for Monitoring Arthritis and Musculoskeletal Conditions

December 2008

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# Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
BAOC	Better Arthritis and Osteoporosis Care
BEACH	Bettering the Evaluation and Care of Health
BMD	bone mineral density
CURF	confidentialised unit record file
DMARD	disease-modifying anti-rheumatic drug
GP	general practitioner
HDL	high-density lipoprotein
HLA	human leukocyte antigen
HRQOL	health-related quality of life
HRT	hormone replacement therapy
ICD	International Classification of Diseases
ILAR	International League of Associations for Rheumatology
IR	inner regional areas of Australia
JIA	juvenile idiopathic arthritis
MC	major cities
MRI	magnetic resonance imaging
NAMSCAG	National Arthritis and Musculoskeletal Conditions Advisory Group
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NHPA	National Health Priority Area
NHS	National Health Survey
NSAID	non-steroidal anti-inflammatory drug
PBS	Pharmaceutical Benefits Scheme
RA	rheumatoid arthritis
RF	rheumatoid factor
RPBS	Repatriation Pharmaceutical Benefits Scheme
SDAC	Survey of Disability, Ageing and Carers
WHO	World Health Organization
YLD	years of life lost due to disability

# Summary

Arthritis and musculoskeletal conditions are the most common chronic conditions in Australia, affecting almost one-third of the population. Although not often direct causes of death, these conditions are major contributors to pain and disability, common reasons for use of health services and responsible for substantial direct health expenditure.

The naming of arthritis and musculoskeletal conditions as a National Health Priority Area in 2002 concentrated national attention initially on three of the most common conditions: osteoarthritis, rheumatoid arthritis and osteoporosis. A fourth condition, juvenile idiopathic arthritis, was added to these in 2006. These four conditions are also the focus of the *Better Arthritis and Osteoporosis Care* (BAOC) 2006 Federal Budget initiative, which aims to improve awareness, diagnosis and management.

Focusing on these four conditions, this report explores some of the 'big issues' in arthritis and osteoporosis today—such as disability, falls and fractures, treatment and management—and provides the latest data on how arthritis and osteoporosis affect Australians and Australia's health system.

## How many Australians have arthritis and osteoporosis?

- Self-reported information suggests that arthritis affects over 3 million Australians, including more than one-third of people aged 65 or over and more than half of those aged 85 years or over.
- More than 1.3 million Australians (6.5%) have osteoarthritis. Prevalence increases with age, from 1 in 1,000 people under 25 years of age up to 1 in 3 people over 85.
- Rheumatoid arthritis affects an estimated 384,000 Australians (1.9%). Females are almost twice as likely as males to report a diagnosis of this type of arthritis.
- Parental reports suggest 2,300 Australian children—mostly girls—have been diagnosed with juvenile arthritis. A similar number of parents report children with symptoms of arthritis but no formal diagnosis.
- Almost 600,000 Australians have been diagnosed with osteoporosis, the majority being females aged 55 years or over. Due to the mostly symptomless nature of the condition, this number is likely to be a substantial underestimate of the true extent of the problem.

## What impacts do arthritis and osteoporosis have on health and functioning?

- Arthritis or a related disorder is the main disabling condition for an estimated 561,000 Australians (3% of the population, and 14% of those with disability); 30% of these people are unable to perform, or need help with, self-care or mobility tasks.
- People of working age with arthritis-associated disability are less likely to be employed full-time compared with people with disability in general or people without disability, and are more likely to not be in the labour force.

- People with arthritis are more likely to experience psychological distress than people with other long-term conditions or no long-term conditions, and are also more likely to rate their health as fair or poor.
- Although in many cases juvenile arthritis goes into remission by adulthood, the physical, emotional and social effects of the disease often persist throughout life.
- Osteoporosis has no symptoms, so its effects are mainly seen through fractures. These generally result in immediate pain and loss of function, and may lead to long-term pain, disability, emotional distress and loss of independence.
- Almost all types of minimal trauma fractures—but especially hip and pelvic fractures—are associated with an increased risk of death in the following 12 months. Fractures are recorded as an associated cause of around 2,500 deaths in Australia each year; around 70% of cases involve hip and pelvic fractures.

### What types of health services do people with arthritis and osteoporosis use?

- Osteoarthritis is among the top 10 problems managed by general practitioners (GPs). Almost 2.7 million Medicare-paid GP consultations in 2007–08 included management of osteoarthritis.
- Rheumatoid arthritis is less likely than osteoarthritis to be managed by GPs; specialists such as rheumatologists and endocrinologists play a greater role.
- The use of medicines is the most common management strategy for arthritis. The most frequently used medications include analgesics, non-steroidal anti-inflammatory drugs and disease-modifying anti-rheumatic drugs.
- Allied health and complementary practitioners also play important roles in arthritis management. Their services are generally aimed at improving and maintaining body structure and function.
- Over 18,000 total hip replacements and almost 28,000 total knee replacements were performed in Australian hospitals in 2006–07, the majority being for osteoarthritis.
- Since 1993–94, the number of total hip replacements per 100,000 persons has increased by 92%, while the rate of total knee replacements has more than doubled.
- An estimated 850,000 GP consultations for osteoporosis were fully or partly funded by Medicare in 2007–08. One in eight consultations were for new cases of the condition.
- There were almost 51,000 hospitalisations for minimal trauma fractures in people aged 40 years or over in 2006–07. Hip and pelvic fractures accounted for 40% of cases.
- The number of minimal trauma hip fractures per 100,000 persons decreased significantly between 1999–00 and 2006–07, by 13% in males and by 15% in females.
- Allied health services, mostly physiotherapy, are the most common interventions provided in hospital separations for minimal trauma fractures, recorded in more than two-thirds of cases.
- Almost 5,000 partial hip replacements for minimal trauma hip fractures in people aged 40 years or over were performed in Australian hospitals in 2006–07.

### Are all Australians equally affected?

- Aboriginal and Torres Strait Islander Australians are more likely than other Australians to report having arthritis, but are much less likely to have hip or knee replacements.
- Osteoporosis is more common among Indigenous males, but less common among Indigenous females, compared with their non-Indigenous counterparts. However, Indigenous people of both sexes are much more likely than non-Indigenous people to be hospitalised with a minimal trauma hip fracture.
- People in the most disadvantaged areas of Australia are less likely than those in the least disadvantaged areas to have a total hip replacement, but more likely to have a total knee replacement.
- People living in regional and remote areas are more likely to have hip or knee replacements than those living in major cities.

### How much money is spent on these conditions?

- In 2004–05, around \$1.2 billion in direct health expenditure was attributed to osteoarthritis—almost one-third of the total amount spent on arthritis and musculoskeletal conditions. Admitted hospital patient services (for example, joint replacements) were the main contributor to this expenditure.
- Direct health expenditure on rheumatoid arthritis in 2004–05 was estimated at \$175 million, with prescription pharmaceuticals accounting for more than half of this.
- More than \$304 million of direct health expenditure in 2004–05 was for osteoporosis. Prescription pharmaceuticals made up almost three-quarters of this amount. (Note that this figure does not include expenditure on fractures resulting from osteoporosis.)
- No information on Australian expenditure for juvenile arthritis is currently available. Direct health expenditure on arthritis and musculoskeletal conditions in people less than 15 years of age was estimated to be \$94 million in 2004–05.

### What can be done to prevent arthritis and osteoporosis?

- Regular physical activity, a balanced diet, maintaining a healthy weight and avoiding repetitive joint-loading tasks (such as kneeling, squatting and heavy lifting) can help to prevent or delay the onset of osteoarthritis.
- Rheumatoid and juvenile arthritis are not considered to be preventable, given current knowledge. However, not smoking may reduce the risk of rheumatoid arthritis.
- Osteoporosis is largely preventable. Key preventive actions include regular weight-bearing exercise, a balanced diet including calcium-rich foods, adequate vitamin D levels and maintaining a healthy weight. Childhood and adolescence is a key time for building healthy bones and ensuring high peak bone mass.
- The risk of falls and fractures can be reduced through maintaining balance and mobility, reviewing medications, addressing environmental hazards and attending a falls prevention class. The use of medications such as bisphosphonates, calcium and vitamin D supplements (where necessary) is also important.

# 1 Introduction

## A GLOBAL PROBLEM

Arthritis and osteoporosis are among the world's leading causes of long-term pain and disability (Lidgren 2003). Although they are not often direct causes of death, these conditions make large contributions to pain, deformity, mobility restriction and functional impairment, as well as affecting mental health and quality of life. The burden of arthritis and osteoporosis applies not only to the individuals affected by these conditions, but to their families, friends and society in general, through reduced social interaction, role restrictions, lost productivity, and the significant cost of ongoing management and treatment.

The World Health Organization (WHO) estimated that musculoskeletal diseases were the fifth largest cause of global years of life lost due to disability (YLD) in 2002, accounting for more than 5% of the total (WHO 2004). This figure does not include the contribution of osteoporotic fractures; falls in people aged 65 years or over were estimated to account for another 0.8% of global YLD in 2002.

Recognition of the burden of arthritis, osteoporosis and other musculoskeletal conditions, and the need for action worldwide, led to the declaration of 2000–2010 as the Bone and Joint Decade. The Decade aims 'to improve the quality of life for people who have musculoskeletal conditions and to advance the understanding and treatment of these conditions through research, prevention and education' (Weinstein 2000). More than 750 professional bodies, advocacy groups, industry and research organisations, and governments across 60 countries (including Australia) support the Decade, confirming the global nature of the musculoskeletal disease burden and its impact on all sectors of society.

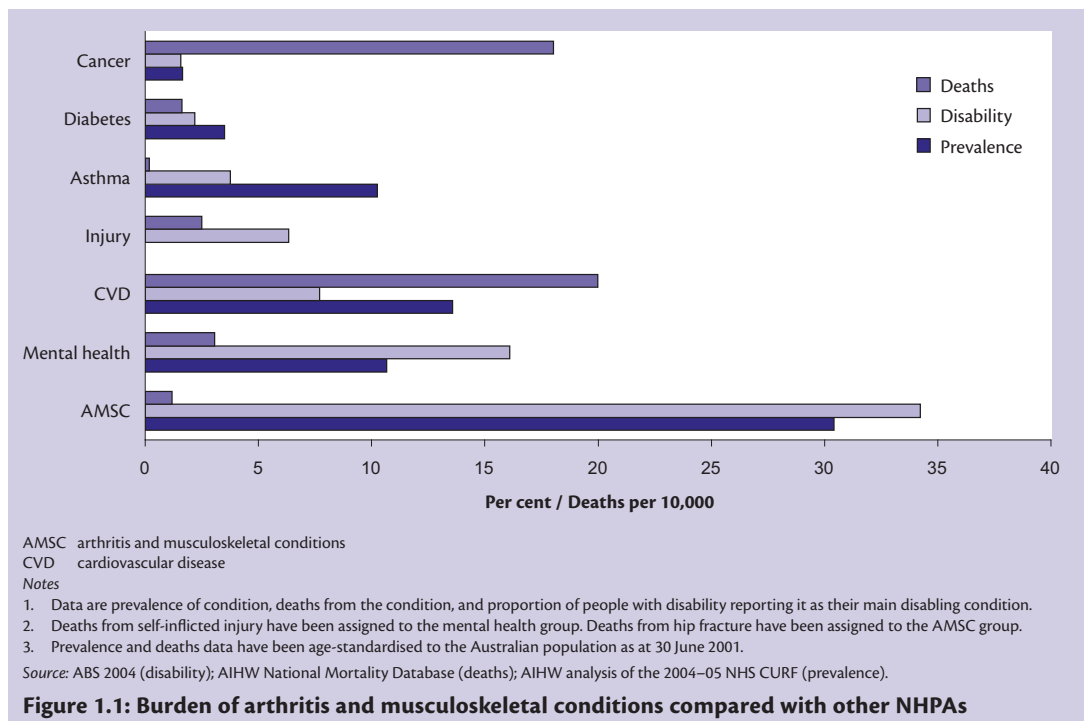
## THE AUSTRALIAN PICTURE

In Australia, arthritis and osteoporosis are identified as a focus under the National Health Priority Area (NHPA) of arthritis and musculoskeletal conditions. Self-reported data suggest that long-term arthritis and musculoskeletal conditions affect 31% of the Australian population, more than 6 million people (ABS 2006). Although these conditions cause relatively few deaths, they are by far the most prevalent of all the NHPA diseases and conditions, and the most commonly reported causes of disability (Figure 1.1). The WHO Global Burden of Disease project estimated that musculoskeletal conditions were the sixth largest contributor to YLD in Australia in 2002, at almost 5% of the total (WHO 2004).

Overall, the most commonly reported musculoskeletal conditions in Australia are arthritis (affecting an estimated 3.0 million people), back pain (2.1 million), disc disorders (1.1 million) and osteoporosis (0.6 million). Prevalence is highest among people aged 65 years or over: two out of three people of this age have arthritis or another musculoskeletal condition, and more than 50% have arthritis, osteoporosis, or both. But those at younger ages are not immune, with 1 in every 36 people aged less than 18 years reportedly having arthritis or a musculoskeletal condition—an estimated 131,000 Australian children and young people.

Arthritis and musculoskeletal conditions are the most common causes of long-term disability in Australia, with 34% of people with disability in 2003 reporting that arthritis or another musculoskeletal condition was their main disabling condition (ABS 2004). Almost half of these people were restricted in schooling or employment due to their disability, and over one quarter had a severe or profound core activity limitation (meaning that they were unable to perform, or sometimes or always needed help with performing, communication, mobility or self-care tasks).

Arthritis and musculoskeletal conditions are also common reasons for the use of health care services. In 2006–07, arthritis and musculoskeletal conditions were managed at 17 out of every 100 of GP encounters reported in the Bettering the Evaluation and Care of Health (BEACH) GP survey (Britt et al. 2007), and accounted for more than 3% of all hospital separations (AIHW 2007). Use of these and other medical and allied health care services, along with the need for medications and high-level residential care services, results in substantial expenditure on these conditions. Arthritis and musculoskeletal conditions were the fourth leading contributor to direct health expenditure in Australia in 2004–05, at \$4.0 billion. The three conditions osteoarthritis, rheumatoid arthritis and osteoporosis together accounted for more than 40% of this expenditure.



## POTENTIAL FOR CHANGE

The effects of arthritis and osteoporosis can be reduced through prevention, early diagnosis and initiation of treatment, and appropriate long-term management. Over the past couple of decades, better understanding of the causes, risk factors and progression of the various conditions has led to new strategies for primary prevention and improved management techniques. Advances in the pharmaceutical field have also resulted in new and more effective medications for treatment, and improvements in surgical techniques have meant that joint replacement surgery is more widely available.

## Primary prevention

Osteoarthritis and osteoporosis can be prevented, or at least have their onset delayed, through preventive action. Although varying in their impact on specific conditions, lifestyle changes (including regular physical activity, maintenance of healthy weight, a balanced diet, limiting alcohol intake and not smoking) are the basic building blocks for prevention of these and many other chronic diseases. In addition, avoidance or limitation of repetitive load-bearing activities and prevention of joint trauma can reduce the risk of developing osteoarthritis.

## Treatment and management

The treatment of arthritis and osteoporosis is focused on alleviating symptoms, optimising function, minimising the impact of disability and maximising quality of life. The use of medication is the most common way of achieving these outcomes, in combination with physical and occupational therapy and self-management education. Early diagnosis and prompt initiation of treatment can minimise functional limitations and slow disease progression. In people with severe osteoarthritis or rheumatoid arthritis, joint replacement surgery is a cost-effective intervention that can reduce pain, increase joint functionality and improve the quality of life. Interventions that reduce the risk of falling, or devices (such as hip protectors) that absorb the impact of falls, can be beneficial in people with osteoporosis.

More detailed information about prevention, treatment and management is provided in chapters 4, 5 and 6. Information about reducing the impact of arthritis-associated disability can be found in Chapter 3.

## NATIONAL ACTION

In July 2002, Australian health ministers formally recognised the burden of arthritis and musculoskeletal conditions in Australia, and the potential for reduction of this burden, by declaring them an NHPA. Listing as an NHPA provides impetus for regular surveillance and monitoring activity, and provides a framework for the introduction of health interventions. The initial focus of the NHPA was on osteoarthritis, rheumatoid arthritis and osteoporosis, with juvenile arthritis added to the list in 2006. Although the importance of other musculoskeletal conditions and their significant impact on health and quality of life is recognised, focusing efforts on a small number of conditions at any one time enables targeted action and the setting of more manageable and achievable goals.

To guide action under the NHPA, a National Action Plan was developed by the National Arthritis and Musculoskeletal Conditions Advisory Group (NAMSCAG), in consultation with stakeholders and consumers (Australian Health Ministers' Conference 2005). The plan aims 'to provide a blueprint for national efforts to improve the health-related quality of life of people living with osteoarthritis, rheumatoid arthritis and osteoporosis, reduce the cost and prevalence of those conditions, and reduce the impact on individuals, their carers and communities within Australia' (Australian Health Ministers' Conference 2005:2). The plan states five key objectives:

- to reduce the burden of disease associated with osteoarthritis, rheumatoid arthritis and osteoporosis
- to advance and disseminate knowledge and understanding of osteoarthritis, rheumatoid arthritis and osteoporosis

- to reduce disadvantage by considering groups with special needs
- to drive national improvements in systems and services
- to measure and manage performance and outcomes.

More recently, the National Chronic Disease Strategy and National Service Improvement Frameworks identified osteoarthritis, rheumatoid arthritis and osteoporosis as conditions of major importance in Australia (National Health Priority Action Council 2006a, b). These documents outline the need for improvements in the prevention, detection and management of chronic diseases, optimisation of self-management strategies, and a focus on population groups with special needs. The need for the development, collection and reporting of measures to monitor program outcomes, and national data systems that can monitor population trends in prevalence, risk factors, comorbidities and service use patterns, is also emphasised.

In the 2002–03 Federal Budget, funding for four years was allocated to the *Better Arthritis Care* initiative. The 2006–07 Budget extended this funding for a further four years as the *Better Arthritis and Osteoporosis Care* (BAOC) initiative, allocating a total of \$14.8 million over 2006–07 to 2009–10. The focus conditions were also expanded at this time to cover juvenile idiopathic arthritis. The aims of the BAOC initiative are to provide better diagnosis, promote best-practice treatment and management, provide multidisciplinary care, promote self-management and support proven self-management options.

The two budget allocations provided funding for a large number of projects for improving care, the development of the National Action Plan, and several projects addressing the plan's key objectives (see DoHA 2008). Funding was also provided for the production of a baseline monitoring report on arthritis and musculoskeletal conditions in Australia, and the establishment of a national monitoring centre.

## NATIONAL MONITORING AND SURVEILLANCE

Data on arthritis and osteoporosis in Australia are limited. The largely non-fatal nature of these conditions, and the perception that arthritis is 'an old person's disease' related to normal wear and tear, has probably contributed to the lesser degree of attention that monitoring of arthritis and musculoskeletal conditions has received in the past, compared to more obvious causes of ill-health and death such as heart disease and cancer. However, arthritis and osteoporosis have a substantial impact on disability and quality of life, and are among the most prevalent long-term health conditions occurring in Australia. It is important, therefore, that accurate, reliable and comprehensive information about them is available, to inform national discussion and decision-making and support further research.

The National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis identifies the need for establishing baselines and implementing ongoing data collection systems to support research (Australian Health Ministers' Conference 2005). The plan also outlines a number of monitoring-related strategies to achieve the five key objectives listed above, including:

- gathering information on the disease burden related to osteoarthritis, rheumatoid arthritis and osteoporosis
- planning and developing the ongoing collection of comprehensive data
- developing and monitoring performance indicators (Australian Health Ministers' Conference 2005).



An effective monitoring and surveillance system can facilitate the prevention and management of arthritis and musculoskeletal conditions; it can determine their impact, reveal variation between population groups and detect underlying trends. This information can underpin workforce and service planning, inform national policies and strategies, and identify groups with special needs.

To progress monitoring and surveillance activities, the National Centre for Monitoring Arthritis and Musculoskeletal Conditions was established in 2005. The primary objective of the centre is to undertake national surveillance and monitoring of arthritis and musculoskeletal conditions, and become a reliable source of national information on these conditions. Located within the Australian Institute of Health and Welfare, the Centre has access to a range of national data relevant to osteoarthritis, rheumatoid arthritis, juvenile arthritis and osteoporosis. The Centre is guided by a steering committee, formerly the Data Working Group of NAMSCAG, which includes representatives from government, professional and consumer organisations, as well as clinical experts.

## PURPOSE AND STRUCTURE OF THIS REPORT

This report is the second in the series of comprehensive surveillance reports that began with *Arthritis and musculoskeletal conditions in Australia 2005* (AIHW: Rahman et al. 2005). That report provided baseline information on the status of arthritis and musculoskeletal conditions in Australia, with a focus on osteoarthritis, rheumatoid arthritis and osteoporosis. The current report provides more in-depth information about prevention, treatment and management of these three conditions, as well as providing insight into significant issues such as disability. In addition, the problem of arthritis in children and young people is discussed, with reference to impacts on development, schooling and quality of life, and the effects of the diagnosis on the child's family.

The report has been organised into seven chapters and two appendixes. This introductory chapter provides an overview of the burden of arthritis and osteoporosis in Australia, and describes national action to reduce this burden. General information on the focus conditions of osteoarthritis, rheumatoid arthritis, juvenile idiopathic arthritis and osteoporosis, including their clinical presentation, prevalence, risk factors and treatment goals, are provided in Chapter 2.

The significant disability caused by arthritis, and the effects this has on quality of life and mental health, is detailed in Chapter 3. The types of problems experienced, forms of assistance needed, and modifications and aids that can be used are described.

Chapter 4 focuses on juvenile arthritis. The various types of arthritis that affect people at young ages are described, along with an overview of their treatment, management and prognosis. The effects of arthritis on the young person's physical and mental health, development, education, social interaction and quality of life are also discussed. In addition, the chapter looks at some of the impacts that the diagnosis of arthritis has on the young person's parents and siblings.

Specific strategies for reducing the burden of arthritis in Australia are discussed in Chapter 5. The chapter details prevention and management options, and presents data about the use of health services for arthritis management.

Chapter 6 is devoted to osteoporosis and fractures. In people with established osteoporosis, the risk of fractures can be greatly decreased through interventions that prevent or reduce the risk of falling. The chapter details the causes and development of osteoporosis, discusses its treatment and management, and outlines prevention strategies. It also describes common fracture types and their treatment, impacts on physical and mental health and quality of life, and fall-related interventions.

Finally, Chapter 7 explores trends and patterns in osteoarthritis, rheumatoid arthritis and osteoporosis through examining the national indicators for these conditions. Information on recent trends in prevalence, use of health services and types of therapies is provided. The chapter also considers variation across population groups and geographic areas. Baseline data for each of the indicators (the most recent year available, by age group and sex) are provided in Appendix 1.

The information presented in this report should complement that provided by the baseline report, *Arthritis and musculoskeletal conditions in Australia 2005*. In addition to providing the most recent data on prevalence, health service use and uptake of therapies, this report considers significant issues in detail, promoting greater awareness and understanding of the burden of arthritis and osteoporosis in Australia.

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## 2 Overviews of the focus areas

The focus of the arthritis and musculoskeletal conditions NHPA and the BAOC initiative is on four conditions, namely osteoarthritis, rheumatoid arthritis, juvenile idiopathic arthritis and osteoporosis. Brief overviews of these conditions are provided below, and more detailed information on specific issues is presented throughout this report. An overview of direct health expenditure on arthritis and osteoporosis is also included.

### OSTEOARTHRITIS

Osteoarthritis is the most common form of arthritis, in which a range of factors leads to cartilage loss, which impairs the normal functioning of the joints. Normally, the cartilage cushions the ends of the bones within joints, allowing them to glide over each other, but when it is lost the bones can rub together, causing pain and swelling, and limiting movement. This can result in disability and reduce the quality of life. The joints most commonly affected are those in the hands and spine, and weight-bearing joints such as the hips and knees.

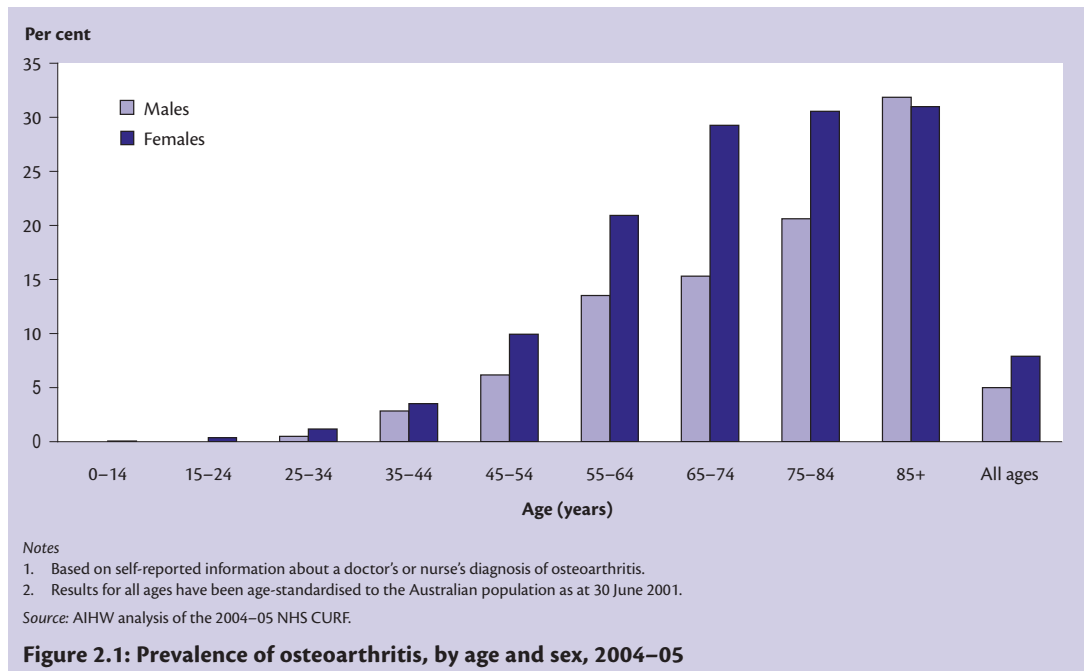
Osteoarthritis most commonly develops in people aged 45 years or over. The main symptoms are pain, stiffness and limitations in joint movement. Although the symptoms and their severity vary from person to person, in general the condition gradually worsens over time and often results in functional impairment. At first, pain is felt during and after activity, but as the condition worsens pain may be felt during minor movements or even at rest. The affected joints may become enlarged and tender, which may affect fine motor skills and lead to difficulty in performing everyday activities.

### Prevalence

Self-reported data suggest that over 1.3 million Australians, or 6.7% of the population, have been diagnosed with osteoarthritis. The condition is more common among women than men, and prevalence increases with age (Figure 2.1). Almost three-quarters of Australians who report having osteoarthritis are aged 55 years or over.

### Causes, risk factors and determinants

The causes of osteoarthritis are not completely understood, but a range of factors have been linked to its development. Older people and females are more likely to have osteoarthritis, and there is also a genetic component, with people who have a family history of the condition being more likely to develop it. Modifiable risk factors for osteoarthritis include overweight (particularly for osteoarthritis of the knee), physical inactivity, joint trauma (such as dislocation or fracture) and repetitive joint-loading tasks (for example, kneeling, squatting and heavy lifting).



## Treatment and management

There is at present no cure for osteoarthritis, and management is primarily aimed at treating the symptoms: reducing pain, improving quality of life, preserving or improving joint function, and maintaining independence. In most cases medications are used for pain relief and to reduce inflammation. These are often used in combination with other strategies including physiotherapy, occupational therapy, weight loss and exercise. Joint replacement surgery may be considered in cases where the symptoms are severe or do not respond to other interventions.

More information about prevention, treatment and management of osteoarthritis is provided in Chapter 5. The effects of arthritis on functioning and quality of life are discussed in Chapter 3.

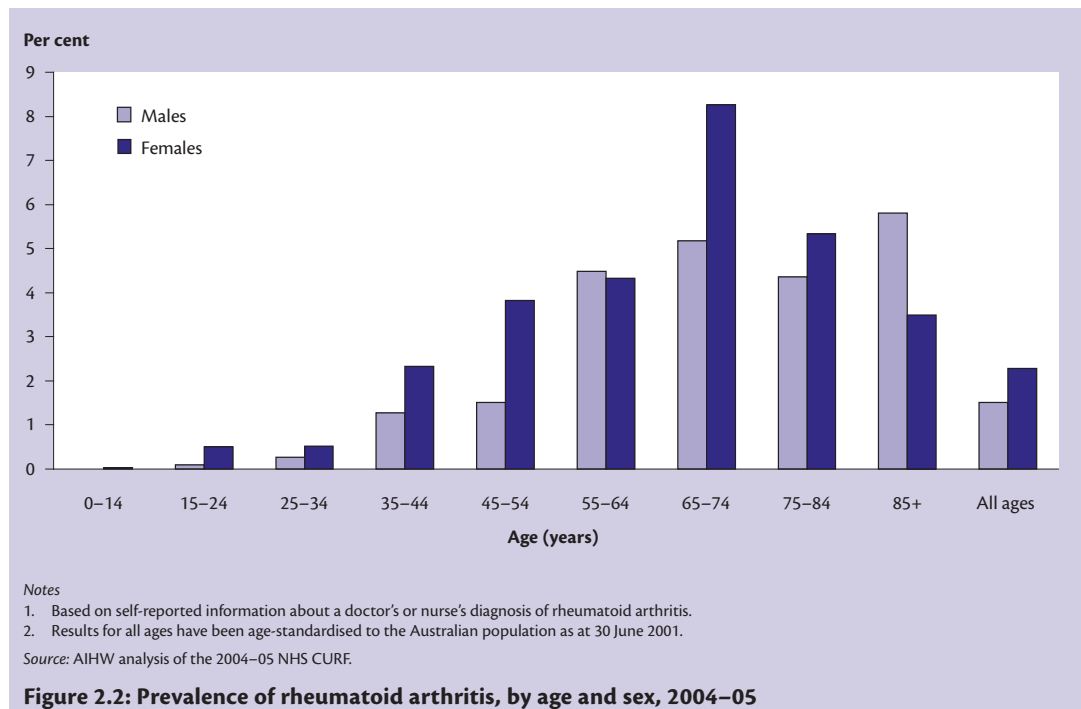
## RHEUMATOID ARTHRITIS

Rheumatoid arthritis is an autoimmune disease—one where the body's immune system mistakenly attacks its own tissues. In rheumatoid arthritis, the immune system attacks the tissues lining the joints (called the synovial membranes), causing inflammation, pain and swelling. This causes progressive and irreversible joint damage, which can result in deformity and severe disability, and greatly reduce the quality of life. Often the joints are affected in symmetrical fashion (that is, the same joint on both sides of the body), with the hands being the most common site affected.

Rheumatoid arthritis is a systemic disease, meaning that the whole body, including the organs, is affected. This can lead to problems with the heart, respiratory system, nerves and eyes. The life expectancy of people with rheumatoid arthritis is significantly lowered compared with the general population, by an average of 5-10 years (Myllykangas-Luosujarvi et al. 1995).

## Prevalence

Worldwide, about 1% of people are believed to have rheumatoid arthritis. Self-reported data indicate that around 384,000 Australians (2.0%) have been diagnosed with the condition, but this is believed to be an overestimate due to confusion between rheumatoid arthritis and 'rheumatism' (a generic word describing pain in the joints and muscles, commonly used in the past). Rheumatoid arthritis can occur at any age, although onset is most common between the ages of 30 and 55 years. More females than males are affected (Figure 2.2).



## Causes, risk factors and determinants

The exact cause of rheumatoid arthritis is unknown. There is a strong genetic component, with the disease tending to 'run' in families, but a person with rheumatoid arthritis will not necessarily pass it on to his or her children. It is possible that some sort of environmental 'trigger' (such as an infection) may prompt development of the disease in those who are susceptible.

Other factors may also contribute to the development of rheumatoid arthritis. The most well-recognised of these is tobacco smoking. People who smoke are at increased risk of the disease, with the risk increasing as the duration of smoking increases (Stolt et al. 2003). The female sex hormone, oestrogen, may also influence development of the disease, with incidence being higher than expected in women experiencing menopause and in the first year following childbirth, and lower during pregnancy (Kuiper et al. 2001). Evidence linking rheumatoid arthritis with obesity, caffeine consumption, air quality and various nutritional factors is inconclusive.

## Treatment and management

Goals of treatment for rheumatoid arthritis include pain relief, minimising joint damage, maintaining function and maximising quality of life. Although there is no cure for the disease, early treatment with disease-modifying anti-rheumatic drugs (DMARDs) can greatly reduce its effects. Early diagnosis and prompt initiation of treatment is therefore vital if the maximum benefits are to be obtained. With new combination medications now available, inducing remission is becoming a valid treatment goal.

Self-management education and regular follow-up to track disease activity and assess comorbidities are important components of management for people with rheumatoid arthritis. Treatment may also include strengthening exercises, occupational therapy, and the use of other medications, such as non-steroidal anti-inflammatory drugs (NSAIDs) and corticosteroids.

More information about the treatment and management of rheumatoid arthritis is provided in Chapter 5. The effects of arthritis on functioning and quality of life are discussed in Chapter 3.

## JUVENILE IDIOPATHIC ARTHRITIS

Juvenile idiopathic arthritis (JIA) is the common term used to describe any of several forms of arthritis occurring in children under the age of 16 years. Other terms that may be used include juvenile rheumatoid arthritis, juvenile chronic arthritis or simply 'juvenile arthritis'. The various forms of juvenile arthritis are distinguished by the number and sites of the affected joints, other symptoms present, and the nature of disease onset (gradual or rapid).

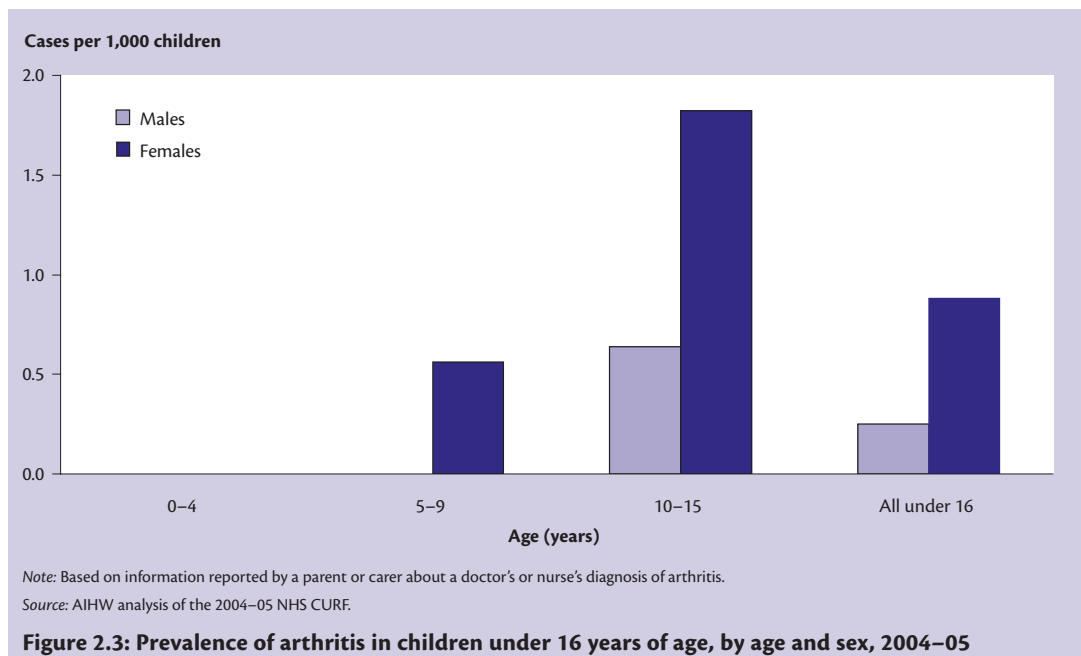
The main symptoms of most forms of juvenile arthritis are swelling, pain and stiffness in the affected joints. These symptoms may be accompanied by fever, skin rash and/or fatigue, and the child may feel generally unwell. For a diagnosis to be made, symptoms must have been present for at least 6 weeks. The type and severity of symptoms may vary between children and from day to day.

In most cases, juvenile arthritis will last from a few months up to a few years and the child will gradually recover. However, the damage done to growing joints may lead to functional impairment in adulthood. Around 15% of children diagnosed with juvenile arthritis may continue to have symptoms and active disease progression into adulthood and throughout life.

## Prevalence

Information from the 2004–05 National Health Survey suggests that around 2,300 people under the age of 16 years have been diagnosed with arthritis—530 boys and 1,780 girls. Although arthritis can occur in very young children, no cases were reported in children under 5 years of age in 2004–05. The majority of children affected were girls aged 10–15 years (Figure 2.3).





## Causes, risk factors and determinants

The causes of juvenile arthritis are unknown. A genetic factor is suspected, although there is often no apparent family history of the condition. No triggers, environmental or lifestyle factors have been found to explain development of the disease.

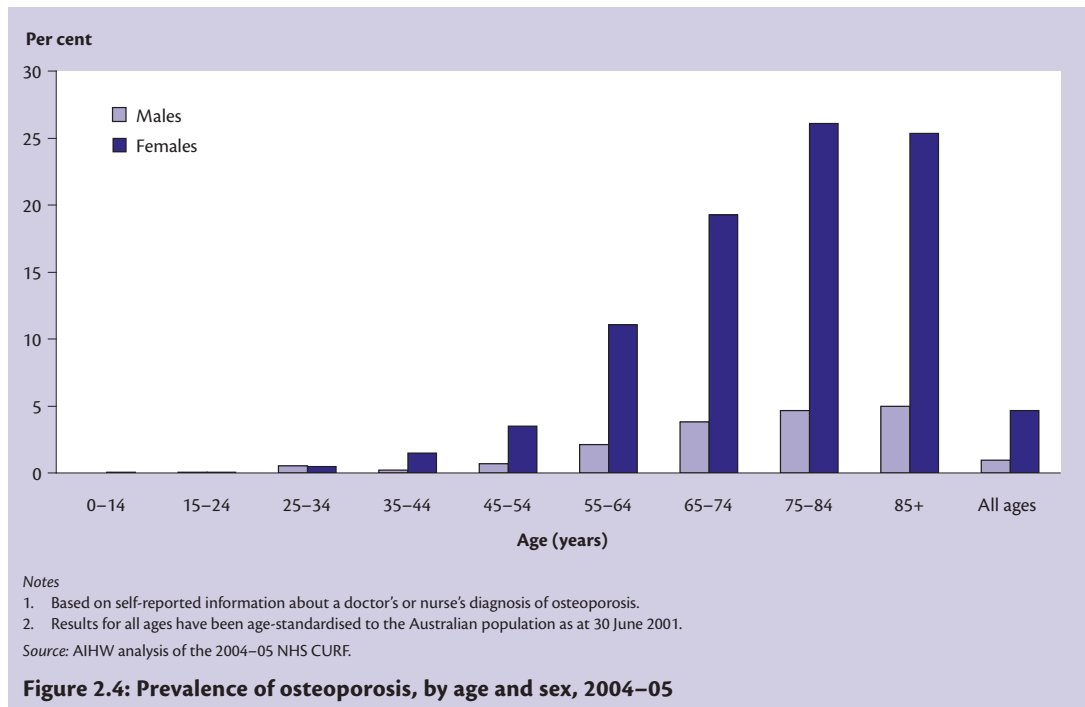
## Treatment and management

As with adult forms of arthritis, treatment for juvenile arthritis consists of medications for pain relief and to reduce inflammation, physical and occupational therapy to optimise joint function, and the use of aids to assist with everyday tasks, school activities and play. Regular follow-up and contact with a variety of specialists is important: children with some forms of juvenile arthritis are at increased risk of eye inflammation and vision problems, and others may develop dental problems if the jawbone is affected.

More detailed information about juvenile arthritis is provided in Chapter 4.

## OSTEOPOROSIS

Osteoporosis (meaning 'porous bones') is characterised by reduced bone density and strength, leading to increased risk of fracture. The condition most commonly presents clinically as a minimal trauma fracture, that is, a fracture sustained in an event where a healthy bone would not be expected to break. Such events might include a fall out of bed or from a chair, or a trip and fall while walking. These fractures may severely impact upon the quality of life, through pain, disability, deformity, mobility impairment and loss of independence, and may even reduce life expectancy. Common fracture sites include the hip, wrist and spine.



## Prevalence

Osteoporosis is much more common among women than men, and mostly occurs in those aged 55 years or over (Figure 2.4). Women have a lower total bone mass than men, and the normal reduction in bone density with ageing is accelerated by the change in oestrogen levels following menopause (NAMSCAG 2004). Self-reported data indicate that more than 581,000 Australians (3.0%) have been diagnosed with osteoporosis, with 85% being female and 83% aged 55 years or over. Among females, prevalence rises rapidly with age until 80-84 years before falling slightly, whereas among males prevalence gradually increases with age.

Because osteoporosis has no overt symptoms, it is often only diagnosed following a fracture. Therefore, it is likely that estimates based on self-reported information considerably underestimate the true prevalence of osteoporosis.

## Causes, risk factors and determinants

A variety of factors are associated with the development of osteoporosis, in addition to increasing age and female gender. These include a family history of the condition, low vitamin D levels, low intake of calcium, low body mass index (a measure of weight relative to height), smoking, excess alcohol consumption, physical inactivity, long-term corticosteroid use and reduced oestrogen levels. People with certain health conditions, including rheumatoid arthritis, chronic respiratory disease, chronic liver disease and inflammatory bowel disease, are also more likely to develop osteoporosis.

## Treatment and management

Medications are the main therapy for established osteoporosis, and can be divided into two classes: those that reduce the absorption of minerals from the bones, and those that promote bone formation. Other interventions include preventing fractures by reducing the risk of falls, for example, through improvements in muscle strength, balance and mobility, home modifications, and appropriate management of medications.

More information about osteoporosis and fractures is provided in Chapter 6.

## EXPENDITURE ON ARTHRITIS AND OSTEOPOROSIS

This section provides information about direct health expenditure on arthritis and osteoporosis. Direct health expenditure is monies spent by governments, private health insurers, companies and individuals to prevent, diagnose and treat health problems. The estimates of expenditure provided here do not include indirect costs (for example, travel costs, child care costs or lost wages), the cost of purchasing or hiring aids and appliances or undertaking home modifications, intangible costs such as reductions in quality of life, or the monies allocated by the Australian Government under the BAOC initiative.

Note that in 2004–05, expenditure was only able to be allocated to the following health service areas:

- hospital services for admitted patients
- out-of-hospital medical services
- prescription pharmaceuticals
- research.

In previous years expenditure was also able to be allocated to hospital services for non-admitted patients, other professional services and over-the-counter pharmaceuticals. It was not possible to allocate expenditure by disease group to these types of services in 2004–05. Expenditure on high-level residential aged care services, also previously included as a component of direct health expenditure, are now considered a component of welfare expenditure and are no longer included in estimates of direct health expenditure.

For comparison purposes, direct health expenditure by disease group for 2000–01 for the four health service areas able to be allocated in 2004–05 are provided in Table 2.1.

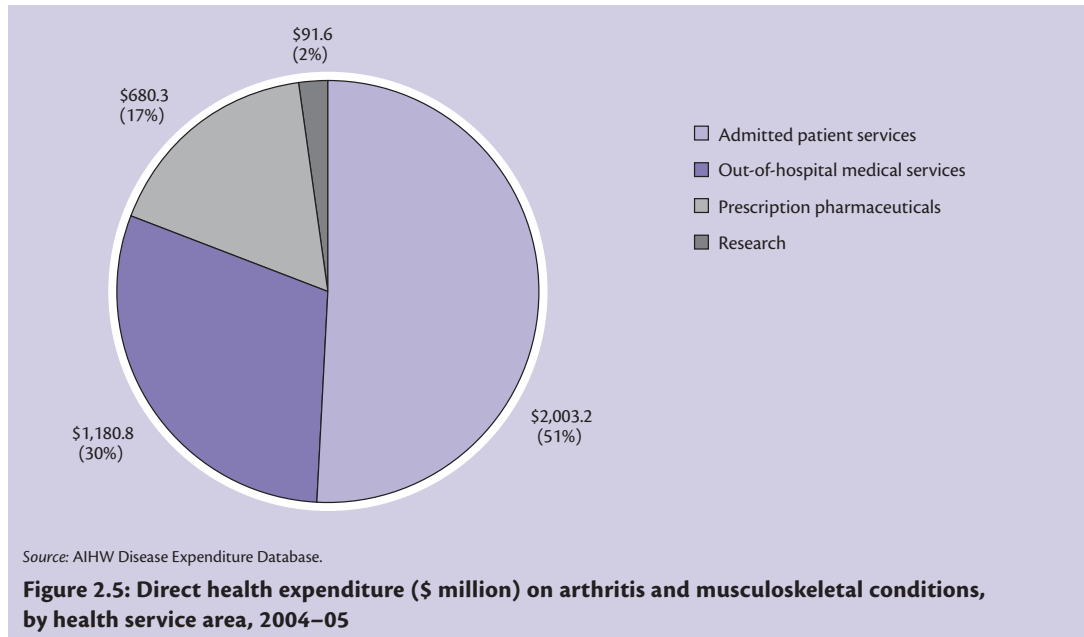
**Table 2.1: Direct health expenditure for arthritis and musculoskeletal conditions, 2000–01**

Health service area	Osteoarthritis	Rheumatoid arthritis	Osteoporosis	All arthritis and musculoskeletal conditions
		\$ million		
Admitted hospital patients	493.5	27.4	31.8	1,286.1
Out-of-hospital medical services	124.6	35.8	29.4	878.7
Prescription pharmaceuticals	102.7	23.9	75.5	467.9
Research	14.1	2.9	2.6	55.2
<b>Total</b>	<b>734.9</b>	<b>90.0</b>	<b>139.3</b>	<b>2,687.9</b>

Source: AIHW Disease Expenditure Database.

## Total expenditure on arthritis and musculoskeletal conditions

In 2004–05, Australia spent more than \$87 billion on health services, almost 10% of gross domestic product (AIHW 2006). Around 60% of this, or \$52.7 billion, was able to be allocated by disease group. Arthritis and other musculoskeletal conditions accounted for just under \$4 billion of this expenditure (7.5%). Admitted patient services in hospitals were the biggest contributor to overall expenditure for these conditions (Figure 2.5).



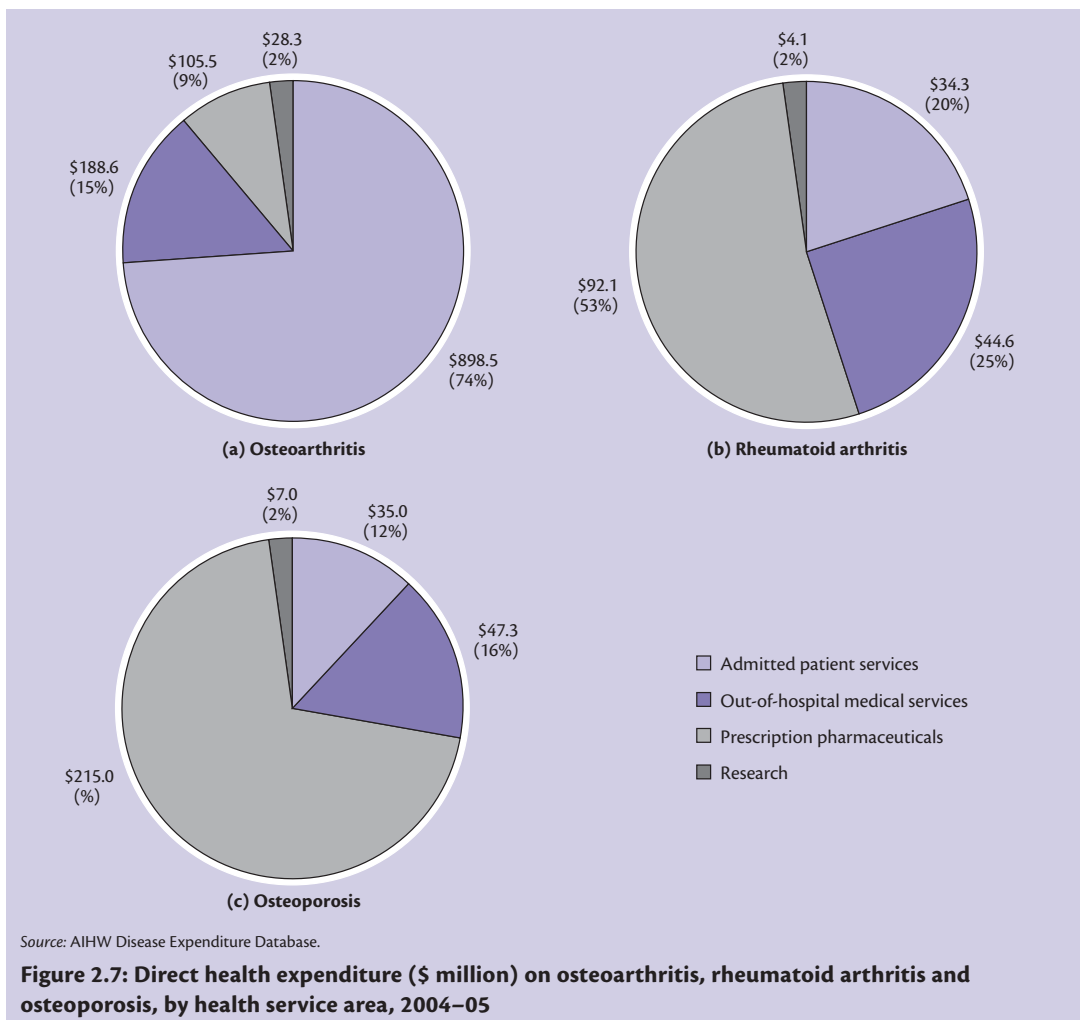
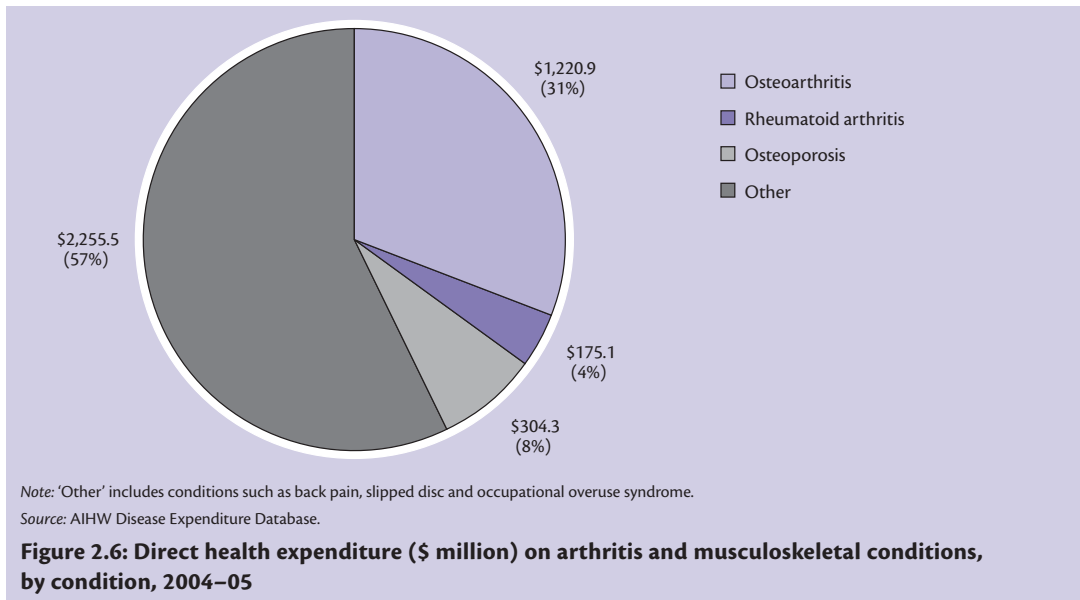
## Expenditure on the focus conditions

**Osteoarthritis** accounted for the largest proportion of direct health expenditure on arthritis and musculoskeletal conditions in 2004–05, at \$1.2 billion (31%) of the total (Figure 2.6). Admitted patient services were the main component of this expenditure, at \$898 million (74% of expenditure on osteoarthritis) (Figure 2.7(a)). Admission for surgical procedures, including joint replacement, is a major contributor to hospital expenditure for osteoarthritis.

A little over 4% (\$175 million) of the direct health expenditure on arthritis and musculoskeletal conditions in 2004–05 was attributed to **rheumatoid arthritis**. Expenditure on prescription pharmaceuticals accounted for more than half of this (53%), at \$92 million (Figure 2.7(b)).

Direct health expenditure on **osteoporosis** was more than \$304 million in 2004–05, almost 8% of the total direct health expenditure on arthritis and musculoskeletal conditions in that year. Prescription pharmaceuticals accounted for the largest proportion of this expenditure, at \$215 million (71%) (Figure 2.7(c)).

No information on direct health expenditure specifically for **juvenile arthritis** is available in Australia. However, it is estimated that direct health expenditure on arthritis and musculoskeletal conditions in people less than 15 years of age amounted to slightly more than \$94 million in 2004–05.



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## 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.

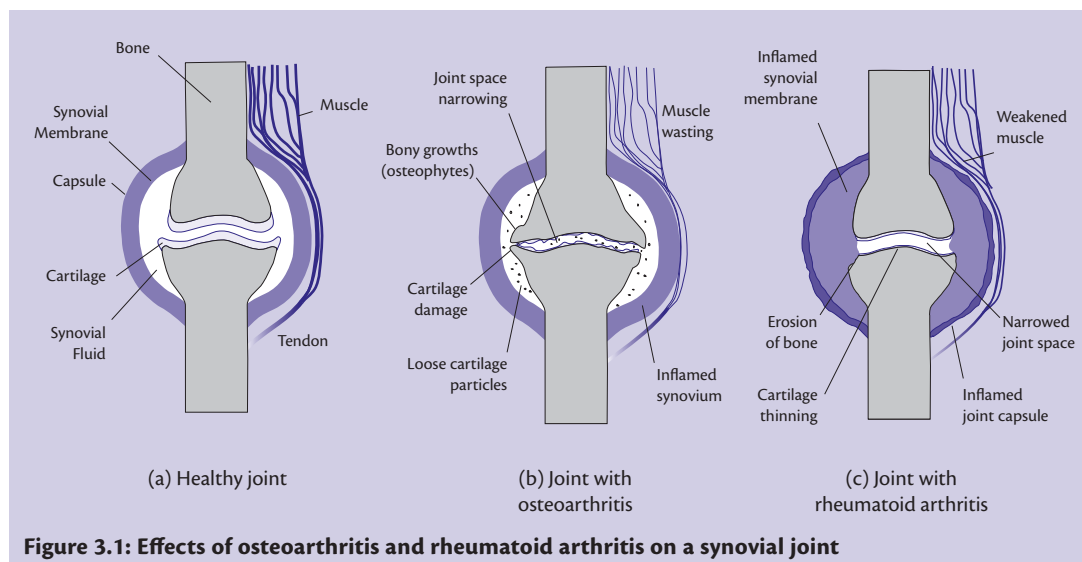


## HOW ARTHRITIS LEADS TO DISABILITY

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.

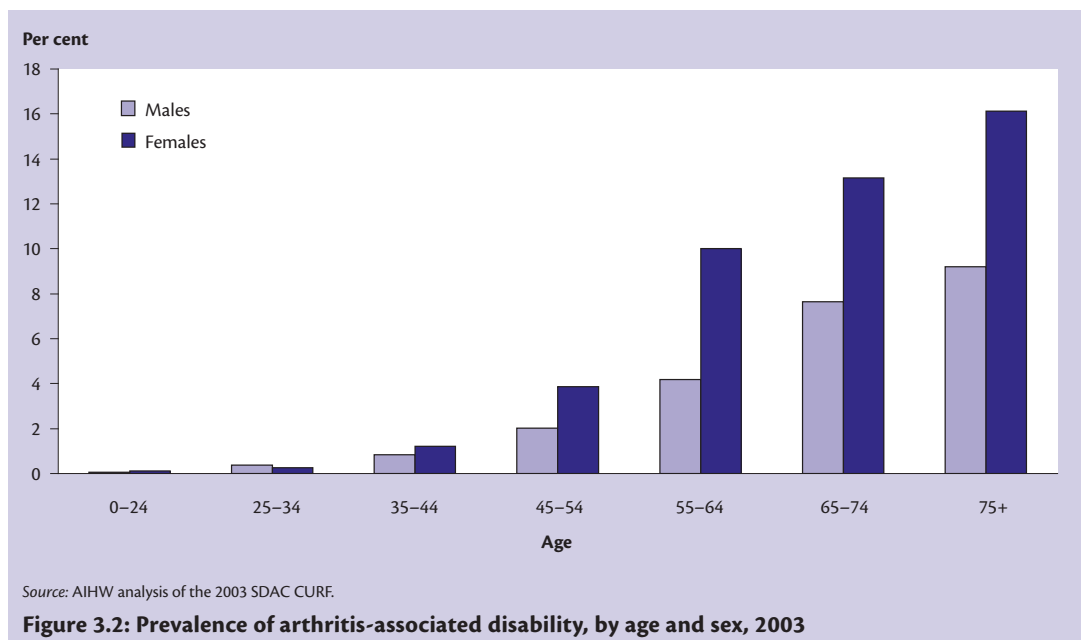
### Different experiences of disability

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).

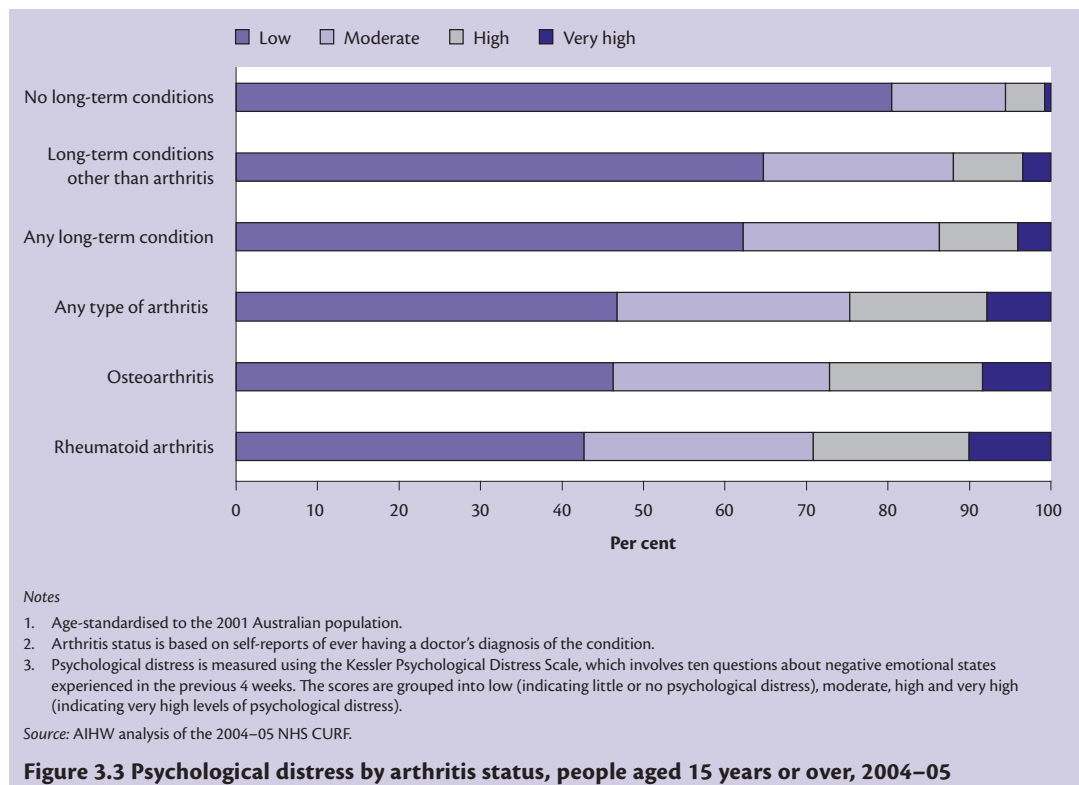


## MENTAL HEALTH

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).

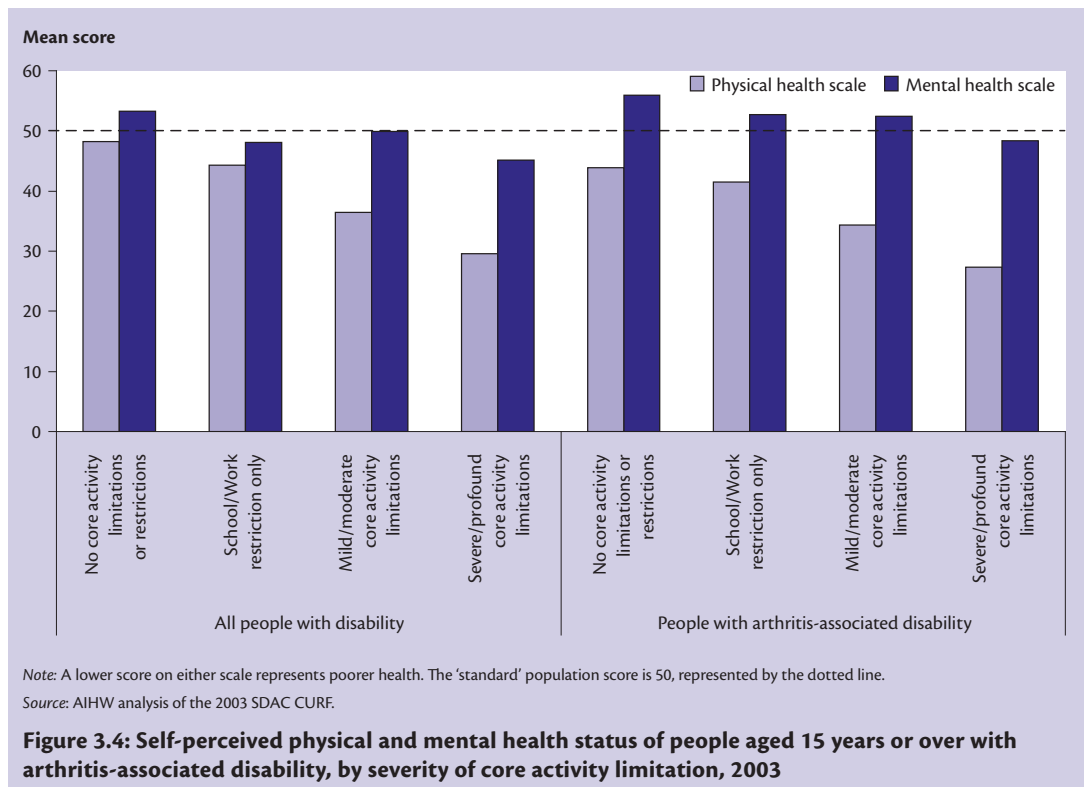
### **Box 3.1: Measuring health-related quality of life (HRQOL)**

*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.

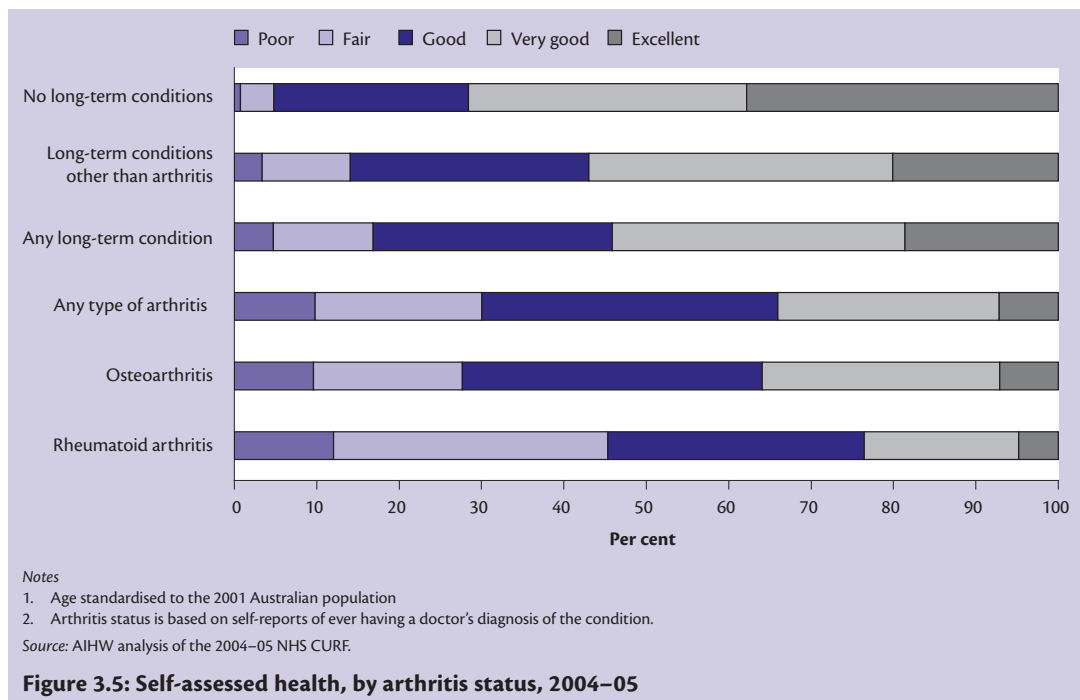


## SELF-ASSESSED HEALTH

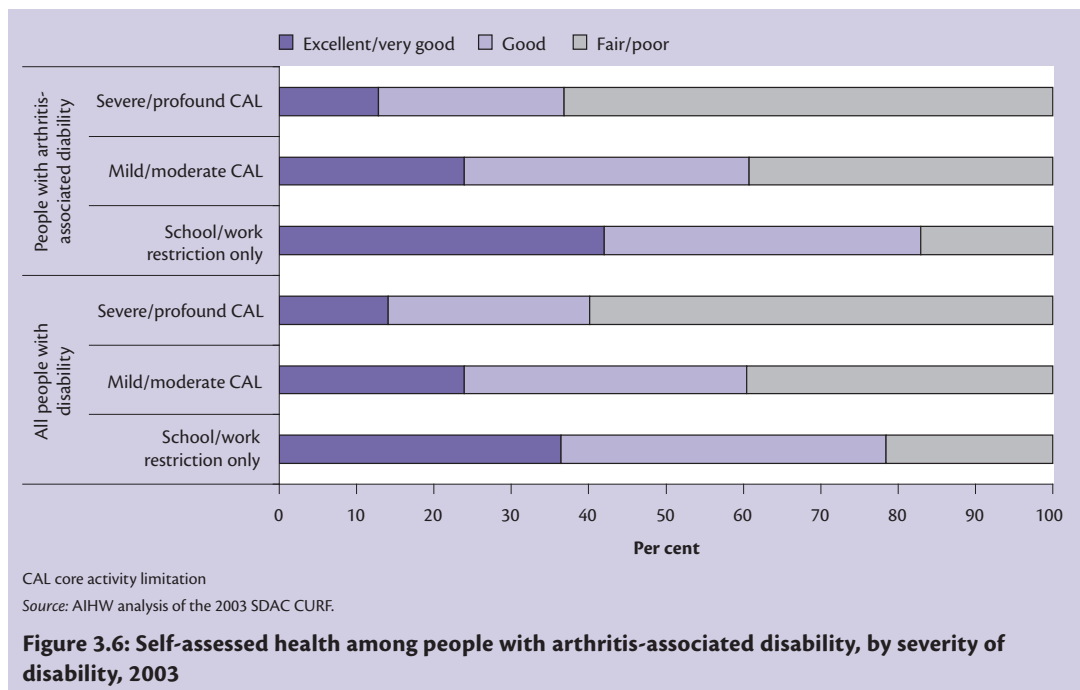
The chronic, pervasive nature of arthritis is likely to have a strong impact upon people’s perception of their own health. Self-assessed health status is therefore a powerful descriptor of psychosocial health.

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*

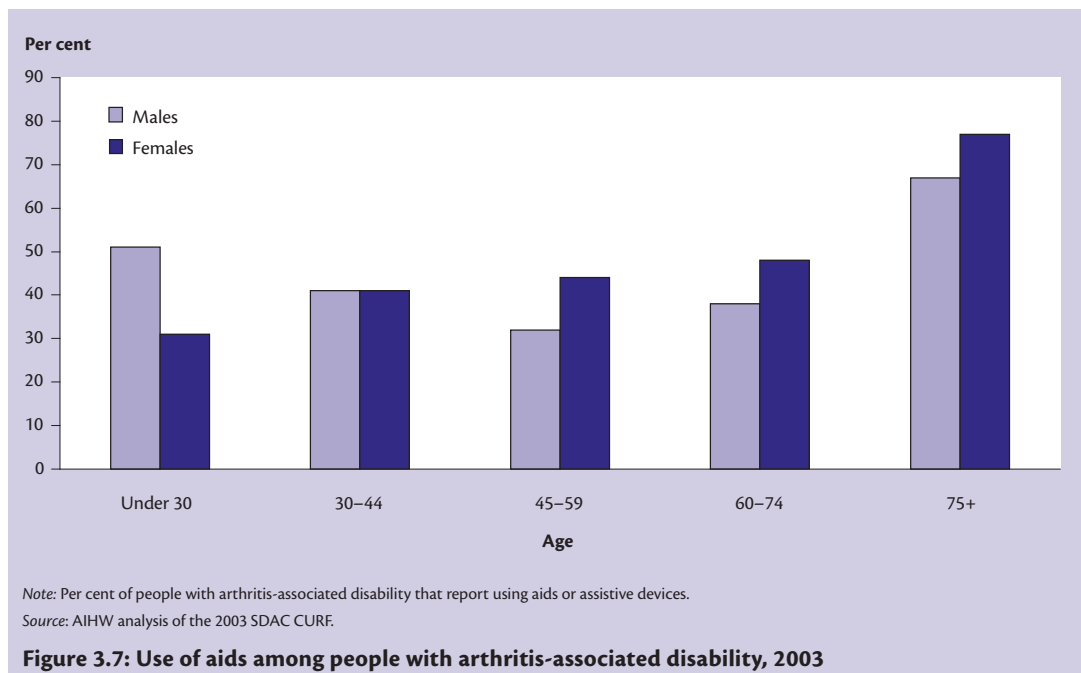
##### **Bathroom**

*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.

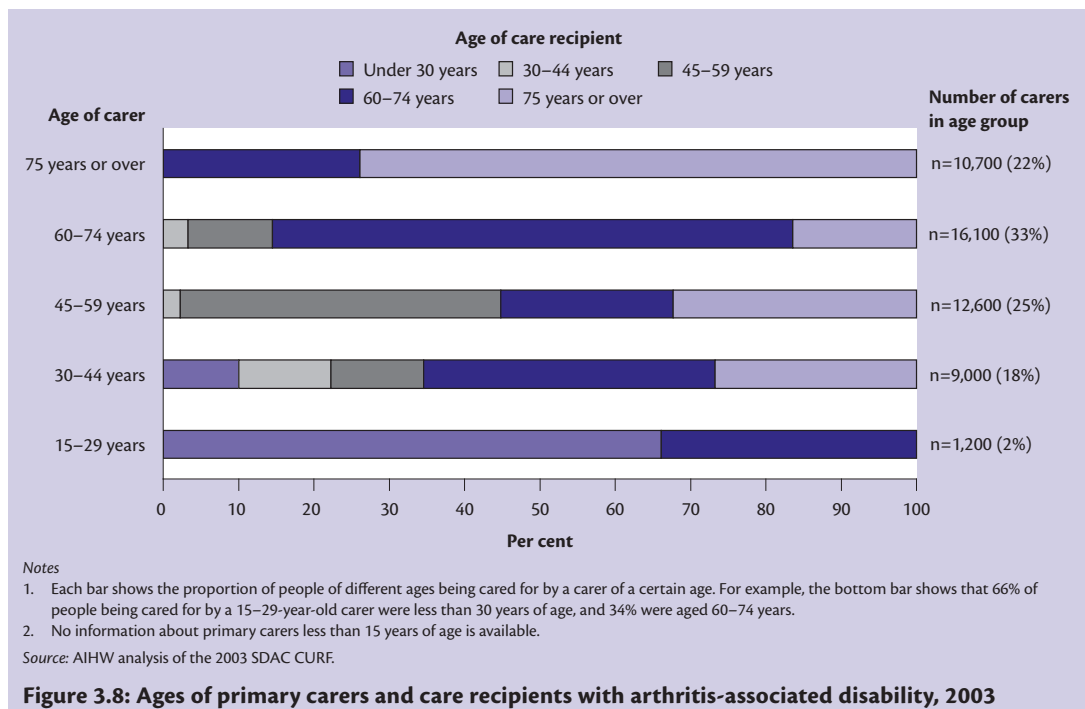
Of 475,000 primary carers identified by the 2003 SDAC, almost 50,000 provided care to people with arthritis-associated disability. Almost two-thirds of these carers were the spouse of the person with disability, and over half provided more than 20 hours of care each week. Almost 40% had spent at least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

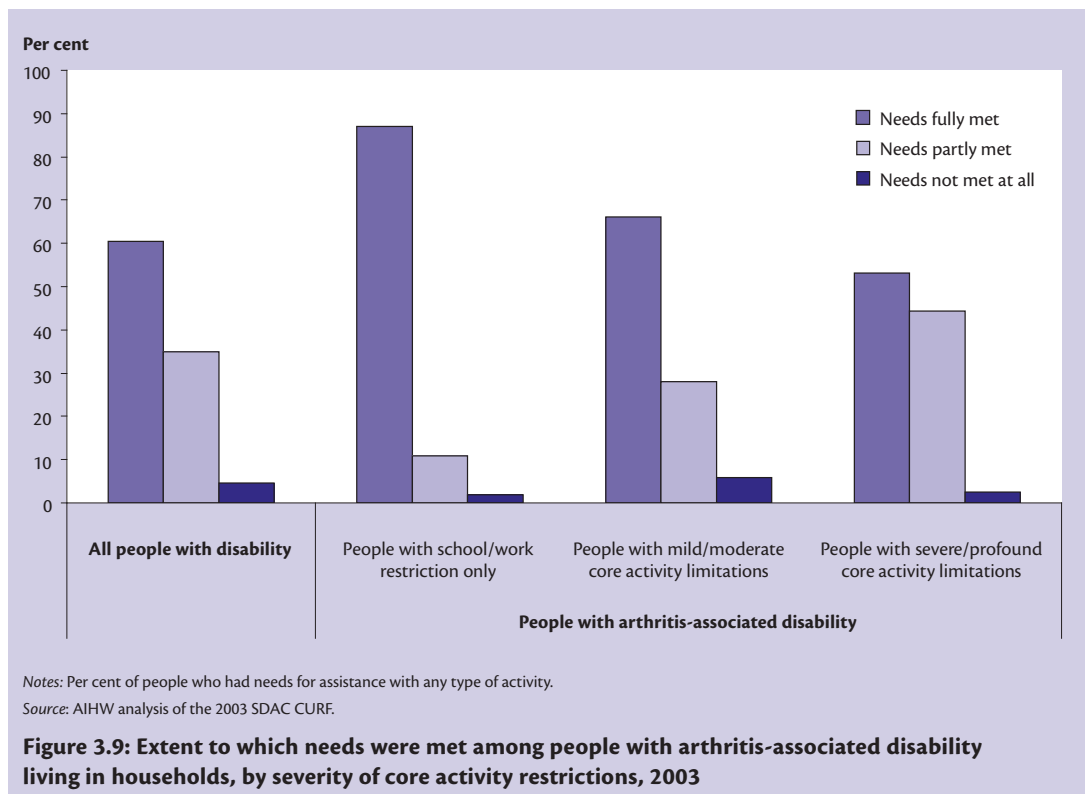
Support services and paid care workers can provide care in the home and in community settings. Services provided include home nursing, domestic assistance, delivered meals, respite care, garden and home maintenance, social support and transport. These services help people to maintain independence, and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



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## 4 Arthritis in children

Although arthritis is often thought of as a disease of ageing, young people can also have it. There are some forms of arthritis that occur mainly or exclusively in children, and children can also be affected by most of the types of arthritis found in adults.

Arthritis is the most common chronic joint condition occurring in children. Parental reports of a doctor's diagnosis indicate that around 2,300 Australians under the age of 16 years (0.06%) have some form of arthritis. A similar number of parents report that their child has arthritis but has not been diagnosed by a doctor. This suggests that up to 4,600 Australian children under 16 years of age (around 1 in 900) may be affected. In comparison, there are an estimated 5,400 Australians of this age with diabetes (around 1 in 800). This suggests that, although arthritis is not a common childhood disease, it is by no means rare in the young. And, as shown below, it can have significant effects on their health, development and quality of life.

The major form of childhood arthritis is called **juvenile idiopathic arthritis** (JIA). This is a general term used to describe any type of inflammatory arthritis of unknown cause where symptoms begin before the sixteenth birthday. It may also be referred to as juvenile chronic arthritis (JCA), juvenile rheumatoid arthritis (JRA) or simply juvenile arthritis. In this report the acronym JIA and the term 'juvenile arthritis' are used interchangeably.

This chapter provides an overview of juvenile arthritis. It describes the most common types of JIA, and the impacts that JIA has on the physical and mental health and everyday life of the affected child and their family. The different treatment options and management strategies used to improve the quality of life of children with JIA are also discussed.

Detailed information about the impacts of juvenile arthritis on Australian children and adults can be found in *Juvenile arthritis in Australia* (AIHW 2008).

### TYPES OF JUVENILE ARTHRITIS

Juvenile arthritis is not a single condition, but a group of conditions with some similar features. There are several different forms of JIA, distinguished by the number and site of joints affected during the first six months of onset, and the presence of other symptoms. In Australia, the International League of Associations for Rheumatology (ILAR) classification system for JIA (outlined in Box 4.1) is followed (Petty et al. 2004). The features and symptoms of the major sub-groups of JIA within the ILAR classification system are described below. Although we can estimate the overall number of Australian children with arthritis, there is no information about the incidence and prevalence in the different sub-groups.

#### Oligoarthritis

Oligoarthritis (also known as pauciarticular arthritis) is the most common form of juvenile arthritis. It usually begins at around two or three years of age and affects girls more often than boys. This form of arthritis affects up to four joints (*oligo-* and *pauci-* both mean 'few'), typically the larger joints

such as the knees, elbows, wrists and ankles. In most cases, joints across the body will be affected non-symmetrically—for example, a knee and an elbow, rather than both knees or both elbows. Involvement of only one joint is common; this may be called ‘monoarticular arthritis’.

The most common symptoms of oligoarthritis are morning stiffness and contracture (formation of fibrous tissues, causing difficulty in straightening) of the affected joints. Joint deformity is uncommon, but the disease may affect the ends of the long bones in the limbs, causing the arms or legs to grow at different rates. This is most noticeable in children who have arthritis affecting one leg, as it can lead to uneven leg lengths and cause limping. Children who have oligoarthritis are also at risk of an eye condition called uveitis (inflammation of the inner eye), and require regular eye checkups. Uveitis is often symptomless and, if untreated, may cause permanent eye damage and affect sight.

In some cases, additional joints may be affected after the first six months of disease. Where five or more joints in total become involved, this is known as ‘extended oligoarthritis’. Cases where no more than four joints are involved may be referred to as ‘persistent oligoarthritis’.

The prognosis for children with oligoarthritis is very good, with 50–80% of cases going into complete remission by adulthood (Adib et al. 2005; Minden et al. 2000; Nigrovic & White 2006). Children with extended oligoarthritis generally have symptoms for longer than those without, and are less likely to have remission (Adib et al. 2005; Arkela-Kautiainen et al. 2005).

#### **Box 4.1: International League of Associations for Rheumatology (ILAR) classification for juvenile idiopathic arthritis**

*The ILAR classification system was first proposed in 1995, and is now used in many parts of the world, including in Australia. The classification describes seven subtypes of **juvenile idiopathic arthritis**, defined as arthritis of unknown cause beginning before the age of 16 years and lasting at least 6 weeks.*

**Systemic arthritis**—arthritis with or preceded by daily fever for at least 2 weeks, with one or more of the following: rash; swollen lymph nodes; enlarged liver or spleen; inflammation of serous tissues.

**Oligoarthritis**—arthritis affecting up to four joints during the first 6 months of disease.

- **persistent**—affects no more than four joints throughout the disease course.
- **extended**—affects additional joints after the first 6 months.

**Polyarthritis**—arthritis affecting five or more joints during the first 6 months of disease.

- **RF-positive**—tests for rheumatoid factor are positive on two occasions at least 3 months apart.
- **RF-negative**—rheumatoid factor is not present.

**Enthesitis-related arthritis**—arthritis and enthesitis, or either arthritis or enthesitis with at least two of the following: sacroiliac tenderness and/or inflammatory spinal pain; HLA\* B27 present; onset of arthritis in a male over 6 years of age; HLA B27-associated disease (such as ankylosing spondylitis or reactive arthritis) in a first-degree relative.

**Psoriatic arthritis**—arthritis and psoriasis, or arthritis with at least two of the following symptoms: dactylitis; nail abnormalities; psoriasis in a first-degree relative.

**Undifferentiated arthritis**—arthritis of unknown cause, that persists for at least 6 weeks and either does not fulfil criteria for any of the above categories or fulfils criteria for more than one category.

\* HLA = human leukocyte antigen, a protein found on white blood cells, that is involved in activating the body's immune system.

Source: Petty et al. 2004.

## Polyarthritis

Polyarthritis, also called polyarticular arthritis (meaning 'many joints'), affects five or more joints within the first 6 months of onset. The joints are usually affected in symmetrical fashion—that is, the same joints on each side of the body. The small joints such as those in the hands and feet are the most commonly involved, but it may also affect the knees, hips, ankles, jaw and neck. As in oligoarthritis, limb growth may be altered.

Polyarthritis is more common in girls than boys, and is generally diagnosed in those aged 6 years or over. Other symptoms may include a mild fever, loss of appetite and anaemia (decreased number of red blood cells, causing weakness, faintness and fatigue).

Around 5–10% of children with polyarthritis, mostly teenage girls, have an antibody called rheumatoid factor (RF) present in their blood. This antibody is also present in most (but not all) adults who have rheumatoid arthritis. A large proportion of cases where rheumatoid factor is present (called 'RF-positive polyarthritis') will have persistent disease activity in adulthood and may experience severe joint damage, which can result in permanent functional limitations and some loss of independence (Adib et al. 2005; Foster et al. 2003; Nigrovic & White 2006; Oen et al. 2002). Early treatment is essential to help prevent this long-term damage to the joints (Manners 2007).

Up to 50% of cases of polyarthritis without rheumatoid factor (called 'RF-negative polyarthritis') go into complete remission by adulthood and there is little permanent damage to the joints (Arkela-Kautiainen et al. 2005; Fantini et al. 2003; Oen et al. 2002).

## Systemic arthritis

Systemic arthritis, also known as Still's disease, is the least common but most serious form of juvenile arthritis. It not only affects the joints but also the rest of the body, including the organs, causing widespread inflammation, rashes, pain and fever. Boys and girls are equally likely to be affected, with onset generally between five and ten years of age. Onset in adulthood is rare.

Children with systemic arthritis usually display a characteristic pattern of daily fever, often peaking in the late afternoon or evening and accompanied at the peak by the appearance of a salmon-pink, non-itchy rash on the trunk, upper arms and thighs. The fever and the rash may come and go quite rapidly, and the child may cycle from feeling very unwell during fever periods to feeling fine at other times of the day. Other symptoms may include fatigue, aching limbs, abnormal enlargement of the liver and spleen, swollen lymph nodes, anaemia, and inflammation of the tissues lining the lungs, heart and abdomen. Joint and muscle pain is often felt in the legs and ankles. In some cases, the non-joint symptoms may occur several weeks or months in advance of any joint pain. Early symptoms may resemble other childhood illnesses such as measles and meningococcal infection, complicating the diagnosis.

Complete remission occurs in up to half of cases of systemic arthritis, with continuing symptoms more likely in those who develop the disease before five years of age (Adib et al. 2005; Minden et al. 2000). Up to 40% of affected children may have aggressive arthritis and experience severe joint damage, which can result in long-term disability (Goldsmith 2006).

## Enthesitis-related arthritis

Enthesitis is inflammation at the places where the tendons and ligaments attach to the bones. Enthesitis-related arthritis (sometimes called juvenile spondylitis) usually affects the large joints of the legs (hips, knees, ankles) and may later affect the spine. It is most common in boys and generally begins at around 9–12 years of age.

Symptoms may include pain or tenderness in the sacroiliac region (the lower back and across the top of the buttocks) and spinal pain caused by inflammation around the vertebrae. The enthesitis itself is most common in the feet and ankles (plantar fascia and Achilles tendons). Children with enthesitis-related arthritis are at risk of acute uveitis, although because the acute form usually presents with pain and reddening of the affected eye, it is easily detected and permanent eye damage is not common (Arthritis Victoria 2002; Goldsmith 2006).

The symptoms of enthesitis-related arthritis may disappear completely within a few months, or come and go throughout childhood and adolescence, and sometimes into adulthood (Manners 2007). Up to half of all cases will go into remission by late adolescence or early adulthood (Flatø et al. 2006). Some children (mainly boys) go on to develop ankylosing spondylitis (Arthritis Victoria 2002). This is a progressive disease involving inflammation of the spine, causing stiffening of its joints and ligaments, that may lead to fusion of the vertebrae and loss of mobility.

### Box 4.2: A few words about inflammation

*Inflammation is a sign of the body's response to infection, irritation or injury. The key features of inflammation are redness, heat, pain and swelling at the site of the injury or infection. There may also be loss of function of the inflamed part, limb or joint.*

*When the body is stimulated by injury or infection, white blood cells accumulate at the site and release certain chemicals. This is called the 'inflammatory response'. These chemicals cause increased blood flow to the area, resulting in redness and heat. Fluid may build up, causing localised swelling which may put pressure on surrounding nerves and cause pain.*

*Normally, inflammation is a short-term (acute) response that helps the body to heal; once the stimulus is gone, the inflammatory process stops. But sometimes the inflammation can be inappropriate or can become out of control, and this may result in serious problems.*

*One example of this is an allergic reaction, where the body is overly sensitive to some substance and produces an excessive inflammatory response. Another example is the case of autoimmune diseases like juvenile arthritis. In these diseases the immune system doesn't recognise the body's own tissues, and so attacks them as if an injury or infection were present. This supposed injury or infection of course does not 'heal', so the immune system continues to respond. Chronic or recurrent inflammation is therefore a common feature of many autoimmune diseases.*

## Psoriatic arthritis

Psoriatic arthritis occurs in both girls and boys, with the most common ages of onset being before 6 years in girls and around puberty in boys (Arthritis Victoria 2002). It is an inflammatory arthritis of the joints accompanied by psoriasis (a common skin condition that is marked by scaly and reddened areas of skin). The psoriasis may not become apparent until some time after the joint symptoms begin, making diagnosis difficult.



Most commonly, multiple joints are affected in non-symmetric fashion. Inflammation of the fingers and/or toes (dactylitis) is common, and nail pits (small depressions in the nail surface) may also occur. Children with psoriatic arthritis are at risk of uveitis and require regular eye tests.

Long-term outcomes for children with psoriatic arthritis vary. The arthritis may be mild and affect only a couple of joints, or it may be more severe and affect multiple joints (Manners 2007). Psoriatic arthritis may remit completely after a short time, or recur throughout life (Arthritis Victoria 2002).

## CAUSES

Juvenile arthritis is an autoimmune disease, that is, a disease where the immune system mistakenly attacks the body's own tissues. The reason the body's immune system turns on itself in this way is unknown. It is suspected that there is a genetic factor that prompts autoimmune action when exposed to a particular environmental trigger (such as a virus or bacterial infection). Because the causes of JIA have not yet been identified, it is not yet possible to prevent it or to predict who will develop it.

A family history of autoimmune diseases (for example, ankylosing spondylitis, multiple sclerosis, rheumatoid arthritis or Type 1 diabetes) is more common among children with JIA than among other children. Particular genes, such as various forms of the human leukocyte antigen (HLA), do occur more commonly in people with autoimmune diseases, but they are not clear markers. For example, although HLA type DR4 is often associated with JIA, not all children who have this gene develop JIA, and not all children with JIA have the gene (Ravelli & Martini 2007). It is still unclear exactly which genes are involved in increasing a person's chance of developing JIA.

## DIAGNOSIS

There is no single test for diagnosing JIA. The diagnosis is one of exclusion, meaning that other potential causes for the symptoms the child displays (Box 4.3) must be ruled out. Diagnosis involves taking a medical history of the child and their immediate family, and performing a physical examination. A variety of tests may be carried out in order to rule out other possible illnesses and to determine the particular type of JIA the child has. These may include X-rays, bone scans, tests of tissues and joint fluid, and blood and urine tests. For a diagnosis of JIA to be made, symptoms must have been present for at least 6 weeks.

### Box 4.3: Potential causes of arthritic symptoms in children

- Bone tumours
- Broken bones
- Crohn's disease
- Growing pains
- Infections
- Juvenile dermatomyositis
- Juvenile idiopathic arthritis
- Lyme disease
- Malignancy
- Reactive arthritis
- Rheumatic fever
- Rickets
- Scleroderma
- Systemic lupus erythematosus (SLE)

Sources: Gardner-Medwin 2001; Junnila & Cartwright 2006; Ravelli & Martini 2007.

## IMPACTS

The experience of a young person with arthritis is very different to that of a person who develops arthritis later in life. Physical, mental, social and academic development may all be affected. The arthritis causes pain, fatigue and disability during what is usually the most active time of life. Participation in play, games, sports and other activities can be difficult. Because the arthritic inflammation affects growing bones and joints, skeletal complications occur in children that are not seen in adult-onset arthritis. Family, peers and teachers can find it hard to accept the diagnosis in a person they consider too young to have arthritis, and may struggle to understand its impacts. And because arthritis is so much more common among older people, support and information relevant to young people may be difficult to obtain. This can all result in stress, anxiety and poor health for both the affected child and their family.

Juvenile arthritis is an unpredictable condition, and its symptoms and effects can vary markedly from person to person and from day to day. Depending on their particular condition, a child with juvenile arthritis may experience pain, stiff or swollen joints, fatigue, fever and lack of appetite. They may find everyday tasks difficult one day, but have no trouble with the same tasks the day after. This unpredictability can lead to feelings of frustration, helplessness and depression, and can make it hard for others to accept that there is a real problem. The physical and emotional effects of juvenile arthritis can impact upon the child's schooling, leisure and social activities, family life, and relationships; these effects may persist into adulthood even if the arthritis itself does not.

Some of the major impacts of juvenile arthritis on the affected child and their family are described below.

### Symptoms

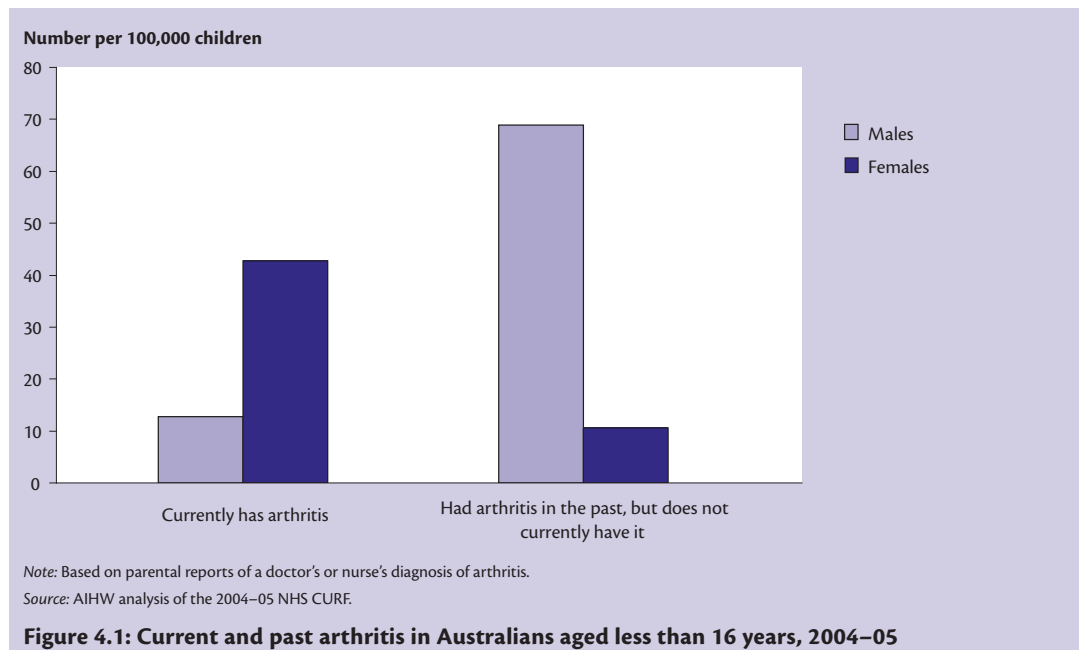
The most common symptom of juvenile arthritis is joint inflammation. The synovial membranes that line the joints produce a fluid, called synovial fluid, that lubricates the joints and helps them to move smoothly. In arthritic joints, the synovial membrane becomes thickened and stiff, and extra synovial fluid is produced, causing swelling, tenderness, heat, stiffness and pain. The child may be reluctant to move the painful joint, and may stop participating in usual activities. Over time, the muscles around the joint may become stiff and weak from under-use, and the tendons may stiffen and tighten, making it difficult to straighten the affected joint. This is called joint contracture, and though it may cause functional problems, it does not generally cause additional pain.

Morning stiffness is another common symptom of juvenile arthritis. The joints may stiffen through lack of movement during sleep, and can take up to a couple of hours to return to normal movement. Stiffness can also occur after prolonged sitting or standing in one position, for example when reading, watching television or doing schoolwork.

### Remission

People with juvenile arthritis go through periods of severe symptoms (called 'flare-ups'), mild to moderate symptoms, and remission (when there are no or very minor symptoms). These periods can last from a few days to a few months. It is impossible to predict when or for how long a child's symptoms will go into remission. Data from the 2004–05 National Health Survey (NHS) suggest that

there are an estimated 3,300 people less than 16 years of age who had arthritis in the past but who are currently in remission. In contrast to the sex distribution of current arthritis, the majority of those reportedly in remission are boys (Figure 4.1).



## Effects on growth and skeletal development

Arthritis has a major impact on the growing skeleton. Generalised growth retardation is common in children with polyarthritis or systemic arthritis. In all forms of juvenile arthritis, the long-term inflammation may speed up or slow down growth of the bones, causing uneven limb lengths. Bone mass may be reduced, and the proper development of the affected joints disrupted. Under-use of painful joints, reduced physical activity levels and long-term use of corticosteroids may worsen these effects (Gardner-Medwin 2001), and can also increase the risk of osteoporosis in adulthood.

Erosive joint disease (where the joint surfaces are damaged) is common in those with polyarthritis. This can cause pain and limitations in joint motion and mobility. Arthritis in the jawbone may affect the growth of the jaws and can lead to micrognathia (abnormal smallness of the jaw). This may result in an overbite and can cause dental problems. Good dental hygiene and regular dental check-ups are particularly important for children with JIA.

## Vision problems

Inflammation of the inner eye (uveitis) is a cause of significant morbidity in people with juvenile arthritis. It is most common in those with oligoarthritis, though it can also occur in polyarthritis, psoriatic arthritis and enthesitis-related arthritis. In most cases, uveitis is asymptomatic, but in young people with enthesitis-related arthritis, acute uveitis generally causes painful, reddened eyes that are sensitive to light.

Uveitis may result in permanent vision damage, most commonly in young children, but the prognosis for vision is generally good if the uveitis is identified and treated early. Potential vision-impairing complications resulting from chronic uveitis include cataracts, band keratopathy (deposit of calcium salts on the cornea) and glaucoma. Children with forms of juvenile arthritis that place them at high risk of uveitis require regular eye screening (up to 4 times per year) (Arthritis Australia 2006; Gardner-Medwin 2001).

## Other physical impacts

### *Osteoporosis*

Osteoporosis is clinically defined as significantly decreased bone mineral density (BMD) when compared with young adults of the same sex (see Chapter 6 of this report). People with JIA often show substantially reduced BMD and may develop osteoporosis later in life, particularly if they have been treated with corticosteroids (Celiker et al. 2003). Long-term use of corticosteroids may affect the density of the bones' internal, honeycomb-like structure (called trabecular bone) (Pereira et al. 1998). However, even those not treated with corticosteroids show reduced BMD compared with healthy controls (Henderson et al. 2000; Zak et al. 1999). Some studies have found reduced bone turnover in children with JIA, which may affect BMD (Lien et al. 2005; Zak et al. 1999). Increased risk of low BMD in people with juvenile arthritis has also been associated with longer duration of active disease, lower height and weight, greater number of joints involved, reduced physical activity and increased disability (French et al. 2002; Lien et al. 2003; Lien et al. 2005; Pereira et al. 1998).

### *Reproductive problems*

Several clinical studies have observed reproductive problems in females with JIA (Musiej-Nowakowska & Ploski 1999; Ostensen et al. 2000). These problems include increased risk of pelvic inflammatory disease, ovarian cysts, irregular menstrual periods, difficulty conceiving and increased risk of miscarriage. Caesarean delivery may be required in those with hip involvement (Packham & Hall 2002b). As with many autoimmune diseases, it is common for JIA to remit during pregnancy, but it may flare up after delivery (Musiej-Nowakowska & Ploski 1999; Ostensen 1991; 1992).

### *Amyloidosis*

Amyloidosis is a group of diseases in which amyloid proteins accumulate in various parts of the body. There are three main types: primary amyloidosis (type AL); secondary or reactive amyloidosis (type AA); and hereditary or familial amyloidosis (type ATTR). It is the AA type that is generally found in people with JIA, most commonly in those with systemic arthritis or polyarthritis (Nigrovic & White 2006).

AA amyloidosis occurs as a result of the long-term inflammation associated with conditions like JIA or rheumatoid arthritis. Inflammation is accompanied by changes in blood chemistry, including increases in the concentration of serum amyloid A protein (SAA). In a small proportion of people, this protein is converted into amyloid fibrils, which accumulate in the body's tissues. This can happen gradually over many years, or more rapidly. It is most common for the fibrils to accumulate in the spleen and kidneys, and the resulting damage may lead to kidney disease and ultimately to kidney failure. In later stages the liver and gut may also be affected. Controlling the underlying inflammatory disease can reduce

the concentration of SAA, slowing, stopping or even reversing the accumulation of amyloid fibrils and minimising damage to the kidneys and other organs (Amyloidosis Australia 2007; National Amyloidosis Centre 2004).

### **Cardiovascular problems**

Young adults with JIA have been found to have elevated triglyceride levels and low high-density lipoprotein (HDL or 'good cholesterol') levels compared with age-matched controls (Ilowite et al. 1989). It is not known whether children with JIA have an increased risk of cardiovascular disease in the long term. Adults with rheumatoid arthritis have an increased risk of cardiovascular disease compared with those without rheumatoid arthritis (del Rincón et al. 2001; Maradit-Kremers et al. 2005).

Young people with systemic or enthesitis-related arthritis may experience aortic insufficiency. This is a problem with the valve linking the aorta to the heart, which can lead to abnormal back-flow of blood.

### **Social interaction**

Children with arthritis may not interact socially as well as or as often as their peers. This may result from pain or functional limitations that make them unable to participate in all of the activities that their friends do, or it may be a conscious decision not to participate or engage with others.

Any young person with a chronic disease or disability can feel uncomfortable in social settings. They may be embarrassed about any real or perceived abnormalities or differences between themselves and others (Gardner-Medwin 2001), for example a limp or a bone deformity, and they may be afraid that others will tease, bully or laugh at them, or that they will be excluded. Negative self-image and fear of persecution can lead to social withdrawal. Arthritis NSW suggests encouraging positive self-image by focusing on the things the child is able to do, rather than the things they can't do (Arthritis NSW 2003).

Participating in sports and more active play is an area where many young people with juvenile arthritis have difficulty and may feel excluded. Huygen et al. (2000) found that children with JIA played with friends less frequently than children without JIA, and that adolescents with JIA were less likely than those without JIA to participate in sports. But there are a variety of ways that young people with arthritis can constructively participate in these activities—for example, as the umpire or scorer, or by writing about or photographing events. Activities such as swimming, board games, chess, debating, book clubs or film societies can provide opportunities for social interaction in young people whose arthritis prevents them from participating in more vigorous sports.

### **Schooling**

Most children with juvenile arthritis are able to attend school. Data from the 2003 Survey of Disability, Ageing and Carers (SDAC) show that all persons aged 5–14 years with arthritis-associated disability were attending school, although most reported some difficulties or restrictions (Table 4.1).

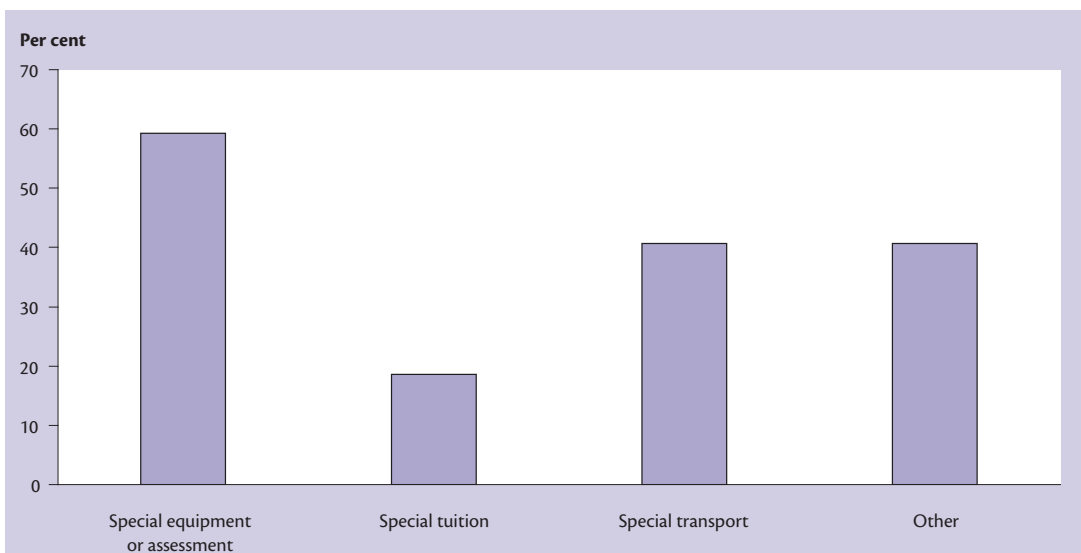
**Table 4.1: Schooling restrictions among people aged 5–14 years with arthritis-associated disability, 2003**

Restriction	Per cent
Needs at least one day off school each week	17
Needs special assistance from a person at school	17
Needs special arrangements or equipment	54
Difficulty sitting	54
Difficulty fitting in socially	74
Difficulty participating in sport	92
<b>Total with restrictions/difficulties in schooling</b>	<b>92</b>

Source: AIHW analysis of the 2003 SDAC CURF.

Depending on the severity of their disease and the types of limitations they have, modifications or allowances may need to be made to accommodate the child’s needs and abilities. These may include:

- an adjustable chair and desk to promote good posture and provide support for the joints
- duplicate textbooks for home and school, so these do not have to be carried
- extra time to move between classrooms
- permission to move around as necessary during lessons, to avoid stiffness
- a rest area in the classroom, so the young person can rest or perform physical therapy (for example, stretching, or applying heat or ice packs) without being excluded
- use of a laptop computer rather than notepads and pens
- variations to physical education and sports activities
- special stationery that is easier to grip and operate (scissors, pens, stapler, etc.)
- a space for rest, physical therapy or seated activities with friends at break times.



Note: 'Other' includes special access arrangements.

Source: AIHW analysis of the 2003 SDAC CURF.

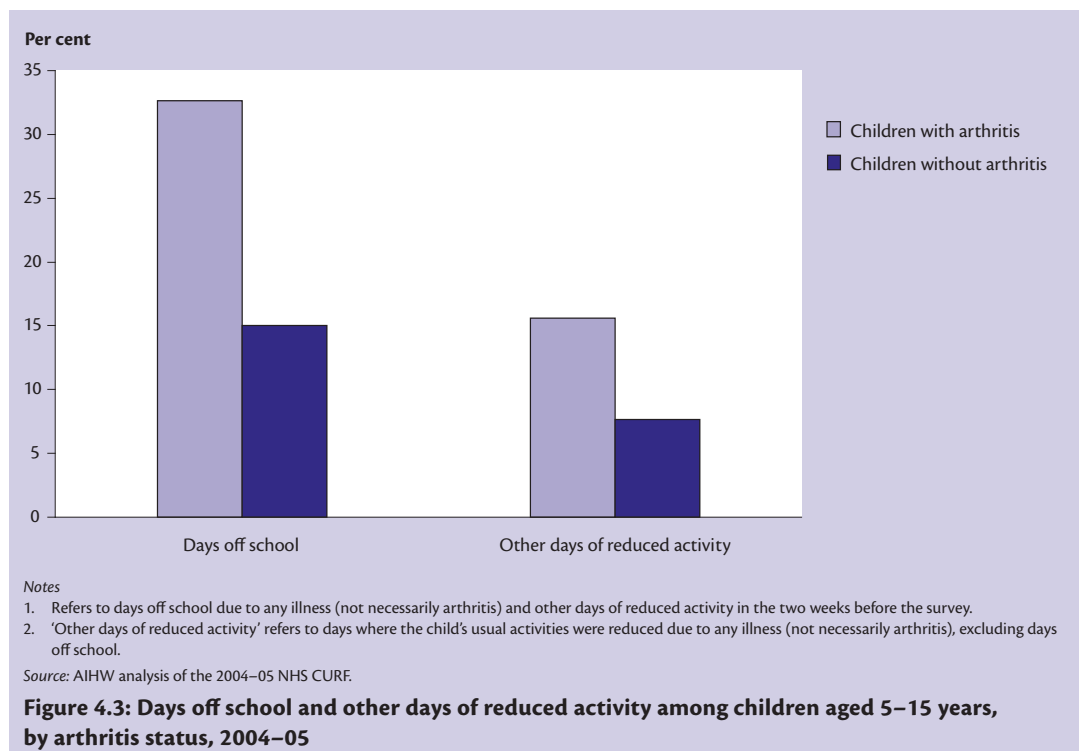
**Figure 4.2: Arrangements made by schools for students with arthritis-associated disability, 2003**

Respondents to the 2003 SDAC reported that various arrangements were made by schools to meet the needs of students with restrictions or disabilities due to arthritis (Figure 4.2).

It is important that teachers and other students understand the unpredictability of juvenile arthritis, and that its effects and the child's needs and abilities may change from day to day, or even from morning to afternoon. Like parents, teachers may find it challenging to adapt to and meet the needs and abilities of the child with arthritis, while not making the child feel singled out or making other students feel that the student with arthritis is receiving special treatment unfairly.

Children with juvenile arthritis may be absent from school more often than their peers. Flare-ups of symptoms may require partial attendance (shortened days), bed rest or, in severe cases, hospitalisation. It may also be difficult to schedule medical appointments outside of school hours. Data from the 2004–05 NHS show that 33% of people aged 5–15 years with arthritis had at least one day off school in the two weeks before the survey, compared with 15% of those without arthritis (Figure 4.3). Those with arthritis were also more likely than those without arthritis to have had other days of reduced activity during this period.

Children who are absent from school due to their arthritis may need to have worksheets or assignments sent home. For those who are in hospital or who expect to be absent for relatively long periods, home or in-hospital schooling may be used. Teaching staff are available at most major hospitals to help hospitalised students continue their education.



## Mental health

The pain, chronic poor health, activity limitations, and real or perceived abnormalities in bodily form and functioning associated with juvenile arthritis can have detrimental effects on a young person's mental health (Gardner-Medwin 2001). People may experience a wide range of emotional reactions to the disease and its effects, including anger, denial, embarrassment, poor self-image, frustration, feelings of isolation, insecurity or inadequacy, lack of confidence, sadness or depression, desire to be like their peers, fear and lack of control. But many studies have demonstrated that young people with JIA in general have good psychological health and are as socially and emotionally confident as their peers, supported by cohesive families and strong social networks (Arkela-Kautiainen et al. 2005; Flatø et al. 2003; Huygen et al. 2000; Peterson et al. 1997).

Poorer quality of life among people with JIA compared with healthy controls is generally attributed to the physical effects of the disease rather than emotional or social impacts. However, increased levels of anxiety and poor self-image have been found among those who still have active arthritis in adulthood, particularly in people whose JIA began in adolescence rather than early childhood (Nigrovic & White 2006; Packham & Hall 2002b; Packham et al. 2002). Depressive symptoms are also relatively common and are more likely to occur in those with disease onset at 6–12 years of age (Packham et al. 2002; Shaw et al. 2006).

## Independence

Although many children will 'grow out of' juvenile arthritis and have no lasting disability, the majority of people affected by JIA will need some form of assistance during their symptomatic periods. Depending on the severity of symptoms, a person with JIA may be mostly independent, needing help only with more strenuous tasks, or may require high-level care, including assistance with personal-care activities such as bathing and dressing. The majority of people will fall between these extremes, and will need different amounts of help from day to day as their symptoms vary.

Often children will need some assistance with getting ready in the mornings as their joints may have stiffened up overnight. Bathroom items with long or thick handles, clothing that is easy to get on and off, and shoes that are slip-on or have Velcro fastenings can make it easier to get ready without help.

Arthritis NSW suggests encouraging children and teenagers with arthritis to take on tasks or chores suited to their abilities, and to make decisions about their involvement in activities, in order to develop independence and a sense of control (Arthritis NSW 2003).

## Family life

As with many chronic or serious childhood illnesses, the child with arthritis is not the only one affected by the condition. Parents, siblings and other family members also have to deal with the effects of arthritis symptoms, management and prognosis. Family routine and activities can be disrupted, and younger children in particular may find it difficult to understand what is happening and why things have changed. Every family reacts differently to such challenges. Some find the experience brings them closer together, while for others it can lead to strained relationships. Support for the whole family is important and can be obtained from a variety of sources including community health centres, patient support groups such as Arthritis Australia, and local medical and mental health professionals.



### ***Effects on siblings without arthritis***

Siblings of children with JIA may experience a range of reactions to the initial diagnosis and the ongoing symptoms and management of the condition. These may include jealousy or resentment, anger, guilt, fear or anxiety, sadness, and helplessness.

These reactions may manifest in various ways including changed behaviour (either better or worse), crying, withdrawing from family life, spending more time in or out of the home, mood swings, depression and general illness.

Like children diagnosed with JIA, siblings need to be involved in what is going on and encouraged to express their feelings about what is happening. The nature of the disease, its management and prognosis need to be explained to them honestly and in a way that they can understand, and any feelings of guilt or fear allayed. The Arthritis Australia offices in each state and territory run support groups and recreational activities that all family members can attend and talk to other people in similar situations.

### ***Effects on parents or carers***

Parents or carers of a child diagnosed with juvenile arthritis may experience many of the same feelings that siblings do. They may feel shock, denial or disbelief, or be relieved to put a name to their child's illness, especially if the diagnosis has been delayed.

To these are added the stress of having responsibility for the child's care and welfare. Parents or carers may be anxious, not only about their child's health and the physical tasks of caring, but also about the economic costs they might incur. These may range from paying for GP and specialist visits, physical therapy sessions and any medications, to the prospect of having to employ a professional carer or give up working to look after their child. Reading books, leaflets and websites about juvenile arthritis, talking to health professionals and contacting local or national support groups may be helpful for obtaining the information needed to make decisions for the future.

## **Adult life**

Although the prognosis varies depending on the particular type of juvenile arthritis a child has, many cases will not persist into adulthood. The majority of children will recover without significant damage to their joints and be able to lead a normal, independent life. However, some children will continue to have active arthritis into adulthood and throughout life, and others may have ongoing functional limitations or disability even though the arthritis itself is in remission. In all cases, management should address issues of personal independence, academic performance, occupational desires and abilities, to help individuals achieve their full potential (Gardner-Medwin 2001).

Adults with a history of JIA may experience higher rates of unemployment compared with their healthy peers, despite on average having equal or better academic achievement (Flatø et al. 2003; Foster et al. 2003; Oen et al. 2002; Packham & Hall 2002a; Peterson et al. 1997). Those who are unemployed tend to have greater physical disability, lower educational attainment and poorer coping strategies than those who are in the workforce (Foster et al. 2003; Packham & Hall 2002a). Packham and Hall (2002a) found that around a quarter of people with current JIA reported experiencing discrimination in the workplace.

Information from the 2004–05 NHS suggests there are around 54,000 Australians aged 16 years or over who were diagnosed with arthritis as a child. More than 40% of these people are currently in remission. Among those of working age (16–64 years), 54% are employed either full- or part-time, compared with 77% of people of this age without arthritis.

For young adults who continue to have active arthritis, maintaining therapy is vital. The transition from paediatric to general medical care, combined with other life events such as leaving home, taking up tertiary studies or starting work, can lead to a loss of contact with medical services and interruption of arthritis management. The costs of treatment may also deter young adults from accessing services they now need to pay for out of their own income. The loss of contact with trusted paediatric health professionals, while at the same time taking on the responsibility for their own care and self-management, can be challenging for any young person with a chronic condition. Medical professionals can help with relevant referrals and the transfer of patient records to new healthcare providers, but adequate 'handover' from the paediatric to the adult health team is also important (Wallis 2007).

## Mortality

Juvenile arthritis is rarely recorded as a cause of death in Australia. In the 10 years 1997–2006 there were five deaths where juvenile arthritis was listed as the underlying cause of death (see Box 4.4) and a further 12 deaths where it was listed as an associated cause. All of these deaths occurred in adults, with an average age at death of 48 years.

Among children under 16 years of age, there were five deaths over the period 1997–2006 where arthritis (of any type) was listed as the underlying cause of death and 11 deaths where arthritis was listed as an associated cause.

Underlying causes of death recorded when arthritis was an associated cause included septicaemia, cancers, cardiovascular diseases and nervous system disorders.

### Box 4.4: Causes of death

*In Australia, deaths are certified by a medical practitioner or coroner and collated by the Registrar of Births, Deaths and Marriages within each state and territory. These data are forwarded to the Australian Bureau of Statistics for coding of the causes of death and compilation to produce national statistics about death and its causes. The AIHW also holds a copy of these data.*

*The **underlying cause of death** is defined as the condition, disease or injury that initiated the train of events leading directly to an individual's death—that is, the condition believed to be the primary cause of death. Any other condition, disease or injury that is not the underlying cause, but is considered to have contributed to the death, is known as an **associated cause**.*

## MANAGEMENT

Although many children with juvenile arthritis will experience natural remission of their disease, there are no treatments that can cure juvenile arthritis or bring on remission. Long-term management is the key to relieving symptoms, preventing or limiting joint damage, reducing the impact of the disease on the child's personal, social and academic development, and maximising quality of life.

Management strategies are similar for all types of juvenile arthritis, being influenced mainly by the symptoms experienced and the severity of these. Strategies generally incorporate a combination of:

- medication (for pain relief and to reduce inflammation and swelling)
- exercise and physical therapy
- a healthy, balanced diet
- pain management (other than through medication)
- joint care, and
- psychosocial support.

Each of these components is described in turn below.

### Medication

Although the majority of children with juvenile arthritis will take some form of medication, the kind of medication taken depends on the particular type of arthritis the child has, and the severity of symptoms. There are five main groups of medications used in the management of juvenile arthritis:

- non-steroidal anti-inflammatory drugs (NSAIDs)
- analgesics
- corticosteroids
- disease-modifying anti-rheumatic drugs (DMARDs), and
- biological agents.

Many of these medications are also used to manage other types of arthritis, such as rheumatoid arthritis and osteoarthritis. Management of these conditions is discussed in Chapter 5.

#### *Non-steroidal anti-inflammatory drugs*

Non-steroidal anti-inflammatory drugs (NSAIDs) are among the world's most commonly used drugs. They help to manage the symptoms of arthritis by relieving fever and minimising inflammation, reducing pain, swelling, stiffness and heat in the affected joints. NSAIDs commonly used in the management of JIA include naproxen, ibuprofen, aspirin, celecoxib, meloxicam and diclofenac.

Different NSAIDs have different side-effects, and an individual may be more sensitive to one drug than to another. In some people, NSAIDs can affect the stomach, causing gastric irritation, nausea, abdominal pain and loss of appetite. They also affect the platelets (blood cells involved in clotting),

which makes bruising easier and mildly increases bleeding on injury. For this reason, people who regularly use NSAIDs are generally told to stop taking them a few days before undergoing any kind of surgery. Other side-effects may include rashes, high blood pressure, fluid retention and kidney problems (American College of Rheumatology Drug Safety Committee 2007).

Some NSAIDs, particularly aspirin and ibuprofen, also have analgesic properties and are sometimes included in the class of analgesic drugs.

### **Analgesics**

Analgesics (pain-killers) are taken alone or in addition to other medications to help manage pain. They cause pain relief by either blocking pain signals going to the brain, or interfering with the brain's response to pain signals (Eustice & Eustice 2007). There are three main types of analgesics: opiate narcotics (for example, morphine, codeine); opioid narcotics (for example, tramadol, pethidine); and non-opioid (sometimes called non-narcotic) analgesics (for example, paracetamol).

Opiates are powerful pain-relievers derived from unripe poppy seeds, whereas opioids are synthetic narcotics derived from or resembling opiates. Often the word 'opioid' is used to refer to both the natural and the synthetic drugs. Both opiates and opioids work by mimicking the body's natural pain-relievers, endorphins. If necessary, very large doses can be tolerated, but only if the dose is increased gradually over time to allow the body to build up a tolerance to the side-effects (for example, decreased respiratory efficiency) (Eustice & Eustice 2007). Common side-effects of these drugs include nausea, drowsiness, dry mouth and constipation.

Paracetamol (sometimes called acetaminophen) is the most commonly used non-opioid analgesic, and is effective for relieving mild to moderate pain. It is believed to work by inhibiting the formation of prostaglandins (chemicals that trigger a range of bodily processes such as muscular contractions, constriction and dilation of the airways, and dilation of the blood vessels) (TGA 2005). This interferes with the body's response to pain. Paracetamol also reduces fever, but it has no clinically significant anti-inflammatory properties. It can be used alone or in combination with other drugs, and is an ingredient in many over-the-counter medications (such as cold and flu tablets, menstrual pain relievers, sinus medication and cough syrup).

Paracetamol is often considered safer than other medications, and side-effects are rare when taken at the recommended dosage. However, serious side-effects and adverse reactions may occur if too much is taken at once (overdose). Paracetamol is metabolised by the liver, and one of the by-products of this metabolism is toxic to the liver. Small amounts of the toxin are easily neutralised, but liver damage can result if the toxin accumulates as a result of overdose (TGA 2005).

### **Corticosteroids**

Corticosteroids are strong anti-inflammatory drugs. They can be used in several ways for managing juvenile arthritis. Given regularly as oral or intravenous medicine, corticosteroids can help to reduce stiffness, inflammation and fever. Corticosteroid creams may be used to reduce skin inflammation (for example, that caused by psoriasis), and eye drops containing corticosteroids can be very effective in treating uveitis. Finally, corticosteroids given by injection directly into an arthritic joint can be very effective in relieving inflammation for weeks or even months at a time.

Corticosteroids can have many side-effects, some of which can be serious. These can include weight gain, acne, high blood pressure, cataracts, fluid retention, bruising, stomach ulcers and osteoporosis (Australian Rheumatology Association 2006a). Side-effects become more common as dosage and length of use increases. With the exception of those with systemic arthritis, children with juvenile arthritis do not usually take corticosteroids long-term (Manners 2007).

Some corticosteroids commonly used in Australia are prednisolone, dexamethasone, hydrocortisone and prednisone.

### ***Disease-modifying anti-rheumatic drugs***

Disease-modifying anti-rheumatic drugs, or DMARDs, are anti-inflammatory drugs that can also prevent damage to the joints and help reduce the risk of long-term disability. They do not act to directly treat the symptoms of arthritis, but instead act on the immune system to interfere with the processes that cause the symptoms. This means that once a course of treatment begins, it may take weeks or months before there are noticeable effects on symptoms.

Several different DMARDs are available, which act in different ways. The most commonly used DMARD is methotrexate. Methotrexate inhibits the action of an enzyme called folic acid reductase, causing interference with tissue cell reproduction. In psoriatic arthritis, this reduces the extra growth of skin cells that causes psoriasis. Methotrexate also reduces the overactivity of the immune system, thereby decreasing the symptoms of inflammation (including pain and swelling) and minimising damage to the joints. Other DMARDs available in Australia include sulfasalazine, leflunomide, azathioprine and cyclosporin.

DMARDs can cause a range of side-effects, including nausea, vomiting, abdominal discomfort and diarrhoea. Regular blood and urine tests are required to check liver function, as in some cases this can be disrupted. Some DMARDs, including methotrexate, may make the skin extra-sensitive to sunlight, so adequate sun protection measures are required to avoid burning. Side-effects are more likely to occur at higher doses (Australian Rheumatology Association 2006c; Cannon 2006).

As DMARDs affect the immune system, there is some decrease in the body's ability to fight off infection, but the risk is very small at the doses generally prescribed for children. However, live virus vaccinations (for example, measles/mumps/rubella (MMR), chicken pox or polio) are usually avoided, so medical advice regarding childhood immunisations should be obtained (Manners 2007).

### ***Biological agents***

Biological agents ('biologics' or biological disease-modifying anti-rheumatic drugs, bDMARDs) are engineered drugs that mimic chemicals found naturally in the body. They are relatively new treatments, having been used only in the last decade. Biologics act by interfering with the action of one of two cytokines (proteins involved in the immune response) that increase inflammation: either interleukin-1 (IL-1) or tumour necrosis factor alpha (TNF- $\alpha$ ). By inhibiting or deactivating these cytokines, biologics reduce inflammatory symptoms such as pain and swelling, and help to prevent joint damage (Australian Rheumatology Association 2006b).

Biologics available in Australia include etanercept, infliximab and adalimumab. They are generally given by injection or intravenous infusion. Biologics are often used in combination with a DMARD (such as methotrexate).

Common side effects of biologic agents include headaches, stomach discomfort and mild infections (particularly upper respiratory tract infections, such as colds). As with DMARDs, live vaccines should not be given (Australian Rheumatology Association 2006b).

## Exercise and physical therapy

Regular exercise is vital for good health, and is also essential for bone growth. Exercise keeps the joints and muscles flexible, builds strength, improves circulation and helps to maintain a healthy weight. In people with juvenile arthritis, movement of the joints through exercise is an effective way of preventing or minimising disability (Arthritis NSW 2003). High-impact exercise, however, may damage the arthritic joints, so the types of exercise that are most suitable should be discussed with the doctor or specialist. Physiotherapists can recommend specific exercises to be done at home to keep the joints active, maintain the range of movement, build and maintain muscle strength, and make movement easier and less painful. This can improve mobility and reduce functional limitations.

In joints that are at risk of contracture, splinting may be used. Splints hold the joint in the uncontracted position for a period of time (often overnight) so that the range of movement in the joint is maintained. The wrists and knees are the most common joints on which splints are used.

## Healthy diet

A balanced diet is important to promote normal bone growth and development, maintain healthy weight, and reduce the risk of conditions such as osteoporosis, heart disease and diabetes. For people with long-term conditions like arthritis, which require regular medication, a healthy diet can help to minimise the side-effects of this medication.

Children with juvenile arthritis sometimes have poor appetites when they feel ill or tired, or they may be reluctant to eat if it is painful to do so (for example, if they have arthritis in the jawbone). Regular meals and snacks of nutrient-rich foods and drinks can help to provide sufficient nutrients for a child who eats little.

Conversely, limitations in activity and the side-effects of some medications may cause young people with arthritis to gain weight. This places additional stress on the joints and can increase pain and activity limitations. A balanced diet combined with appropriate exercise can help in achieving and maintaining a healthy weight.

## Pain management

Pain in juvenile arthritis is a response to damage, injury or strain of the affected joint(s). Therefore, it is important to prevent pain, not just to avoid the physical sensation but to reduce the joint damage that causes it.

Strategies that can help to manage pain include:

- applying heat by using heat packs (as advised by a doctor), hot water bottles, taking a warm bath or shower, and wearing warm clothes, including socks, gloves and scarves
- gentle stretching, as advised by a doctor or physiotherapist
- massage
- use of splints and joint support bandages
- meditation and relaxation
- distraction, and
- use of medications.

## Joint care

Activities that put strain on the arthritic joints can lead to increased pain and joint damage. Often it is not clear how a joint will respond to a new activity, and determining what a person with JIA can and cannot do becomes a matter of trial and error. Activities that cause pain may need to be done less vigorously, done in a different manner, or avoided altogether. Occupational therapists can suggest alternative ways of doing everyday tasks and recommend assistive devices. Arthritis NSW suggests a range of strategies that can help to reduce strain on the joints and make it easier to perform various tasks. These include:

- alternating between heavy and lighter activities, to rest the joints and muscles
- changing position often, to reduce stiffness
- maintaining a healthy weight
- using assistive devices, such as jar openers, pen grips and adjustable chairs, and
- managing painful or inflamed joints appropriately (Arthritis NSW 2003).

## Psychosocial support

Children with arthritis and their families often need help and support in coping with the condition and its impacts. Dealing with pain, frustrations with activity limitations, depression about chronic illness, anxiety about falling behind at school and fear of teasing or bullying are some of the issues that may be faced by children with juvenile arthritis. Societies such as Arthritis Australia and their affiliate offices in each state and territory provide advice on many aspects of life with arthritis, and also organise family activity days and camps for children with arthritis. This enables affected children and families to learn more about the condition, to make contact with others like themselves and to realise that they are not alone.

Support is also available from registered health professionals and counsellors, and from a variety of agencies including Kids Help Line, Beyondblue, Carers Australia, community services and Aboriginal medical services.

## Management by general practitioners and specialists

The management of arthritis in persons less than 16 years of age was reported in relatively few general practitioner (GP) encounters in the 2007–08 BEACH GP survey, managed in less than 1 per 1,000 encounters for people of this age. This probably reflects the fact that juvenile arthritis is more likely to be managed by specialists such as paediatricians or rheumatologists. The BEACH data suggest that arthritis was managed in approximately 11,400 Medicare-paid GP consultations among people less than 16 years of age in 2007–08, equating to around 2.5 GP visits per child with arthritis.

GPs employed a variety of management strategies during these consultations. The most common was to prescribe or advise medications: paracetamol, methotrexate and meloxicam were the most frequently recorded medications.

Data from the 2004–05 National Health Survey show that 23% of people under 16 years with arthritis had visited a GP or specialist for their arthritis in the 2 weeks before the survey. No specific information is available regarding the number of specialist visits for juvenile arthritis, or the management strategies employed during these visits.

## Hospital treatment

Children with juvenile arthritis sometimes need to be admitted to hospital. This may be for treatment of a severe flare-up of their symptoms, for specialised forms of therapy such as injections into the joint, or (rarely) for surgery such as soft tissue release or joint replacement (see Box 4.5).

### Box 4.5: Procedures used in juvenile arthritis

**Joint aspiration** involves taking fluid out of the joint with a needle and syringe. This can be a diagnostic procedure (where a sample of fluid is sent for testing to determine if there is infection in the joint or to confirm a diagnosis) or a therapeutic procedure. Draining of a badly swollen joint can relieve pain and improve joint mobility.

**Joint injections** deliver medication directly into the joint. These are usually corticosteroids, which are anti-inflammatory drugs that slow down the accumulation of cells that cause inflammation. Often both joint aspiration and joint injection procedures will be recorded in the same hospital visit. A joint injection will not be performed if the joint is infected, so aspiration may be performed first to make sure there is no infection in the joint.

**Soft tissue release** is a treatment to relieve severe joint contracture. It involves division of the nerves and lengthening or division of the muscles and tendons around the affected joint. This allows the joint to regain movement and can improve posture and mobility. Soft tissue release may be performed in children with congenital or acquired joint disorders, cerebral palsy and synovitis as well as in those with arthritis. Almost 1,700 such procedures were performed on children under 16 years of age in 2006–07.

**Joint replacement** refers to the replacement of damaged joint structures with artificial components. It is sometimes necessary in people with JIA, but is usually performed in adulthood once skeletal growth has stopped. Joint replacement in older teenagers is occasionally required in those with more severe arthritis where substantial joint damage has occurred. The hip is the most common joint replaced in people with JIA. A small number of joint replacement procedures in people aged less than 16 years were recorded in 2006–07, however none of these had the principal diagnosis of juvenile or rheumatoid arthritis. Thirteen cases of joint replacement for juvenile or rheumatoid arthritis were recorded in people aged 16–24 years in 2006–07, including 5 hip and 4 knee replacements.



In 2006–07 there were 780 hospital separations of people less than 16 years of age with the principal diagnosis of juvenile or rheumatoid arthritis. The most common procedures or interventions recorded during these separations were joint injections, other administration of medications, allied health interventions and joint aspiration (Table 4.2).

**Table 4.2: Most common interventions provided in hospital separations for juvenile or rheumatoid arthritis in people under 16 years, 2006–07**

Procedure/intervention	Number of procedures performed <sup>(a)</sup>	Per cent of separations <sup>(b)</sup>
Joint injection	361	46
Other administration of medication <sup>(c)</sup>	205	26
Allied health interventions	160	15
<i>Physiotherapy</i>	98	13
<i>Occupational therapy</i>	15	2
<i>Pharmacy</i>	14	2
Joint aspiration	147	19

(a) Total number of times each procedure was recorded. A person may have more than one procedure, and any procedure may be performed more than once within a separation. See Appendix 2 Table A2.2 for codes used.

(b) Per cent of separations in which the procedure was performed, based on a total of 780 separations.

(c) Includes medications (excluding operative anaesthetics and sedatives) administered via any method other than injection directly into the joint. This includes intravenous, intramuscular, subcutaneous, oral and other forms of administration.

Source: AIHW National Hospital Morbidity Database.

## Treatment by other health professionals

Along with the GP and specialist, a variety of other health professionals may be involved in the management of juvenile arthritis.

Allied health professionals such as physiotherapists and massage therapists can assist with maintaining joint mobility, releasing tight muscles and ligaments, and recommending stretches and exercises that can be done between visits to keep the joints supple and build muscle strength. Occupational therapists can teach alternative ways of doing things, including recommending assistive devices, so that the child with juvenile arthritis can undertake daily activities without putting too much strain on their arthritic joints.

Pharmacists can provide advice on medications, assistive devices, and joint-care products like supports, braces and splints. They can also discuss options for pain relief, such as over-the-counter medications, heat and cold packs, and alternative therapies. However, it is important that any non-prescription medications or natural remedies do not replace medications prescribed by the doctor or specialist, and that both the doctor and the pharmacist are made aware of all the medications the young person is taking so that possible interactions or side-effects can be managed.

Children with arthritis affecting the jawbone may have jaw misalignment, and have trouble with eating and brushing teeth, which can affect dental hygiene. Dentists and orthodontists can help to manage these problems. In the 2004–05 NHS, 79% of children with arthritis aged 2–15 years had visited a dentist in the previous 12 months, compared with 63% of children of this age without arthritis.

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## 5 Reducing the burden of arthritis

Arthritis is a very common condition, and one that makes a significant contribution to pain, functional limitation, disability and reduced quality of life. Health expenditure attributable to arthritis, through medical and allied health consultations, the use of medications and surgical procedures, is also substantial. However, the burden of arthritis can be reduced through intervention at various points along the disease continuum, including prevention, early diagnosis, prompt initiation of treatment, ongoing management and timely access to joint replacement.

This chapter highlights opportunities for reducing the burden of arthritis in Australia, by examining the various points at which intervention can be undertaken. The discussion centres on osteoarthritis and rheumatoid arthritis, as these are the two most common forms of arthritis, as well as being targets of public health strategies under the National Health Priority Area of arthritis and musculoskeletal conditions.

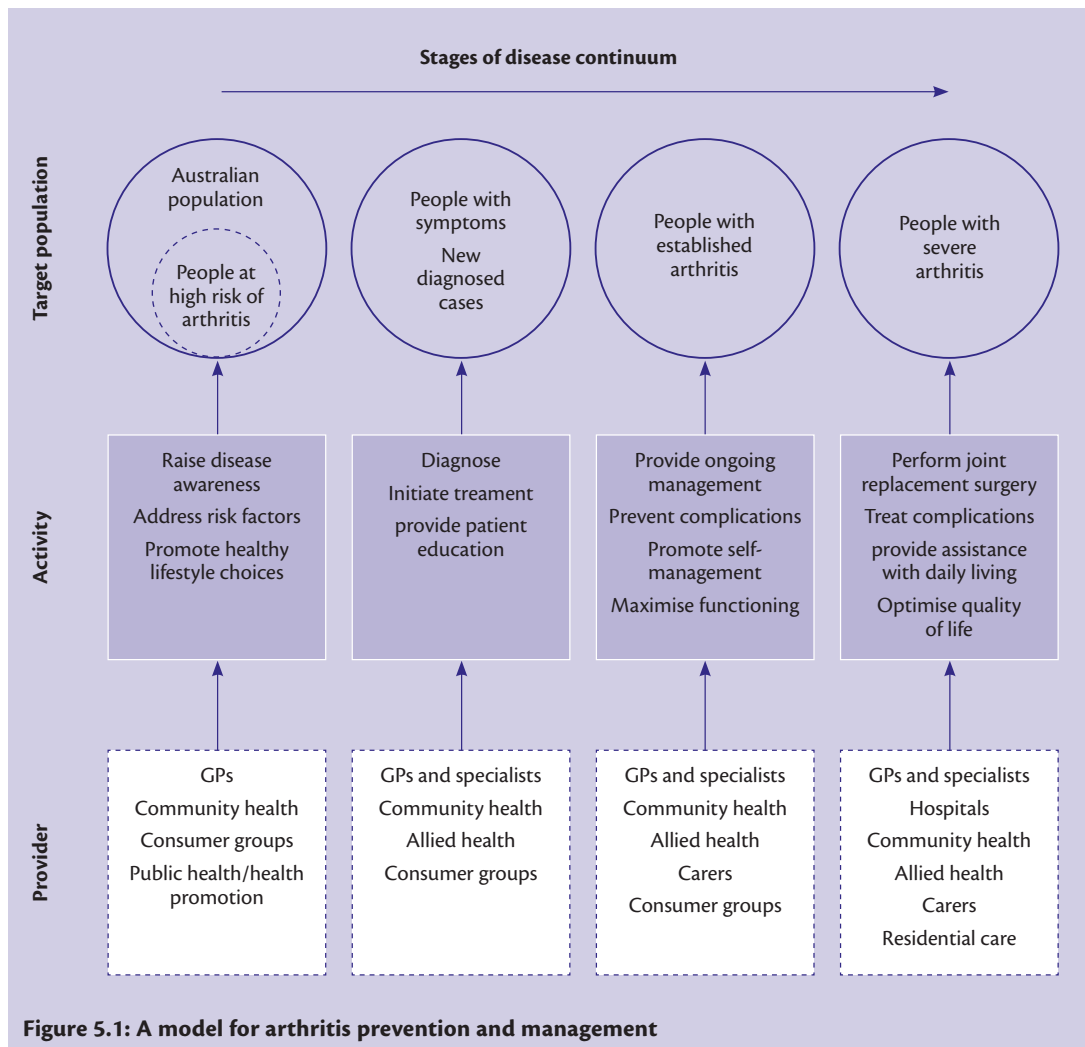
### THE DISEASE CONTINUUM

In their report *Preventing chronic disease: a strategic framework* (NPHP 2001), the National Public Health Partnership described a generic model of chronic disease prevention and control, which illustrated various intervention points across the continuum of care and identified the health services that could contribute at each stage. Drawing on this generic model, the arthritis-specific model shown below highlights potential intervention points for arthritis and identifies the health service areas responsible for these (Figure 5.1). This new model provides a framework for the following discussion of opportunities for reducing the burden of arthritis in Australia.

### PREVENTION

Understanding the causal mechanisms that lead to a disease, and identifying factors that increase the likelihood of developing it (known as 'risk factors'), are vital elements for its prevention. In terms of public health strategies for disease prevention, targeting of modifiable risk factors (that is, those that are able to be changed) can result in widespread health benefits. Many public health strategies for chronic disease prevention are centred on encouraging positive lifestyle choices—for example, undertaking regular physical activity, consuming a balanced diet and maintaining healthy weight. These actions promote general good health and wellbeing, as well as reducing the risk of a range of chronic diseases including Type 2 diabetes, osteoarthritis, cardiovascular disease, osteoporosis and some forms of cancer (AIHW 2002).

Although some risk factors (for example, family history, age or sex) are not able to be modified and so are not in themselves able to be the targets of prevention strategies, these factors can help to identify people or groups at high risk of developing a disease so that prevention strategies and relevant medical services can be targeted and located to best effect.



### Risk factors for osteoarthritis

In recent years, increased understanding of some of the causes of and risk factors for osteoarthritis has helped to develop public health strategies to prevent or delay its onset. Several potentially modifiable risk factors have been identified. In addition to the positive lifestyle choices outlined above, avoiding or limiting repetitive load-bearing activities and preventing joint trauma are beneficial. The links between some of these factors and the development of osteoarthritis are outlined below.

#### *Overweight and obesity*

Being overweight or obese can contribute to osteoarthritis, particularly in females (Sandmark et al. 1999). Osteoarthritis develops gradually over many years, with the degenerative process beginning long before any symptoms are noticed. Exposure to risk factors early in life, therefore, influences health status at older ages. The Framingham Study, for example, predicted knee osteoarthritis among obese people as early as three decades in advance of its onset (Felson et al. 1988).

Obesity increases the load across the weight-bearing joints, thus increasing the stress on the cartilage and ligaments. It is more strongly associated with osteoarthritis of the knee than the hip, although it is related to both (Lievence et al. 2002). However, obesity has also been associated with osteoarthritis of non-weight-bearing joints such as the joints of the hand. This suggests that obesity may cause metabolic changes that can promote osteoarthritis (Eaton 2004).

Osteoarthritis can in turn contribute to overweight and obesity. The painful joints may limit physical activity, causing weight gain. However, exercise is an important part of the management of osteoarthritis, and the type and length of exercise undertaken can be modified to avoid pain and minimise the strain on the joints. This is discussed in more detail later in this chapter.

### ***History of joint trauma or injury***

Individuals with a history of joint trauma or injury are more likely to develop osteoarthritis (Gelber et al. 2000; Lau et al. 2000). Injury damages the tissues within the joint, which can increase the stress on the cartilage. The process of osteoarthritis then develops slowly over many years before it starts to cause symptoms of pain or stiffness in the previously injured joint.

Joint injuries associated with increased risk of osteoarthritis include dislocation, contusion, fracture, and tears of the menisci or ligaments. These injuries are common in sporting and recreational activities that place repeated high impacts or torsional (twisting) loads on the joints (for example, football, netball and basketball); the knee is frequently injured in this manner. However, participation in moderate exercise has many health benefits and does not of itself increase osteoarthritis risk. In fact, regular physical activity may actually decrease the risk of osteoarthritis (Rogers et al. 2002), and strong muscles may protect against cartilage loss in middle age (Foley et al. 2007). Case-control studies have found that the sports-related increase in risk of osteoarthritis can be explained by joint injury (Sutton et al. 2001; Thelin et al. 2006).

Joint trauma caused by surgery (such as meniscectomy, the surgical removal of the meniscus) can also increase the risk of osteoarthritis at the site of surgery later in life (Felson et al. 2000).

### ***Repetitive joint-loading tasks***

Repetitive movements that involve placing abnormal strain, stress or heavy loads on the joints increase the risk of osteoarthritis. These types of movements are often required in certain manual occupations, such as jobs in the building industry. Jobs involving continuous kneeling, squatting, and climbing stairs are associated with higher rates of knee osteoarthritis, whereas jobs that require heavy lifting, including farming and construction, are associated with higher rates of hip osteoarthritis (Felson et al. 2000; Lau et al. 2000).

### ***Joint misalignment***

Congenital abnormalities (conditions that are present at birth) can cause an abnormal load distribution across the joint due to an alteration of the mechanical alignment of the joint during movement (Arden & Nevitt 2006). The alignment of a joint affects the load across the cartilage and other tissues. Areas of cartilage under high load or pressure can degrade faster or be damaged by joint movement, increasing the risk of early-onset osteoarthritis.

## **Non-modifiable influences on osteoarthritis**

### **AGE**

The prevalence of osteoarthritis in all joints increases sharply with age. Radiological and autopsy surveys show a steady rise in osteoarthritic changes in joints from age 30 years onwards. By age 65 years, around 80% of the population have some radiographic evidence of osteoarthritis, though only one-quarter report any pain or disability (Nuki et al. 1999). Possible mechanisms for the influence of age on osteoarthritis include diminished capacity for cartilage repair, hormonal changes and the cumulative effects of environmental exposures (Petersson & Jacobsson 2002).

### **GENDER**

Females are at higher risk of developing osteoarthritis of the hand and knee than males (Arden & Nevitt 2006; Srikanth et al. 2005). They are affected more frequently, more severely, and at more sites. Females have a higher rate of knee cartilage tissue loss than males (Ding et al. 2007), though the reasons for this are unknown. Factors that might contribute to the increased risk of osteoarthritis in females include the effects of female sex hormones and growth factors, the different distribution of weight in females compared to males, and the possible advantages of the larger bone and body size of males on the volume of cartilage tissue at certain joints (Ding et al. 2003).

### **FAMILY HISTORY AND GENETICS**

Osteoarthritis appears to run in families. Children of parents with early-onset osteoarthritis, or osteoarthritis involving more than one joint, are at increased risk of developing the disease (Loughlin 2002).

Genetic factors can affect cartilage repair mechanisms and joint alignment. Twin studies have shown that genetic factors account for 60–65% of the variation in osteoarthritis of the hands and hips, and 40–50% in osteoarthritis of the knees (March & Bagga 2004). Multiple genes are involved, but their roles in affecting an individual's risk of osteoarthritis have not yet been clarified (Lally 2004).

## **Risk factors for rheumatoid arthritis**

Although recent advances in the understanding of disease progression in rheumatoid arthritis have led to the development of new treatment options (for example, biologic drugs), the causes or triggers of the autoimmune response that leads to the disease have not yet been isolated. Only one modifiable factor relating to the development of rheumatoid arthritis—tobacco smoking—has been clearly identified, and its nature as a disease trigger is complex. Other factors such as diet, obesity and the use of oral contraceptives have been linked to increased or decreased risk of rheumatoid arthritis in some studies, but the evidence is not conclusive.

Given the uncertainty surrounding modifiable risk factors for rheumatoid arthritis, primary prevention of the disease itself is not yet a reality. However, secondary prevention (that is, preventing progression of disease in people who have already been diagnosed) through early diagnosis and prompt initiation of treatment, can reduce the extent of disability and functional limitations generally associated with rheumatoid arthritis. This is discussed in detail later in this chapter.

Some influences on rheumatoid arthritis risk are described below.



### ***Tobacco smoking***

Tobacco smoking is the only modifiable influence on rheumatoid arthritis that has been clearly identified to date. Exactly how smoking increases the risk of the disease is unclear, but may relate to its effect as a trigger of immune response for certain proteins, its effect on sex hormone levels and its propensity to cause damage to a variety of bodily tissues (Harrison 2002; Klareskog et al. 2006b). Only certain subtypes of rheumatoid arthritis are related to smoking, namely the anticitrulline antibody-positive form and the seropositive (or rheumatoid factor positive) form.

Smoking has not been found to independently increase the risk of rheumatoid arthritis in the general population, but rather to interact with certain genetic factors associated with rheumatoid arthritis and lead to high risk in people with these factors (Klareskog et al. 2006a).

### ***Genetic factors***

Family studies indicate the high heritability of rheumatoid arthritis. Severe rheumatoid arthritis is found at approximately four times the expected rate in first-degree relatives of people with the disease. Approximately 10% of people with rheumatoid arthritis have an affected first-degree relative (Silman & Hochberg 2001). The disease also exhibits a higher concordance rate in identical twins than in fraternal twins (Silman et al. 1993). Certain genes (including a particular combination of human leukocyte antigens, referred to as the HLA-DR shared epitope) have been found to be highly associated with rheumatoid arthritis.

### ***Gender (hormonal factors)***

Rheumatoid arthritis is more common among females than males. This may be due to the role of female sex hormones, particularly during menopause (Kuiper et al. 2001). Other factors that may be involved in the higher incidence of rheumatoid arthritis in females include their low levels of the male sex hormones and high levels of prolactin (a protein involved in milk production) (Brennan & Silman 1995). Pregnancy also influences the timing of the disease, with the period just after childbirth being a high-risk time for developing first symptoms (Silman et al. 1992).

### ***Environmental factors***

The presence of high-risk genes is not sufficient to develop rheumatoid arthritis. Additional environmental factors are required to expose this susceptibility—in other words, something must happen to trigger the onset of the disease. Exposure to an infectious agent, such as a virus or bacteria, is suspected, though none have been clearly linked with the disease. However, any infectious agent involved is merely a trigger, and not a cause: rheumatoid arthritis is not transmissible from person to person.

### ***Other influences***

In addition to the above-mentioned genetic, environmental and biochemical factors, several other factors such as socioeconomic status, education and psychosocial wellbeing may play a role in the development and progression of rheumatoid arthritis (Callahan & Pincus 1988; Symmons 2003).

Rheumatoid arthritis is not as common in less developed countries (Woolf & Pfleger 2003). It is also less common in rural areas (Symmons 2002), although the differences between rural and non-rural areas are small. Among some populations where the prevalence of rheumatoid arthritis is naturally very low (for example, among tribal African communities), increased prevalence in urbanised groups compared with those still living traditionally has been documented (Solomon et al. 1975). The reasons for this variation are not well understood, and likely relate to a combination of genetic, sociological and environmental factors.

## DETECTION AND DIAGNOSIS

Pain and stiffness are often the first symptoms of arthritis. However, musculoskeletal symptoms can have many causes, and sometimes it can be difficult to distinguish the symptoms of arthritis from those of other diseases and conditions. For this reason, diagnosis usually involves a combination of investigations including a medical history, physical examination, and pathology and imaging tests. The main symptoms of osteoarthritis and rheumatoid arthritis, and the ways these conditions are diagnosed, are described below.

### Symptoms

The **osteoarthritis** process occurs gradually over many years, and symptoms tend to come on gradually. They may vary from day to day and between individuals, but generally include the following symptoms in the affected joints:

- pain (generally worse when moving, and eased by rest)
- tenderness
- stiffness (generally worse after rest, and improved by movement)
- limitation of movement
- swelling
- a creaking sound or sensation on movement (known as 'crepitus').

By comparison, the symptoms of **rheumatoid arthritis** usually develop quite quickly, over a few weeks to months or in some cases over just a few days. The main joint symptoms are:

- pain (usually worse in the morning or after long periods of rest)
- stiffness (generally worse in the morning and lasting more than an hour)
- heat
- swelling
- weakening of the surrounding muscles
- painless lumps under the skin (called 'nodules').

People with rheumatoid arthritis also often experience a general feeling of being unwell.

## Diagnosis

A diagnosis of **osteoarthritis** is generally based on a description of symptoms, physical examination and medical history. Occasionally, pathology tests may be ordered; these are to rule out other potential causes of the symptoms displayed and not to detect osteoarthritis itself. X-rays are sometimes used, but as cartilage does not show up on X-rays these only show results when the osteoarthritis is severe and the bone itself has been damaged. Other imaging techniques such as ultrasound and magnetic resonance imaging (MRI) are being used in clinical studies to see if they are able to detect osteoarthritic changes at an earlier stage.

**Rheumatoid arthritis** can be difficult to diagnose in its early stages, as symptoms vary in appearance and severity. There is no single test that can detect rheumatoid arthritis, and since the symptoms may be similar to those of other joint disorders it can take time to rule out other conditions. An accurate diagnosis is obtained through a combination of blood tests, joint X-rays, physical examination and the use of other imaging techniques such as MRI and ultrasound. MRI and ultrasound are very sensitive tools for detecting early joint symptoms and erosions, and may help to diagnose rheumatoid arthritis at an early stage (Oliver et al. 2005), but these techniques are not yet in routine clinical use.

Diagnostic criteria for rheumatoid arthritis have been developed by the American College of Rheumatology (ACR) (Box 5.1) (Arnett et al. 1988). These criteria identify 'definite' rheumatoid arthritis, and are used to classify the disease in epidemiological studies and clinical trials. Initiating treatment in patients with undifferentiated inflammatory arthritis or 'probable' rheumatoid arthritis before the ACR criteria are met may be beneficial in many cases (van Dongen et al. 2007).

### Box 5.1: ACR 1987 revised criteria for the diagnosis of rheumatoid arthritis

*Rheumatoid arthritis is defined by the presence of any four of the following:*

1. *morning stiffness in and around the joints, lasting at least 1 hour and present for at least 6 weeks*
2. *arthritis of three or more joints including the elbows, wrists, hands, knees, ankles or feet, present for at least 6 weeks*
3. *arthritis of hand or wrist joints present for at least 6 weeks*
4. *symmetrical arthritis of joints listed in criterion 2, present for at least 6 weeks*
5. *rheumatoid nodules*
6. *serum rheumatoid factor positive*
7. *radiographic changes in the hand or wrist joints, including erosions or bony decalcification.*

Source: Arnett et al. 1988.

### Importance of early diagnosis and intervention for rheumatoid arthritis

Early diagnosis of rheumatoid arthritis is important for reducing the severity of symptoms and preventing disability. Degeneration occurs early in the course of disease, so before this happens it is important to make a diagnosis and begin treatment. Treatment with disease-modifying anti-rheumatic drugs (DMARDs), if appropriate, is commenced as early as possible. Treatment with these drugs aims to reduce joint pain and swelling and prevent joint damage. The type of DMARD used is determined by the likely prognosis or history of the condition, based on how the person presents initially. Careful monitoring by a doctor or specialist is required to achieve optimal results and minimise side effects.

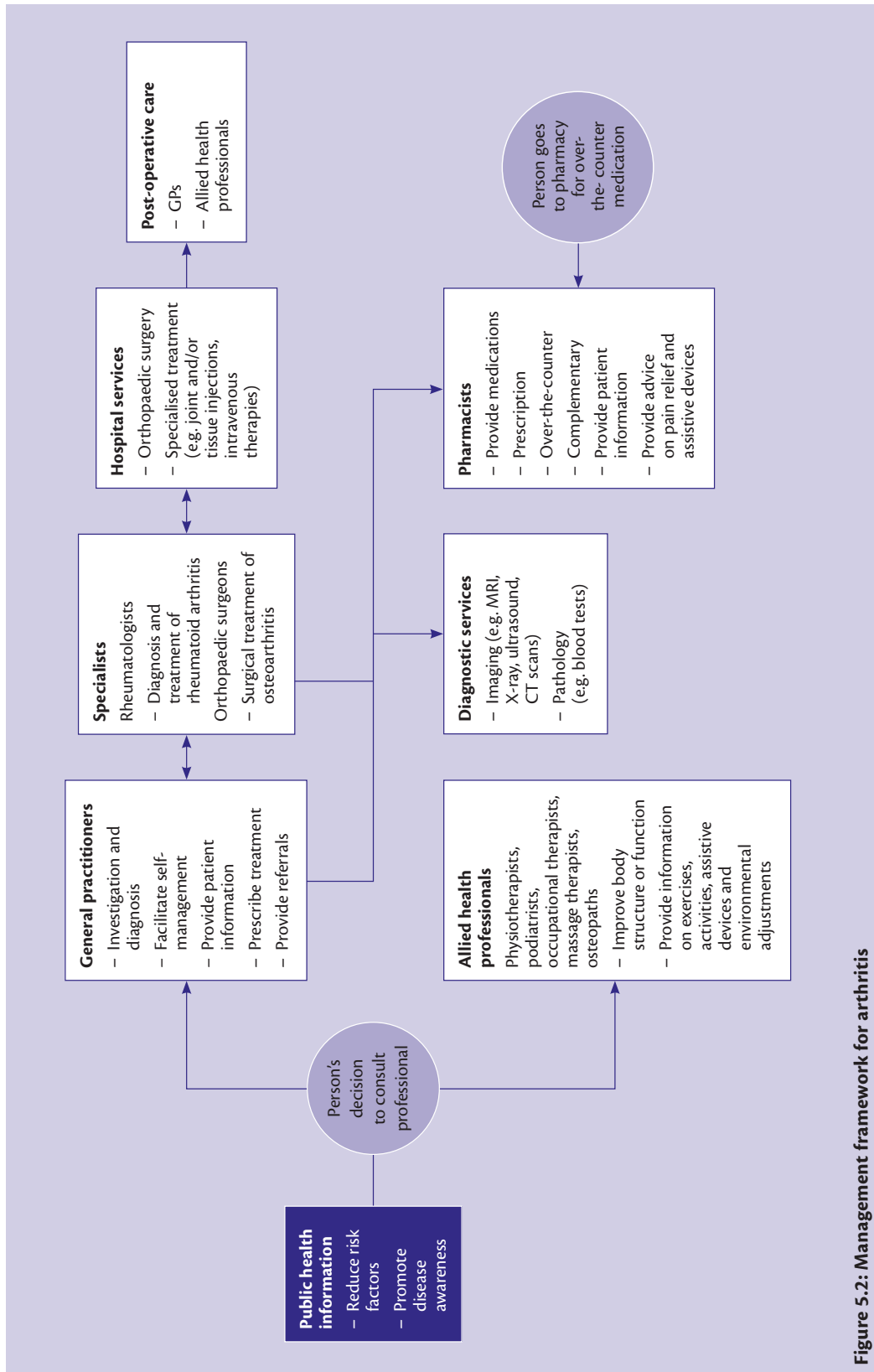


Figure 5.2: Management framework for arthritis

The goals of treatment for rheumatoid arthritis are controlling symptoms, preventing or limiting degeneration of the joints and minimising subsequent disability. Recently, combination therapies (a biologic plus a DMARD; for example, etanercept with methotrexate) have been shown to be effective in improving symptoms, reducing disease progression and inducing remission in a large proportion of patients (Breedveld et al. 2006; Goekoop-Ruiterman et al. 2007; van der Heijde et al. 2006). Remission is now considered a realistic treatment goal (Montecucco 2006), although therapy usually needs to be maintained.

## ARTHRITIS MANAGEMENT

Effective management of arthritis involves a variety of health practitioners. Treatment options are complex: a combination of physical therapy, medication and lifestyle modification is required to limit pain, maximise function and optimise quality of life. In some cases, joint replacement surgery may be necessary to relieve pain and improve function at a badly affected joint; this is more common in osteoarthritis. Improvements in surgical and anaesthetic techniques have meant that joint replacement surgery is now more widely available, particularly for those at older ages.

People with arthritis seek health care both for acute flare-ups of symptoms and for the ongoing management of their condition. A person's knowledge about the condition, self-management skills and confidence, access to primary health care services, disease severity, symptoms and personal beliefs can affect their help-seeking behaviour and influence their choice of health professional.

The general practitioner sees the largest volume of people with arthritis; they can refer to and coordinate care with specialists and other health professionals (Figure 5.2). Guidelines for the diagnosis and management of osteoarthritis and rheumatoid arthritis have been developed by the Royal Australian College of General Practitioners (see <[www.racgp.org.au](http://www.racgp.org.au)>). Specialists such as rheumatologists and orthopaedic surgeons are important for diagnosis of rheumatoid arthritis and surgical treatment of osteoarthritis. Allied health practitioners (such as physiotherapists, occupational therapists and podiatrists) also play key roles in the management team.

### Management options

Arthritis cannot be cured. The aims of management are therefore to relieve pain, reduce inflammation, protect the joints from damage, maintain joint function and (for rheumatoid arthritis) to prevent or reduce involvement in other parts of the body. Early prevention of joint damage and induction of remission are key goals in rheumatoid arthritis. Management generally comprises a combination of medication, physical therapy, self-management education and (where necessary) surgery.

The most common management actions reported by people with arthritis in the 2004–05 National Health Survey (NHS) were taking vitamin and mineral supplements and using pharmaceuticals (Table 5.1). A range of physical therapies were also reported, with exercise being the most common. Approximately 30% of people with arthritis reported that they took no actions or treatments for arthritis in the 2 weeks before the survey was conducted. Note that not all of the treatments described below are recommended for all types of arthritis.

Medications and physical therapy act through different mechanisms to treat arthritis. Medications act by suppressing pain, providing non-specific suppression of the immune system or inflammatory process, or preventing progressive damage to joint structures. Physical therapy strengthens and maintains mobility of the muscles and ligaments surrounding the joint, protecting the joint from further damage and improving functioning. Physical activity also improves mental health.

**Table 5.1: Management actions taken for arthritis, 2004–05**

Action	Per cent
Exercised most days	18.8
Strength or resistance training	5.5
Water therapy	3.7
Weight loss	5.2
Change of diet or eating pattern	3.5
Massage	6.3
Used physical aids	2.3
Used vitamin/mineral supplements	39.0
Used pharmaceutical medication	37.4
Visited a GP or specialist	10.8
Visited an allied health professional	4.4
Other actions	1.8
No action	29.5

*Notes*

1. Includes people that self-reported a doctor's or nurse's diagnosis of any form of arthritis. Data were not reliable enough to allow separation into specific types of arthritis.
2. More than one action may be reported.

Source: AIHW analysis of the 2004–05 NHS CURF.

## Exercise

Exercise can have many benefits for people with arthritis and is an essential part of therapy. In addition to reducing joint stiffness and maintaining mobility, regular exercise can reduce the risk of developing other chronic diseases such as diabetes and cardiovascular disease. In people who already have other chronic conditions, exercise can help manage these conditions and reduce the risk of complications.

The main types of exercise recommended for people with arthritis are aerobic fitness, quadriceps (thigh) muscle strengthening and resistance exercises. People with arthritis may find it difficult to exercise, or they may be reluctant to do so because of the pain experienced in the joints. However, exercise programs can be tailored to suit the needs and abilities of a person with arthritis and to provide support for the affected joints—for example, by exercising in water. No matter what type of exercise is performed, to obtain the greatest benefit it is important that it is done regularly.

Exercise for people with rheumatoid arthritis is directed at maintaining muscle strength and joint mobility without increasing joint inflammation. Regular aerobic and resistance exercises are beneficial for people with rheumatoid arthritis, and have been shown to reduce symptoms and disease activity, and increase functional capacity (Hakkinen et al. 2001).

## Self-management

Educating people with arthritis about their condition, how they can best manage it and how to reduce the risk of exacerbation or complications is known as self-management. Self-management courses can provide counselling, encouragement and a support network. These courses can also advise on the appropriate use of aids, joint protection (that is, how to avoid aggravating the joint and causing further injury), the likely progression of the condition and the purpose of and options for treatment.

Informing patients about their condition can lead to improvements in pain, functioning and quality of life. In Australia, arthritis-specific self-management courses are offered by the Arthritis Australia affiliates in each state and territory (freecall 1800 011 041), and general chronic disease self-management courses are offered by community and Aboriginal health centres, and through some general practices.

## Aids to realign joints

When the bones are out of alignment in a joint, certain surfaces of cartilage are put under higher load, causing osteoarthritis in that part of the joint. Realignment of knee joints can be achieved through the use of orthotics and taping. There is no clear evidence for whether this practice can actually prevent osteoarthritis from developing, but it may reduce symptoms.

In people with osteoarthritis in one side of the knee, a wedged insole may help take pressure off the affected side and put the knee joint into better alignment. This can reduce pain and improve functioning of the joint. An Australian trial is currently assessing the effectiveness of wedged insoles in people with medial (inner) knee osteoarthritis (Bennell et al. 2007).

When the area behind the kneecap (patella) is affected, symptoms may be improved by taping the kneecap into correct alignment. Taping can be used along with exercises to strengthen the muscles that hold the patella in the correct alignment.

## Weight loss and reduction of joint loading

Carrying excess body weight or performing certain repetitive movements puts additional pressure (or 'load') on the joints, particularly the hips and knees. In people with osteoarthritis, this causes pain and increases the rate of cartilage breakdown. Reducing the load on the joints is therefore an important part of osteoarthritis treatment.

In people who are overweight, weight loss helps to reduce the pain and disability associated with knee osteoarthritis, can slow the progression of the disease and may even reverse cartilage damage (Ding et al. 2006). Similarly, avoiding prolonged standing, kneeling and squatting can improve symptoms in people with knee or hip osteoarthritis. This may be difficult because these activities are often part of a person's job. In these cases, an occupational therapist can advise on appropriate activities and recommend different ways of doing tasks so that the load on the affected joints is minimised.

For people with arthritis affecting the hands, flexible splinting of some joints in the hand can reduce unwanted motion and pain and may be useful for short periods, but used long term this can cause muscle wasting that is detrimental to joint function.

## RICE therapy

RICE therapy (rest, ice, compression and elevation) is used to manage acute flare-ups of arthritis symptoms. It is generally undertaken in the first 48 hours after an injury or flare-up of symptoms, to reduce pain and swelling. The joint is rested and kept in an elevated position, ice is applied for 10 minutes every 1–2 hours, and compression bandages or strapping are used to support the joint. Heat therapy should not be used during this time, but can be applied for pain relief after the initial 48-hour period.

Rest can also improve symptoms of rheumatoid arthritis.

## Use of medications

Medications are an important part of the management of arthritis. Prescribing, advising or supplying medications is the most common management action taken by general practitioners in consultations for osteoarthritis and rheumatoid arthritis. A wide variety of medications for the treatment of arthritis are available in Australia.

Medications can be obtained either by prescription or over the counter (that is, without a prescription). The major types of prescription and over-the-counter medications used in arthritis management are described in Chapter 4. Natural and herbal supplements, vitamins and minerals ('complementary medicines') are also widely available and commonly used, though evidence for the effectiveness of these types of medicines is limited. The complementary medicines most commonly used by people with arthritis are glucosamine and chondroitin (Box 5.2).

In the 2004–05 NHS, 19% of people with osteoarthritis and 47% of those with rheumatoid arthritis reported that they were taking at least one pharmaceutical (that is, medications other than complementary medicines) for their condition. Use of complementary medicines was reported by 28% of people with osteoarthritis and 19% of those with rheumatoid arthritis.

Pharmaceuticals commonly used for osteoarthritis include paracetamol and other analgesics, and non-steroidal anti-inflammatory drugs (NSAIDs) such as celecoxib. For rheumatoid arthritis, commonly used pharmaceuticals include paracetamol and other analgesics, NSAIDs, corticosteroids and disease-modifying anti-rheumatic drugs (DMARDs) such as methotrexate.

### Box 5.2: Glucosamine and chondroitin: complementary medicines commonly used for arthritis

*Glucosamine and chondroitin are the building blocks of one of the components of cartilage. Taking dietary supplements of these compounds may reduce pain in people with mild to moderate symptoms of osteoarthritis, although evidence for the effectiveness of these supplements is limited.*

*Glucosamine comes in two forms: glucosamine sulphate and glucosamine hydrochloride. It is made from crab, lobster or shrimp shells, so it can have adverse effects in people allergic to seafood. Glucosamine can cause gastrointestinal upsets and be a problem for people with abnormal glucose tolerance.*

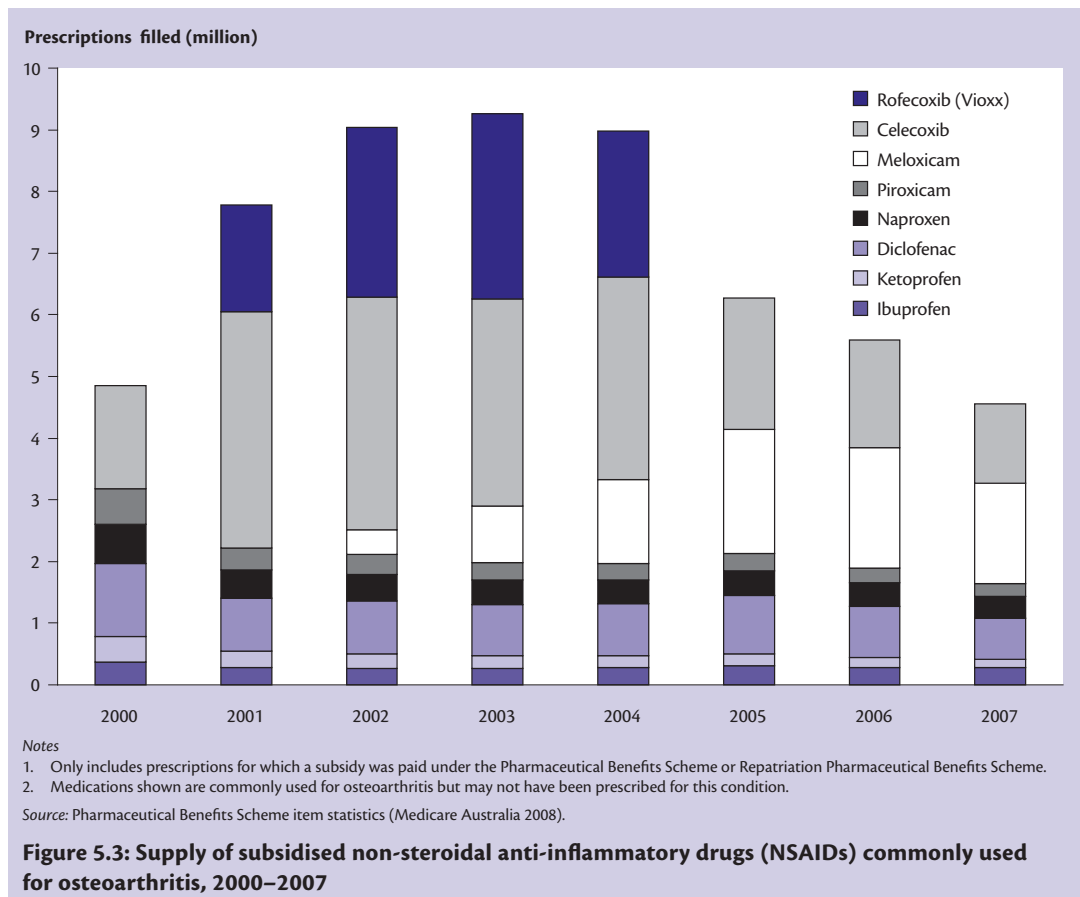
*Chondroitin is made from animal cartilage and can cause adverse effects in people taking blood-thinning agents such as heparin and warfarin.*



**Trends in pharmaceutical use**

Between 2000 and 2005 there were significant changes in the type of NSAID prescriptions supplied with a subsidy from the Australian Government’s Pharmaceutical Benefits Scheme (PBS) or Repatriation PBS (Figure 5.3). This occurred because of the introduction of two COX-2 specific NSAIDs—rofecoxib (also known as Vioxx<sup>®</sup>) and celecoxib—into the schemes. The number of subsidised prescriptions filled for rofecoxib peaked in 2003, but in late 2004 the drug was recalled from the market because of increased risks of cardiovascular and renal complications. Over the following 12 months, the supply of celecoxib prescriptions decreased, while the supply of meloxicam increased. Over 2006 and 2007 the supply of celecoxib continued to decrease, but the number of meloxicam prescriptions was stable. The number of subsidised prescriptions filled for other NSAIDs (piroxicam, naproxen, diclofenac, ketoprofen and ibuprofen) declined between 2000 and 2001, but have since remained relatively steady.

Trends in the use of other subsidised pharmaceuticals commonly taken for osteoarthritis, including paracetamol, opioids and corticosteroids, are not shown here. These types of drugs can be used for many different conditions, and so the trend in supply may not be related to the treatment of osteoarthritis.



## Complications and comorbidities

'Complications' in this sense are health problems or other diseases a person may have as a result of their arthritis. These problems may be related to the disease process itself, or they may be a side-effect of arthritis treatment.

### *Complications in osteoarthritis*

As previously noted, osteoarthritis involves only the joints and the osteoarthritic process does not directly affect other parts of the body. As age increases, people with osteoarthritis are likely to also have other diseases, known as comorbid conditions. Although the presence of these comorbid conditions may affect the way that osteoarthritis is managed (for example, the type of medication taken), they are not complications of osteoarthritis.

One problem to which osteoarthritis may contribute is obesity. Joint pain and stiffness may make people with osteoarthritis reluctant to exercise, or they may have difficulty doing so, and this can lead to weight gain. As well as putting extra stress on the weight-bearing joints, obesity is a risk factor for many chronic diseases including heart disease, stroke and Type 2 diabetes, so maintaining a healthy weight is important. As described above, exercise and weight loss are essential therapies for arthritis, and activities can be tailored to ensure affected joints are properly supported.

Some of the medications used to manage osteoarthritis may cause adverse side effects, such as high blood pressure, heart failure, nausea and peptic ulcers. These are complications of osteoarthritis treatment. To reduce the risk of these side effects, medication should be used as instructed and monitored by a health professional. The types of medication used for arthritis are described in detail in Chapter 4.

### *Complications in rheumatoid arthritis*

In addition to joint deformities and associated disability, people with rheumatoid arthritis may experience a range of complications, resulting both from the disease process and from the medications used to manage it.

The underlying autoimmune process may attack tissues throughout the body, including the lungs, the membranes surrounding the heart, the eyes and occasionally the blood vessels. This can lead to potentially serious complications such as heart failure, heart attack, myocarditis (inflammation of the heart muscle), breathing difficulties and anaemia. Regular monitoring for signs of these conditions is necessary so that appropriate treatment or preventive action can be initiated as early as possible. Aggressive control of cardiovascular risk factors (blood pressure and cholesterol levels) is recommended (RACGP 2007).

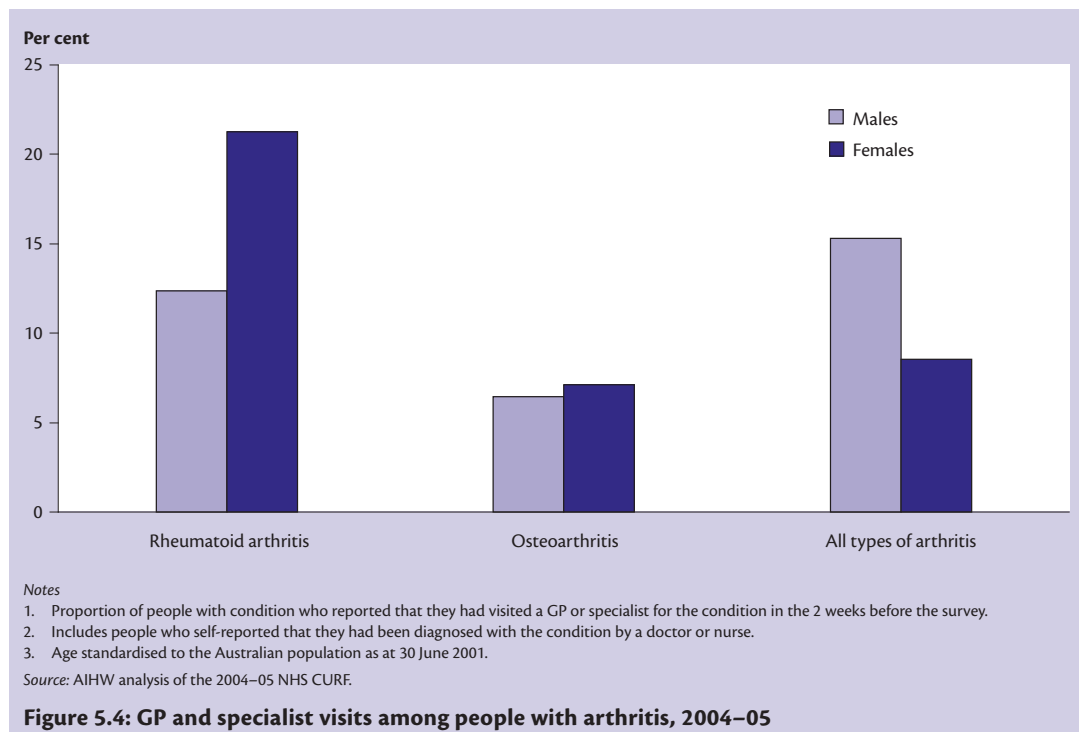
The medications used to manage rheumatoid arthritis can also have adverse side effects. These may include ulcers, osteoporosis, nausea, kidney problems, headaches and disruption of liver function. Some of the medications may depress the immune system, leading to increased risk of infections and immune-related diseases such as cancer (Sihvonen et al. 2004). Careful monitoring of medication use, regular testing for side-effects and early treatment of complications is needed (RACGP 2007). Detailed information about the various types of medication used in rheumatoid arthritis management is provided in Chapter 4.

People with rheumatoid arthritis have an increased risk of premature death, with a life expectancy on average 5–10 years younger than the general population (Kvien 2004). Begg et al. (2007) estimated that more than 1,600 years of life lost in Australia in 2003 could be directly attributed to rheumatoid arthritis. Cardiovascular disease and cancers are the most common causes of death in people with the disease.

## Management by GPs and specialists

General practitioners play a central role in the management of arthritis in the community. This role includes assessment, prescription, education, referral and review. Specialist services are also important, particularly for people with rheumatoid arthritis and among those for whom surgery is being considered.

In the 2004–05 NHS, 6% of males and 7% of females with osteoarthritis reported that they had visited a GP or specialist for their condition in the 2 weeks before the survey was conducted (Figure 5.4). Among people with rheumatoid arthritis, 12% of males and 21% of females reported visiting a GP or specialist for their condition during that 2-week period.



## Services provided by GPs

The BEACH survey of general practice found that osteoarthritis was the eighth most common problem managed by GPs in 2007–08 (Britt et al. 2008). Osteoarthritis made up 1.7% of all problems managed by GPs in that year, and was managed in 26 out of every 1,000 encounters (more than one problem can be managed at each encounter). This equates to almost 2.8 million Medicare-paid GP consultations between 1 April 2007 and 31 March 2008. Of osteoarthritis problems managed by GPs, 20% were new problems (that is, the first presentation of the problem to a medical practitioner).

Rheumatoid arthritis is less commonly managed by GPs than osteoarthritis. This most likely reflects the lower prevalence of rheumatoid arthritis and the greater role of specialists in its management. Rheumatoid arthritis made up 0.3% of problems managed by GPs in 2007–08, managed at 5 out of every 1,000 encounters. Twelve per cent of rheumatoid arthritis problems managed by GPs were new problems.

**Table 5.2: Management provided by general practitioners for osteoarthritis and rheumatoid arthritis, 2007–08**

Type of management	Osteoarthritis (OA)		Rheumatoid arthritis (RA)	
	Per cent <sup>(a)</sup> of all OA encounters (n = 2,474)	Per cent <sup>(a)</sup> of new OA encounters <sup>(b)</sup> (n = 485)	Per cent <sup>(a)</sup> of all RA encounters (n = 435)	Per cent <sup>(a)</sup> of new RA encounters <sup>(b)</sup> (n = 53)
Medications	70	63	69	70
Referrals	11	13	14	34
<i>Orthopaedic surgeon</i>	5	4	0	0
<i>Physiotherapist</i>	3	5	2	12
<i>Rheumatologist</i>	1	2	9	23
Pathology	2	3	18	16
<i>C-reactive protein</i>	—	1	6	6
<i>Erythrocyte sedimentation rate</i>	—	—	8	9
<i>Full blood count</i>	—	2	15	9
<i>Liver function test</i>	—	1	9	2
<i>Rheumatoid factor</i>	—	—	2	6
Imaging	14	36	6	24

— less than 1%

(a) Per cent of encounters where at least one management action of this type was undertaken. Where more than one such action has been undertaken in a single encounter it has been counted once, for example, if two medications were prescribed at a single encounter it was counted once.

(b) Encounters where the problem was being presented to a medical practitioner for the first time.

Source: AIHW analysis of the 2007–08 BEACH survey.

GPs manage osteoarthritis and rheumatoid arthritis using a variety of strategies (Table 5.2). Medication is the most common management strategy employed for arthritis by GPs, with at least one medication being prescribed, advised or supplied in 70% of encounters for osteoarthritis and 69% of those for rheumatoid arthritis in 2007–08. As might be expected, imaging and referrals were more commonly used for new problems than for existing problems.

The most common medications prescribed, advised or supplied for osteoarthritis were paracetamol (prescribed/advised in 23% of encounters), meloxicam (13%) and celecoxib (8%), with methotrexate (20% of rheumatoid arthritis encounters), paracetamol (8%) and meloxicam (7%) being the most commonly prescribed, advised or supplied medications for rheumatoid arthritis (Table 5.3).

**Table 5.3: Top 10 medications prescribed, advised or supplied by GPs for osteoarthritis and rheumatoid arthritis, 2007–08**

Osteoarthritis (n = 2,474)			Rheumatoid arthritis (n = 435)		
Medication	Class	Per cent <sup>(a)</sup>	Medication	Class	Per cent <sup>(a)</sup>
Paracetamol	Non-opioid analgesic	23	Methotrexate	DMARD	20
Meloxicam	NSAID (COX-2)	13	Paracetamol	Non-opioid analgesic	8
Celecoxib	NSAID (COX-2)	8	Meloxicam	NSAID (COX-2)	7
Paracetamol/Codeine	Opioid analgesic	7	Prednisolone	Corticosteroid	6
Tramadol	Opioid analgesic	4	Hydroxychloroquine sulphate	DMARD	6
Diclofenac sodium systemic	NSAID	4	Celecoxib	NSAID (COX-2)	5
Glucosamine	Natural medicine	4	Diclofenac sodium systemic	NSAID	3
Oxycodone	Opioid analgesic	3	Sulfasalazine digestive	DMARD	3
Naproxen	NSAID	2	Tramadol	Opioid analgesic	3
Buprenorphine	Opioid analgesic	2	Prednisone	Corticosteroid	3

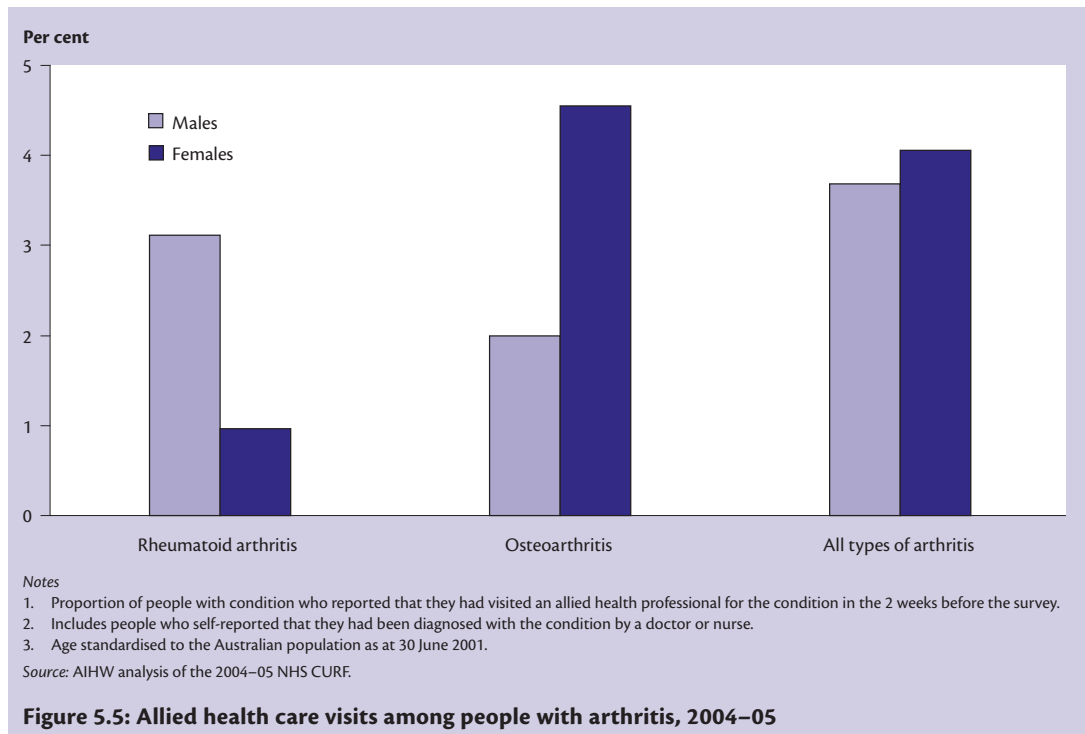
(a) Per cent of encounters for the condition in which the medication was prescribed, advised or supplied for that condition.

Source: AIHW analysis of the 2007–08 BEACH survey.

## Use of allied health services

Allied health and complementary practitioners (such as physiotherapists, podiatrists, occupational therapists, pharmacists, massage therapists, osteopaths and chiropractors) play important roles in the management of arthritis. The treatment that allied health professionals provide is generally aimed at improving body structure or function. They may also recommend or provide information about self-management (including exercises, activities and other therapies) and suggest environmental adjustments that can be made to help people overcome functional limitations, maintain independence and reduce the risk of injury.

Among respondents to the 2004–05 NHS who reported a diagnosis of rheumatoid arthritis or osteoarthritis, few people (2% and 4%, respectively) reported that they visited allied health professionals for their condition in the 2 weeks before the survey was conducted (Figure 5.5).



## Surgery

Surgery can be a very useful and successful form of management for arthritis, particularly in people with severe disease. A number of procedures are available (Box 5.3), of which joint replacement (also called ‘arthroplasty’) is the most common.

In 2006–07, almost 99,000 surgical procedures were performed on people with the principal diagnosis of osteoarthritis, and over 5,000 procedures were performed on people with the principal diagnosis of rheumatoid arthritis (Table 5.4). The average length of stay in hospital was 6.9 days for surgery due to osteoarthritis and 10.5 days for surgery due to rheumatoid arthritis. Knee and hip replacements were the most common procedures performed for osteoarthritis, whereas knee replacement and excision of lesion of soft tissue were the most common procedures performed for rheumatoid arthritis.

**Box 5.3: Common surgical procedures for arthritis**

**Osteotomy:** to cut or reshape bone. It is performed to slow the progression of disease, especially when wear is occurring on a single disc of cartilage.

**Arthroscopy:** to look inside the joint. This procedure is used in the early stages of osteoarthritis for temporary symptom relief and to know what is happening in the joint. This procedure may be accompanied with a meniscectomy, where all or part of a torn meniscus is removed, and other repairs such as debridement, osteoplasty or chondroplasty (described below).

- **Debridement:** the surgical removal of lacerated, devitalized, or contaminated tissue.
- **Osteoplasty:** replacement of lost bone tissue or reconstruction of defective bony parts.
- **Chondroplasty:** shaving of articular cartilage.
- **Incision:** a cut or wound of body tissue made especially in surgery.
- **Excision:** surgical removal of all or part of diseased tissue or organ.

**Arthrodesis:** where bones within a joint are fused together. This procedure can successfully relieve pain and is most commonly performed in the spine and in the small joints of the wrist, hand and foot.

**Arthroplasty:** joint replacement, or to replace some or all of the bones in the joint with artificial components. It is the most common surgical treatment of the osteoarthritic hip, knee and shoulder joint; the pain and disability of severe osteoarthritis can be reduced, restoring some patients to near-normal function.

**Table 5.4: Most common surgical procedures performed in separations with the principal diagnosis of osteoarthritis or rheumatoid arthritis, 2005–06**

Principal diagnosis	Procedure	Number	Per cent <sup>(a)</sup>
<b>Osteoarthritis</b>	Total arthroplasty of knee, unilateral	24,462	25
	Total arthroplasty of hip, unilateral	17,829	18
	Arthroscopic meniscectomy of knee with debridement, osteoplasty or chondroplasty	9,344	9
	Hemiarthroplasty of knee	3,208	3
	Arthroscopic debridement of knee	2,033	2
	Other	41,893	42
	<b>Total</b>		<b>98,769</b>
<b>Rheumatoid arthritis</b>	Total arthroplasty of knee, unilateral	312	6
	Excision of lesion of soft tissue, not elsewhere classified	245	5
	Administration of agent into joint or other synovial cavity, not elsewhere classified	225	4
	Arthrodesis of 1st metatarsophalangeal joint	177	3
	Aspiration of joint or other synovial cavity, not elsewhere classified	173	3
	Other	4,303	79
	<b>Total</b>		<b>5,435</b>

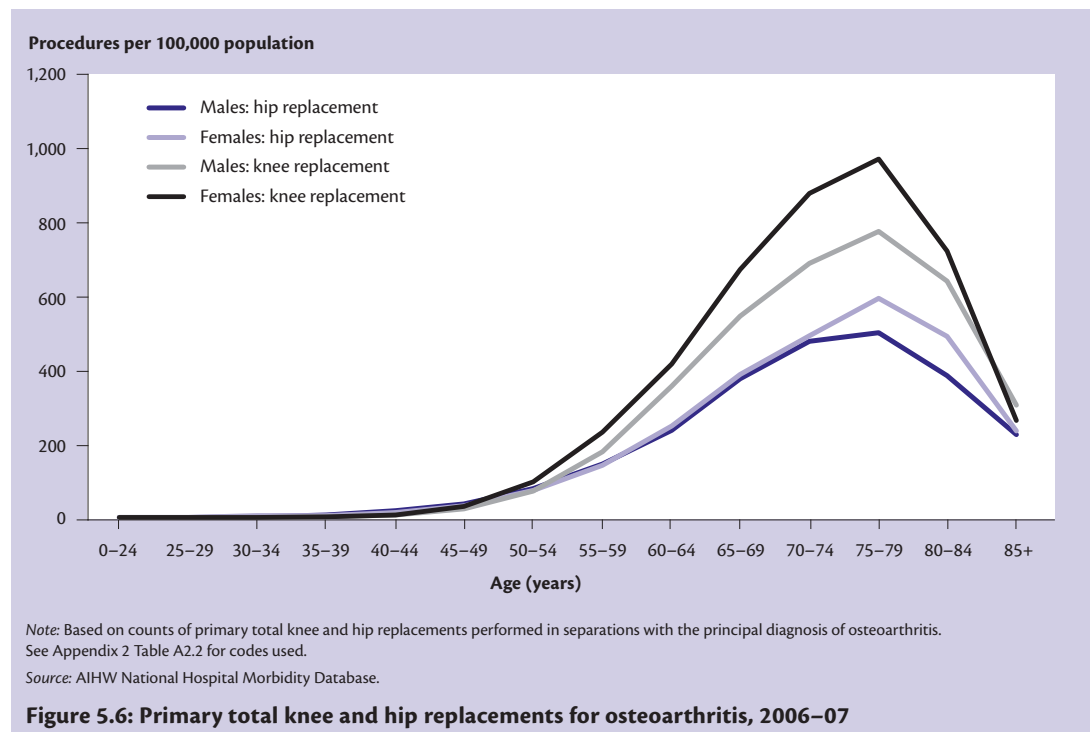
(a) Per cent of total surgical procedures performed for the condition.

Source: AIHW National Hospital Morbidity Database.

**Joint replacement**

Joint replacement has been one of the most significant advancements in the management of osteoarthritis during the last few decades. This procedure has become more accessible because of improvements in surgical techniques and anaesthesia, and better blood products used during surgery. Total joint replacement is generally indicated when a person no longer responds to less invasive forms of management and the pain and/or loss of function experienced makes normal daily living difficult.

Rates of primary total knee and hip replacement in people with the principal diagnosis of osteoarthritis are highest in the 75–79 years age group (Figure 5.6). The procedure rate among females is higher than among males, particularly for knee replacement. This is most likely a result of the higher prevalence of osteoarthritis in females.





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## 6 Osteoporosis and fractures

Osteoporosis (meaning 'porous bones') is a condition in which the bones weaken and lose structural integrity, resulting in high risk of fracture. People with osteoporosis may have substantially decreased bone mass, clinically defined as bone mineral density (BMD) a certain amount below the average level in young adults. The decrease in bone mass makes the bones more fragile and they are broken more easily than bones of 'normal' mass.

A major feature of osteoporosis is fractures that occur following little or no trauma, known as 'minimal trauma fractures'. These fractures may affect bodily movement and functioning, which can result in disability, affect social interaction and quality of life, and lead to a loss of independence. Hip fractures in older people are a common result of longstanding osteoporosis and are associated with high levels of morbidity and increased mortality.

This chapter provides an overview of the nature, impacts and treatment of osteoporosis. It also describes some of the more common osteoporotic fractures, and outlines various fracture prevention strategies.

### PREVALENCE AND DETECTION OF OSTEOPOROSIS

Self-reported data indicate that almost 581,000 Australians have been diagnosed with osteoporosis, with the vast majority being over 55 years of age. Women are much more likely to report osteoporosis than men. However, osteoporosis has no outward symptoms, and people often do not know that they have the condition until a fracture occurs. It is believed that the number of people who have osteoporosis, and who are therefore at high risk of fracture, is much larger than the estimates obtained from self-reported information.

Osteoporosis is most commonly diagnosed when a person visits a doctor, clinic or hospital following a minimal trauma fracture (also known as a 'low-impact fracture', 'fragility fracture' or 'osteoporotic fracture'). This is a fracture sustained in an event which would not be expected to fracture a healthy bone—for example, a trip and fall while walking. Some of the more common osteoporotic fracture sites are the hip, wrist and spine.

Osteoporosis may also be diagnosed by measuring bone mineral density (Box 6.1). However, not all people with low bone mineral density will experience minimal trauma fractures, and vice versa. Factors that increase the risk of fractures are discussed later in this chapter.

The turnover of bone causes various molecules (such as osteocalcin) to be released into the bloodstream or excreted in the urine. Although they are not specific enough to be used alone as a diagnostic tool, some of these biochemical 'markers' can be useful in determining the rate of bone loss or bone formation, which can help to estimate a person's risk of osteoporosis or assess their response to treatment (Sambrook et al. 2002).

**Box 6.1: Diagnosing osteoporosis using bone mineral density testing**

The 'gold standard' method for measuring bone mineral density (BMD) is dual-energy X-ray absorptiometry, also known as DXA or DEXA. Low-dose X-ray beams are aimed at the bones, and bone density can be determined from the amount of X-rays that are absorbed. This is the most common method used in clinical practice, with measurements usually taken at the hip and/or spine.

BMD results can be divided into three categories:

- **Normal:** BMD less than 1 standard deviation below the average BMD in young adults of the same sex.
- **Osteopenia (literally 'poor bones'):** BMD between 1 and 2.5 standard deviations below the average BMD in young adults of the same sex.
- **Osteoporosis:** BMD more than 2.5 standard deviations below the average BMD in young adults of the same sex.

Other methods used for measuring BMD include quantitative computed tomography (QCT) and quantitative ultrasound (QUS). QUS is the screening test often seen at pharmacies or shopping centres, where the measurement is taken at the heel. This test can help to identify persons who might need further investigation, but is not used alone for diagnosis or monitoring as its responsiveness to therapy or change over time is uncertain.

Source: WHO Scientific Group 1994.

## Osteoporotic fractures

Almost any of the body's 206 adult bones can be affected by osteoporosis, and therefore more easily fractured than would normally be the case. However, fractures are more likely to occur at some sites than at others. The most common fractures in people with osteoporosis include bones that are under strain because they bear weight (such as the spine, pelvis and hips) or that take the stress when a person catches him- or herself when falling (such as the wrists, forearms and upper arms). Some features of these common fracture sites are described below.

### Hip and pelvis

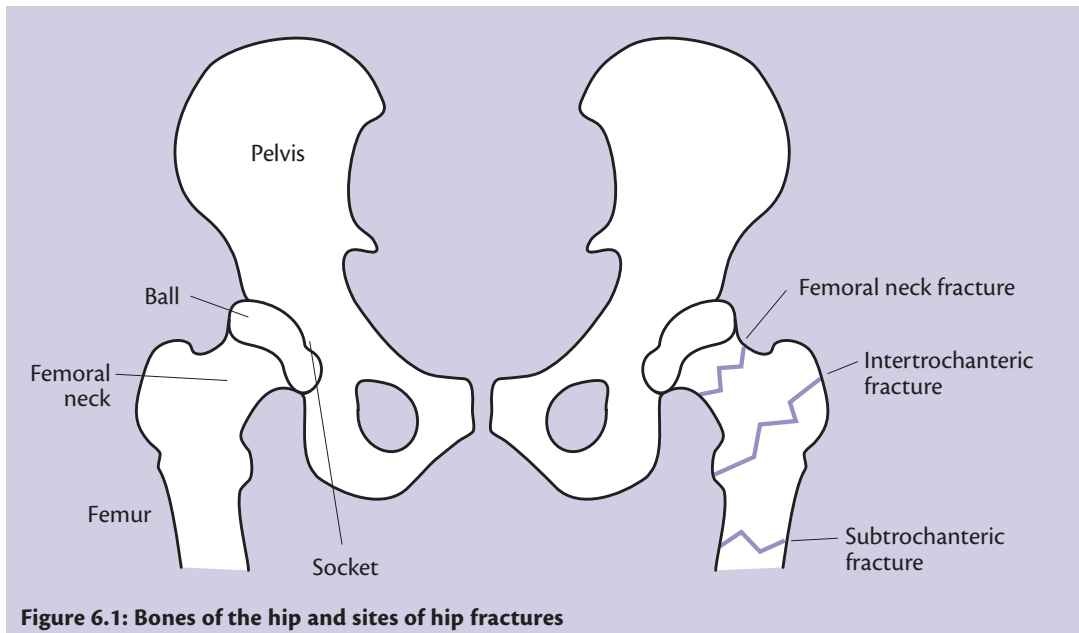
The hip joint is an example of a ball-and-socket joint, the most mobile type of joint in the body. At the upper end of the femur (thigh bone) the bone projects inward and forms a ball (Figure 6.1). This ball sits inside a cup-like socket at the side of the pelvis, and allows a wide range of movements of the legs.

The two most common types of hip fractures, as shown on the right side of Figure 6.1, are:

- **femoral neck fractures**, occurring in the narrow section of bone between the main shaft of the femur and the ball
- **intertrochanteric hip fractures**, where the shaft of the femur breaks just below the femoral neck.

Fractures may also occur slightly further down the shaft of the femur; these are known as subtrochanteric fractures and are less common.

Fractures to the hip or pelvis are normally caused by a fall, but may also result from impact to the hip. In people whose bones are weakened from osteoporosis, relatively minor impacts (such as bumping into a piece of furniture) may be enough to cause a hip fracture. This type of fracture is the most serious osteoporotic fracture, and has the most complications.



**Figure 6.1: Bones of the hip and sites of hip fractures**

### *Wrist and forearm*

Falls are the most common cause of fractures of the wrist and forearm, both in people with osteoporosis and in people with normal bone density. The sudden force applied when a person catches him- or herself after a fall puts great stress on the bones in this region, and can cause one or more of them to fracture. However, the severity of fall required to cause a wrist or forearm fracture in a person with osteoporosis is much less than in a person with normal bone density, due to the greater fragility of the bones.

The two most common types of wrist fracture are:

- **Colles' fracture**—this is a fracture to the lower end of the radius, and very common in people with osteoporosis.
- **Scaphoid fracture**—the scaphoid is a wedge-shaped bone located on the thumb side of the wrist, just where it meets the radius. These fractures are less commonly related to osteoporosis.

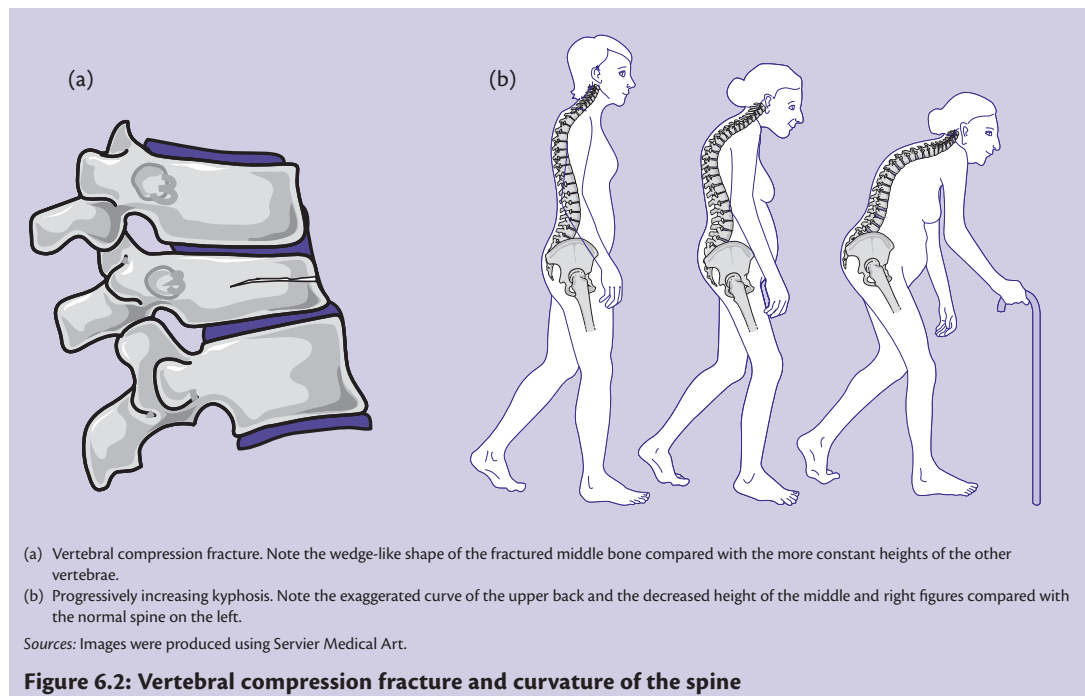
### *Spine*

The spine is made up of 24 individual bones, called vertebrae. These are stacked on top of one another and are separated by discs of tissue. The spine can be separated into three regions: the cervical spine (the neck), consisting of seven vertebrae; the thoracic spine (upper and middle back), made up of 12 vertebrae; and the lumbar spine (lower back), made up of five vertebrae. At the lower end of the lumbar spine are the sacrum and coccyx, or tail bone.

The most common type of spinal fracture (also known as a 'vertebral fracture') in people with osteoporosis is called a wedge or compression fracture. These generally occur in the thoracic region of the spine (particularly at the lower end) or the upper end of the lumbar region. In this type of fracture, one or more of the vertebrae collapses, most commonly at the front, forming a wedge shape

(Figure 6.2(a)). This can cause curvature of the spine, and people who have had a number of spinal compression fractures may display a characteristic bent-forward, hunched posture known as kyphosis (sometimes called a 'widow's or dowager's hump'), and have a noticeable loss of height (Figure 6.2(b) and (c)). Kyphosis can also result from degenerative spinal disease.

In people with severe osteoporosis, a spinal fracture may be caused by simple movements such as lifting a light object, sneezing, or even just bending forward. In people with less severe osteoporosis, more force may be required, for example, a fall or lifting a heavy object. In many cases, compression fractures may cause no pain, or minor, indistinct pain, which may be mistaken for arthritis or muscular symptoms, meaning they often remain undiscovered.



## Ankle

Fractures to the ankle usually involve a break at the bottom of one or both of the two lower leg bones (tibia and fibula). The lower ends of these bones wrap around the sides of the ankle bone (talus); these are the bony lumps (called the malleoli) that can be felt on either side of the ankles.

Ankle fractures can occur when the ankle rolls in or out, putting stress on the joint. In many cases, rolling of the ankle will injure only the surrounding muscles or ligaments; this is a sprain or 'twisted ankle'. But in some cases the end of the tibia or fibula will be broken. Fractures of the bones under the ankle joint may also occur, but are less common.

Although ankle fractures are relatively common in older people, they are not generally related to osteoporosis (Greenfield & Eastell 2001; Hasselman et al. 2003; Seeley et al. 1996). Rather, fractures of the ankle are more common in people with a history of falls and in those who are overweight (Hasselman et al. 2003; Seeley et al. 1996).



## Shoulder

The shoulder consists of three bones: the upper arm bone (humerus), the shoulder blade (scapula) and the collarbone (clavicle). Like the hip, the shoulder joint is a ball-and-socket joint, with the upper arm bone ending in a ball that fits into a shallow socket in the shoulder blade. The socket is surrounded by a fibrous ring of cartilage that helps to hold the arm bone in place and stabilise the joint, assisted by the surrounding muscles.

Fractures to the shoulder normally involve either the collarbone or the neck of the humerus (the region just below the ball). Falls are the most common cause of fractures at either of these sites.

Fractures of the upper humerus are commonly associated with osteoporosis.

### Box 6.2: Bone development and loss

The likelihood that a person will develop osteoporosis is related to the way their bones develop and are maintained over the life span. Throughout life, minerals such as calcium and phosphorous are constantly deposited and absorbed from the bones. This is a normal part of healthy bone growth and maintenance. At different periods throughout life, the rates of deposition and absorption change. Deposition levels are at their highest during childhood and adolescence, when large amounts of bone are formed during 'growth spurts'. By the age of around 20–30 years, bone mass has reached its peak. Factors affecting peak bone mass include diet, calcium intake, exercise levels and genetics.

For around the next 20 years of life, bone is absorbed at about the same rate as it is deposited, maintaining the skeletal structure. After the age of about 40–50 years, the rate of absorption increases and bone mass is lost. Various factors, including diet, calcium intake, activity levels and hormonal changes, can influence the rate of loss.

Figure 6.3 shows the effects of different patterns of bone growth and loss on the development of osteoporosis. Person 1 represents a person without osteoporosis; he achieves a good peak bone mass and has a modest rate of bone loss with age. Person 2 reaches 'normal' peak bone mass, but has a relatively high rate of bone loss and eventually develops osteoporosis. Person 3 has a 'normal' rate of bone loss, but reaches the osteoporotic level due to her relatively low peak bone mass.

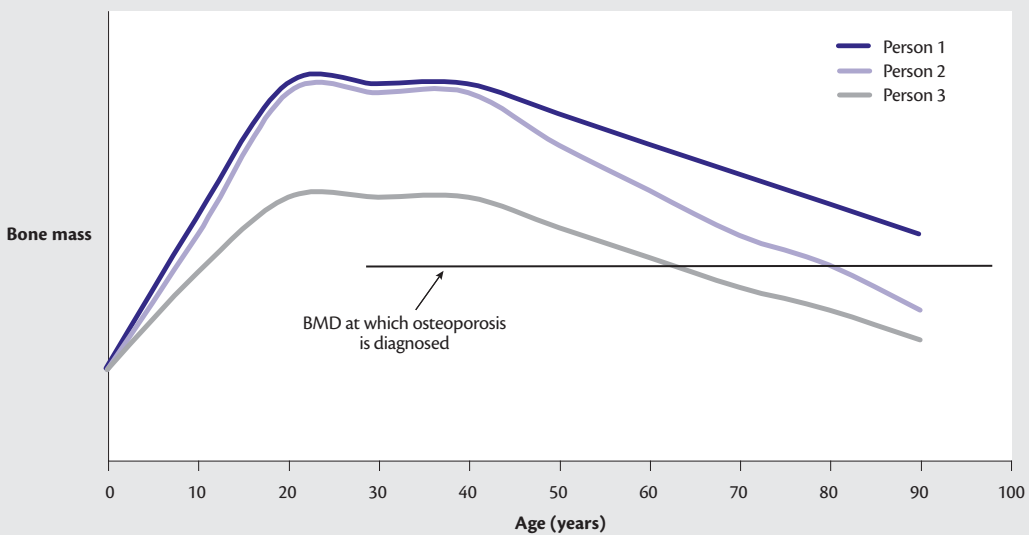


Figure 6.3: Patterns of bone growth and loss through life

## RISK FACTORS FOR OSTEOPOROSIS AND FRACTURES

A number of modifiable and non-modifiable factors increase the risk of osteoporosis and osteoporotic fractures (Table 6.1). These include older age, being physically inactive, having a family history of osteoporosis or minimal trauma fractures, poor calcium intake, vitamin D deficiency and (in women) being post-menopausal. Where possible, reducing exposure to these factors can help to prevent osteoporosis. Some prevention strategies are discussed later in this chapter.

Since minimal trauma fractures are an outcome of having low bone mineral density (BMD), the factors that increase the risk of having low BMD also increase the risk of a fracture. However, low BMD is not the only contributor to fracture risk. In fact, a person can experience a minimal trauma fracture without having BMD in the osteoporotic range. Factors that can increase the risk of fracture independently of BMD include a history of falls and high propensity to fall. These and other risk factors are described briefly below.

**Table 6.1: Risk factors for osteoporosis and fracture**

Biomedical and genetic factors	Behavioural factors	Other factors
Female sex, particularly after menopause	Smoking	Systemic illnesses (e.g. rheumatoid arthritis)
Excessively low body weight	Physical inactivity	Metabolic disorders
Older age	Poor calcium intake	Long-term corticosteroid use
Action of genes associated with skeletal maintenance	Lack of sunlight exposure	Physical disabilities that restrict weight-bearing exercise
White or Asian heritage		History of falls
Previous minimal trauma fractures		Propensity to fall
Family history of osteoporosis or fractures		Disorders involving malabsorption (e.g. coeliac disease)

### Biomedical and genetic factors

- Women are at greater risk of osteoporosis than men, particularly once they have reached menopause. Total bone mass in females is naturally lower than in males, and the normal decrease in bone mass with age is accelerated in post-menopausal women due to their decreased oestrogen levels.
- Weight is related to bone mineral density, as having a higher body mass means that more weight is borne by the bones, which then strengthen in response to this stress. People who are significantly underweight tend to have lower bone mineral density, which may lead to increased risk of osteoporosis and fractures. Weight loss is also associated with increased bone loss.
- People with a family history of osteoporosis or minimal trauma fracture are also at increased risk. Daughters of women with osteoporosis of the spine tend to have decreased bone mass. A maternal history of hip fracture doubles the risk of hip fracture in women and increases the risk of spinal deformities in men (Cummins et al. 1995; Diaz et al. 1997).
- People from certain population groups may be more likely to develop osteoporosis. White and Asian populations tend to have a lower average bone mass than black or Hispanic groups (Cumming et al. 1997).

- Several genes have been found to be associated with skeletal maintenance, and genetic variation has been found to account for a large proportion of the variation in bone mineral density (Nuki et al. 1999). However, it is difficult to identify relevant genetic pathways due to the large number of genes interacting with each other and with environmental factors.
- People who have had a minimal trauma fracture are at increased risk of subsequent fractures, an effect known as the 'fracture cascade'. Data from the Dubbo Osteoporosis Epidemiology Study show that the increase in risk persists for up to 10 years, and that 40% of women and 60% of men will experience a second fracture within this period (Center et al. 2007). Although almost all fracture types are associated with an increased risk of further fractures, men aged 60–69 years with hip or vertebral fractures are at greatest risk.

### Behavioural factors

- Smokers tend to have a lower bone mass than non-smokers. It is believed that smoking lowers body weight, interferes with the hormones that affect bone strength and may have a detrimental effect directly on the bones (Wong et al. 2007).
- Exercise is important in building and maintaining bone mass. Low physical activity levels during childhood and adolescence result in lower peak bone mass, so bone loss later in life more quickly reaches the level of osteoporosis.
- Calcium is essential for bone formation. The body cannot make calcium so it must be obtained from the diet. Low calcium intake is associated with low bone mineral density.
- Vitamin D helps the body to absorb calcium and is needed to regulate bone formation. Although small amounts of vitamin D may be obtained from the diet, the majority is synthesised by the body via exposure of the skin to sunlight. People who are institutionalised or housebound, or those who wear clothing that covers most of the body, may be particularly at risk of having low vitamin D levels.

### Other factors

- Some systemic illnesses affect bone metabolism and increase the risk of osteoporosis. These include rheumatoid arthritis, chronic kidney disease, metastatic cancer and thyrotoxicosis (a condition resulting from excessive amounts of thyroid hormones).
- The metabolic disorders hypogonadism (abnormally decreased activity of the ovaries or testes, which retards growth and sexual development) and hyperparathyroidism (over-production of parathyroid hormone, which leads to increased absorption of calcium from the bones) are associated with decreased bone mass.
- In a similar manner to people who are underweight, people with physical disabilities may be at increased risk of osteoporosis if they are unable to perform weight-bearing exercise to build and maintain bone mass. This may be particularly the case for those who are affected by disability in the peak bone formation periods of childhood and adolescence. People who have disabilities affecting their mobility may also be more likely to fall, putting them at increased risk of fractures.
- Long-term use of corticosteroid medications increases the risk of fractures. Conditions that may require long-term corticosteroid treatment include asthma and rheumatoid arthritis.

- Malabsorption reduces calcium absorption and vitamin D levels, increasing the risk of osteoporosis. Causes of malabsorption include coeliac disease and inflammatory bowel disease.
- People who have a propensity or predisposition to falling are also more likely to experience fractures. There are many reasons why a person may be more likely to fall, including problems with balance, use of medications causing dizziness and problems with mobility.
- A history of falls is associated with increased risk of fractures, regardless of BMD. Data from the Dubbo Osteoporosis Epidemiology Study showed that among men and women whose BMD was not in the osteoporotic range, those who had had a fall in the previous 12 months were twice as likely to experience a fracture as those who had not fallen (Nguyen et al. 2007). The study also found that women who fell were at high risk of subsequent falls, and that each fall further increased the risk of a fracture (Nguyen et al. 2001).

### Markers of increased risk

A number of other factors, which are not in themselves direct risk factors, can act as markers to indicate people with an increased risk of fracture. These include loss of height, poor quadriceps strength and body sway. Although not direct risk factors, these three indicators are easily measured in clinical practice and are highly correlated with fracture risk.

Loss of height may indicate that a person has suffered several vertebral compression fractures. As these fractures may cause no pain, or only moderate, non-specific pain that may be mistaken for a muscular strain, disc problem or arthritis, the loss of height and stooping posture caused by compression of the spine may be the only recognisable sign that fractures have occurred. People who have experienced vertebral fractures are at high risk of further fractures (Center et al. 2007).

Poor quadriceps strength is a risk factor for falls, but not for fractures. Data from the Dubbo Osteoporosis Epidemiology Study show associations between lower quadriceps strength, falls in the previous 12 months, and recent fall-related fractures (Lord et al. 1994). The association between poor quadriceps strength and fractures is mediated by an increased risk of falling (Nguyen et al. 2007).

'Body sway' describes the extent to which a person sways (in any direction) while standing still on a flat surface. Significant body sway may indicate physical instability, muscle weakness, side-effects of medication or problems with balance. All of these can increase a person's risk of falling and hence of experiencing a fracture.

## IMPACTS OF OSTEOPOROTIC FRACTURES

Since osteoporosis has no symptoms, its impacts are mainly seen in terms of the fractures and the effects these have on functioning and quality of life. Apart from the pain and loss of function associated with the fracture event itself, there can also be more long-term impacts on physical and mental health and functioning. These may include not only ongoing pain, physical impairments and disability, but also reduced social interaction, emotional distress, and self-limitation caused by the fear of falling and fracturing a bone. In a small proportion of cases the fracture and its after-effects may lead to death.

## Pain

In most cases, the pain associated with breaking a bone is the patient's most immediate concern. The amount of pain felt varies widely between individuals and depends on the site and severity of the fracture.

In the case of spinal fracture, the event may be nearly or completely painless, and the fracture may go undetected (Haczynski & Jakimiuk 2001). It has been suggested that up to two-thirds of spinal fractures may not receive medical attention (Cooper et al. 1992). The sudden onset of low back pain in a person with osteoporosis may be a sign of spinal fracture.

People who have experienced fractures may have ongoing or chronic pain well after the bone has healed. This pain can result from the changes in posture and strain on muscles, ligaments and joints that occurs to compensate for the injury. Untreated or persistent pain may lead to sleeplessness and depression, and reduce the quality of life (Lukert 1994; Oglesby et al. 2003; Silverman et al. 2001).

## Functional limitations and disability

Different types of fractures are associated with varying degrees and types of functional limitation. For example, fractures involving the shoulder, arm, wrist or hand may affect the ability to write, prepare meals, manage household chores and perform personal-care activities (such as dressing or brushing teeth and hair). Fractures involving the spine, hips, legs or feet affect mobility as well as the ability to perform personal and household tasks. Spinal fractures may also interfere with actions such as bending, reaching, lifting, and pulling or pushing, particularly if several fractures have occurred.

Data from the 2003 Survey of Disability, Ageing and Carers suggest that around 50,000 Australians aged 35 years or over have a disability caused mainly by osteoporosis (AIHW: Rahman & Bhatia 2007). Almost half of these people have severe or profound core activity limitations—that is, they require assistance with one or more activities of daily living (such as self-care or mobility). Various assistive devices (for example, walking frames, grab bars, special tooth brushes and long-handled reachers) are available to enable people with functional limitations to perform their daily activities. More than half of people aged 35 years or over who have osteoporosis as their main disabling condition report using such devices (AIHW: Rahman & Bhatia 2007). Additional assistance from family, friends, community volunteers or paid care workers may also be required.

Hip fracture is among the top 10 causes of burden of disease among women in developed countries, estimated to account for 1.4% of disability-adjusted life years (Johnell & Kanis 2004). Cooper (1997) reported that one year after hip fracture, 30% of women were unable to walk independently, 60% had difficulty with at least one activity of daily living, and 80% were limited in activities such as driving and shopping. Long-term functional limitations are also common: Willig and colleagues found that people who had had a hip fracture were significantly less likely than age- and sex-matched controls to be able to perform basic activities of daily living (such as using the bath or toilet, dressing, cooking and doing housework) seven years after the event (Willig et al. 2001).

## Social isolation

The immediate effects of a fracture on mobility and performing usual activities can also affect a person's social life. For example, they may be temporarily unable to participate in games, sports or hobbies, or find it difficult to travel to meeting places, clubs or friends' homes. In the longer term, any ongoing functional limitations or disability can extend these immediate effects on social participation for months or years. At a seven-year follow-up of people with trochanteric hip fracture, 74% reported they were unable to visit friends (Willig et al. 2001). This can reduce the quality of life and lead to feelings of frustration, loneliness and depression. In the 2003 Survey of Disability, Ageing and Carers, around one-third of people aged 35 years or over who had osteoporosis as their main disabling condition reported that they could not go out as often as they would like due to their condition (AIHW: Rahman & Bhatia 2007).

People who have had a fracture may be anxious about or afraid of the potential consequences of further fractures, such as loss of independence and the possibility of needing permanent care. Those who have had a fracture due to falling may also be fearful of having another fall (Salkeld et al. 2000). People who have such fears may limit their participation in social activities in an effort to reduce their risk (Fletcher & Hirdes 2004; Gold 2001).

## Quality of life and mental health

The physical effects of a fracture can have a substantial impact on a person's quality of life and mental wellbeing. The pain, functional limitations and need for assistance with daily activities can lead to feelings of anger, sadness, hopelessness and helplessness, reduced self-confidence and self-esteem, embarrassment and loss of dignity (Haczynski & Jakimiuk 2001; Sitoh et al. 2005). In addition, the person may experience fear and anxiety about their future and the risk of further fractures (Salkeld et al. 2000).

Although quality of life is generally reduced in the period immediately following a fracture, regardless of the type of fracture sustained, in the long term people with more severe fractures or fractures in sites resulting in greater limitations continue to experience poorer quality of life compared with people with less severe fractures or without fractures (Hallberg et al. 2004). Two years after fracture, people with forearm or upper arm fractures report similar health-related quality of life to the general population, but people with hip and spinal fractures report poorer quality of life across a range of domains including physical functioning, bodily pain and social functioning (Hallberg et al. 2004).

## Loss of independence

The limitations in activity and possible long-term disability resulting from a fracture can seriously affect a person's independence. Depending on the site and severity of the injury, the person may need assistance with household tasks (such as cleaning and cooking), transport, mobility, or personal-care tasks (such as bathing, toileting and dressing). In some cases (for example, if the effects of the injury are long-term or if the person has no-one to assist them until they recover) the person may need to temporarily or permanently move from their own home into a rehabilitation unit, nursing home or aged care facility. People who move to a nursing home following a fracture tend to be older and in poorer pre-fracture health than those who remain in their own homes (Osnes et al. 2004).

In 7% of hospitalisations for minimal trauma fracture among Australians aged 40 years or over in 2006–07, the patient was discharged to an aged care facility where this had not previously been their usual residence. This was most common for fractures of the hip and pelvis: patients previously resident in the community were discharged to an aged care facility in 10% of cases. People who have had a hip fracture are significantly less likely to be living in their own home seven years later than people of the same age without hip fracture (Willig et al. 2001).

The need for assistance with daily activities and the need to move from their own home may greatly affect the person's self-esteem, social contact and emotional wellbeing.

## Mortality

Fractures are recorded as an associated cause of around 2,500 deaths in Australia each year. (Coding standards specify that injuries should not be reported as the underlying cause of death.) More than 80% of these are deaths in people aged 75 years or over. High trauma events (such as motor vehicle accidents) account for around 10% of cases; of the remainder, about 25% are accidents caused by low-trauma events, 20% are accidents caused by 'exposure to an unspecified factor', and the rest are attributed to various diseases and conditions and other external causes. The fracture sites most commonly reported on death certificates are the hip and pelvis, accounting for around 70% of cases.

Almost all types of minimal trauma fractures are associated with increased mortality over the following 12 months (Center et al. 1999; Johnell et al. 2004; NAMSCAG 2004). However, fractures of the hip and pelvis are the most commonly associated with an increased risk of death. The majority of deaths occur within the first few months, although the mortality rate in people who have had a hip fracture is still higher than expected up to 5 years after the event (Empana et al. 2004). In 2006–07, 1,163 separations for minimal trauma hip or pelvic fracture (6%) resulted in death in hospital.

In 2006, a hip or pelvic fracture was recorded as an associated cause of 1,516 deaths in Australia. Almost all of these deaths occurred in persons aged 65 years or over, with 63% (949 deaths) among people aged 85 years or over. In cases where hip or pelvic fracture was an associated cause of death, the most commonly recorded underlying causes of death were falls (accounting for 24% of deaths) and diseases of the circulatory system (23%). 'Exposure to an unspecified factor' was recorded as the underlying cause of death in 18% of cases (267 deaths), and osteoporosis was recorded as the underlying cause of 4 deaths. Analysis by the National Injury Statistics Unit suggests that the majority of deaths from 'exposure to an unspecified factor' where a fracture was also recorded would have involved falls (AIHW: Kreisfeld & Harrison 2005).

It has been suggested that the contribution of injuries to deaths may be underestimated due to the tendency to record 'natural' causes (for example, cardiovascular disease) in preference to external causes as the underlying cause of death for elderly persons (AIHW: Kreisfeld & Newson 2006; Calder et al. 1996; Roberts & Benbow 1996). The extent to which this might affect estimates of mortality due to osteoporosis and minimal trauma fractures is unknown.

## PREVENTION OF OSTEOPOROSIS AND FRACTURES

Avoiding or (where possible) altering exposure to risk factors forms the basis of many prevention strategies. For osteoporosis this includes getting enough calcium and vitamin D, keeping physically active, maintaining a healthy weight and not smoking. Preventing falls is also an important component of fracture prevention strategies, particularly among people who have a low bone mineral density or who are frail. In addition, there is some evidence that protecting the bones during a fall or other impact may help to prevent fractures.

### Preventing osteoporosis

A good diet is essential for good health. Adequate intake of foods containing calcium (such as dairy products, green leafy vegetables and fish with edible bones) is important for bone formation. Children, adolescents, pregnant or breastfeeding women, postmenopausal women, and men aged 70 years or over require higher than average amounts of calcium to build bone mass and offset bone and calcium losses (NHMRC 2003).

A balanced diet will also help to maintain a healthy weight. Excessively low body weight or weight loss may result in low bone mineral density and increased risk of osteoporosis and fractures. People who are overweight tend to have a lower risk of fracture due to their higher bone density, and also because the additional soft tissue provides protection for the bones during a fall or other low-trauma impact. However, since being overweight or obese may increase the risk of other conditions, such as osteoarthritis, Type 2 diabetes and heart disease, it is important to maintain a healthy weight throughout life.

Vitamin D is necessary for the absorption of calcium. Although there are some dietary sources of vitamin D (for example, oily fish, liver and eggs), the majority of Australians obtain most to all of their vitamin D through exposure to sunlight (Nowson & Margerison 2002). In people with moderately fair skin, exposure of the hands, face and arms for up to 10 minutes per day during summer and up to 45 minutes per day during winter (depending on latitude) is recommended for adequate vitamin D synthesis (Working Group of the Australian and New Zealand Bone and Mineral Society et al. 2005). However, it is important to avoid excessive sun exposure, and limit exposure to the early morning or late afternoon periods, to reduce the risk of skin cancer.

Exercise in childhood and adolescence is also vital for building strong bones and achieving a high peak bone mass. Continuing to exercise throughout life can help to maintain bone mass by slowing the normal loss experienced with age. Although all types of exercise are valuable for improving general health, muscle strength and cardiovascular fitness, high-impact weight-bearing exercise (such as brisk walking, running, skipping and aerobics) is particularly beneficial for bone health.

Hormone replacement therapy (HRT) can increase bone mineral density and decrease the risk of fractures in postmenopausal women (Cauley et al. 2003). However, the long-term use of HRT for the prevention of osteoporosis is not recommended in Australia, due to the risks of HRT in relation to breast cancer and cardiovascular disease (NHMRC 2005).

Raising awareness about osteoporosis and its effects, and educating people about how they can reduce their risk, are also important components of population-wide prevention strategies.



## Fall prevention

A wide range of factors may influence an individual's risk of falling (Box 6.3). Environmental hazards (for example, uneven or slippery surfaces, loose rugs and poor lighting) may be thought of as the most obvious causes of falls, but individual factors play a significant role. Older people are more prone to falls because of the general deterioration in bodily function associated with ageing. This may include muscular weakness, poor circulation (which may cause temporary dizziness when getting up out of a chair or bed) and changes in cognitive function. People with certain chronic illnesses, congenital conditions or disabilities that affect muscular strength, balance, consciousness or mobility are also at higher risk of falling. Other factors that increase risk include problems with eyesight, use of sleeping pills, and side-effects of some medications (for example, dizziness and drowsiness).

As with osteoporosis prevention, the focus of most fall prevention activities is to target modifiable risk factors. These include changing or adapting behaviours to limit the risk posed by individual factors, and removing or limiting exposure to environmental hazards (for example, by installing grab rails and non-slip floor strips). Regular physical activity is important as this can help to strengthen the muscles and improve balance and mobility. In particular, Tai Chi has been found to be effective in improving muscular strength and balance and reducing the incidence of falls (Choi et al. 2005; Li et al. 2004; Voukelatos et al. 2007). Appropriate management of medications is another key fall-prevention strategy. Some strategies for preventing falls in the home are outlined in Box 6.4.

### Box 6.3: Risk factors for falling

- *Chronic illness*
- *Balance, gait or mobility problems*
- *Visual impairment*
- *Cognitive impairment*
- *General deterioration associated with ageing*
- *History of falls*
- *Fear of falling*
- *Depression*
- *Blackouts/fits*
- *Indoor and outdoor hazards*
- *Use of medications or other drugs that cause dizziness or drowsiness*
- *Physical inactivity*
- *Foot problems.*

## Using hip protectors

If a person with osteoporosis does experience a fall or other impact, the use of hip protectors may help to prevent fractures of the hip or pelvis (Sinaki 2004). These protectors generally take the form of padded leggings or shorts, and are designed to absorb the impact that could otherwise have broken a bone. However, compliance with wearing hip protectors has been found to be variable; people may find them uncomfortable, difficult to put on and take off, and irritating to the skin, and may consider them to be unattractive (van Schoor et al. 2002). A recent systematic review has suggested that, although hip protectors may help to prevent hip fractures in people living in nursing or residential care settings, they may be ineffective for persons living in their own home because of poor compliance (Parker et al. 2006). Hip protectors are only effective if they are worn correctly.

**Box 6.4: Preventing falls in the home**

*A few relatively simple adjustments can decrease the risk of falls in the home and garden:*

- *stay active, and include some exercises to help with balance and posture*
- *attend a falls prevention class*
- *have medications reviewed by a doctor or chemist, as some may cause dizziness and increase the risk of falling*
- *remove or repair trip hazards in walkways (for example, loose rugs, electrical cords, unsecured carpet edges, and uneven paving or tiles)*
- *use bright lighting, have bedside lamps for use during the night, and install sensor lights in walkways*
- *install railings in the bathroom and toilet to assist with sitting, rising and general balance*
- *wear sensible, well-fitting shoes (avoid backless slippers, high heels and thongs), and ensure hems of skirts and trousers are above the floor*
- *install non-slip safety strips in the bath and shower, near the bathroom, kitchen and laundry sinks, and on uncarpeted or outdoor stairs*
- *avoid excessive alcohol intake*
- *use a walking aid if required*
- *have eyesight checked regularly.*

*Sources: Adapted from Osteoporosis Australia 2006 and National Osteoporosis Foundation 2006.*

## **TREATMENT AND MANAGEMENT OF OSTEOPOROSIS AND OSTEOPOROTIC FRACTURES**

Osteoporosis is generally managed with medication, including prescription drugs and vitamin and mineral supplements. The most commonly used medications are calcium supplements, calcium combined with vitamin D, and bisphosphonates. All of these medications act to reduce the rate of bone loss.

Two drugs that increase bone formation are currently available in Australia: parathyroid hormone and strontium ranelate. Parathyroid hormone is given as daily injections. Although continuously having excess amounts of this hormone in the blood (as in people with hyperparathyroidism) can actually cause osteoporosis, small amounts given intermittently as a daily injection stimulate the formation of new bone (Cranney et al. 2006). The precise mechanism by which this occurs is not yet fully understood. Parathyroid injections are not currently subsidised under the Pharmaceutical Benefits Scheme (PBS). Strontium ranelate is also taken daily, but in oral form. It both stimulates bone formation and reduces bone resorption. Strontium ranelate is subsidised under the PBS for treatment of osteoporosis in postmenopausal women with previous minimal trauma fractures and in women aged 70 years or over with a BMD T-score of  $-3.0$  or less.

Regular exercise in people with established osteoporosis can help to reduce further decreases in BMD, as well as assisting in maintaining a healthy weight. Exercise can also help to increase and maintain mobility and balance, which can reduce the risk of falling (a major cause of osteoporotic fractures).

Tai Chi has been found to be particularly effective in reducing falls and fractures among older people. A healthy diet, incorporating sufficient calcium and other nutrients, is also important for maintaining healthy weight and reducing further bone loss. As previously noted, a medications review may be beneficial to reduce the risk of medication side-effects leading to a fall. These reviews are subsidised through Medicare for eligible persons; more than 75,000 home medicines reviews were provided under Medicare during 2007–08 at a cost to the Australian Government of over \$8.5 million (Medicare Australia 2008).

A major component of management of people with osteoporosis is the prevention of falls, and the treatment of any fractures that occur. Fracture treatment includes appropriate follow-up, investigation of the causes of the fracture in people who have not previously been diagnosed with osteoporosis, and initiation of osteoporosis treatment if necessary. There are a number of places where treatment for a fracture may be received, including GP surgeries, clinics, and at hospitals, either in the emergency department or as an admitted patient. However, at all points in the continuum of patient care, the majority of osteoporotic fractures are both under-diagnosed and under-treated (NAMSCAG 2004).

### Management by general practitioners

General practitioners (GPs) are the first line of care for people with osteoporosis, advising on diet and exercise, treating minor fractures and prescribing appropriate medications. Osteoporosis was managed at a rate of 9 per 1,000 encounters reported to the BEACH (Bettering the Evaluation and Care of Health) GP survey in 2007–08. This equates to around 980,000 Medicare-paid GP consultations for osteoporosis between April 2007 and March 2008. One in five encounters were for 'new' cases of osteoporosis (that is, the person had not previously seen a medical practitioner for osteoporosis). The vast majority (99%) of encounters where osteoporosis was managed were for people aged 40 years or over; osteoporosis was managed at 15 per 1,000 encounters among people of this age.

The most common action taken by GPs to manage osteoporosis was to prescribe, advise or supply medication. Calcium supplements, vitamin D supplements, and the bisphosphonates alendronate and risedronate were the most frequent medications reported. Bone mineral density tests and X-rays of the chest/spine were ordered for 21% and 8% of new osteoporosis cases, respectively.

Fractures were managed at a rate of 6 per 1,000 encounters for persons aged 40 years or over reported to the BEACH GP survey in 2007–08, equating to more than 390,000 Medicare-paid GP consultations. Thirty-eight per cent of fractures managed were new fractures (that is, the first time the patient had seen a medical practitioner for that fracture).

Fractures of the spine or wrist/forearm were the most common fractures managed among persons aged 40 years or over in 2005–06, accounting for 22% and 15% of new fracture problems, respectively. At least one medication was prescribed, advised or supplied in 84% of encounters for new fractures, with analgesics (painkillers) being the most common drugs recorded. X-rays, CT scans or ultrasound scans of the fracture site were ordered in 47% of new cases, and bone mineral density testing was requested in 9% of new cases. Note that although an encounter may be for a new fracture, the person may have already been diagnosed with osteoporosis and so diagnostic tests such as bone mineral density scans may not be required.

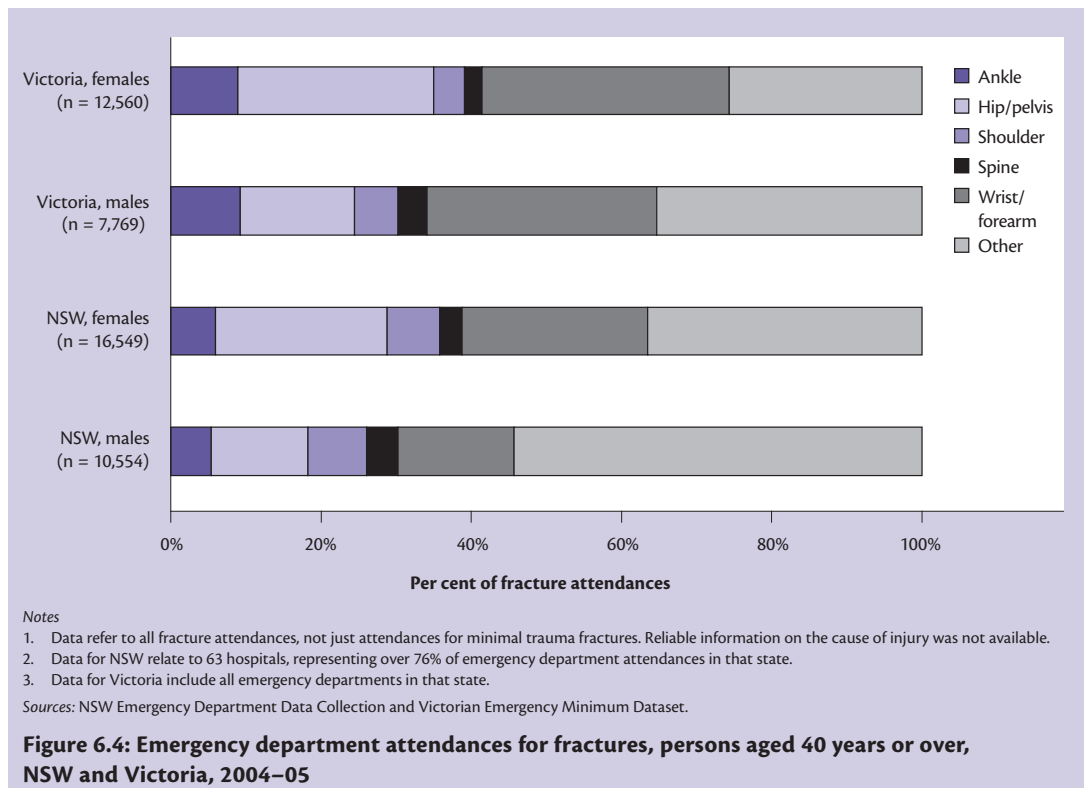
## Emergency department attendances for fractures

Data relating to services provided in hospital emergency departments are limited. The national administrative data collection (the Non-Admitted Patient Emergency Department Care Database, held at the AIHW) does not include any diagnostic information, and so national data on emergency department attendances for particular conditions or injuries are not able to be generated. However, some information on fractures is available at the state and territory level.

Over 27,000 fractures among people aged 40 years or over were reported to the New South Wales Emergency Department Data Collection in 2004–05, with 61% of these occurring in women (Figure 6.4). Reliable information on the cause of the fracture was not available. Fractures of the wrist and forearm were the most common, followed by fractures of the hip and pelvis.

Data from the Victorian Emergency Minimum Dataset show that 20,198 fractures in persons aged 40 years or over presented to Victorian emergency departments during 2004–05 (Figure 6.4). The proportion of these fractures that were the result of minimal trauma is unknown. Fractures were more common among females than males, with the most common fracture sites being the wrist and forearm.

Although these emergency department data do not specify whether fractures were the result of minimal trauma, it is likely that the majority of fractures in people aged 40 years or over would be related to osteoporosis.



Patients presenting to the emergency department may be formally admitted to the hospital for further treatment or care. In this case they will also be included in counts of admitted patient episodes, as presented in the next section. The decision to admit a person with a fracture to hospital depends on the type of treatment required, the severity of the injury and whether the patient would be able to care for him- or herself (or has somebody to care for them) at home. The numbers in Figure 6.4 include all cases presenting to emergency departments, regardless of whether or not they were later admitted to hospital.

## Hospital services for fractures

In 2006–07 there were 50,993 hospital separations for minimal trauma fractures in persons aged 40 years or over. (Cases where the patient was transferred between hospitals have been counted only once.) More than three-quarters of these separations (77%) involved fractures at one of the major sites described above (hip/pelvis, wrist/forearm, spine, ankle or shoulder), with hip and pelvic fractures accounting for 40% of minimal trauma fracture separations in this age group (Table 6.2). These data substantially underestimate the number of minimal trauma fractures occurring in Australia, as the majority will not be treated in hospital.

**Table 6.2: Hospital separations for minimal trauma fractures, persons aged 40 years or over, 2006–07**

Fracture region and site <sup>(a)</sup>	Males	Females	Persons	Per cent
Ankle	824	2,377	3,201	6
Hip and pelvis	5,294	15,209	20,503	40
– Femoral neck fracture	2,362	6,400	8,762	17
– Intertrochanteric fracture	1,337	3,659	4,996	10
– Pelvic fracture	751	3,185	3,936	8
– Other	844	1,965	2,809	6
Shoulder	990	3,154	4,145 <sup>(b)</sup>	8
– Fracture of clavicle	197	258	456 <sup>(b)</sup>	1
– Fracture of neck of humerus	722	2,782	3,504	7
– Other	71	114	185	—
Spine	863	1,915	2,778	5
Wrist and forearm	1,381	7,442	8,823	17
– Colles fracture	428	3,786	4,214	8
– Scaphoid fracture	56	52	108	—
– Other	897	3,604	4,501	9
Other or multiple sites	4,154	7,389	11,543	23
<b>Total</b>	<b>13,506</b>	<b>37,486</b>	<b>50,993<sup>(b)</sup></b>	<b>100</b>

— Less than 1%

(a) Based on principal diagnosis.

(b) Includes one case where the sex of the patient was not recorded.

### Notes

1. A separation for minimal trauma fracture was defined as any separation of a person aged 40 years or over with the principal diagnosis of a fracture and an external cause code indicating minor trauma (see Appendix 2 Table A2.1 for codes used).
2. Separations where the patient was transferred from another hospital were excluded (7,298 cases, or approximately 13% of all minimal trauma fracture separations). This provides a more accurate estimate of the number of fractures that required hospital treatment as an admitted patient.

Source: AIHW National Hospital Morbidity Database.

Interventions provided during separations for minimal trauma fractures range from simple immobilisation of the fracture area or limb to surgical realignment and fixation of the fractured bone. In some cases involving fracture at a joint, total or partial replacement of the joint is undertaken. People with hip fractures are the most likely to undergo joint replacement; over 4,700 partial hip replacements for minimal trauma hip fractures were undertaken in 2006–07.

Allied health interventions are very common in people with minimal trauma fractures, particularly where the fractures involve the spine, hip, pelvis or lower limbs. These interventions can help people to regain movement, improve mobility, adapt to any functional limitations caused by their injury, and reduce their risk of further fractures and falls. The most common types of allied health intervention provided are physiotherapy (provided in 65% of separations for minimal trauma fractures in 2006–07), occupational therapy (32%), social work (19%) and dietetics (12%) (Table 6.3).

**Table 6.3: Interventions provided in separations for minimal trauma fractures, persons aged 40 years or over, 2006–07**

Intervention	Number <sup>(a)</sup>	Per cent (n=58,291)
Immobilisation or non-surgical fixation	632	1.1
Reduction <sup>(b)</sup> with or without fixation	25,937	44.5
Arthroplasty (joint replacement)	6,295	10.8
– Partial arthroplasty of hip	4,777	8.2
Allied health interventions	40,120	68.8
– Physiotherapy	37,835	64.9
– Occupational therapy	18,527	31.8
– Social work	11,021	18.9
– Dietetics	6,955	11.9

(a) Refers to the number of separations in which the intervention was provided. Interventions may have been provided more than once within a separation, and multiple interventions may have been provided. See Appendix 2 Table A2.2 for codes used.

(b) Adjusting the alignment of the broken ends of the bone, to help it heal correctly. This can be done surgically or non-surgically. The ends of the bone can then be held in place ('fixed') non-surgically with a cast or splint, or surgically by inserting pins, plates, screws or rods through or along the bone.

*Notes*

1. A separation for minimal trauma fracture was defined as any separation of a person aged 40 years or over with the principal diagnosis of a fracture and an external cause code indicating minor trauma (see Appendix 2 Table A2.1 for codes used).
2. Separations where the patient was transferred from another hospital have been included in order to capture all treatment provided.

Source: AIHW National Hospital Morbidity Database.

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## 7 Trends and patterns in arthritis and osteoporosis

The number of people who have a particular disease or condition is generally not constant between different population groups or geographic areas, or over time. Factors that affect the distribution of disease include:

- variations in exposure to risk factors or causes of disease
- changes in population structure (for example, increased numbers of older people)
- differences in access to treatment
- changes in treatment practices
- variations in genetic susceptibility to disease
- the effects of disease prevention and awareness strategies.

For these reasons and others (for example, differences in help-seeking behaviour), rates of health service use also vary. Examining variation in disease rates and service use across the population and over time can give us insights into the risk factors for and causes of disease, and the effects of public health strategies and interventions. It can also help to identify population groups that are at high risk or who have high rates of a disease so that interventions and health services can be located and targeted appropriately.

This chapter uses the national indicators for osteoarthritis, rheumatoid arthritis and osteoporosis as a basis for looking at trends and patterns in arthritis and osteoporosis in Australia. National data for each indicator (the most recent year available, by age group and sex) can be found in Appendix 1.

### TRENDS OVER TIME

#### Prevalence

The prevalence of a disease (that is, the number of cases existing in the population) may change over time as exposure to risk factors changes, treatments improve (or are discovered) or death rates vary. For arthritis and osteoporosis—diseases that are more common in older people, rarely cause death directly and are not curable—the main factors influencing prevalence are population ageing and exposure to risk factors. Two risk factors for which time series data are available are physical inactivity in adults, and overweight and obesity in adults and children.

#### *Physical inactivity*

Exercise is essential for building and maintaining healthy bones. It also helps to improve and maintain balance, strength and joint flexibility, improves cartilage health, and may reduce the risk of falls.

Although the exact amount of exercise required for bone health is unclear, Australian and international guidelines recommend that adults undertake at least 30 minutes of moderate physical activity (such as brisk walking) on at least 5 days of the week for good health. Self-reported information from the Australia Bureau of Statistics' National Health Surveys (NHS) suggests that around 60% of Australian adults undertake less than this amount of activity, and that this has not changed significantly since 1989–90 (Table 7.1).

**Table 7.1: Proportion of adults undertaking insufficient physical activity, 1989–90 to 2004–05**

	1989–90	1995	2001	2004–05
Males	58	58	57	58
Females	65	65	64	64
Total	62	62	60	61

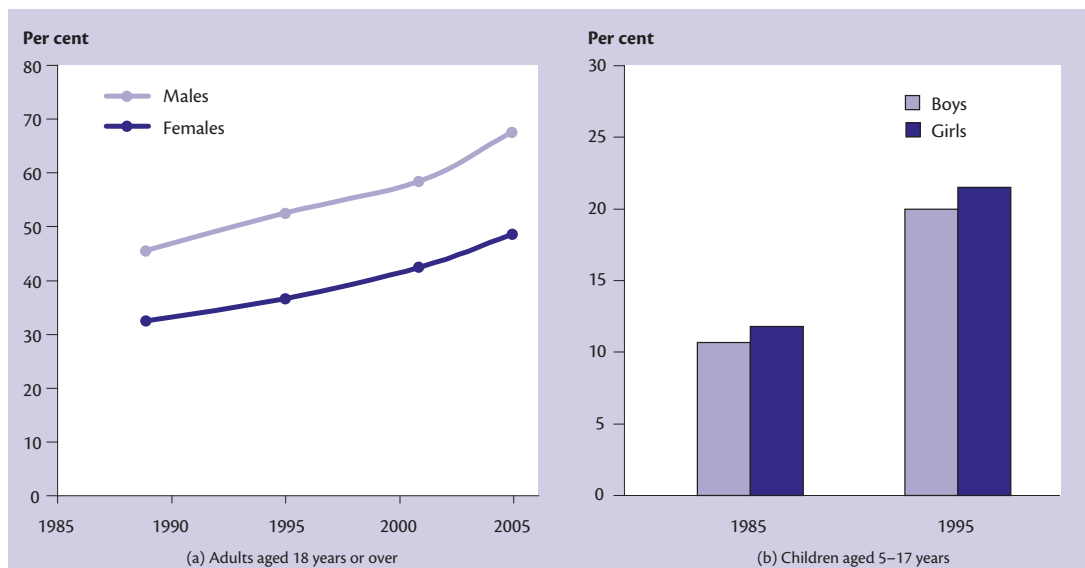
*Notes*

1. Classified as undertaking less than 300 minutes of leisure-time activity during the two weeks prior to the survey, based on self-reported information.
2. Proportion of people aged 18 years or over.
3. Age-standardised to the Australian population as at 30 June 2001.

Sources: AIHW analysis of the 1989–90, 1995, 2001 and 2004–05 NHS CURFs.

**Overweight and obesity**

Although body mass is a factor in building strong bones, being overweight or obese increases the risk of osteoarthritis, particularly in the knees. Excess weight is also a risk factor for other chronic conditions such as heart disease and Type 2 diabetes. Self-reported information from the NHS suggests that the number of Australians who are overweight or obese is rising. Between 1989–90 and 2004–05, the proportion of adults who were overweight or obese increased from 45% to 67% in men and from 32% to 48% in women (Figure 7.1(a)).



*Notes*

1. Overweight and obesity in adults is classified as body mass index (BMI = weight/height<sup>2</sup>) of 25 or greater, based on self-reported height and weight.
2. Overweight and obesity in children is classified using age- and sex-specific BMI values as determined by Cole et al. (2000), and based on measured height and weight.
3. Rates for adults are age-standardised to the Australian population as at 30 June 2001.

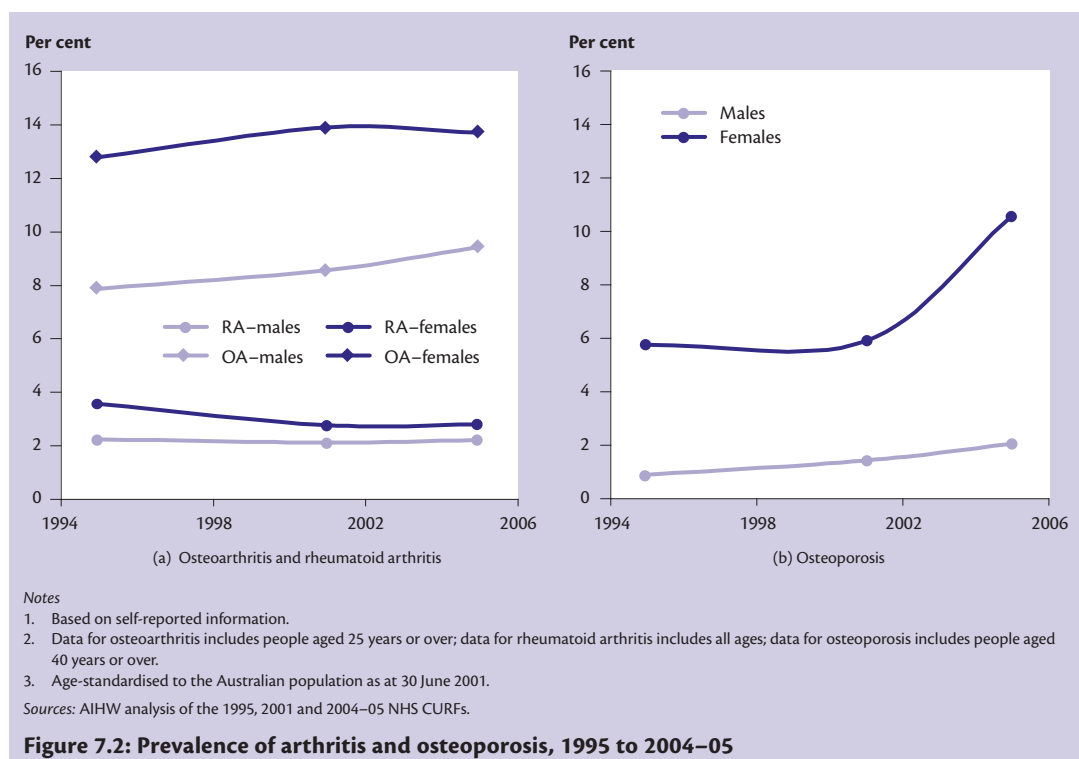
Sources: AIHW analysis of the 1989–90, 1995, 2001 and 2004–05 NHS CURFs (adults) and Magarey et al. 2001 (children).

**Figure 7.1: Overweight and obesity in Australian adults and children**

Overweight and obesity among Australian children and adolescents is also believed to be increasing. The most recent national data show that the proportion of 5–17 year olds who were overweight or obese doubled between 1985 and 1995 (Figure 7.1(b)). More recent data collected in New South Wales and Western Australia suggest that the upward trend has continued (Booth et al. 2006; Hands et al. 2004).

## Arthritis

The prevalence of osteoarthritis in people aged 25 years or over (based on self-reported information) increased slightly between 1995 and 2004–05, from 8% to 9% among men and from 13% to 14% among women (Figure 7.2(a)). Over the same period, the prevalence of rheumatoid arthritis stayed relatively constant among males but decreased slightly in females.



It is believed that self-reported information may overestimate the prevalence of rheumatoid arthritis. The similarity to the word 'rheumatism' (which is a generic term describing painful, inflamed joints and muscles) may cause confusion and lead to reporting of rheumatoid arthritis in people who do not actually have the disease. Some of the apparent decrease in the prevalence of rheumatoid arthritis seen in Figure 7.2(a) could be due to a better understanding of these terms in the population.

## Osteoporosis

Self-reported information suggests that the prevalence of osteoporosis in women aged 40 years or over increased rapidly between 2001 and 2004–05 (Figure 7.2(b)). It is likely that such a sharp increase is the result of greater awareness of osteoporosis among women and health professionals, leading to more cases being diagnosed, rather than a real increase in the number of cases. The prevalence of osteoporosis among men aged 40 years or over has also been increasing, but at a much slower rate.

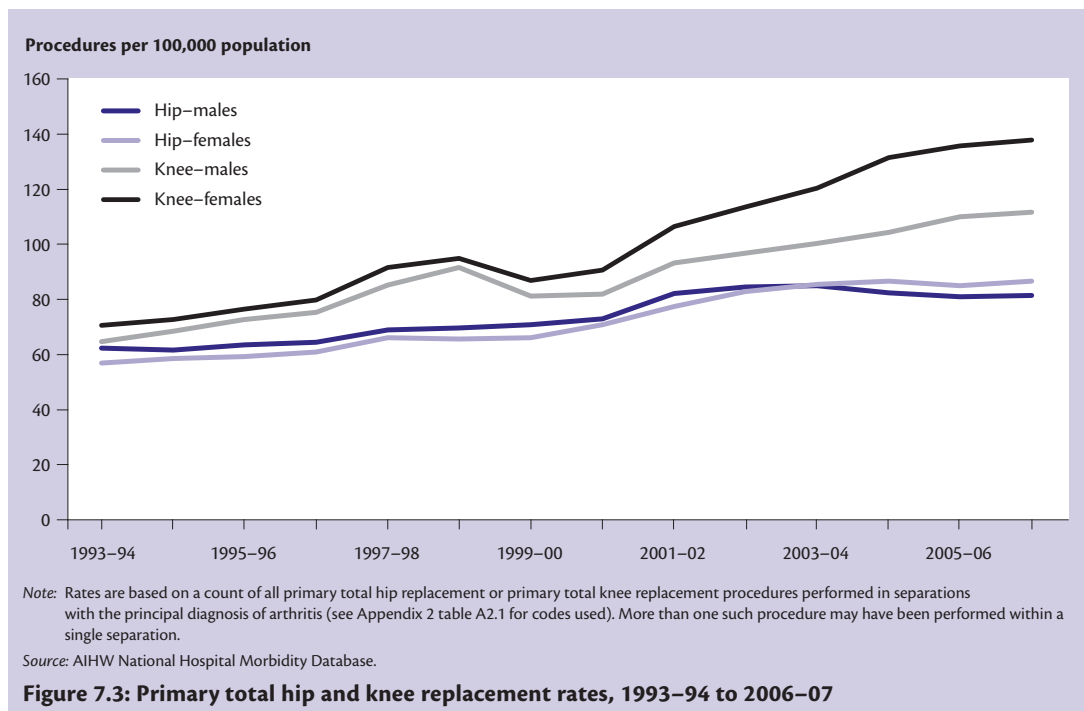
## Health service use

Many factors influence the amount of health services used for a particular disease or condition. These include disease incidence and prevalence, disease severity, treatment patterns, and health service availability and accessibility, as well as cultural and personal choices about seeking and accepting medical assistance. The use of health services will vary as these factors change, both over time and across different population groups.

Two major forms of health service use for arthritis and osteoporosis are hip and knee replacements (mainly used for osteoarthritis) and hospital treatment of hip fractures (often the result of osteoporosis). This section presents information on changes in the use of these services over the past decade; variation in service use across the population is discussed later in this chapter.

### Hip and knee replacements

When osteoarthritis is severe and conventional treatments (such as medications and physical therapies) do not provide sufficient relief, surgical replacement of the affected joint(s) with artificial components may be considered. These procedures can restore joint function, relieve pain and improve the quality of life, and have been shown to be a cost-effective treatment. The hips and knees are by far the most common joints replaced.

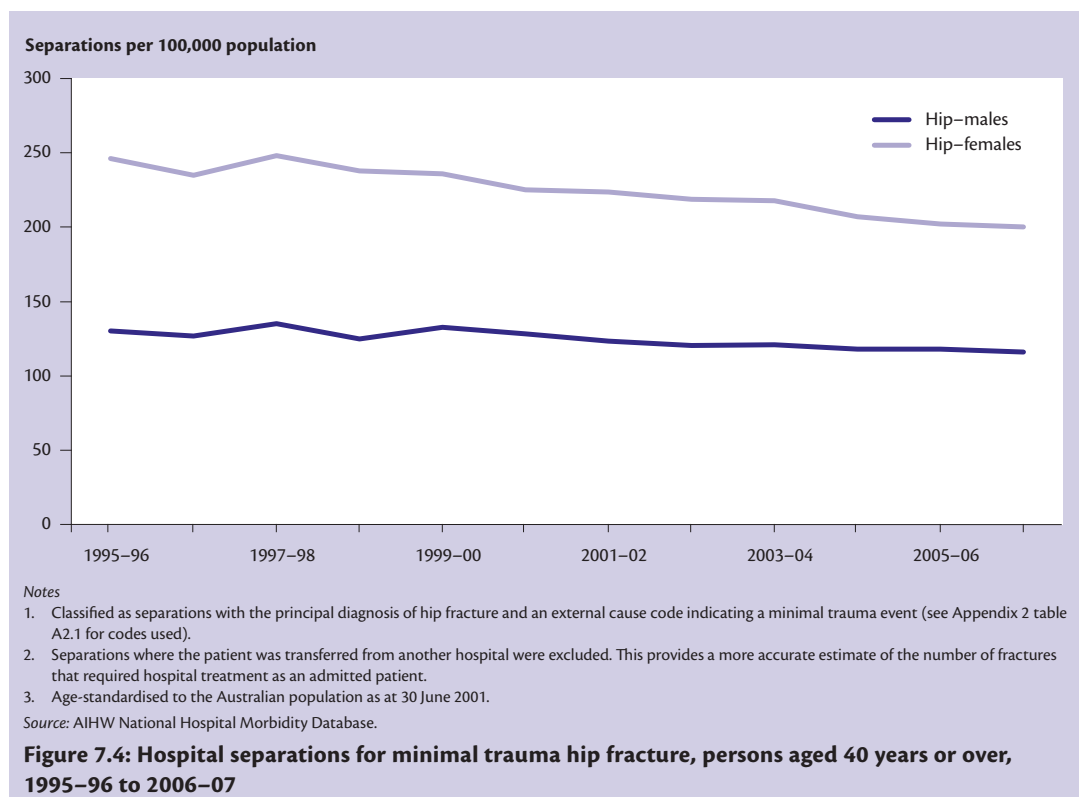


Demand for hip and knee replacement surgery is increasing worldwide, and Australia is no exception (Figure 7.3). The number of primary total hip replacements for arthritis increased by 92% between 1993-94 and 2006-07 (from 9,532 to 18,316), while the number of primary total knee replacements more than doubled over the same period (from 10,959 to 27,295). Rates of hip and knee replacements

have increased significantly in both the younger and oldest age groups, reflecting the rising demand for surgery at younger ages and improvements in medical techniques and outcomes enabling major surgery to be successfully undertaken on older persons.

### Hip fractures

A large proportion of minimal trauma fractures are treated in clinics or hospital emergency departments. Unfortunately data on these services in Australia are limited and it is not possible to determine the total number of minimal trauma fractures that occur. However, due to the severe nature of hip fractures, people with these fractures are almost always admitted to hospital for treatment, and so the number of minimal trauma hip fractures can be determined with reasonable accuracy.



Between 1995-96 and 1999-00 the rate of hospital separations for minimal trauma hip fracture was relatively stable. From 1999-00 to 2006-07 the rate decreased by 13% in men (from 131 to 114 separations per 100,000 population) and 15% in women (from 234 to 198 per 100,000) (Figure 7.4).

### Mortality

Arthritis and musculoskeletal conditions are not major contributors to mortality in Australia, accounting for around 1% of deaths. However, around 20% of these deaths are attributed to rheumatoid arthritis. People with rheumatoid arthritis are at increased risk of premature death, with a lifespan on average 5-10 years shorter than the general population (Kvien 2004). The systemic nature

of the disease can lead to life-threatening complications of the cardiovascular and respiratory systems (Gabriel et al. 2003). In addition, some of the treatments for rheumatoid arthritis can depress the immune system, leading to increased susceptibility to infection and the risk of immune-system-related diseases such as cancer (Sihvonen et al. 2004; Young et al. 2007).

Death rates for rheumatoid arthritis as the underlying or an associated cause of death did not vary greatly between 1999 and 2006 (Table 7.2). Females were more likely than males to have rheumatoid arthritis recorded on their death certificate.

**Table 7.2: Death rates for rheumatoid arthritis, 1999 to 2006**

Year	RA as the underlying cause of death		RA as an associated cause of death	
	Males	Females	Males	Females
<b>Deaths per million population</b>				
1999	7	12	24	37
2000	6	12	23	38
2001	6	10	23	37
2002	6	11	23	38
2003	6	11	21	38
2004	6	11	21	34
2005	4	11	20	31
2006	5	10	25	32

RA rheumatoid arthritis

Note: Age-standardised to the Australian population as at 30 June 2001.

Source: AIHW National Mortality Database.

## POPULATION VARIATION

### Rural and remote Australians

Australians living in rural and remote areas generally experience poorer health than their major city counterparts. On average, people living in more inaccessible regions of Australia are disadvantaged with regard to educational and employment opportunities, income, access to goods and services and, in some areas, access to basic necessities such as clean water and fresh food (AIHW 2008b). Other factors including the types of work available, socioeconomic status of residents and cultural or societal 'norms' may also influence the health of people living in different areas of Australia.

Men and women living in outer regional, remote or very remote areas ('outer areas') are more likely to be overweight or obese than those in major cities, and men in outer areas are more likely to undertake insufficient physical activity (Table 7.3). But despite these risk factors, people in outer areas are not significantly more likely than those in major cities to self-report having been diagnosed with arthritis or osteoporosis. In fact, women in the outer areas are less likely to self-report that they have been told by a doctor that they have osteoporosis. It is possible that people living in the outer areas may be less likely to attend a doctor and so obtain a diagnosis of arthritis or osteoporosis. However, people living outside major cities are more likely to have primary total hip and knee replacements than those in major cities. This difference has been reported in several international studies and may be related to the higher proportion of people with manual occupations (such as farming) in non-urban areas (Dunsmuir et al. 1996; Thelin & Holmberg 2007; Willis et al. 2000).



**Table 7.3: Indicators for arthritis and osteoporosis by sex and geographic area of residence**

Indicator	Males				Females			
	MC rate	rate ratio			MC rate	rate ratio		
		MC	IR	Outer <sup>(a)</sup>		MC	IR	Outer <sup>(a)</sup>
Insufficient physical activity (per cent of people aged 18 years or over)	56	1.00	1.05	*1.16	64	1.00	1.00	1.00
Overweight or obese (per cent of people aged 18 years or over)	60	1.00	1.02	*1.12	43	1.00	*1.09	*1.10
Prevalence of osteoarthritis (per cent of people aged 25 years or over)	7	1.00	1.21	0.98	12	1.00	1.15	0.88
Prevalence of rheumatoid arthritis (per cent)	1	1.00	1.38	1.09	2	1.00	1.41	1.32
Prevalence of osteoporosis (per cent of people aged 40 years or over)	2	1.00	1.08	0.84	11	1.00	0.86	*0.65
Primary total hip replacements for arthritis (number per 100,000 population)	75	1.00	*1.37	*1.27	102	1.00	*1.12	1.01
Primary total knee replacements for arthritis (number per 100,000 population)	98	1.00	*1.38	*1.27	146	1.00	*1.14	*1.09
Minimal trauma hip fractures (number per 100,000 population aged 40 years or over) <sup>(b)</sup>	100	1.00	1.00	1.02	246	1.00	*1.04	*1.16
Rheumatoid arthritis as underlying cause of death (deaths per million population)	3	1.00	1.21	*2.67	10	1.00	*1.60	1.33
Rheumatoid arthritis as associated cause of death (deaths per million population)	19	1.00	1.16	1.04	36	1.00	*1.21	*1.38

MC major cities

IR inner regional

\* Significantly different from the rate in major cities.

(a) Hospital and mortality data include outer regional, remote and very remote areas. Data for physical activity, overweight and obesity, and disease prevalence does not include very remote areas.

(b) Separations where the patient was transferred from another hospital were excluded. This provides a more accurate estimate of the number of fractures that required hospital treatment as an admitted patient.

**Notes**

1. Rate ratios are a comparison of the number of events (or people self-reporting the characteristic) observed compared with the number that would be expected if the rate in major cities applied in all areas. See Appendix 2 for further information.
2. Area of residence is classified using the Australian Standard Geographic Classification devised by the ABS. See Appendix 2 for further information.
3. Data for physical activity, overweight and obesity, and disease prevalence are for 2004–05. Hospital data are for 2006–07. Mortality data are for 2006.

Sources: AIHW analysis of the 2004–05 NHS CURF, AIHW National Hospital Morbidity Database and AIHW National Mortality Database.

## Aboriginal and Torres Strait Islander people

Australia's Indigenous peoples have much poorer health than other Australians across a wide range of measures. They have a lower life expectancy, are more likely to experience disability and reduced quality of life, and have a higher prevalence of diseases such as Type 2 diabetes, chronic kidney disease, cardiovascular disease and acute rheumatic fever (ABS & AIHW 2008).

Indigenous people are more likely than non-Indigenous people to undertake insufficient physical activity, and Indigenous females are more likely than non-Indigenous females to be overweight or obese (Table 7.4). As might be expected, given these and other risk factors (such as smoking and injury), Indigenous people are more likely to report being diagnosed with osteoarthritis or rheumatoid arthritis, compared with non-Indigenous people. The onset of arthritis also occurs at a younger age in Indigenous people compared with other Australians (AIHW: Rahman et al. 2005). Despite this, they are much less likely than other Australians to have a hip or knee replacement. Factors that may affect

access to joint replacement among Indigenous people include cost, transport difficulties, problems with accessing culturally appropriate care, remoteness and treatment preferences.

Indigenous males are also more likely to report being diagnosed with osteoporosis, compared with non-Indigenous males, and are twice as likely as other Australian males to have a hip fracture. But although Indigenous females are more likely than other Australian females to have a hip fracture, they are less likely to report being diagnosed with osteoporosis.

**Table 7.4: Indicators for arthritis and osteoporosis by sex and Indigenous status**

Indicator	Males		Females	
	Non-Indigenous	Indigenous	Non-Indigenous	Indigenous
	rate	rate ratio	rate	rate ratio
Insufficient physical activity (per cent of people aged 18 years or over) <sup>(a)</sup>	58	*1.17	63	*1.24
Overweight or obese (per cent of people aged 18 years or over)	62	1.05	45	*1.41
Prevalence of osteoarthritis (per cent of people aged 25 years or over) <sup>(a)</sup>	8	*1.49	12	*1.42
Prevalence of rheumatoid arthritis (per cent) <sup>(a)</sup>	2	1.89	2	*1.96
Prevalence of osteoporosis (per cent of people aged 40 years or over)	2	*2.48	11	*0.59
Primary total hip replacements for arthritis (number per 100,000 population)	80	*0.36	93	*0.19
Primary total knee replacements for arthritis (number per 100,000 population)	109	*0.47	149	*0.43
Minimal trauma hip fractures (number per 100,000 population aged 40 years or over) <sup>(a)</sup>	103	*2.01	259	*1.25

\* Significantly different from the rate in the non-Indigenous population.

(a) Includes persons living in non-remote areas of Australia only.

Notes

1. Data for non-Indigenous Australians are crude rates. Data for Indigenous Australians are indirectly standardised rate ratios relative to the non-Indigenous population.
2. Rate ratios are a comparison of the number of events (or people self-reporting the characteristic) observed compared with the number that would be expected if the rate among non-Indigenous Australians applied among Indigenous Australians (see Appendix 2).
3. The numbers were too low to allow analysis of deaths related to arthritis or osteoporosis for the Indigenous population.
4. Data for physical activity, overweight and obesity, and disease prevalence are for 2004–05. Hospital data are for 2005–07.
5. Data on joint replacements and minimal trauma fracture are for NSW, Victoria, Queensland, SA, WA and NT only and may not be representative of other jurisdictions.

Sources: AIHW analysis of the 2004–05 NATSIHS CURF and AIHW National Hospital Morbidity Database.

## Socioeconomically disadvantaged groups

Socioeconomic status is influenced by a range of factors, including employment status, occupation, income and education level. A person's socioeconomic status can affect where they live and in what conditions, the food they eat and the types of services they use. People who live in the most socioeconomically disadvantaged areas of Australia often experience poorer health than those who live in the least disadvantaged areas (AIHW 2008a).

Issues of location and cost can mean that socioeconomically disadvantaged Australians may have difficulty accessing health services and obtaining specialised treatments. They are also less likely to take advantage of screening tests such as Pap smears (ABS 2002). People living in socioeconomically disadvantaged areas are more likely to display health risk factors such as smoking, lack of exercise and obesity (ABS 2006), and are more likely to be exposed to environmental and occupational hazards (for example, heavy lifting, use of dangerous machinery, and exposure to dust and chemicals) (Evans & Kantrowicz 2002).

**Table 7.5: Indicators for arthritis and osteoporosis by sex and socioeconomic status of area of residence**

Indicator	Males		Females	
	Least disadvantaged fifth	Most disadvantaged fifth	Least disadvantaged fifth	Most disadvantaged fifth
	rate	rate ratio	rate	rate ratio
Insufficient physical activity (per cent of people aged 18 years or over)	51	*1.27	55	*1.26
Overweight or obese (per cent of people aged 18 years or over)	59	1.10	36	*1.41
Prevalence of osteoarthritis (per cent of people aged 25 years or over)	7	1.28	10	1.25
Prevalence of rheumatoid arthritis (per cent)	1	2.18	2	1.37
Prevalence of osteoporosis (per cent of people aged 40 years or over)	1	2.34	11	0.76
Primary total hip replacements for arthritis (number per 100,000 population)	88	*0.88	120	*0.80
Primary total knee replacements for arthritis (number per 100,000 population)	96	*1.11	139	*1.15
Minimal trauma hip fractures (number per 100,000 population aged 40 years or over)	98	*1.09	263	1.00
Rheumatoid arthritis as underlying cause of death (deaths per million population)	4	1.07	14	1.06
Rheumatoid arthritis as associated cause of death (deaths per million population)	17	*1.29	39	*1.13

\* Significantly different from the rate in the least disadvantaged fifth of the population.

**Notes**

1. Socioeconomic status of area of residence was determined using the Index of Disadvantage as calculated by the ABS (see Appendix 2).
2. Data for the least disadvantaged fifth are crude rates. Data for the most disadvantaged fifth are indirectly standardised rate ratios relative to the least disadvantaged fifth population.
3. Rate ratios are a comparison of the number of events (or people self-reporting the characteristic) observed compared with the number that would be expected if the rate in the least disadvantaged fifth applied in the most disadvantaged fifth. See Appendix 2 for further information.
4. Data for physical activity, overweight and obesity, and disease prevalence are for 2004–05. Hospital data are for 2005–06. Mortality data are for 2004–2006.

Sources: AIHW analysis of the 2004–05 NHS CURF, AIHW National Hospital Morbidity Database and AIHW National Mortality Database.

People living in the most disadvantaged areas of Australia were more likely than those in the least disadvantaged areas to undertake insufficient physical activity (Table 7.5). Females in these areas were also more likely to be overweight or obese. Correspondingly, people in the most disadvantaged areas tended to be more likely than those in the least disadvantaged areas to report being diagnosed with arthritis, but the difference was not statistically significant.

Males living in the most disadvantaged areas were more likely than those living in the least disadvantaged areas to experience a minimal trauma hip fracture, but there was no difference among females. Interestingly, people living in the most disadvantaged areas of Australia were less likely than those in the least disadvantaged areas to undergo a hip replacement for arthritis but more likely to undergo a knee replacement.

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# Appendix 1: Indicators for arthritis and osteoporosis

A set of key indicators for osteoarthritis, rheumatoid arthritis and osteoporosis was developed by the National Centre and the NAMSCAG Data Working Group for national monitoring (AIHW 2006). The set consists of 16 indicators, covering risk factors, prevalence, quality of life, health service use and mortality (Table A1).

This appendix provides data for each indicator, by age group and sex, for the most recent year available.

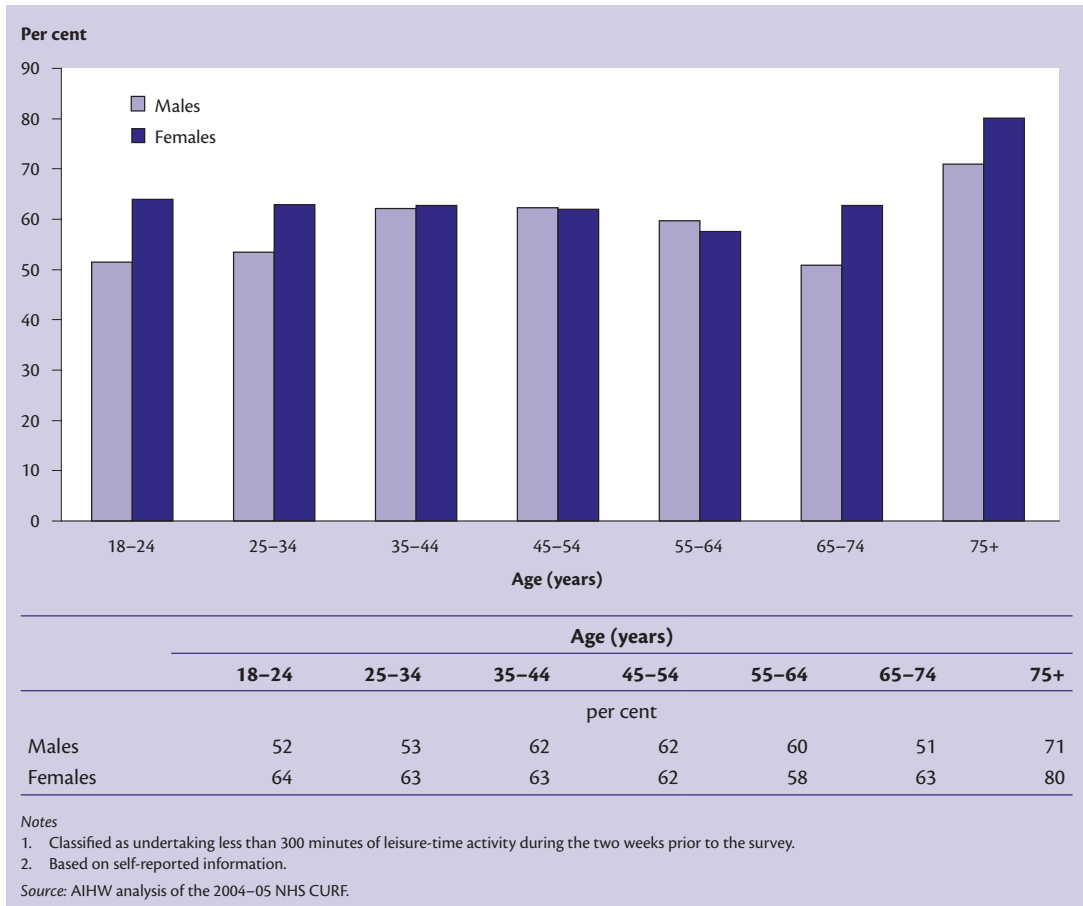
**Table A1: National indicators for monitoring osteoarthritis, rheumatoid arthritis and osteoporosis**

Category and number	Indicator
<b>1 Risk factors</b>	
1.1	Proportion of persons aged 18 years or over who are not engaged in sufficient physical activity to confer a health benefit <sup>(a)</sup> .
1.2	Proportion of persons aged 18 years or over who are overweight or obese <sup>(a)</sup> .
1.3	Proportion of persons aged 2–17 years who are overweight or obese.
<b>2 Prevalence</b>	
2.1	Prevalence of osteoarthritis among persons aged 25 years or over.
2.2	Prevalence of rheumatoid arthritis.
2.3	Prevalence of osteoporosis among persons aged 40 years or over.
2.4	Prevalence of arthritis among Aboriginal and Torres Strait Islander persons aged 25 years or over.
<b>3 Quality of life</b>	
3.1	Quality of life among persons aged 25 years or over with osteoarthritis.
3.2	Quality of life among persons with rheumatoid arthritis.
3.3	Quality of life among persons aged 40 years or over with osteoporosis.
<b>4 Health service use</b>	
4.1	Waiting time to see a rheumatologist for diagnosis of rheumatoid arthritis <sup>(b)</sup> .
4.2	Number of primary total hip replacements for arthritis.
4.3	Number of primary total knee replacements for arthritis.
4.4	Number of hospital separations for minimal trauma hip fractures among persons aged 40 years or over.
<b>5 Mortality</b>	
5.1	Death rates for rheumatoid arthritis as the underlying cause of death.
5.2	Death rates for rheumatoid arthritis as an associated cause of death.

(a) These indicators are also reported as part of the NHPA Risk Factors indicator set.

(b) No data for this indicator are currently available.

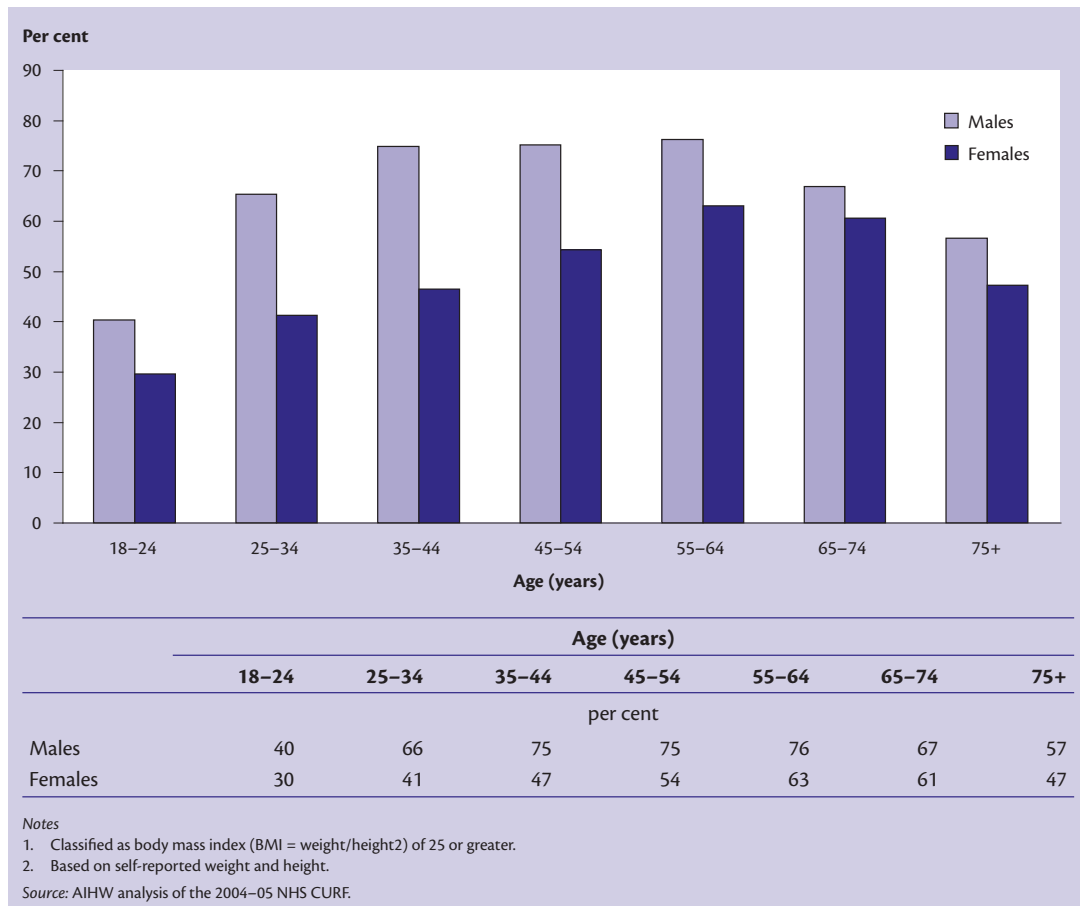
### 1.1 Proportion of persons aged 18 years or over who are not engaged in sufficient physical activity to confer a health benefit (2004–05)



- Australian and international guidelines recommend undertaking 30 minutes of moderate intensity physical activity on at least 5 days of the week to obtain significant health benefits (DHAC 1999). Some common moderate intensity activities are brisk walking, swimming, social tennis, golf, table tennis and cricket.
- Including some vigorous activity each week provides extra health benefits. Football (all types), squash, jogging, basketball, cross-country hiking, martial arts and step aerobics are popular vigorous activities among Australians.
- Around 60% of Australian adults do not undertake sufficient physical activity for good health. At most ages, females are less likely than males to undertake sufficient activity.
- People aged 75 years or over are the most likely not to undertake sufficient activity, followed by those aged 35–54 years.
- Reduced functional capacity and the presence of multiple health conditions are likely to contribute to lower physical activity levels among older Australians.

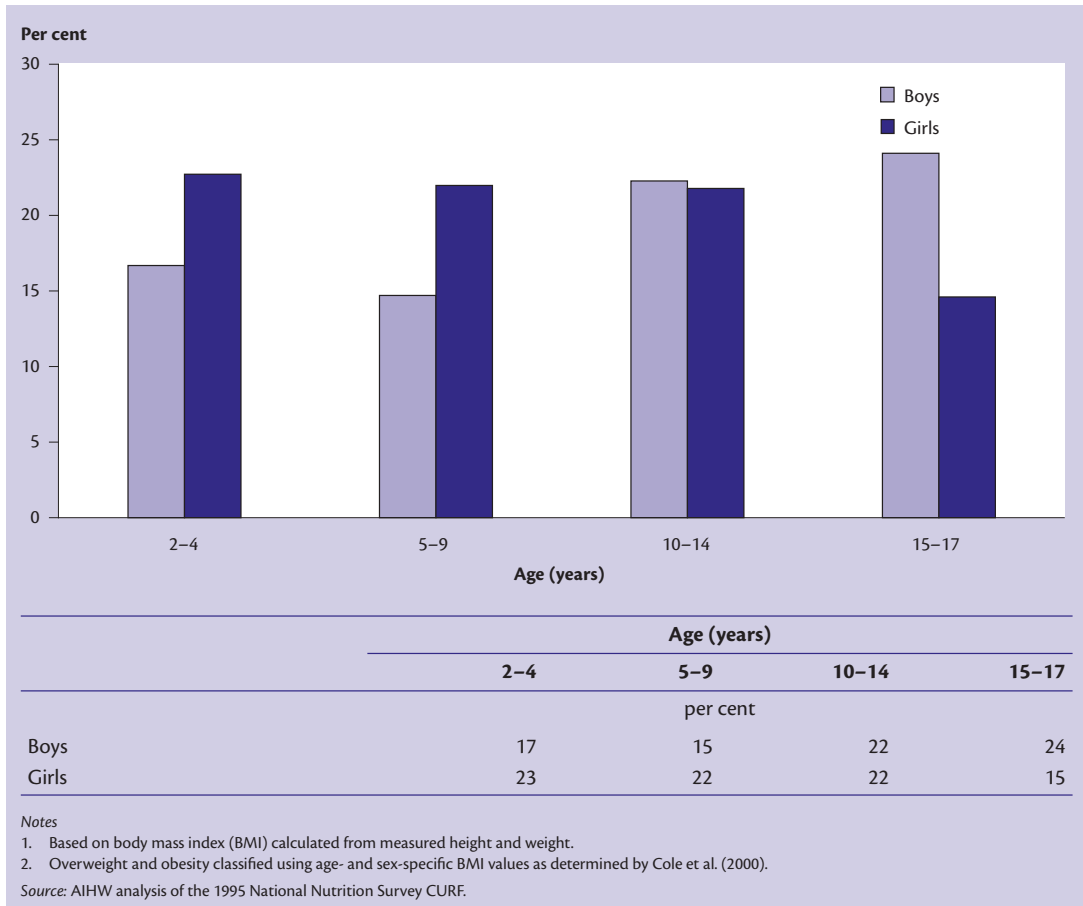


## 1.2 Proportion of persons aged 18 years or over who are overweight or obese (2004–05)



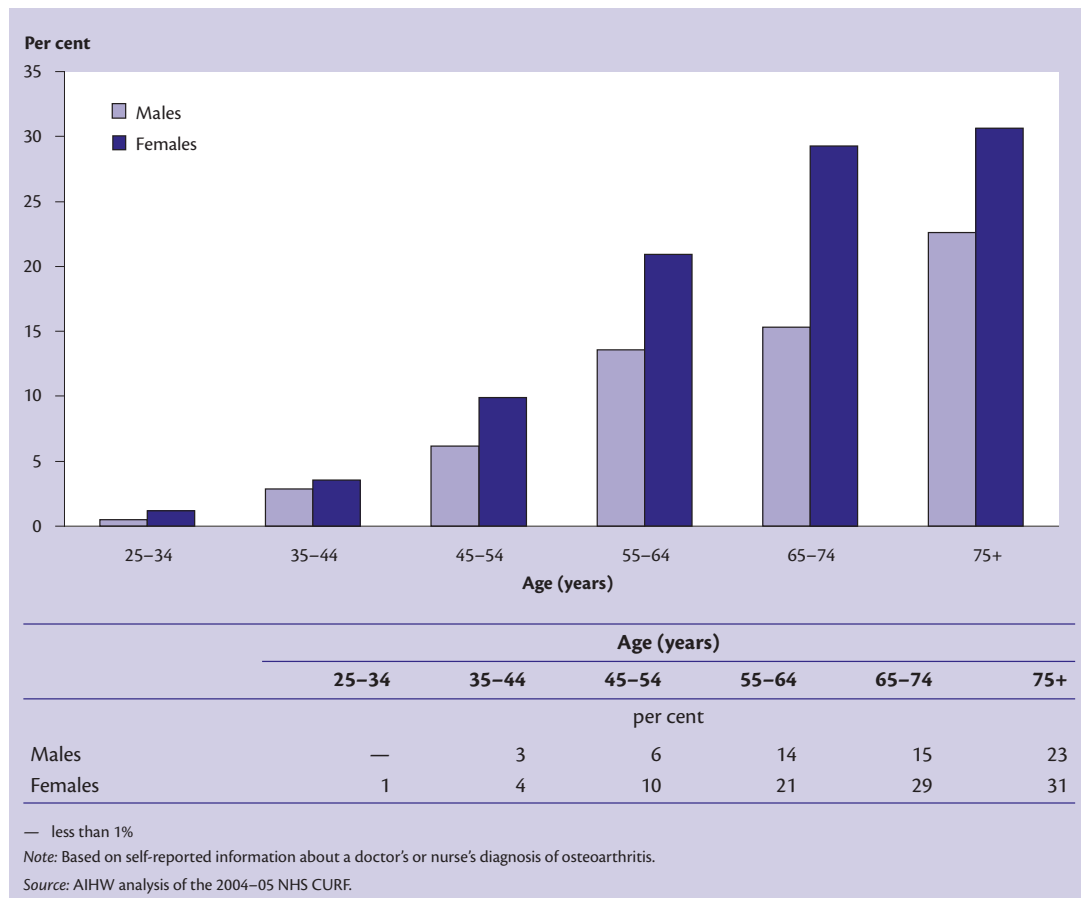
- Overweight and obesity are associated with a range of chronic health conditions, including Type 2 diabetes, coronary heart disease, stroke, osteoarthritis and some types of cancer.
- In 2004–05 it was estimated that two-thirds of Australian adult males and almost half of adult females were overweight or obese.
- Three-quarters of males aged 35–64 years were overweight or obese in 2004–05. Males in this age group were the least likely to undertake sufficient physical activity.
- Females aged 55–74 years were more likely than older or younger females to be overweight or obese, but were also more likely to undertake sufficient physical activity.
- Overweight and obesity rates in Australian adults increased significantly between 1989 and 2004–05. A similar trend was observed in many other countries, including England, Canada, New Zealand, the United States and Japan.

### 1.3 Proportion of persons aged 2–17 years who are overweight or obese



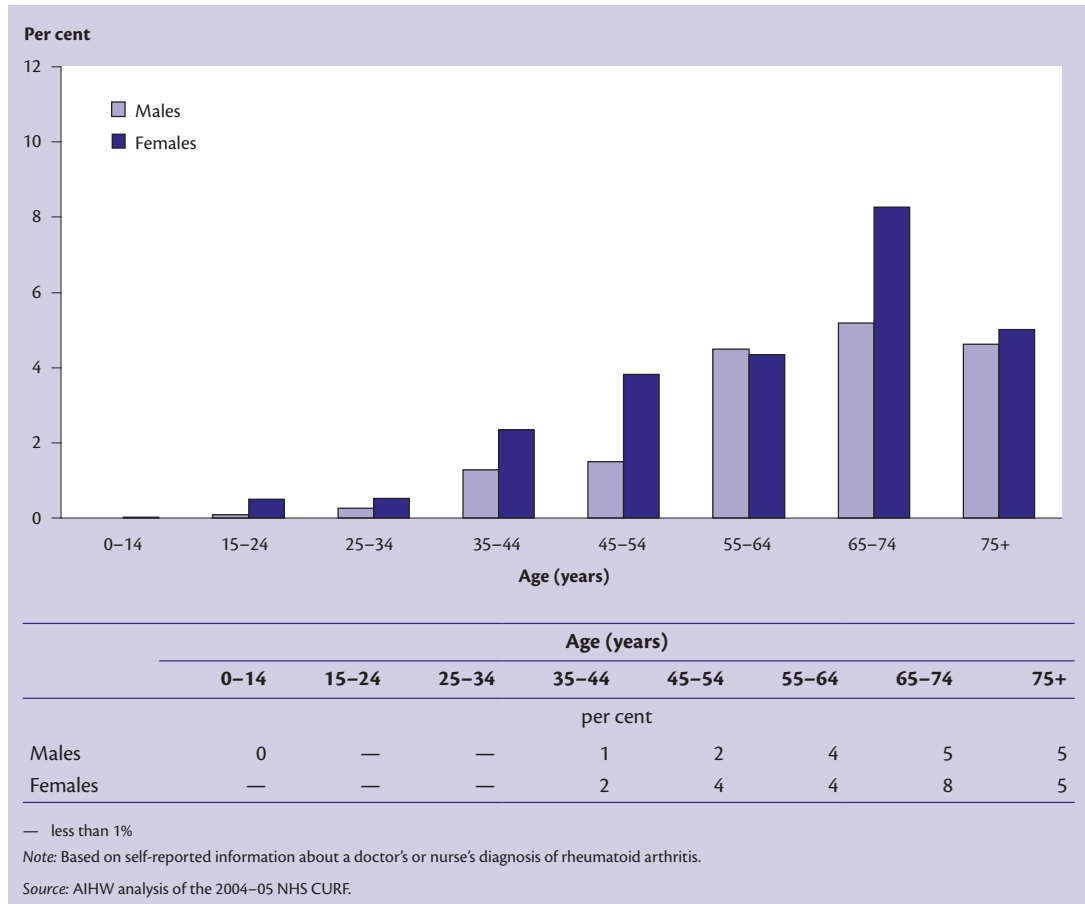
- In 1995, around 20% of Australians aged 2–17 years were overweight or obese for their age and sex.
- More recent data from state-based surveys suggests that this proportion may have risen to around 25% (Booth et al. 2006; Hands et al. 2004).
- At younger ages, girls are more likely than boys to be overweight or obese, whereas at older ages the reverse is true.
- Obesity in childhood is strongly predictive of obesity in adulthood (Magarey et al. 2003; Venn et al. 2007; Williams 2001).
- A high BMI at age 18 years is strongly associated with an increased risk of total hip replacement for osteoarthritis (Karlson et al. 2003).

## 2.1 Prevalence of osteoarthritis among persons aged 25 years or over (2004–05)



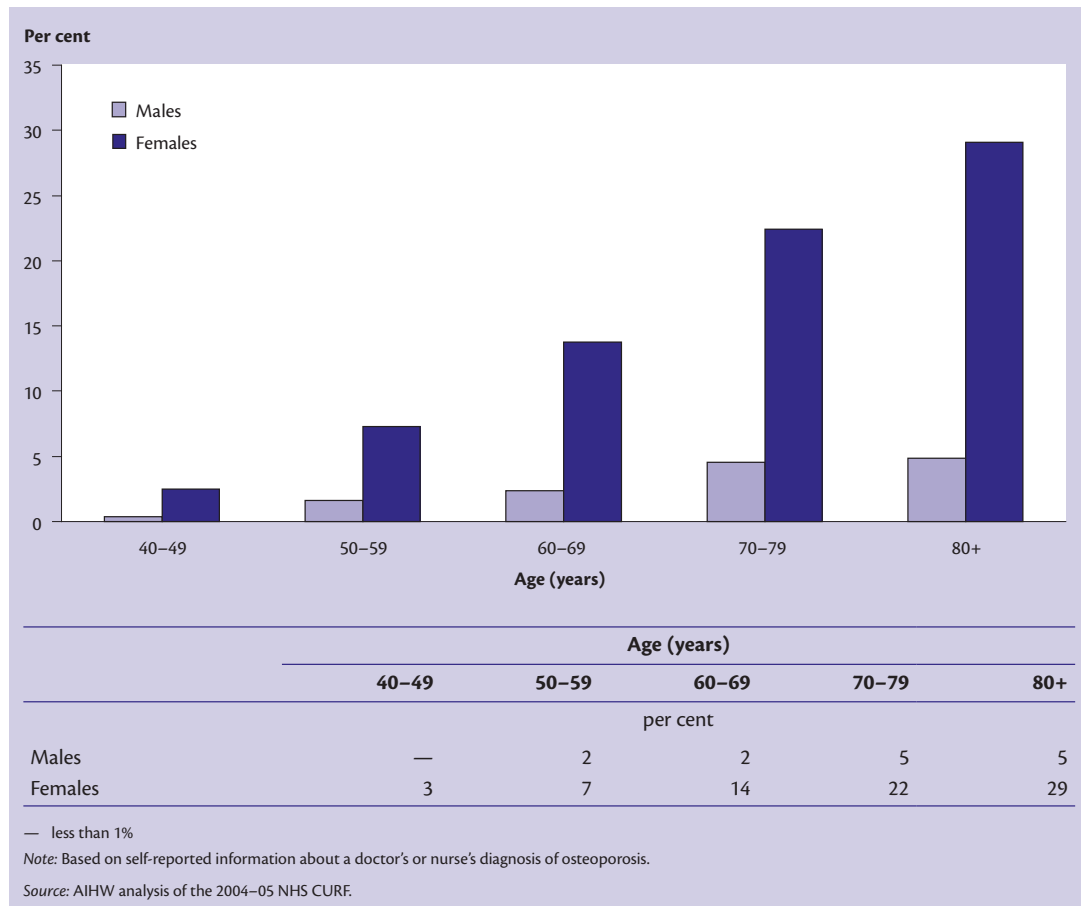
- Osteoarthritis is the most common form of arthritis, affecting over 1.5 million Australians.
- Females are more likely than males to report having been diagnosed with osteoarthritis.
- The prevalence increases rapidly with age, affecting 1% of Australians aged 25–34 years and rising to more than one-quarter of Australians aged 75 years or over.
- Modifiable risk factors for osteoarthritis include obesity, joint trauma or injury, repetitive joint-loading tasks, and joint misalignment.

## 2.2 Prevalence of rheumatoid arthritis (2004–05)



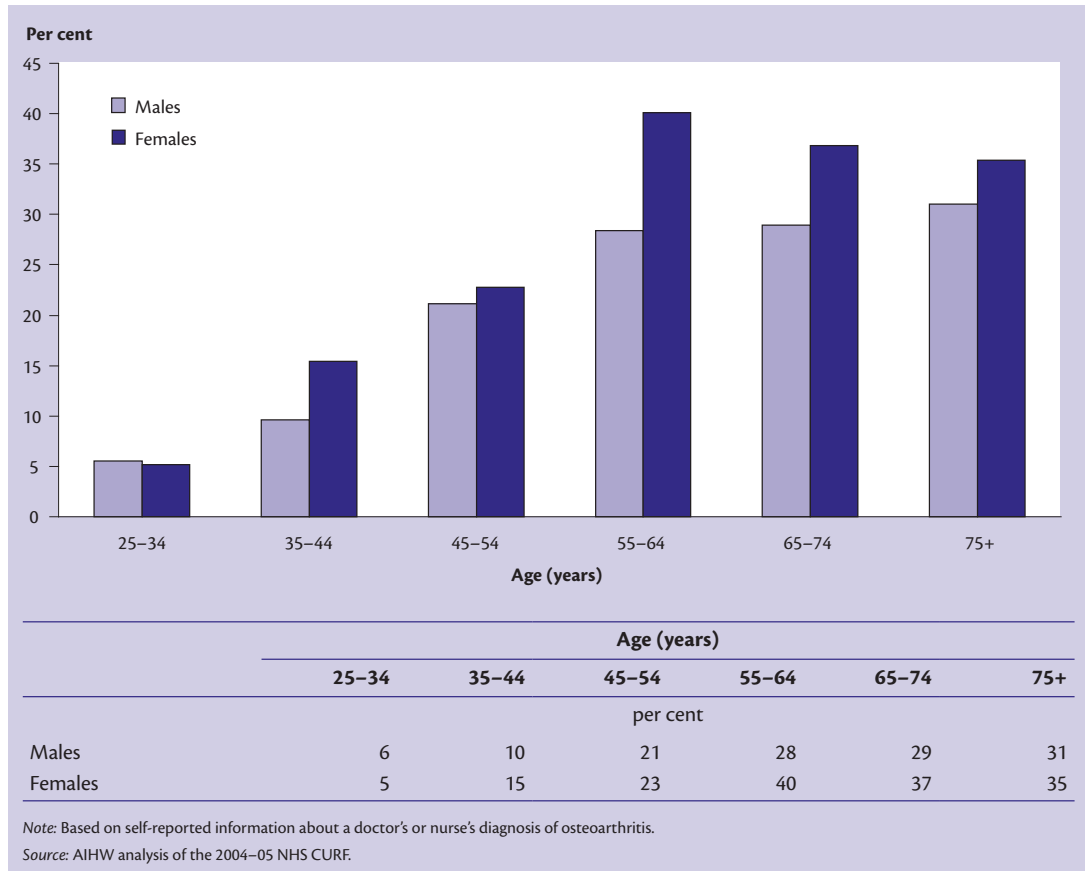
- Rheumatoid arthritis is an autoimmune disease causing inflammation of the synovial joints.
- Almost 384,000 Australians (2% of the population) self-report that they have been diagnosed with rheumatoid arthritis.
- Females are more likely than males to self-report rheumatoid arthritis.
- Prevalence increases with age up to 65–74 years, declining thereafter.
- Self-reported data are believed to significantly overestimate rheumatoid arthritis prevalence. Overseas studies report very high false positive rates in self-reports of rheumatoid arthritis (Bellamy et al. 1992; Kvien et al. 1996; Picavet & Hazes 2003; Star et al. 1996).
- In other developed countries, the prevalence of rheumatoid arthritis ranges from 0.3% to 1% (WHO Scientific Group 2003).

### 2.3 Prevalence of osteoporosis among persons aged 40 years or over (2004–05)



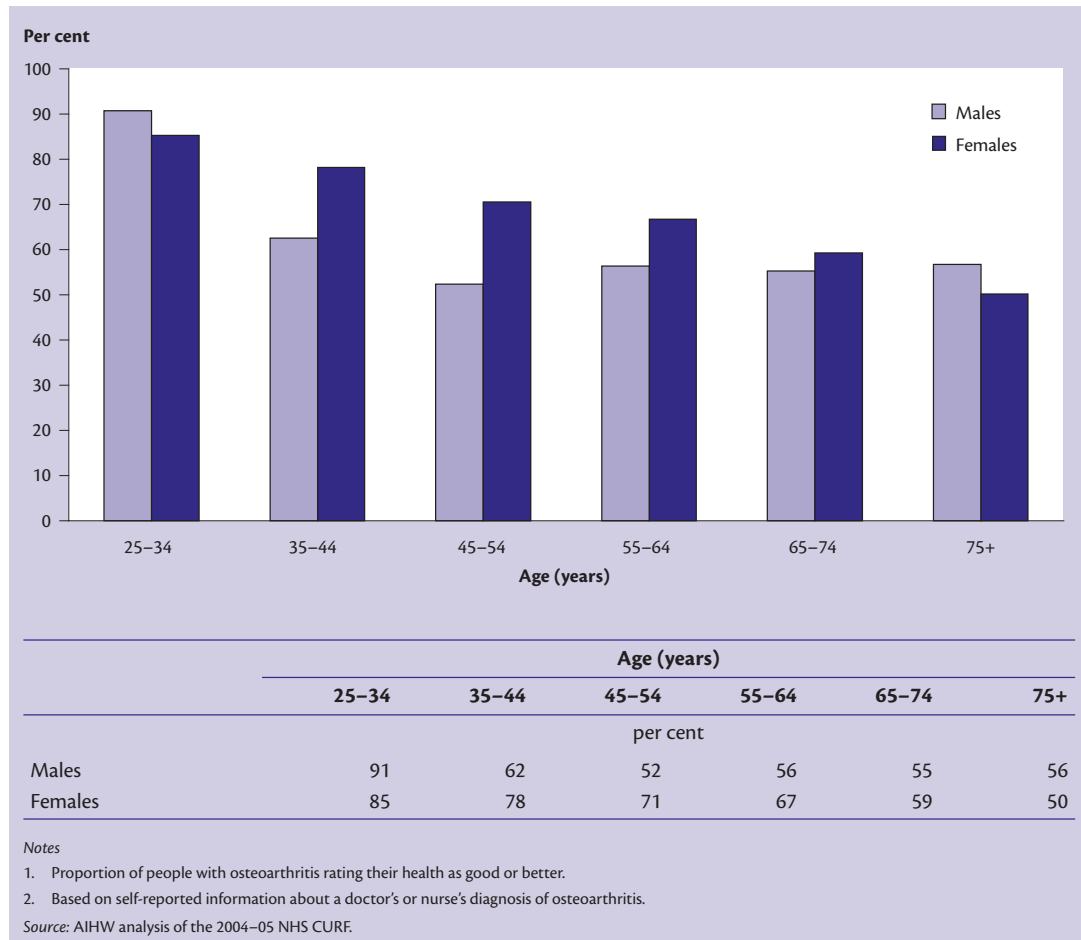
- Self-reported data suggest that almost 558,000 Australians aged 40 years or over (2% of males and 10% of females) have been diagnosed with osteoporosis.
- Prevalence increases rapidly with age; almost 1 in 3 females aged 80 years or over has osteoporosis compared with 1 in 33 females aged 40–49 years.
- Osteoporosis occurs without symptoms, so self-reported data are likely to considerably underestimate its prevalence.
- Around 4% of males and 20% of females aged 60 years or over self-report having been diagnosed with osteoporosis. Studies involving measurement of bone mineral density indicate that the prevalence of osteoporosis is 11% among males and 27% among females of this age (Nguyen et al. 2004).

## 2.4 Prevalence of arthritis among Aboriginal and Torres Strait Islander persons aged 25 years or over (2004–05)



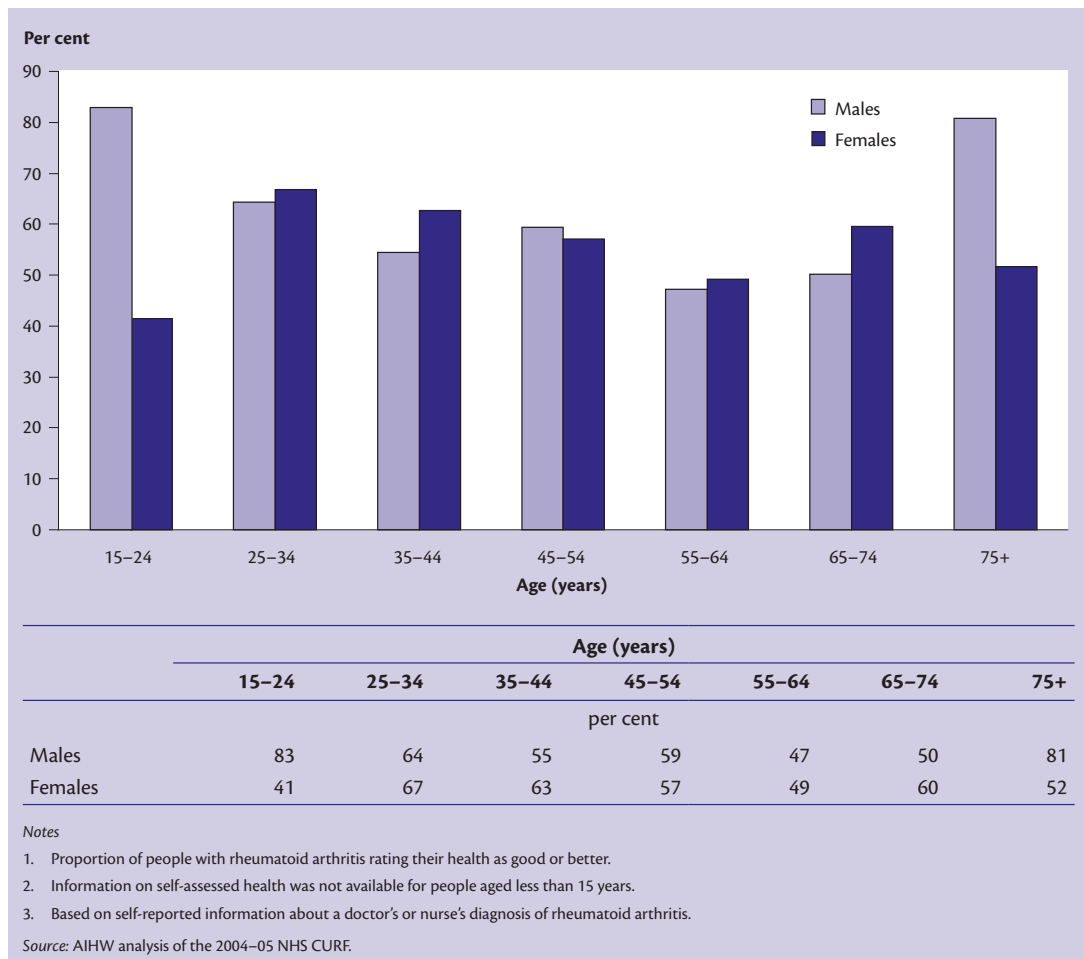
- Self-reported data indicate that more than 31,000 Aboriginal and Torres Strait Islander people aged 25 years or over have been diagnosed with arthritis.
- Indigenous females are more likely to report arthritis than Indigenous males.
- For both sexes, prevalence increases with age until 55 years, then is relatively stable.
- Indigenous Australians are more likely than non-Indigenous Australians to report having been diagnosed with arthritis (20% compared with 17%).
- Among people aged less than 65 years, arthritis is more common among Indigenous people, but for people aged 65 years or over it is more common among non-Indigenous people.
- The majority of arthritis cases in Indigenous Australians are likely to be cases of osteoarthritis (Minaur et al. 2004; Roberts-Thomson & Roberts-Thomson 1999).

### 3.1 Quality of life among persons aged 25 years or over with osteoarthritis (2004–05)



- Around two-thirds of people with self-reported doctor-diagnosed osteoarthritis in 2004–05 rated their general health as good, very good or excellent.
- The proportion rating their health as good or better generally decreased with age, and was higher among females than males in most age groups.

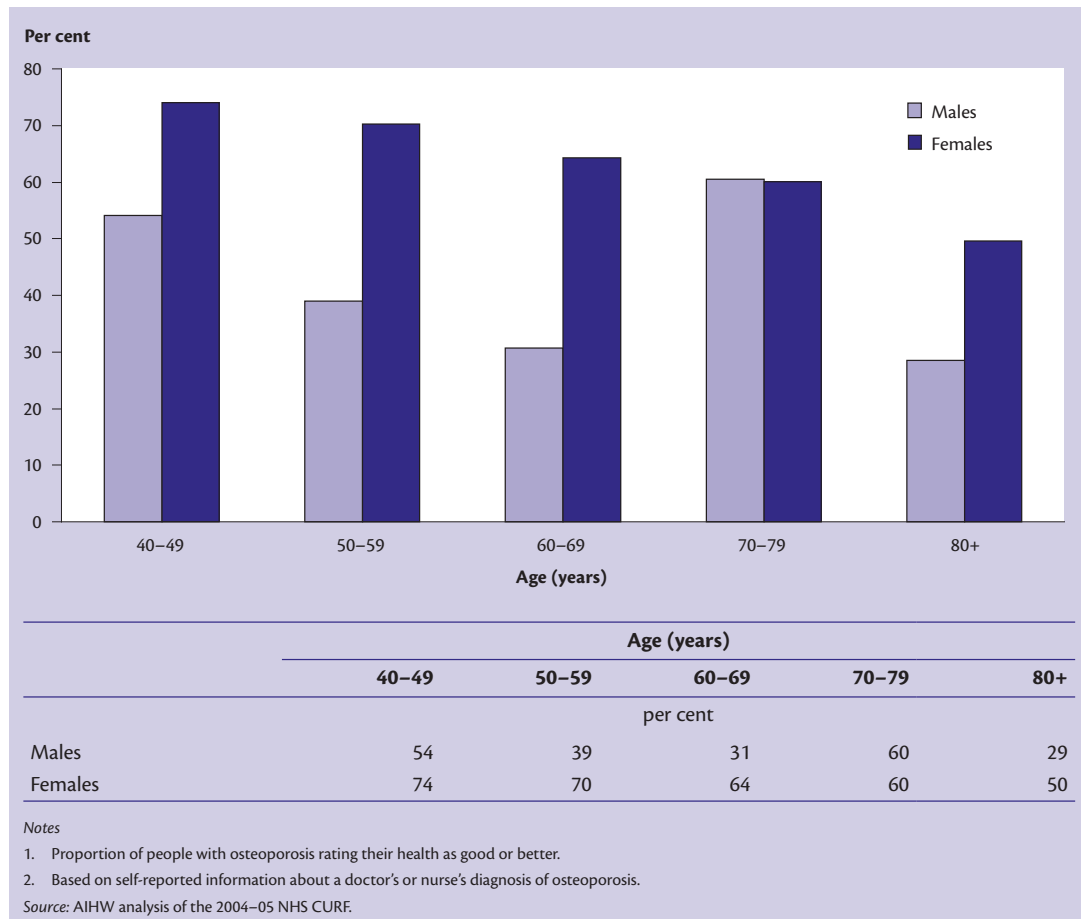
### 3.2 Quality of life among persons with rheumatoid arthritis (2004–05)



- Around 60% of people with rheumatoid arthritis aged 15 years or over in 2004–05 rated their general health as good, very good or excellent.
- Young women were the least likely to rate their health as good or better.
- Among females, the proportion rating their health as good or better decreased as time since diagnosis increased; for males the reverse was true.

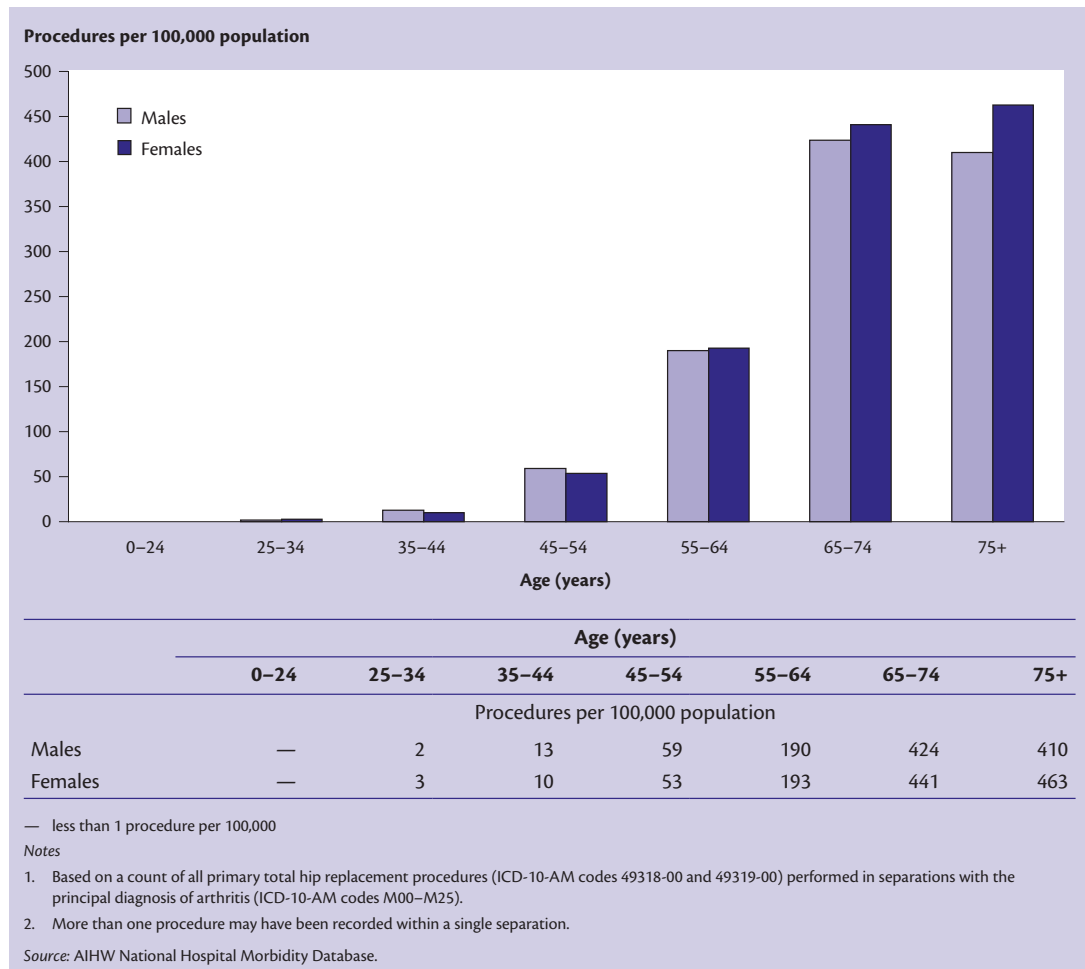


### 3.3 Quality of life among persons aged 40 years or over with osteoporosis (2004–05)



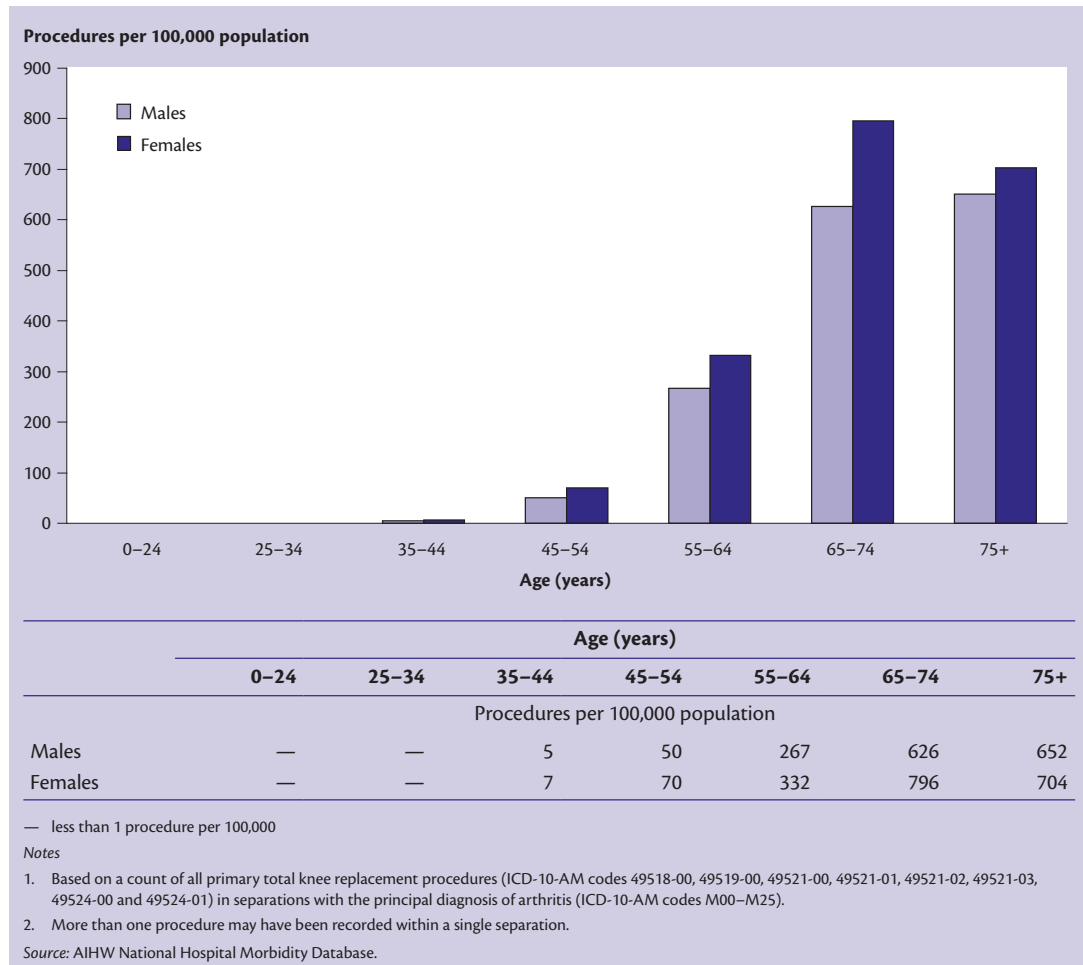
- Approximately half of males and two-thirds of females aged 40 years or over with osteoporosis rated their general health as good, very good or excellent.
- For both sexes, the proportion rating their health as good or better generally decreased with age.

## 4.2 Number of primary total hip replacements for arthritis (2006–07)



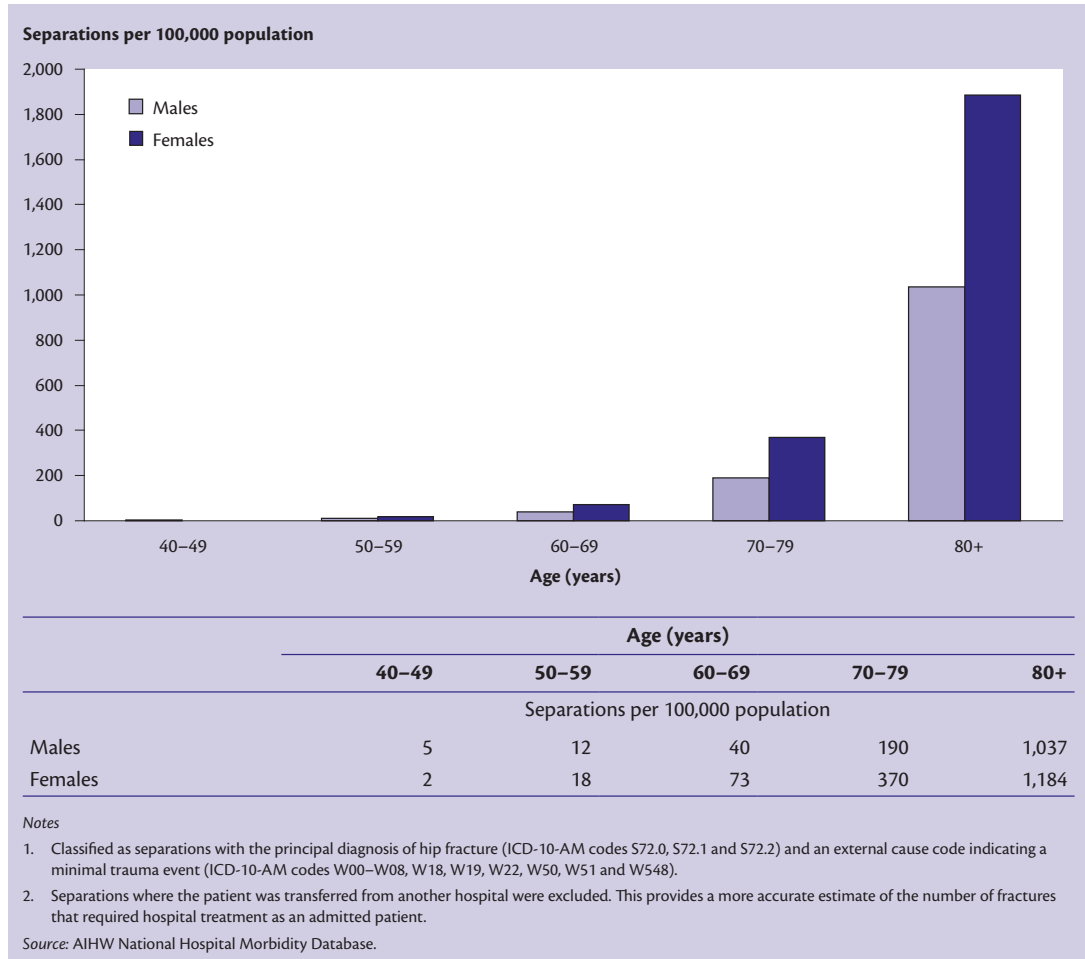
- Total hip replacements can effectively reduce pain and improve function in people with osteoarthritis of the hip.
- More than 18,300 primary total hip replacement procedures were performed in Australia in 2006–07.
- Females are slightly more likely than males to have a total hip replacement (84 compared with 81 procedures per 100,000 population in 2006–07).
- Total hip replacements are most common among people aged 65 years or over.

### 4.3 Number of primary total knee replacements for arthritis (2006–07)



- Total knee replacement is an effective treatment for osteoarthritis of the knee.
- Almost 27,900 primary total knee replacement operations were performed in Australia in 2006–07.
- At all ages, females are more likely to undergo total knee replacement than males.

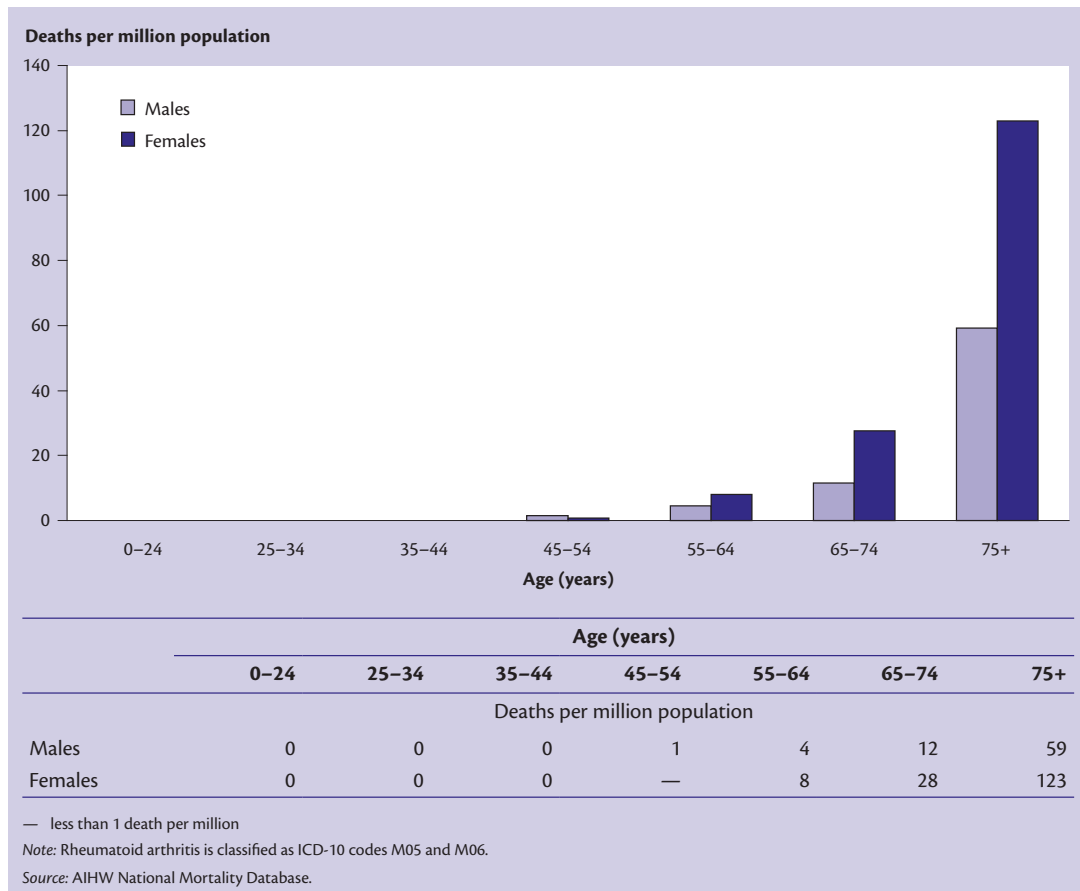
#### 4.4 Number of hospital separations for minimal trauma hip fractures among persons aged 40 years or over (2006–07)



- Minimal trauma hip fracture is one of the most serious complications of osteoporosis.
- Half of all people suffering a hip fracture do not regain their pre-fracture mobility and independence (Johnell 1997).
- People who had a minimal trauma hip fracture 1 year previously are much more likely than others of the same age to have mobility problems, to be unable to walk independently and to need assistance with activities of daily living (Boonen et al. 2004).
- Mortality following minimal trauma hip fracture is increased, with a risk of death 2–3 times greater than normal in the first 12 months post-fracture (Center et al. 1999). This increased risk is seen at all ages and in both sexes.
- There were more than 16,600 minimal trauma hip fractures among people aged 40 years or over in 2006–07.

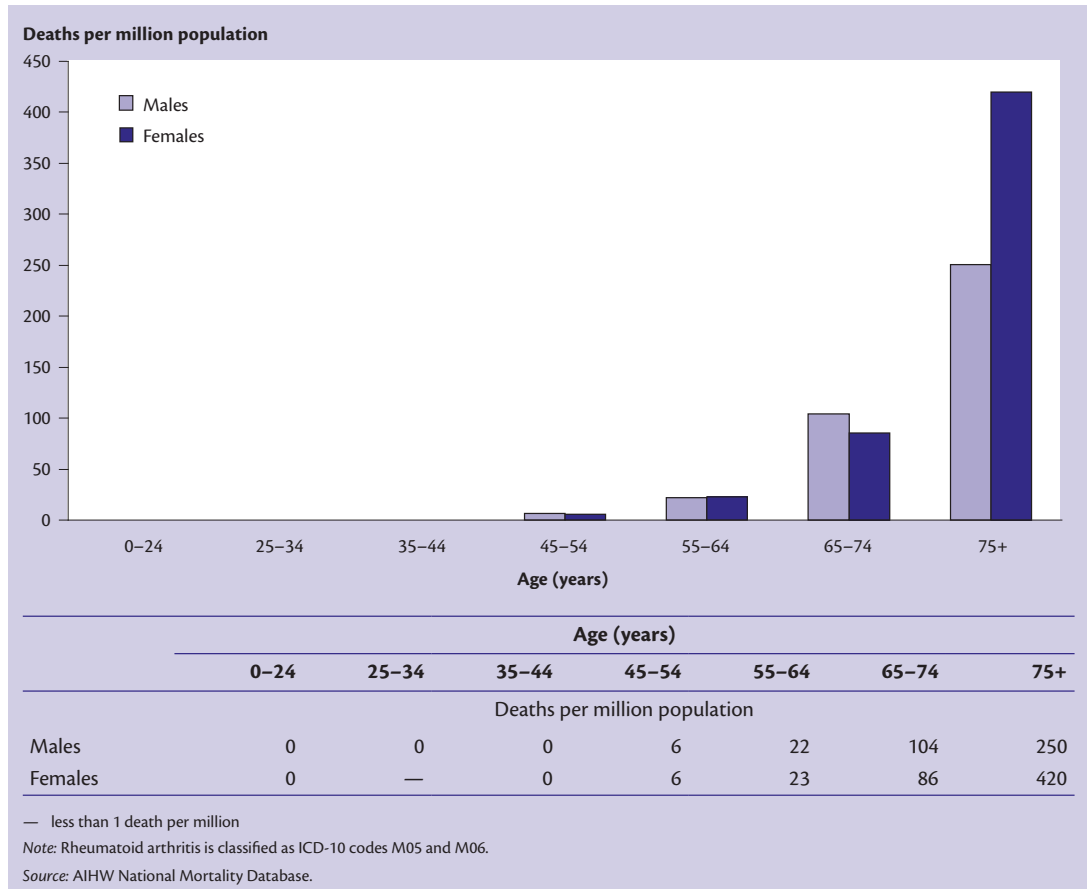
- In most age groups, minimal trauma hip fractures are almost twice as common among women compared with men.
- The minimal trauma hip fracture rate increases dramatically with age, with rates among people aged 80 years or over being around 100 times those among people aged 50–59 years and 5 times those among people aged 70–79 years.

### 5.1 Death rates for rheumatoid arthritis as the underlying cause of death (2006)



- The underlying cause of death is defined as the disease, condition or injury initiating the sequence of events leading directly to death.
- Rheumatoid arthritis was the underlying cause of 169 deaths in Australia in 2006.
- Corresponding to the higher prevalence of the disease among females, the death rate for rheumatoid arthritis was higher among females than males (10 compared with 5 per million population).
- The majority of deaths from rheumatoid arthritis occurred in people aged 65 years or over.

## 5.2 Death rates for rheumatoid arthritis as an associated cause of death (2005)



- An associated cause of death is defined as any condition, disease or injury (other than the underlying cause) considered to contribute to death.
- Rheumatoid arthritis was listed as an associated cause of 652 deaths in Australia in 2006.
- The majority of deaths where rheumatoid arthritis was listed as an associated cause were among people aged 55 years or over.
- Rheumatoid arthritis is much more likely to be recorded as an associated cause of death than as the underlying cause.
- Common underlying causes of death in cases where rheumatoid arthritis is listed as an associated cause include cardiovascular diseases (45% of such deaths in 2006), cancers (19%) and respiratory diseases (11%).

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# Appendix 2: Data sources, methods and classifications

## DATA SOURCES

A variety of data sources were used in the production of this report. These are described briefly below.

### Population surveys

Population surveys are designed to gather information about the characteristics and behaviours of the general population. To conduct a population survey, a random sample of the population is selected and asked to participate. ('Random' means that every person in the population has an equal chance of being selected.) If a reasonably large proportion of the people selected agree to participate, then the results of the survey can be generalised to the whole population. In this case, the sample is said to be 'representative' of the population.

#### *National Health Survey*

The National Health Survey (NHS), conducted every three years by the Australian Bureau of Statistics, is designed to obtain national information on the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle (ABS 2006a). The most recent survey was conducted in 2004–05, with previous surveys being conducted in 2001, 1995, 1989–90, 1983 and 1977. The survey is community-based and does not include information from people living in nursing homes or those who are otherwise institutionalised.

Data available from the NHS include self-reports of long-term conditions, including various forms of arthritis, back pain, osteoporosis and other diseases of the musculoskeletal system and connective tissues. Some information on age at diagnosis, medications used and other actions taken for arthritis or osteoporosis is also available. The survey also collects information about health risk factors and behaviours, injuries and use of health services.

#### *National Aboriginal and Torres Strait Islander Health Survey*

The National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) was conducted by the Australian Bureau of Statistics in 2004–05, concurrently with the NHS. It is intended that the NATSIHS be repeated at 6-yearly intervals. The 2004–05 survey included responses from 10,439 Aboriginal and Torres Strait Islander people, and aimed to provide information about the health circumstances of Indigenous Australians from remote and non-remote areas (ABS 2006b). Questions were similar to those asked in the NHS. Data collected from Aboriginal and Torres Strait Islander respondents to the NHS also contribute to estimates for Indigenous Australians calculated from the NATSIHS.

### ***Survey of Disability, Ageing and Carers***

Conducted by the Australian Bureau of Statistics, the Survey of Disability, Ageing and Carers (SDAC) collects national information on people with disabilities, older people (aged 60 years or over) and their carers (ABS 2004a). The survey is conducted every 5 years (with surveys in 1988, 1993, 1998 and 2003), and covers people in private and non-private dwellings, including people in cared accommodation establishments, but excluding those in correctional institutions. The survey collects data on disability due to impairments, activity limitations and/or participation restrictions, and also collects information about the role of various diseases and health conditions as disabling conditions.

### **Other surveys**

Instead of gathering information about the whole population, the surveys described below are designed to obtain information from or about a specific group of people, for example, information about people visiting doctors or specialists, or people with a certain health condition.

#### ***Bettering the Evaluation and Care of Health (BEACH) GP surveys***

The BEACH Survey of General Practice is an ongoing survey looking at the clinical activities of general practitioners (GPs). The study is conducted by the Australian General Practice Statistics and Classification Centre (an AIHW collaborating unit) at the University of Sydney. BEACH began in April 1998 and involves an ever-changing random sample of approximately 1,000 GPs per year, collecting information on almost 100,000 GP–patient encounters (Britt et al. 2005). Data collected include reasons for encounter, problems managed, management techniques, and details of pharmacological and non-pharmacological treatments prescribed.

#### ***Voice of Arthritis Social Impact Study***

The Voice of Arthritis Social Impact Study was conducted by Arthritis Australia to investigate the impact of arthritis on people with the condition, their families and carers. The survey was mailed out to 3,000 people with arthritis in March 2004, with 1,016 responding. About three quarters of respondents (76%) were 60 years of age or older and 61% were female. The majority of respondents had osteoarthritis (68%) or rheumatoid arthritis (28%). The study explored respondents' levels of satisfaction or dissatisfaction with medication, therapy, information available, physical health, economic issues, education, relationships, lifestyle and employment.

### **Administrative data collections**

Administrative data are collected for reasons other than research; for example, to track expenditure or for auditing government programs. In many cases, however, administrative data can be very useful for research purposes.

#### ***AIHW Disease Expenditure Database***

The Disease Expenditure Database contains information about the money spent by both governments and individuals to purchase or provide goods and services for particular diseases. The information is collected from a wide range of sources including the Australian Bureau of Statistics, Commonwealth,

state and territory health authorities, the Department of Veterans' Affairs, the Private Health Insurance Administration Council, Comcare, and the major workers' compensation and compulsory motor vehicle third-party insurers in each state and territory.

The first detailed Australian study of expenditure across disease and injury groups was published in 1998 and referred to the financial year 1993–94. The latest study refers to the financial year 2004–05. The information from the database is linked to other non-monetary data sources and analyses to provide information specific for diseases, injury groups, age and sex. The database does not include information on other costs incurred by patients (such as the cost of pain and suffering, travel costs, lost quality and quantity of life) or by their carers and families.

### ***AIHW National Hospital Morbidity Database***

The AIHW National Hospital Morbidity Database contains data on episodes of care for patients admitted to hospital in Australia. The data are supplied to the AIHW by state and territory health authorities and the Department of Veteran's Affairs using standard definitions contained in the National Health Data Dictionary. The database includes information on sex, age, Indigenous status, area of usual residence, diagnoses and procedures (AIHW 2006). Diagnoses and procedures are coded based on the International Statistical Classification of Diseases and Related Health Problems, Australian Modification (ICD-AM), 9th revision from 1993–94 to 1998–99 and 10th revision from 1998–99 onwards (both ICD-9-AM and ICD-10-AM codes were included on the database for 1998–99). Since 1996–97 the database includes data from almost all hospitals including public, private, psychiatric and day hospital facilities. It is not possible to count patients individually as the data are episode-based, and therefore estimates of disease incidence and prevalence cannot be obtained from this data source.

### ***AIHW National Mortality Database***

The AIHW National Mortality Database contains information pertaining to deaths registered in Australia. Deaths are registered by the State and Territory Registrars of Births, Deaths and Marriages. The information is provided to the Australian Bureau of Statistics for coding of the cause of death and compilation into aggregate statistics. Information available includes sex, age at death, date of death, area of usual residence, Indigenous status, country of birth and cause of death. The cause of death is certified by the medical practitioner or the coroner and coded using the International Classification of Diseases (ICD), the 9th revision from 1979 to 1996 and 10th revision from 1997. Multiple causes of death, including the underlying and all associated causes of death recorded on the death certificate, are available from 1997 onwards.

### ***Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme***

The Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) are national government-funded schemes that subsidise the cost of a wide range of pharmaceutical medicines to help provide affordable access to medications for Australians. About 80% of all prescription medications available in Australian pharmacies are listed on the PBS or RPBS. This data source contains information about prescription medications dispensed by Australian pharmacies that were subsidised under either scheme. It includes details of medication type, date of prescription and supply, pharmacy post code, patient details (date of birth, sex, post code), prescribing doctor type (GP or specialist) and type of payment (that is, general, concession or safety net). Monthly data are available from 1992 onwards, however the data are more consistently reliable from 1996 onwards.

## STATISTICAL METHODS

### Incidence

Incidence refers to the number of new cases (of a disease, condition or event) occurring during a given period.

### Prevalence

Prevalence refers to the number or proportion (of cases, instances, etc.) present in a population at a given time. It includes both new and existing cases.

### Age-specific rates

Age-specific rates are calculated by dividing the number of events (such as deaths, disease cases or hospital separations) occurring in each specified age group by the estimated resident population for the corresponding age group. The rates are expressed as events per 100 (that is, a percentage or proportion), per 1,000, per 100,000 or per million population.

### Age-standardised rates

Age standardisation is a method of removing the influence of age when comparing populations with different age structures. Age-standardised rates in this report generally use the direct age-standardisation method. The directly age-standardised rate is the weighted sum of age-specific (five-year age group) rates, where the weighting factor is the corresponding age-specific standard population. For this report, the Australian estimated residential population as at 30 June 2001 was used as the standard population. The same standard population was used for males and females to allow valid comparison of age-standardised rates both between the sexes and over time.

#### *Direct age standardisation*

Direct age standardisation is the most common method of age standardisation, and is used in this report for prevalence, incidence, hospitalisations and deaths data. This method is generally used when the population under study is large and the age-specific rates are reliable. The calculation of direct age-standardised rates comprises three steps:

- Step 1: Calculate the age-specific rate for each age group.
- Step 2: Calculate the expected number of cases in each age group by multiplying the age-specific rate by the corresponding standard population for each age group.
- Step 3: Sum the expected number of cases in each age group and divide this sum by the total of the standard population to give the age-standardised rate.

In interpreting age-standardised rates, some issues need to be taken into consideration:

- The age-standardised rate is for comparison purposes only. The magnitude of an age-standardised rate has no intrinsic value since it is only an index measure. Therefore an age-standardised rate is not a substitute for age-specific rates.
- An age-standardised rate is not only influenced by the frequency of the underlying diseases, but is also dependent on the differences between the age structure of the population of interest and the standard population selected. Therefore, the results of comparisons based on age-standardised rates may not only reflect the difference in the frequency of the diseases compared, but also will be partly dependent on the standard population used. However, since the standard population used in this report is the total Australian population in 2001, the age distribution closely reflects that of the current Australian population. The results of comparisons based on these age-standardised rates are valid.

### **Indirect age standardisation and rate ratios**

In situations where populations are small or where there is some uncertainty about the stability of age-specific rates, indirect standardisation is used. This effectively removes the influence of different age structures, but does not provide a result in terms of a rate. Rather, the summary measure is a ratio (called a 'rate ratio') of the number of observed cases compared to the number that would be expected if the age-specific rates of the standard population applied in the population under study. Calculation of a rate ratio comprises the following steps:

- Step 1: Calculate the age-specific rates for each age group in the standard population.
- Step 2: Apply these age-specific rates to the number of people in each age group of the population under study, and sum these to derive the total expected number of cases in that population.
- Step 3: Sum the observed cases in the population under study and divide this number by the expected number derived in step 2. This is the rate ratio. Depending on the types of cases involved, the rate ratio may be called the standardised incidence ratio (SIR), standardised prevalence ratio (SPR), standardised mortality or morbidity ratio (SMR).

A rate ratio of 1 indicates the same number of observed cases as were expected, suggesting rates in the two populations are similar. A rate ratio greater than 1 indicates more cases observed than were expected, suggesting rates in the population under study are higher than in the standard population.

In this report, the indirect method is used in Chapter 7 when comparing the arthritis and osteoporosis indicators between different population groups.

### **Significance testing**

Significance testing is a way of detecting differences between different population groups. Saying that two values are 'significantly different' means that we have strong evidence that there is a real difference between the two values that has not come about purely by chance. In this report significance tests for differences in rates between two population groups (as shown in Chapter 7) have been based on calculating 95% confidence intervals for the rate ratios. Confidence intervals were calculated using the two methods described below.

### **Confidence intervals for census-type data (e.g. mortality, hospital separations)**

Confidence intervals for death and hospitalisation rates were calculated on the basis of the number of observed events using the square-root transform, as described by Breslow & Day (1987: 70–71).

This formula calculates the 100(1- $\alpha$ )% confidence interval as:

$$\text{Lower bound} = RR \left( 1 - \frac{Z_{\alpha}}{2D^{1/2}} \right)^2$$

$$\text{Upper bound} = RR \left( \frac{D+1}{D} \right) \left( 1 + \frac{Z_{\alpha}}{2(D+1)^{1/2}} \right)^2$$

Where RR is the rate ratio,  $Z_{\alpha}$  is the 100(1- $\alpha$ ) percentile of the unit normal distribution and D is the observed number of events in the population of interest.

### **Confidence intervals for survey data (e.g. NHS)**

Confidence intervals for survey data were calculated using the method described in *Rural, regional and remote health—Indicators of health* (AIHW 2005: 304), after Kendall & Stuart (1969).

## **CLASSIFICATIONS**

### **Aboriginal and Torres Strait Islander people**

For the period 2000–2005, the Indigenous identifiers on the AIHW National Mortality Database and the AIHW National Hospital Morbidity Database were considered usable only for deaths or hospital separations registered in certain jurisdictions. (The states and territories included in analyses are noted in the relevant text, figure or table.) This makes it difficult to get accurate national estimates of Indigenous hospitalisation and mortality rates, make comparisons with the non-Indigenous population, and examine geographical variation. Trends in indicators for the Indigenous population need to be interpreted with caution as differences may reflect changes in data quality, coverage, or collection methods rather than real changes in Indigenous health. The reliability of Indigenous status as reported by another person (for example, when registering a death) is also unknown.

In this analysis, only persons specifically identified as being of Aboriginal and/or Torres Strait Islander origin were classified as Indigenous. All other persons were classified as non-Indigenous. The non-Indigenous group therefore includes data where the person's Indigenous status was unknown or not recorded.

### **Area of usual residence**

In most Australian national data collections, area of usual residence is recorded at the Statistical Local Area (SLA) level. Since SLA boundaries may change from year to year, concordance files supplied by the ABS were used to map all data used in this analysis to the 2001 SLA boundaries. Geographical areas were therefore able to be defined consistently over time.

For this report, three major geographical regions were defined: major cities, inner regional Australia, and other areas (including outer regional, remote and very remote locations). SLAs can be classified into these three regions based on their score on the Accessibility/Remoteness Index of Australia (DoHA & University of Adelaide 1999). This index is calculated based on how distant a place is by road from urban centres of different sizes, and therefore provides a relative indication of how difficult it might be for residents to access certain services, such as health care and education. Records that could not be mapped to one of the three regions were excluded from the geographic analyses in this report.

### Socioeconomic status

In this report, the Index of Disadvantage (IoD) was used to determine socioeconomic status (ABS 2004b). This index is one of several socioeconomic indexes derived by the Australian Bureau of Statistics from information collected in the Census of Population and Housing. The IoD is an area-based measure that represents the average level of disadvantage across a geographic area, in this case the SLA. It is derived from social and economic characteristics of the SLA such as low income, low educational attainment, high levels of public sector housing, high unemployment, and jobs in relatively less skilled occupations.

Individual records can be classified into quintiles of socioeconomic disadvantage based on the IoD value of the SLA of the person's usual residence. SLAs can then be grouped into quintiles so that each quintile contains approximately 20% of the total Australian population. Quintile 1 includes the most disadvantaged households and Quintile 5 the least disadvantaged households. Records that could not be mapped to an IoD value were excluded from the analyses of socioeconomic status presented in this report.

It is important to note that the IoD relates to the average disadvantage of all people living in the SLA. It will therefore tend to understate the true inequality in health at an individual level.

### Classification of causes of death, diagnoses and procedures

The International Statistical Classification of Diseases and Related Health Problems (ICD) is used to classify diseases and other health problems (including symptoms and injuries) in clinical and administrative records. The use of a standard classification system enables the storage and retrieval of diagnostic information for clinical and epidemiological purposes that is comparable between different service providers, across countries and over time.

The latest version, ICD-10, was endorsed by the 43rd World Health Assembly in May 1990 and officially came into use in WHO member states from 1994. In Australia, ICD-10 has been used for classifying causes of death since 1999. The Australian modification of ICD-10, the ICD-10-AM, has been used for classifying diagnoses in hospital records since 1998–99.

The current version of the ICD does not incorporate a classification system for health interventions. Work on revising the International Classification of Procedures in Medicine (ICPM), first published in 1978, virtually ceased in 1989 due to the difficulty in keeping up with the rapid and extensive changes in the field. Several countries, including Australia, the UK and the USA, developed their own systems of classification for health interventions. The Australian Classification of Health Interventions (ACHI) (previously known as MBS-Extended) is used in conjunction with ICD-10-AM for classifying surgical procedures and other health interventions in Australian hospital records.

A renewed focus on developing an international classification system has seen work restarted in recent years, with field trials of the International Classification of Health Interventions (ICHI) undertaken by the Australian National Centre for Classification in Health (NCCH) in 2007.

Further information about the ICHI, ACHI and ICD-10-AM can be obtained from the NCCH web site at <[www3.fhs.usyd.edu.au/ncchwww/site/index.htm](http://www3.fhs.usyd.edu.au/ncchwww/site/index.htm)>.

**Table A2.1: ICD-10 and ICD-10-AM codes used in identifying arthritis and musculoskeletal diseases and injuries in hospital morbidity and mortality data**

Disease or injury	ICD-10/ICD-10-AM codes
<b>Diseases</b>	
Rheumatoid arthritis	M05, M06
Osteoarthritis	M15–M19
Juvenile arthritis	M08, M09
Osteoporosis	M80–M82
<b>Fractures</b>	
Fracture of ankle	S82.5–S82.6, S82.8, S92.1
<i>Fracture of hip and pelvis</i>	
– Femoral neck fracture	S72.0
– Intertrochanteric fracture	S72.11
– Pelvic fracture	S32.3–S32.5, S32.81, S32.83, S32.89
– Other	S72.1–S72.2, S72.9
<i>Fracture of shoulder</i>	
– Fracture of clavicle	S42.0
– Fracture of neck of humerus	S42.2
– Other	S42.1, S42.7–S42.9
Fracture of spine	S12.0–S12.7, S12.9, S22.0–S22.1, S32.0–S32.2, S32.7, S32.82, T08
<i>Fracture of wrist or forearm</i>	
– Colles' fracture	S52.51
– Scaphoid fracture	S62.0
– Other	S52, S62.1
Fractures at other sites	S02, S12.8, S22.2–S22.9, S42.3–S42.4, S62.2–S62.8, S72.3–S72.8, S82.0–S82.4, S78.7, S82.9, S92, T02, T10, T12, T14.2
<b>External cause of injury</b>	
Minimal trauma falls	W00, W01, W03–W08, W18, W19
Other minimal trauma events	W22, W50, W51, W54.8



**Table A2.2: ICD-10-AM codes used to identify clinical interventions for people with arthritis and musculoskeletal conditions**

Intervention	ICD-10-AM codes
Partial hip replacement	47522-00, 49315-00
Primary total hip replacement	49318-00, 49319-00
Revision hip replacement	49346-00, 49324-00, 49327-00, 49330-00, 49333-00, 49339-00, 49342-00, 49345-00
Partial knee replacement	49517-00
Primary total knee replacement	49518-00, 49519-00, 49521-00, 49521-01, 49521-02, 49521-03, 49524-00, 49524-01, 49534-00
Revision knee replacement	49530-00, 49530-01, 49533-00, 49554-00, 49527-00
<i>Allied health interventions</i>	
– physiotherapy	95550-03
– occupational therapy	95550-02
– social work	95550-01
– dietetics	95550-00
– other	95550-04 through 95550-13

## Classification of general practice encounters

The International Classification of Primary Care (ICPC) is used as a classification for primary care or general practice wherever applicable. Development of the ICPC was initiated in the early 1970s to overcome a number of problems faced in applying the ICD system in primary care settings (such as difficulty in classifying symptoms and undiagnosed disease).

The second edition of ICPC, known as ICPC-2, was published in 1998 by the World Organization of Family Doctors (WONCA). ICPC-2 classifies patient data and clinical activity in the domains of general/family practice and primary care, taking into account the frequency distribution of problems seen in these domains. It allows classification of the patient's reason for encounter, the problems/diagnoses managed, interventions, and the ordering of these data in an episode of care structure. In Australia, an extended terminology known as ICPC-2-PLUS is used to classify general practice encounter data in electronic health record systems, research projects and the BEACH GP survey program.

Further information about ICPC-2 and ICPC-2-PLUS can be obtained from the Family Medicine Research Centre website at <[www.fmrc.org.au](http://www.fmrc.org.au)>.

**Table A2.3: ICPC-2-PLUS codes used in identifying arthritis and musculoskeletal conditions in general practice data**

Condition	ICPC-2 and ICPC-2-PLUS codes
Diseases of the musculoskeletal system and connective tissue	L
Rheumatoid arthritis (includes juvenile arthritis)	L88
Osteoarthritis	L83011, L84004, L84009, L84010, L84011, L84012, L89001, L90001, L91001, L91003, L91008, L91015, L92007
Osteoporosis	L95

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# Glossary

<b>additional diagnosis</b>	Conditions or complaints either co-existing with the <b>principal diagnosis</b> or arising during the episode of care. Additional diagnoses give information on factors that result in increased length of stay, more intensive treatment or the use of greater resources.
<b>admitted patient</b>	A patient who undergoes a hospital's formal admission process to receive treatment and/or care. This treatment and/or care is provided over a period of time and can occur in hospital and/or in the person's home.
<b>age-specific rate</b>	A rate for a specific age group. Both the numerator and denominator relate to the same age group.
<b>age-standardisation</b>	A method of removing the influence of age when comparing populations with different age structures. This procedure is required because the incidence and prevalence of many diseases varies strongly (usually increasing) with age. The age structures of different populations are converted to the same 'standard' structure, and the incidence/prevalence rates are calculated.
<b>ankylosing spondylitis</b>	An autoimmune disease that causes arthritis of the spine, resulting in pain, stiffness and loss of motion in the joints and ligaments.
<b>arthritis</b>	A group of disorders in which there is inflammation of the joints, which can become stiff, painful, swollen or deformed. The two main types of arthritis are <b>osteoarthritis</b> and <b>rheumatoid arthritis</b> .
<b>associated cause(s) of death</b>	Any condition(s), diseases and injuries—other than the <b>underlying cause</b> —contributing to death. See also <b>cause of death</b> .
<b>autoimmune diseases</b>	Diseases, such as rheumatoid arthritis and Type 1 diabetes in which the immune system reacts against its own body tissues.
<b>body mass index (BMI)</b>	A standardised measure of weight adjusted for person's height. BMI is calculated by dividing the person's weight (in kilograms) by their height (in metres) squared, that is, $\text{kg} \div \text{m}^2$ . For adult men and women, underweight is a BMI below 18.5, acceptable weight is from 18.5 to less than 25, overweight is 25 and above (includes obese), and obese is 30 and over.
<b>carer</b>	Someone who looks after a relative or friend who has a <b>disability</b> , a chronic illness, or is a frail, aged person. Carers come from all walks of life, cultural backgrounds and age groups.

<b>cause of death</b>	From information reported on the medical certificate of cause of death, each death is classified by the <b>underlying cause of death</b> , according to rules and conventions of various editions of the <b>International Classification of Diseases</b> . The underlying cause is defined as the disease or condition that initiated the train of events leading directly to death. Deaths from injury or poisoning are classified according to the circumstances of the event that produced the fatal injury, called the <b>external cause(s)</b> of death, rather than to the nature of the injury.
<b>chronic</b>	Persistent and long-lasting.
<b>chronic diseases</b>	Term applied to a diverse group of diseases, such as heart disease, cancer and arthritis, that tend to be long lasting and persistent in their symptoms or development. Although these features also apply to some communicable diseases (infections), the term is usually confined to non-communicable diseases.
<b>comorbidity</b>	The occurrence of two or more health problems in a person at the same time.
<b>conjunctivitis</b>	Inflammation of the conjunctiva, the membrane that coats the eye and the inside of the eyelids.
<b>Crohn's disease</b>	An inflammatory disease of the gastrointestinal tract. Symptoms include recurrent abdominal pain, fever, nausea, vomiting, weight loss and diarrhoea.
<b>dermatitis</b>	Inflammation of the skin.
<b>dermatomyositis</b>	A disease of the connective tissue, characterised by swelling, dermatitis and inflammation of the muscle tissue.
<b>direct costs</b>	Financial costs to the Australian health system for providing prevention and treatment services, such as hospitals, aged care homes, primary care and specialist services, pharmaceuticals and other medications, allied health services, research, health administration and public health programs.
<b>disability</b>	A concept of several dimensions relating to an <b>impairment</b> in body structure or function, a limitation in activities (such as mobility and communication), a restriction in participation (involvement in life situations such as work, social interaction and education), and the affected person's physical and social environments.
<b>disability-adjusted life year (DALY)</b>	Years of healthy life lost through either premature death or through living with disability due to illness or injury.
<b>early intervention</b>	Timely identification and tailored advice and support for those identified with a condition. 'Early' does not necessarily mean early in life but rather early in the time course or progress of a condition; a nexus between prevention and treatment.

<b>enthesitis</b>	Inflammation at the place where the tendons or ligaments attach to the bones.
<b>external cause</b>	An environmental event, circumstance or condition as the cause of injury, poisoning or other adverse effect. The term is used in disease classification (for example, in describing causes of death).
<b>health professional</b>	A person who helps in identifying, preventing or treating illness or disability, such as a general practitioner, allied health professional or specialist.
<b>health-related quality of life</b>	A measure of the degree to which a person's satisfaction or happiness with various aspects of life (for example, physical functioning or social interaction) is affected by their health status.
<b>hostel</b>	An establishment for people who cannot live independently but who do not need nursing care in a hospital or <b>nursing home</b> . Hostels provide board, lodging or accommodation and cater mostly for the aged, distressed or those with a disability. Residents are generally responsible for their own provisions but may be given domestic assistance such as help with meals, laundry and personal care.
<b>impairment</b>	Any loss or abnormality of psychological, physiological or anatomical structure or function.
<b>incidence</b>	The number of new cases (of an illness or event) occurring during a given period. Compare with <b>prevalence</b> .
<b>indicator</b>	A key statistic chosen to describe (indicate) a situation concisely, help assess progress and performance, and act as a guide to decision making. It may have an indirect meaning as well as a direct one; for example, overall death rate is a direct measure of mortality but is often used as a major indicator of population health.
<b>Indigenous person</b>	A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander and is accepted as such by the community with which he or she is associated.
<b>indirect costs</b>	The costs to the community due to a condition other than <b>direct costs</b> , such as the loss of earnings due to absenteeism and early retirement, the loss of potential tax revenue, and the value of volunteer carers.
<b>inflammation</b>	Response to injury or infection, marked by localised redness, heat, swelling and pain. Can also occur when there is no clear external cause and the body reacts against itself, as in <b>autoimmune diseases</b> .
<b>International Classification of Diseases</b>	The World Health Organization's internationally accepted classification of death and disease. The 10th revision (ICD-10) is currently in use.
<b>intervention</b>	In the context of health, refers to actions for the prevention, treatment or management of health problems, for example medicines, surgery, counselling or lifestyle advice.

<b>juvenile arthritis</b>	A term describing any form of inflammatory arthritis of unknown cause first occurring before the 16th birthday and lasting at least 6 weeks.
<b>length of stay</b>	Duration of hospital stay, calculated by subtracting the date the patient is admitted from the date of <b>separation</b> . All leave days, including the day the patient went on leave, are excluded. A same-day patient is allocated a length of stay of one day.
<b>Lyme disease</b>	A bacterial disease transmitted by ticks. Symptoms include a rash at the site of the tick bite, fever, headache, muscle aches and swollen lymph nodes. May cause arthritis and heart problems if untreated.
<b>medicines</b>	Agents used to treat disease or injury; includes both pharmaceuticals and non-pharmaceuticals. Can include items purchased from a pharmacy (prescribed or not prescribed), health food shop or supermarket, including vitamins and herbal products.
<b>morbidity</b>	Refers to ill health in an individual and to levels of ill health in a population or group.
<b>mortality</b>	Death.
<b>multi-disciplinary care</b>	A team approach to the provision of health care by all relevant health and non-health community-based, medical and allied health disciplines.
<b>multiple sclerosis</b>	An autoimmune disease that affects the central nervous system.
<b>musculoskeletal</b>	Relating to the muscles, joints and bones.
<b>National Health Priority Areas (NHPAs)</b>	A collaborative initiative of Commonwealth, State and Territory Governments that seeks to focus public attention and health policy on areas that contribute significantly to the burden of disease in Australia and for which there is potential for health gain.
<b>non-admitted patient</b>	A patient who receives care from a recognised non-admitted patient service or clinic of a hospital, including emergency departments and outpatient clinics.
<b>nursing homes</b>	Establishments which provide long-term care involving regular basic nursing care for people who are frail, disabled, convalescing or with a chronic illness, or for senile inpatients.
<b>obesity</b>	Marked degree of overweight, defined as <b>body mass index</b> of 30 or over.
<b>optimal</b>	Most desirable possibility under a restriction expressed or implied.
<b>osteoarthritis</b>	A chronic and common form of <b>arthritis</b> , affecting mostly the spine, hips, knees and hands. It first appears from the age of about 30 and is more common and severe with increasing age.
<b>osteoporosis</b>	Thinning and weakening of the bone substance, with a resulting risk of fracture.

<b>overweight</b>	Defined as a <b>body mass index</b> of 25 or over. See also <b>obesity</b> .
<b>prescription drugs</b>	Pharmaceutical drugs available only on the prescription of a registered medical practitioner and available only from pharmacies.
<b>prevalence</b>	The number of cases (of illness or events) present in a population at a given time. Compare with <b>incidence</b> .
<b>prevention</b>	Stopping an event or episode from occurring or progressing by performing or avoiding certain activities.
<b>principal diagnosis</b>	The diagnosis describing the problem that was chiefly responsible for the patient's episode of care in hospital.
<b>principal procedure</b>	The most significant procedure that was performed for treatment of the <b>principal diagnosis</b> .
<b>psoriasis</b>	A condition marked by red, scaly areas of skin, particularly on the knees, elbows and scalp but affecting any part of the body. It is thought to be due to increased activity of the immune system in the skin. In some cases the joints may also be involved, leading to arthritis, often in the knees, back or ankles.
<b>reactive arthritis</b>	A form of arthritis that develops after an infection, often marked by the combination of arthritis, conjunctivitis and urethritis. It occurs mainly in young men and in most cases resolves within 12 months. Sometimes called Reiter's syndrome.
<b>rheumatic fever</b>	A delayed complication of an untreated streptococcal infection, involving fever, inflammation of the joints and damage to the heart valves.
<b>rheumatoid arthritis</b>	A chronic autoimmune disease whose most prominent feature is joint inflammation, most often affecting the hand joints in symmetrical fashion. Other parts of the body, notably the eyes, heart and blood vessels, may also be affected. Can occur in all age groups but most commonly appears between ages 35 to 45.
<b>rickets</b>	A disease caused by vitamin D deficiency, which leads to softening and weakening of the bones.
<b>risk factor</b>	Any factor that presents a greater risk of a health disorder or other unwanted condition or event. Some risk factors are regarded as causes of disease, others are not necessarily so.
<b>same-day patients</b>	Hospital patients who are admitted and separated on the same day.
<b>scleroderma</b>	A chronic disease that causes thickening and tightening of the skin. The deeper tissues and internal organs may also be affected. Also called systemic sclerosis.

<b>self-management</b>	Involves (the individual with the condition) engaging in activities that protect and promote health; monitoring and managing of <b>symptoms</b> and signs of illness; managing the impacts of illness on functioning, emotions and interpersonal relationships; and adhering to treatment regimes.
<b>separation</b>	The formal process by which a hospital records the completion of treatment and/or care for an <b>admitted patient</b> .
<b>special needs group/ at risk group</b>	Refers to groups of people who have needs relating to their health that are not always considered initially, or who have particular requirements, or who may be disadvantaged. Examples include people living in rural and remote areas, Indigenous communities, socioeconomically or intellectually disadvantaged people, and people in custody.
<b>statistical significance</b>	An indication from a statistical test that an observed difference or association may be significant or 'real' because it is unlikely to be due alone to chance. A statistical result is usually said to be 'significant' if it would occur by chance less than once in 20 times.
<b>symptom</b>	Any indication of a disorder.
<b>systemic lupus erythematosus (SLE)</b>	A chronic autoimmune disease that affects the skin, joints and organs, commonly causing joint pain and arthritis.
<b>Type 1 diabetes</b>	A chronic autoimmune disease in which the body produces little or no insulin, and therefore cannot process glucose (a type of sugar) into energy. People with Type 1 diabetes need insulin replacement for survival. It occurs mostly among children and young adults, but can arise at any age.
<b>Type 2 diabetes</b>	The most common form of diabetes, occurring mostly in people aged 50 years or over, though becoming more common in younger people. People with Type 2 diabetes produce insulin, but may not produce enough or cannot use it effectively. It may be managed with changes to diet and exercise, oral glucose-lowering drugs, insulin injections, or a combination of these.
<b>underlying cause of death</b>	The condition, disease or injury initiating the sequence of events leading to death; that is, the primary, chief, main or principal cause. Compare with <b>associated cause(s) of death</b> .
<b>underweight</b>	Defined as a <b>body mass index</b> of less than 18.5.
<b>urethritis</b>	Inflammation of the urethra, the tube that passes urine from the bladder to the outside.
<b>uveitis</b>	Inflammation of the inner eye.



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