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

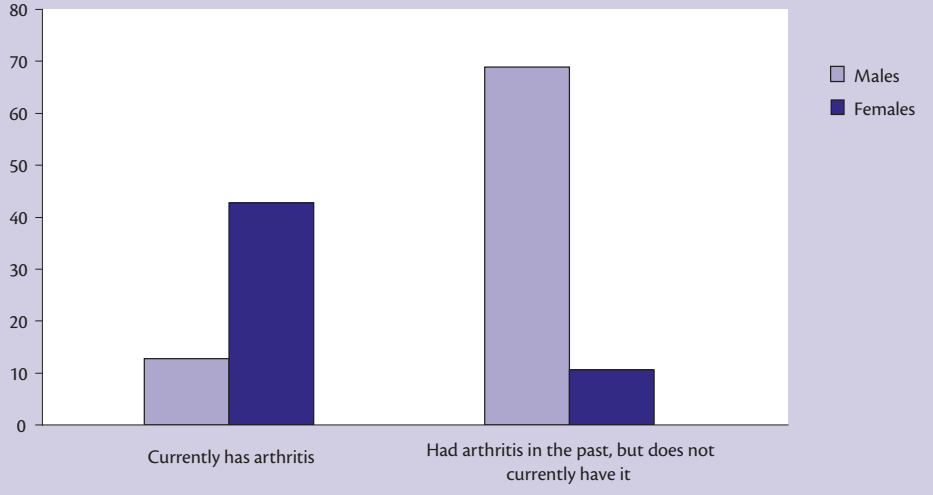
The most common symptom of juvenile arthritis is joint inflammation. The synovial membranes that line the joints produce a fluid, called synovial fluid, that lubricates the joints and helps them to move smoothly. In arthritic joints, the synovial membrane becomes thickened and stiff, and extra synovial 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).



Note: Based on parental reports of a doctor's or nurse's diagnosis of arthritis.

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

Figure 4.1: Current and past arthritis in Australians aged less than 16 years, 2004–05

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 at 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).

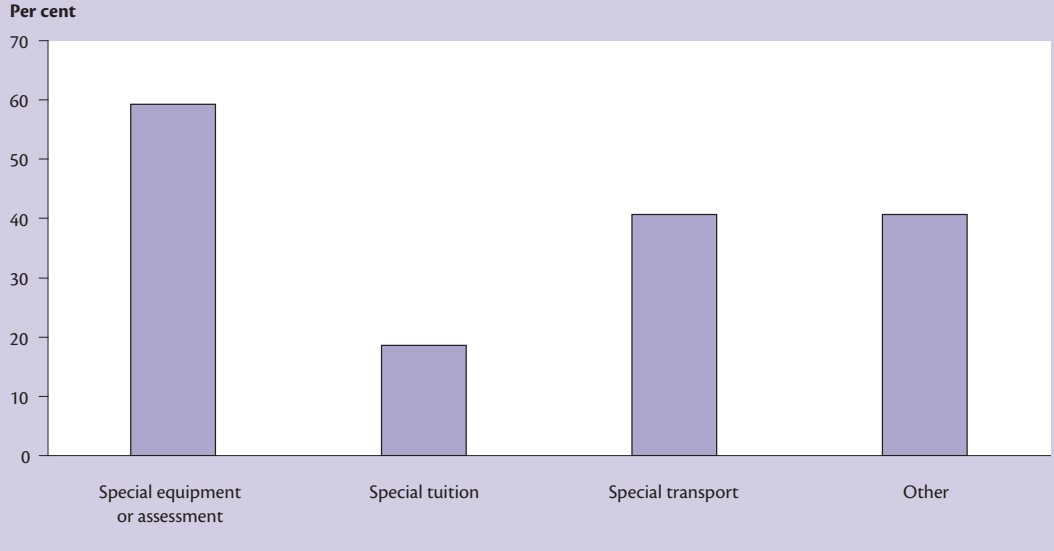
Table 4.1: Schooling restrictions among people aged 5–14 years with arthritis-associated disability, 2003

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
Total with restrictions/difficulties in schooling	**92**

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.

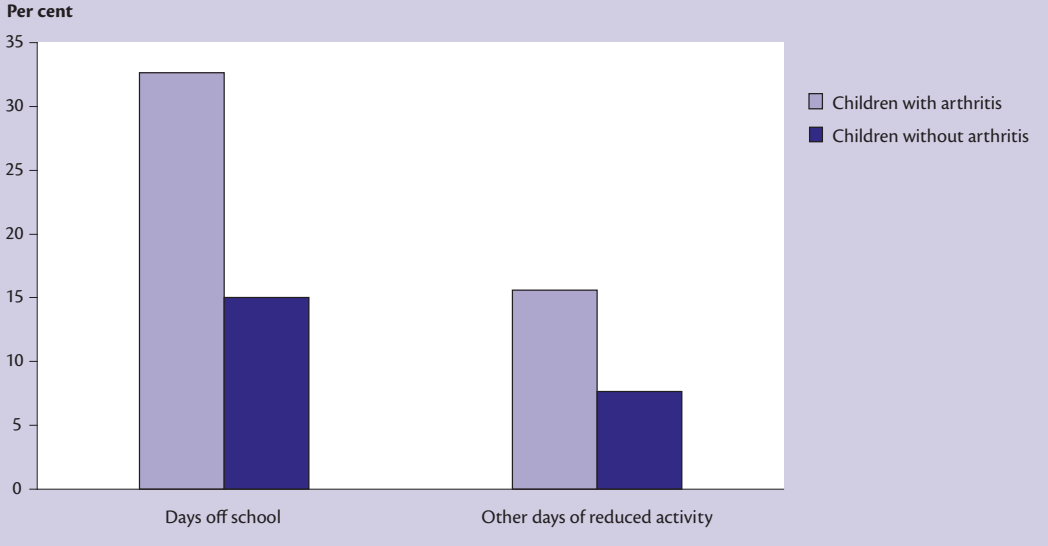
Figure 4.2: Arrangements made by schools for students with arthritis-associated disability, 2003

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.



Notes
1. Refers to days off school due to any illness (not necessarily arthritis) and other days of reduced activity in the two weeks before the survey.
2. 'Other days of reduced activity' refers to days where the child's usual activities were reduced due to any illness (not necessarily arthritis), excluding days off school.

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

Figure 4.3: Days off school and other days of reduced activity among children aged 5–15 years, by arthritis status, 2004–05

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 metabolisation 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 Australian 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-α). 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[a]	Per cent of separations[b]
Joint injection	361	46
Other administration of medication[c]	205	26
Allied health interventions	160	15
Physiotherapy	*98*	*13*
Occupational therapy	*15*	*2*
Pharmacy	*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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