BULLETIN II3 + JANUARY 2013

A snapshot of juvenile arthritis

Summary

- Juvenile arthritis refers to the types of arthritis that affect children. It may cause significant pain, disability and restrictions in school and other activities. This snapshot focuses on arthritis in children 0 to 15 years old, although some children may enter into their adulthood with the condition.
- Juvenile arthritis is not a common condition, affecting less than 1% of children.
- In the past decade, a new class of medicine, referred to as biologic disease-modifying anti-rheumatic drugs (bDMARDs), became available for treatment of juvenile arthritis in Australia, broadening the treatment options.
- For this relatively uncommon condition, only limited national statistics are available, making it
 difficult to evaluate the full extent of the effects of this condition on the children who have it and
 those who care for them.
- The available data show that:
 - While the total expenditure on medicines used to manage juvenile arthritis is not known, the Australian Government subsidies paid for bDMARDs have increased each year since their introduction, to \$4.7 million in 2011.
 - In the 10 years to 2009–10, the age-standardised hospitalisation rates for juvenile arthritis have increased for girls. The reasons for this increase are not yet clear.

ContentsSummary1Introduction3Who gets juvenile arthritis?4How is juvenile arthritis managed?5How does juvenile arthritis affect quality of life?11Appendix 1: Detailed statistical tables14Glossary15Acknowledgments16Abbreviations16References16Related publications19

Introduction

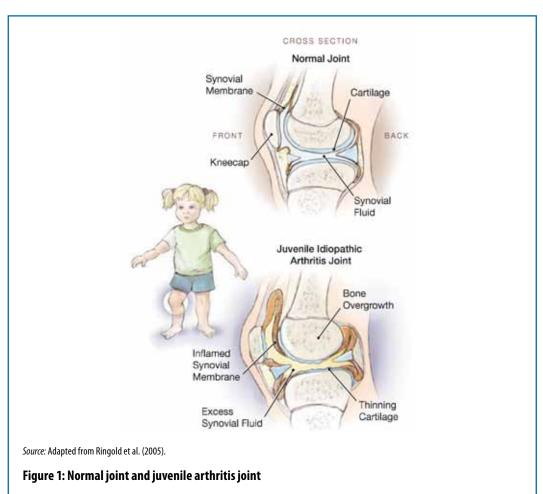
Juvenile arthritis is a general name for several different kinds of arthritis in children. Most forms of juvenile arthritis are believed to be autoimmune disorders, where the body's immune system attacks its own tissues.

Juvenile arthritis is sometimes referred to as juvenile idiopathic arthritis. 'Juvenile' means that it affects young people, 'idiopathic' means that the cause is unknown, and 'arthritis' means inflammation in the joints.

A widely accepted definition of juvenile arthritis is 'persistent arthritis of unknown cause that begins before the age of 16, and persists for at least 6 weeks' (Petty et al. 2004).

Signs and symptoms of juvenile arthritis

In juvenile arthritis, the immune system attacks the tissues lining the joints (called the synovial membranes) (Figure 1). In healthy joints, synovial membranes produce synovial fluid that provides nutrition to the cartilage as well as lubrication and cushioning to the connecting bones. When the synovial membrane becomes inflamed, as in the case of juvenile arthritis, it produces more fluid and joints may become swollen, painful and stiff. Over time, inflammation may cause progressive and irreversible joint damage, resulting in physical disability and chronic pain that affects daily life (Ostlie et al. 2009).



1

Juvenile arthritis is a systemic disease, meaning that the whole body, not just the joints, is affected. This can lead to problems with the heart, respiratory system, nerves and eyes (Cassidy et al. 2011). Children with juvenile arthritis may experience sleep disturbance and fatigue (Aviel et al. 2011; Ward et al. 2011). They may also have other symptoms such as fever, loss of appetite and weight loss (RACGP 2009a).

Juvenile arthritis is extremely diverse in its features and occurs with varying severity (Boros & Whitehead 2010). Many children are affected in just one or only a few joints, but there are some who have arthritis in multiple joints (Cassidy et al. 2011).

For many children, juvenile arthritis is a short-term event, while for others the condition persists for a long period of time. Signs and symptoms of juvenile arthritis can vary from day to day in the same child. Typically, juvenile arthritis has an unpredictable pattern of activity, with periods without symptoms followed by a reappearance of signs and symptoms (known as 'flare-ups') (NIAMS 2011a).

Diagnosis of juvenile arthritis

It is often difficult to diagnose juvenile arthritis because the symptoms can vary a lot between children. In addition, other childhood conditions may resemble the joint pain associated with arthritis (Ravelli & Martini 2007).

Doctors may suspect juvenile arthritis, along with several other possible conditions, when they see children with:

- · persistent joint pain or swelling
- unexplained skin rashes
- · fever associated with swelling of lymph nodes
- inflammation of internal organs
- excessive clumsiness (NIAMS 2011b).

There is no single diagnostic test for juvenile arthritis. This condition is diagnosed after ruling out other possibilities.

There are several subtypes of juvenile arthritis. Medical observation and clinical tests help determine which subtype the child has. More detailed information about the subtypes of juvenile arthritis can be found in *Juvenile arthritis in Australia* (AIHW 2008).

Who gets juvenile arthritis?

Identifying who gets juvenile arthritis is an important task as this condition can cause pain and disability, affecting the lives of both the children with the condition and their carers. This task, however, is challenging as neither the exact causes of nor the risk factors for juvenile arthritis have yet been identified.

Complex interactions between genetic predisposition (inherited risk of developing a condition) and environmental exposures such as viruses, bacterial infections, psychological stress and physical trauma have long been suspected. Recent advancements in genetic sciences have helped researchers identify several genetic factors that influence the susceptibility to, course of and outcome of juvenile arthritis (Haas 2010). In contrast, researchers note that the investigation into environmental triggers that may precipitate the disease has not shown the same progress (Ellis et al. 2009).

Number of children with juvenile arthritis

It is also difficult to estimate exactly how many children have this uncommon condition. A large review of studies from various countries reported that the prevalence estimates of juvenile arthritis ranges from 0.007% to 0.401% (Manners & Bower 2002)—a more than 50-fold difference between the lowest and highest estimates.

Estimating the prevalence in Australia also requires some care. Based on the self-reported data from the 2007–08 National Health Survey (NHS), about 0.3% of Australian children had juvenile arthritis at the time of the survey. This prevalence estimate, however, needs to be treated with caution as it is based on a small sample size of children in the NHS (less than 5,000 children). A statistical analysis showed that we can be 90% confident that the prevalence of this condition in 2007–08 was between 0.03% and 0.52%.

The NHS does not produce reliable estimates of the prevalence of this uncommon condition separately for boys and girls. Research literature consistently suggests, however, that more girls suffer from juvenile arthritis than boys (Ravelli & Martini 2007).

How is juvenile arthritis managed?

Severity and progression of juvenile arthritis vary across affected children (Boros & Whitehead 2010). While some recover from the disease after a relatively short period (Foster et al. 2003), others may require ongoing medical intervention to manage the disease effectively. This section of the bulletin outlines how this condition is managed by medicines, in primary health care and in hospitals.

What medicines are used to manage juvenile arthritis?

General practitioners (GPs), medical specialists and allied health professionals recommend/prescribe medicines for the management of juvenile arthritis.

GPs may recommend medicines such as paracetamol, codeine, and non-steroidal anti-inflammatory drugs (NSAIDs), depending on an assessment of the benefit to the patients. Medicines used to manage juvenile arthritis are briefly described in Box 1, and more detailed information about these are provided in *Medication use for arthritis and osteoporosis* (AIHW 2010).

Paracetamol, codeine and NSAIDs are sometimes called the 'first-line' medicines in management of juvenile arthritis as these are the initial medicines to be provided for symptom relief.

Stronger medicines such as corticosteroids and DMARDs may be prescribed when insufficient symptom control is obtained by paracetamol, codeine or NSAIDs alone. Corticosteroids and DMARDs require close medical monitoring to ensure effectiveness and to detect signs of side effects. They are typically prescribed and monitored by paediatric rheumatologists.

Box 1: Medicines used to manage juvenile arthritis

Paracetamol is a simple analgesic (painkiller) commonly used to manage pain in children, including pain associated with juvenile arthritis.

Codeine (also a painkiller) is a weak opioid used to treat persistent pain in children and adolescents (RACGP 2009a). Codeine may be used in addition to paracetamol when adequate pain relief is not achieved by the latter alone.

Non-steroidal anti-inflammatory drugs (NSAIDs) are used not only for pain but also to reduce inflammation in arthritis. NSAIDs may provide effective pain relief in some children (Haines 2007); however, as with other medicines, children who are provided with NSAIDS may experience some side effects. Therefore, NSAIDs are typically used as short-term therapy (Rheumatology Expert Group 2010).

Corticosteroids are manufactured versions of natural hormones. They reduce both inflammation and the activity of the immune system. Corticosteroids may be administered orally or by injection into the affected joint.

Corticosteroid injection is considered an established treatment in the management of local joint inflammation in children with juvenile arthritis that may contribute to a decrease in long-term joint complications with fewer side effects than oral corticosteroids (RACGP 2009b).

Long-term use of corticosteroids may cause side effects such as loss of bone density, poor growth, high blood pressure, acne, infection, weight gain, mood changes and depression (ACR 2011: Henry & Joyner 2006).

Disease-modifying anti-rheumatic drugs (DMARDs) are a group of anti-inflammatory and immune-suppressing agents. These medicines may delay the erosion of bone and facilitate healing and thereby alter the course of the condition.

DMARDs include antimalarial drugs, anti-inflammatory metals, immunosuppressants, sulpha drugs and biologic agents (Lavelle et al. 2007). Two major types are recognised: biologic DMARDs (bDMARDs or biologics) and conventional or non-biologic DMARDs. bDMARDs are produced by recombinant DNA technology. They generally target cytokines or their receptors, or are directed against other cell surface molecules. The term 'conventional DMARD' is reserved for small molecular drugs synthesised chemically that have broad effects upon the immune system.

National statistics on supply of medicines for juvenile arthritis

Most of the medicines used to manage juvenile arthritis are used to manage a large number of other conditions, and it is not possible using available data to work out how much of these are used to manage juvenile arthritis.

An exception to this pattern are the new types of DMARDs called biologic DMARDs. Biologic DMARDs are designed to have more specific inhibitory effects on the immune system than older non-biologic DMARDs (Breda et al. 2011). They have much improved short-term and, according to early evidence, long-term outcomes for juvenile arthritis (Staples et al. 2010; Hashkes et al. 2010). More detailed information about DMARDs can be found in *The use of disease-modifying anti-rheumatic drugs for the management of rheumatoid arthritis* (AIHW 2011).

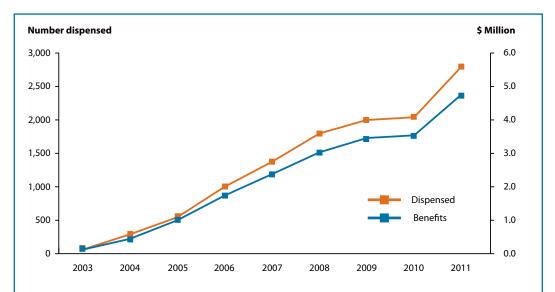
While biologic DMARDs are also used for other autoimmune conditions such as rheumatoid arthritis, psoriatic arthritis and Crohn's disease, it is possible to delineate the supply amount of this group of medicines specifically for juvenile arthritis by using Pharmaceutical Benefits Scheme (PBS) data.

The volume of, and associated PBS subsidies for, biologic DMARDs used to manage juvenile arthritis steadily increased from their introduction in 2003—in 2011, more than 2,800 units were dispensed and \$4.7 million in benefits were paid (Figure 2).

Due to a lack of statistics on the total expenditure for medicines used to manage juvenile arthritis, it is unknown what proportion of total expenditure the bDMARDs account for.

Etanercept and adalimumab are biologic DMARDs currently available in Australia on the PBS for management of active juvenile arthritis. Etanercept has been prescribed for this condition since November 2003 and adalimumab since November 2010.

Other biologic DMARDs may be used for management of juvenile arthritis but these are funded by means other than the PBS and not included in Figure 2.



Note: In the years 2003—11, biologic DMARDs indicated for management of juvenile arthritis in children included adalimumab and etanercept. The PBS item codes for adalimumab were 9661L, 9662M, 9663N, 9678J, 9679K, and 9680L; for etanercept were 5733R, 5734T, 5735W, 6367D, 9615C and 9641K.

Source: Department of Health and Ageing 2012.

Figure 2: Volume of, and associated subsidy for, biologic DMARDs for juvenile arthritis, 2003–11

How is juvenile arthritis managed in primary health care?

Musculoskeletal conditions are among the most common problems managed by GPs (Britt et al. 2011). No inflammation is involved in many cases where children present with musculoskeletal symptoms (Rheumatology Expert Group 2010). GPs distinguish between those with non-inflammatory conditions and those with significant inflammatory musculoskeletal disorders that require specific intervention.

The NHS, conducted every three years by the Australian Bureau of Statistics (ABS), is designed to obtain national information on the health status of Australians as well as their use of health services. The NHS conducted in 2007–08, however, did not collect information about health service use of respondents younger than 15 years of age.

Although national statistics on the use of primary health care services among children with juvenile arthritis are currently unavailable, general practitioners and various other health professionals are typically involved in their care (Rheumatology Expert Group 2010; Royal Children's Hospital Melbourne 2011).

General practitioners

GPs are usually the first port of call for children with symptoms of juvenile arthritis. GPs have an ongoing role in providing appropriate referral to medical specialists and allied health and other health professionals, as well as in optimising communication between them (RACGP 2009a). Juvenile arthritis requires well-coordinated, patient-centred care that is continuous, comprehensive and consistent (RACGP 2009a).

A multidisciplinary approach in primary health care

Recent evidence shows that input from a multidisciplinary team benefits long-term management of juvenile arthritis. Early diagnosis and proactive treatment of the condition is likely to reduce the risk of many of the complications of the condition (RACGP 2009b).

The range of allied health professionals involved in caring for children with juvenile arthritis in primary health care is listed in Box 2.

Box 2: Allied health professionals involved in caring for children with juvenile arthritis

Physiotherapists, who specialise in the mechanics of joints and muscles, may develop exercises customised to individual needs to keep joints moving well.

Occupational therapists may provide splints (a medical device to immobilise limbs or the spine) for supporting joints and other aids to help the child with everyday activities such as getting dressed or writing.

Podiatrists may be able to help children whose feet and ankles have been affected by juvenile arthritis. Podiatrists may also introduce orthotics—custom-made inserts that fit inside the shoe to reduce foot pain and better align the foot—to help the child with juvenile arthritis walk without pain or with reduced pain.

Registered paediatric nurses who specialise in caring for children and families with juvenile arthritis can provide education and support as well as help coordinate the child's treatment.

Social workers can help find community resources to help families cope with juvenile arthritis, such as patient support groups, financial assistance or respite care.

Mental health workers and **psychologists** may help to ensure adjustment to life at school and outside school, and to restore quality of life lost due to pain and disability associated with the condition.

Pharmacists may dispense medications for symptoms of juvenile arthritis at a community chemist. They are able to provide information about how to take medications, possible side effects, and how these might be managed.

Source: Royal Children's Hospital Melbourne 2011.

Australian children who have juvenile arthritis that has lasted, or is likely to last, longer than six months are eligible for a GP management plan (GPMP)—an individual patient care plan prepared by GPs.

The GPMP may be complemented by Team Care Arrangements (TCA), which provide multidisciplinary care (involving the GP and at least two other health care providers). The GPMP and TCA are used to coordinate the care of patients with chronic or terminal conditions to optimise the care they receive.

Whether a patient is eligible for chronic disease management is a clinical judgement for the GP, taking into account the patient's medical condition and care needs, as well as the general guidance set out in the Medicare Benefits Schedule (DoHA 2011).

Statistics on the number of GPMPs and TCAs for juvenile arthritis are not available as Medicare data do not include information about the diagnosis of rebate recipients.

What role do hospitals play in managing juvenile arthritis?

Many children with juvenile arthritis recover from the disease after a relatively short period and may not need to use health services long term; however, some children receive hospital care. Treatments for juvenile arthritis provided in hospitals are described in Box 3.

Box 3: Treatment for juvenile arthritis in hospital

Splints: Splints are medical devices to restrict movement in the arm, leg or spine. Splints may be worn to protect damaged joints and to minimise further damage.

Pain management: Aside from taking medications, other strategies can be used to manage pain during procedures and everyday life. These may include relaxation, deep breathing, distraction from pain, and helpful ways to think about pain.

Joint injections: For children with juvenile arthritis who have inflamed joints, a needle may be inserted into a joint to deliver a dose of anti-inflammatory medicine, such as corticosteroids and/ or anaesthesia. Most children notice that the joint is a lot less painful and swollen within a few days after the injection. Injection can make joints feel better for weeks, months or even longer.

Blood tests and medical imaging tests: Blood tests may be used to look for signs of inflammation in the body, side effects of medicines, and chemical substances that help classify the type of arthritis. Medical imaging tests such as X-ray, ultrasound, bone scans and magnetic resonance imaging (MRI) scans are used to check if there is inflammation in different parts of the body.

Exercise/physiotherapy: Being active to keep the joints moving well and muscles strong is an essential part of juvenile arthritis management (Royal Children's Hospital Melbourne 2011).

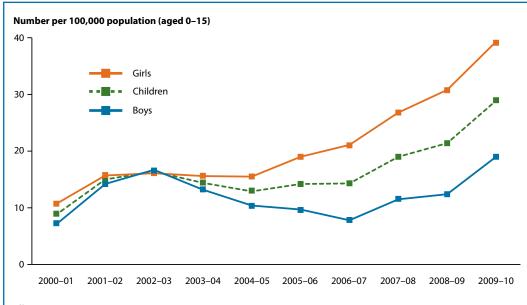
Hospital service use

The AIHW National Hospital Morbidity Database (NHMD) contains information about admitted-patient services provided in Australia. In the NHMD, data are collected at the level of 'hospital separation', the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another facility, or changing their type of care. In this bulletin, the term 'hospitalisation' is used to describe a separation.

According to the NHMD, juvenile arthritis was the principal diagnosis for a total of 1,287 hospitalisations in 2009–10. The hospitalisation rate for girls (39 per 100,000 population) was more than double that of boys (19 per 100,000 population) (Figure 3).

In the 10 years from 2000–01 to 2009–10, hospitalisations for children with juvenile arthritis as the principal diagnosis tripled. The hospitalisation rate rose from 8.8 per 100,000 population in 2000–01 to 28.9 per 100,000 population in 2009–10. Girls accounted for most of this increase. Much of the increase in the hospitalisation rate is for same-day admissions.

A number of reasons may account for the increase in the hospitalisation rate. They include an increase in the number of children with the condition, changes in hospital admission practices for this condition, changes in the procedures available to treat the condition in hospital, and broader changes in the way this condition is managed in the health care system—to name just a few. Currently it is not known which of these factors are contributing to the increasing hospitalisation rate for juvenile arthritis among girls. However, a closer examination of hospital procedure patterns may provide some insight into the types of treatment being delivered over this period.



Note

- 1. Rates were age-standardised to the Australian population as at 30 June 2001.
- 2. Juvenile arthritis was classified according to ICD-10-AM, 6th edition (NCCH 2008) for 2008-09 and 2009-10, and the earlier editions were used for the years 2000-01 to 2007-08. In all editions of ICD-10-AM used, the ICD-10-AM codes for juvenile arthritis were M08 and M09.
- Hospitalisations for which the care type was reported as Newborn (without qualified days), and records for Hospital boarders and Posthumous organ procurement have been excluded.
- 4. Changes in the number of hospitalisations for juvenile arthritis may be due to changes in the severity and prevalence of the disease in the community and/or procedures available to treat the condition. Changes in admission practices and administrative policies also affect hospital usage data

Source: AIHW National Hospital Morbidity Database.

Figure 3: Rate of hospitalisation for juvenile arthritis, 2000–01 to 2009–10

According to the NHMD, the number of hospital procedures provided for children with juvenile arthritis increased along with the rise in the number of hospitalisations for this condition, with the total number of procedures tripling from 1,016 to 3,128 in the 10 years to 2009–10.

During the 10-year period, four categories of hospital procedures were most commonly provided:

- · administration of corticosteroids and local anaesthetic into joints
- · draining of fluid from a joint or joints
- · intravenous administration of pharmacological agents
- + physiotherapy.

The increase in the number of hospital procedures provided for juvenile arthritis was predominantly related to administration of corticosteroids and local anaesthetic into joints and intravenous administration of pharmacological agents.

How does juvenile arthritis affect quality of life?

Living with juvenile arthritis can be challenging at any age (Shaw et al. 2006), although its impact during adolescence may be particularly difficult (Shaw et al. 2004; Suris et al. 2004). Growth and puberty can be affected, and developmental milestones such as consolidation of identity, independence from parents, establishing relationships outside the family, and finding a vocation, may also be disrupted (Secor-Turner et al. 2011; Shaw et al. 2004).

Pain, stiffness and fatigue associated with juvenile arthritis can lead to impaired psychological wellbeing, increased functional limitation, and reduced participation in school and social activities (Schanberg et al. 2003; Secor-Turner et al. 2011).

Pain

While pain is a key expression of arthritis, the experience of it varies greatly from child to child, and even from day to day in the same child. Research studies show that the quality of life of children with juvenile arthritis decreases with increasing pain and disability (Gutierrez-Suarez et al. 2007; Sawyer et al. 2004).

Currently, only limited statistics are available on the experience of pain in Australian children with juvenile arthritis (for example, the Australian Rheumatology Association Database), and it is difficult to ascertain how common the experience of pain is among them.

Effects on self-perceived health

Self-perceived health status of children may be adversely affected by juvenile arthritis, especially if they suffer from severe pain, deformity and disability for a long period of time. The NHS collects information about health status of Australians as well as self-perceived health. The NHS conducted in 2007–08, however, did not collect information about self-perceived health of respondents younger than 15 years of age.

Findings from studies of health-related quality of life show that children with juvenile arthritis rate their physical, emotional and social functions lower than their healthy peers (Duffy et al. 2011). It has also been shown that health-related quality of life of children with juvenile arthritis decreases with increasing pain and disability (Gutierrez-Suarez et al. 2007; Sawyer et al. 2004).

Schooling restrictions

The physical and emotional effects of juvenile arthritis may affect the child's schooling (Schanberg et al. 2003). Some children may find it difficult to participate in regular school activities and sports, and children with juvenile arthritis may play with friends less frequently than children without juvenile arthritis (Hackett 2003).

Side effects from medicines or recovering from medical procedures may also cause irregular absences from school (Reitter-Purtill et al. 2003).

The 2009 Survey of Disability, Ageing and Carers (SDAC) conducted by the ABS asked questions about physical as well as social aspects of schooling restrictions among children with arthritis-related disabilities. Due to a small sample size of children with arthritis-related disability in the survey, however, reliable national statistics on difficulties Australian children with juvenile arthritis face at school are currently unavailable.

Patient information from the United Kingdom listed the following as challenges children with juvenile arthritis may experience at school:

- · sitting with legs crossed or getting up from the floor
- · fatiguing during playtime, or stiffening up in cold weather
- · sitting in the same position for long periods
- walking quickly, or being jostled
- · getting dressed and undressed
- carrying heavy things
- feeling comfortable using school furniture
- · managing a full school day
- · writing quickly or for long periods
- · moving from primary to secondary school, or from secondary school to college or university
- getting appropriate career counselling (Arthritis Care 2011).

Effects on family

Every child with juvenile arthritis is affected differently by the condition, and so are their families.

In some cases, caring for a child with juvenile arthritis may place considerable demands on parents. They may experience higher levels of physical health complaints and psychosocial problems such as stress, anxiety and depression compared to their counterparts with children without the condition (Turner et al. 2001). An Australian study of carers showed that caring for children with disability imposes greater burden than caring for adults, and that wellbeing of carers decreases with increasing number of hours of care (Cummins et al. 2007).

In other cases, the level of distress in the family where a child has juvenile arthritis is comparable to those families of healthy children (Gerhardt et al. 2003).

The SDAC collects national information on people with disability as well as their carers. While some children with juvenile arthritis and their carers are represented in the SDAC sample, the number is not large enough to provide reliable information about them.

The lack of reliable information about the experience of family members caring for children with juvenile arthritis appears to be a worldwide issue. Often, in studies of the effects of juvenile arthritis on family members, people are asked to recall their experience in the past rather than to monitor their current experience of caring for a child. Also, the number of people included in studies has not been large enough to provide generalisable information.

While some families may be more resilient than others, anecdotal evidence suggests that parents of a child with juvenile arthritis may feel:

- stressed by the uncertainty of juvenile arthritis and its effects
- guilty, and wonder if they could have done anything differently to improve their child's symptoms
- · isolated and alone
- · angry, and question why their child has juvenile arthritis
- · helpless and emotionally drained
- some level of strained family relationship (Arthritis Care 2011).

Siblings of a child with juvenile arthritis may feel:

- · worried that they may also develop juvenile arthritis
- frightened that their sibling may die (although death from juvenile arthritis is rare)
- · jealous of extra attention that the child with juvenile arthritis receives
- · confused by changes in family routine
- · protective of their sibling with juvenile arthritis
- able to carry on as before, except for the occasional bad day (Arthritis Care 2011).

Appendix 1: Detailed statistical tables

Table A1.1: Estimated prevalence of children with juvenile arthritis in Australia, 2007–08 (per cent)

	Prevalence estimate	90% CI ^(a)			
2007-08 NHS	0.278	0.032-0.515			

(a) Shows the lower and upper limits of confidence interval (CI). We can be 90% confident that the true value is within the interval.

Note: Children aged 0–15 who had juvenile arthritis (medically diagnosed or not) were included in the analysis.

Source: AIHW analysis of ABS National Health Survey, 2007–08.

Table A1.2: Volume of, and associated subsidy for, biologic DMARDs for juvenile arthritis, 2003–2011

	2003	2004	2005	2006	2007	2008	2009	2010	2011
Dispensed	82	219	599	1,087	1,408	1,805	2,040	2,114	2,814
Benefits (\$'000)	138	365	995	1,829	2,337	3,005	3,444	3,551	4,722

Note: In the years 2003—11, biologic DMARDs indicated for management of juvenile arthritis in children included adalimumab and etanercept. The PBS codes for adalimumab were 9661L, 9662M, 9663N, 9678J, 9679K, and 9680L; for etanercept were 5733R, 5734T, 5735W, 6367D, 9615C and 9641K.

Source: Department of Health and Ageing (2012).

Table A1.3: Rate of hospital separations for juvenile arthritis (aged 0–15), 2000–01 to 2009–10

	2000-01	2001-02	2002-03	2003-04	2004-05	2005-06	2006-07	2007-08	2008-09	2009–10
	Age-standardised rate per 100,000 population ^(a)									
Admission type										
Same day	6.6	12.2	13.8	11.3	11.0	11.2	10.8	15.8	19.4	26.2
Overnight	2.2	2.8	2.6	3.0	1.9	3.0	3.5	3.2	2.0	2.7
Sex										
Boys	7.1	14.2	16.7	13.2	10.4	9.7	7.8	11.5	12.4	19.0
Girls	10.7	15.7	16.1	15.6	15.5	19.0	21.1	26.8	30.8	39.3
Children	8.8	15.0	16.4	14.4	12.9	14.2	14.3	19.0	21.4	28.9

(a) Rates were age-standardised to the Australian population as at 30 June 2001.

Note

- 1. Juvenile arthritis was classified according to ICD-10-AM, 6th edition (NCCH 2008) for 2008-09 and 2009-10, and the earlier editions were used for the years 2000-01 to 2007-08. In all editions of ICD-10-AM used, the ICD-10-AM codes for juvenile arthritis were M08 and M09.
- 2. Hospitalisations for which the care type was reported as *Newborn* (without qualified days), and records for *Hospital boarders* and *Posthumous organ procurement* have been excluded.
- 3. Changes in the number of hospitalisations for juvenile arthritis may be due to changes in the severity and prevalence of the disease in the community and/or procedures available to treat the condition. Changes in admission practices and administrative policies also affect hospital usage data.

Source: AIHW National Hospital Morbidity Database.

Table A1.4: Number of hospitalisations and procedures for juvenile arthritis (aged 0–15), 2000–01 to 2009–10

	2000-01	2001–02	2002-03	2003-04	2004–05	2005-06	2006-07	2007-08	2008-09	2009–10
Hospitalisations	375	638	698	614	555	614	621	829	941	1,287
All procedures	1,016	1,275	1,704	1,908	1,593	1,725	2,042	2,405	2,410	3,128

Notes

- 1. Juvenile arthritis was classified according to ICD—10—AM, 6th edition (NCCH 2008) for 2008—09 and 2009—10, and the earlier editions were used for the years 2000—01 to 2007—08. In all editions of ICD-10-AM used, the ICD—10—AM codes for juvenile arthritis were M08 and M09.
- 2. Hospitalisations for which the care type was reported as Newborn (without qualified days), and records for Hospital boarders and Posthumous organ procurement have been excluded.
- The Australian Classification of Health Interventions (ACHI) codes 6th edition (NCCH 2007) were used to identify hospital procedures for patients
 admitted to hospital for principal diagnosis of juvenile arthritis for 2008–09 and 2009–10. The earlier editions were used for the years 2000–01 to
 2007–08.
- 4. Changes in the number of hospitalisations for juvenile arthritis may be due to changes in the severity and prevalence of the disease in the community and/or procedures available to treat the condition. Changes in admission criteria and administrative policies also affect hospital usage data.

Source: AIHW National Hospital Morbidity Database.

Glossary

Prevalence

Prevalence refers to the number or proportion (for example, of cases, instances) present in a population at a given time. Prevalence data provide an indication of the extent of presence of a condition and may have implications for the provision of services in a community.

Confidence interval

A statistical term describing a range (interval) of values within which we can be confident that the true value lies.

Age-standardised rate

Age-standardised rates enable comparisons to be made between populations that have different age structures. The method used to obtain age-standardised hospital separation rates in this bulletin is composed of three steps:

- Step 1: Calculate age-specific rates for the age groups 0-4, 5-9 and 10-15 by dividing the number of hospital separations occurring in each specific age group by the corresponding population in the same age group.
- Step 2: Calculate the expected number of cases in age-groups by multiplying the age-specific rates by corresponding standard population (Australian population as at 30 June 2001 was used as the standard population).
- Step 3: Sum the expected number of cases in each age group and divide by the total of the standard population for children aged 0–15, and express the rate per 100,000 population.

Acknowledgments

Tomoko Sugiura, Naila Rahman and Louise York from the National Centre for Monitoring Arthritis and Musculoskeletal Conditions at the Australian Institute of Health and Welfare prepared this report. The Centre would like to acknowledge the input of Adrian Webster, Mark Cooper-Stanbury, Xingyan Wen, Ilona Brockway, Geoff Neideck and Lisa McGlynn in its preparation. Thanks are also due to members of the National Arthritis and Musculoskeletal Monitoring Advisory Group for their advice on the contents of the report.

The Australian Government Department of Health and Ageing funded this project.

Abbreviations

ABS Australian Bureau of Statistics

AIHW Australian Institute of Health and Welfare
DMARD Disease-modifying anti-rheumatic drugs

bDMARD Biologic disease-modifying anti-rheumatic drugs

ICD-10-AM International Statistical Classification of Diseases and Related Health

Problems, 10th Revision, Australian Modification

GP General Practitioner

GPMP General Practitioner Management Plan NHMD National Hospital Morbidity Database

NHS National Health Survey

NSAIDs Non-steroidal anti-inflammatory drugs

PBS Pharmaceutical Benefits Scheme

RACGP Royal Australian College of General Practitioners

SDAC Survey of Disability, Ageing and Carers

TCA Team Care Arrangements

References

ACR (American College of Rheumatology) 2011. Arthritis in Children. Viewed 15 May 2012, http://www.rheumatology.org/practice/clinical/patients/diseases_and_conditions/juvenilearthritis.asp.

AIHW (Australian Institute of Health and Welfare) 2008. Juvenile arthritis in Australia. Arthritis series no. 7. Cat. no. PHE 101. Canberra: AIHW.

AIHW 2010. Medication use for arthritis and osteoporosis. Arthritis series no. 11. Cat. no. PHE 121. Canberra: AIHW.

AIHW 2011. The use of disease-modifying anti-rheumatic drugs for the management of rheumatoid arthritis. Arthritis series no. 16. Cat. no. PHE 138. Canberra: AIHW.

Arthritis Care 2011. My child has arthritis. A practical guide for parents. Arthritis Care. London UK.

Aviel BY, Stremler R, Benseler SM, Cameron B, Laxer RM, Ota S et al. 2011. Sleep and fatigue and the relationship to pain, disease activity and quality of life in juvenile idiopathic arthritis and juvenile dermatomyositis. Rheumatology 50(11):2051–60.

Boros C & Whitehead B 2010. Juvenile idiopathic arthritis. Australian Family Physician 39(9):630–6.

Breda J, Del Torto M, De Samctos S & Chiarelli F 2011. Biologics in children's autoimmune disorders: efficacy and safety. European Journal of Pediatrics 170(2):157–67.

Britt H, Miller G, Charles J, Henderson J, Bayram C, Valenti L et al. 2011. General practice activity in Australia 2010–11. General Practice Series no. 29. Sydney: Sydney University Press.

Cassidy JT, Petty RE, Laxer RM & Lindsley CB 2011. Textbook of Pediatric Rheumatology 6th Edition. Philladelphia: Elsevier Saunders.

Cummins, RA, Hughes J, Tomyn A, Gibson, A, Woerner, J and Lai, L 2007, The Wellbeing of Australians: Carer health and wellbeing, Australian Unity Wellbeing Index Survey Report 17.1, Australian Centre on Quality of Life and School of Psychology, Deakin University, Australian Unity and Carers Australia, October.

DoHA (Department of Health and Ageing) 2011. Fact Sheet on Chronic Disease Management (CDM) Medicare items. Viewed 18 April 2012, < http://www.health.gov.au/internet/main/publishing.nsf/content/D38484960A44DEF8CA2576720000E4EE/\$File/Fact%20sheet-%20CDM%20items,%20final%20July%202012.pdf >.

DoHA 2012. Pharmaceutical benefits schedule reports. Viewed 2 February 2012, https://www.medicareaustralia.gov.au/statistics/pbs_item.shtml.

Duffy CM, Wells GA, Russell AS & Haraoui B 2011. Quality of life issues in pediatric immune-mediated inflammatory disease. The Journal of Rheumatology Supplement 38 Suppl 88: 20–25.

Ellis JA, Munro JE & Ponsonby AL 2009. Possible environmental determinants of juvenile idiopathic arthritis. Rheumatology 49(3):411–25.

Foster HE, Marshall N, Myers A, Dunkley P & Griffiths ID 2003. Outcome in adults with juvenile idiopathic arthritis. A quality of life study. Arthritis and Rheumatism 48(3):767–75.

Gerhardt CA, Vannatta K, McKellop M, Zeller M, Taylor J, Passo M et al. 2003. Comparing parental distress, family functioning, and the role of social support for caregivers with and without child with juvenile arthritis. Journal of Pediatric Psychology 28:5–15.

Gutierrez-Suarez R, Pistorio A, Cespedes Cruz A, Norambuena X, Flato B, Rumba I et al. 2007. Health-related quality of life of patients with juvenile idiopathic arthritis coming from 3 different geographic areas. The PRINTO multinational quality of life cohort study. Rheumatology 46:314–20.

Haas JP 2010. Genetic background of juvenile idipathic arthritis. Zeitschrift für Rheumatologie. 69(6):488–95.

Hackett J 2003. Perceptions of play and leisure in junior school aged children with juvenile idiopathic arthritis: what are the implications for occupational therapy. The British Journal of Occupational Therapy 66 (7):303–310.

Haines KA 2007. Juvenile idiopathic arthritis. Therapies in the 21st Century. Bulletin of the New York University Hospital for Joint Diseases 65:205–11.

Hashkes PJ, Uziel Y & Laxer RM 2010. The safety profile of biologic therapies for juvenile idiopathic arthritis. Nature Reviews Rheumatology 6(10):561–71.

Henry JA & Joyner B 2006. The Royal Australian College of General Practitioners concise guide to medicines and drugs. London: Dorling Kindersley Limited.

Lavelle L, Lavelle W & Demers E 2007. Disease-modifying anti-rheumatic drugs. In: McCleane G & Smith HS (eds). Clinical management of bone and joint pain. New York: The Haworth Medical Press, 221–242.

Manners PJ & Bower C 2002. Worldwide prevalence of juvenile arthritis—Why does it vary so much? The Journal of Rheumatology 29(7):1520–30.

NCCH (National Centre for Classification in Health) 2007. The Australian Classification of Health Interventions (ACHI)—Sixth edition—Tabular list of interventions and alphabetic index of interventions. Sydney: NCCH, Faculty of Health Sciences, The University of Sydney.

NCCH 2008. The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM)—Sixth edition—Tabular list of diseases and alphabetic index of diseases. Sydney: NCCH, Faculty of Health Sciences, The University of Sydney.

NIAMS (National Institute of Arthritis and Musculoskeletal and Skin Diseases) 2011a. Questions and answers about juvenile arthritis. Viewed 28 February 2012, http://www.niams.nih.gov/health_info/juv_arthritis/juvenile_arthritis_ff.asp#4.

NIAMS 2011b. Questions and answers about juvenile arthritis. Viewed 28 February 2012, http://www.niams.nih.gov/Health_Info/Juv_Arthritis/#2.

Ostlie IL, Aasland A, Johansson I, Flato B & Moller A 2009. A longitudinal follow-up study of physical and psychological health in young adults with chronic childhood arthritis. Clinical and Experimental Rheumatology 27:1039–46.

Petty RE, Southwood TR, Manners P, Baum J, Glass DN, Goldenberg J et al. 2004. International League of Associations for Rheumatology Classification of juvenile idiopathic arthritis. 2nd revision. Journal of Rheumatology 31(2):390–2.

RACGP (Royal Australian College of General Practitioners) 2009a. Clinical guideline for diagnosis and management of juvenile idiopathic arthritis. Viewed 6 February 2012, < http://www.racgp.org.au/download/documents/Guidelines/Musculoskeletal/racgp_jia_guideline.pdf >.

RACGP 2009b. Juvenile idiopathic arthritis: a literature review of recent evidence August 2009. Viewed 6 February 2012, http://www.racgp.org.au/download/Documents/Guidelines/Musculoskeletal/jia_literaturereview.pdf >.

Ravelli A & Martini A 2007. Juvenile idiopathic arthritis. The Lancet 369:767–776.

Reitter-Purtill, Gerhardt CA, Vannatta K, Passo MH & Noll RB 2003. A controlled longitudinal study of the social functioning of children with juvenile rheumatoid arthritis. Journal of Pediatric Psychology 28(1):17–28.

Rheumatology Expert Group 2010. Therapeutic guidelines: rheumatology, version 2. Melbourne: Therapeutic Guidelines Ltd.

Ringold S, Burke A & Glass RM 2005. Juvenile idiopathic arthritis. Journal of American Medical Association 294(13):1722.

Royal Children's Hospital Melbourne 2011. Rheumatology: For parents. Viewed 6 December 2012, http://www.rch.org.au/rheumatology/ information_about_rheumatological_conditions/For_Parents/>.

Sawyer MG Whitham JN, Roberton DM, Taplin JE, Varni JW & Baghurst PA 2004. The relationship between health-related quality of life, pain and coping strategies in juvenile idiopathic arthritis. Rheumatology 43(3):325–30.

Schanberg LE, Anthony KK, Gil KM & Maurine EC 2003. Daily pain and symptoms in children with polyarticular arthritis. Arthritis and Rheumatism 48(5):1390–1397.

Secor-Turner M, Scal P, Garwick A, Horvath K & Wells CK 2011. Living with juvenile arthritis: adolescents' challenges and experiences. Journal of Pediatric Health Care: 25(5):302–7.

Shaw KL, Southwood TR, McDonagh JE & The British Paediatric Rheumatology Group 2004. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. Rheumatology (Oxford) 43:770–8.

Shaw KL, Southwood TR, McDonagh JE & The British Paediatric Rheumatology Group 2006. Health-related quality of life in adolescents with juvenile idiopathic arthritis. Arthritis & Rheumatism 55(2):199–207.

Staples MP, March L, Lassere M, Reid C & Buchbiner R 2010. Health-related quality of life and continuation rate on first-line anti-tumour necrosis factor therapy among rheumatoid arthritis patients from the Australian Rheumatology Association Database. Rheumatology 50:166–175 doi:10.1093/rheumatology/keq322.

Suris JC, Michaud PA & Viner R 2004. The adolescent with a chronic condition. Part I: developmental issues. Archives of Disease in Childhood 89:938–42.

Turner A, Barlow JH & Wright CC 2001. Residential workshop for parents of adolescents with juvenile idiopathic arthritis: a preliminary evaluation. Psychology, Health and Medicine 6:447–461.

Ward TM, Ringold S, Metz J, Archbold K, Lentz M, Wallas M et al. 2011. Sleep disturbances and neurobehavioral functioning in children with and without juvenile idiopathic arthritis. Arthritis Care & Research 63(7):1006–12.

Related publications

The following AIHW publications relating to juvenile arthritis, disease-modifying anti-rheumatic drugs, and musculoskeletal conditions might also be of interest:

- AIHW (Australian Institute of Health and Welfare) 2008. Juvenile arthritis in Australia. Arthritis series no. 7. Cat. no. PHE 101. Canberra: AIHW.
- AIHW 2008. Arthritis and osteoporosis in Australia 2008. Arthritis series no. 8. Cat. no. PHE 106. Canberra: AIHW.
- AIHW 2010. Medication use for arthritis and osteoporosis. Arthritis series no. 11.
 Cat. no. PHE 121. Canberra: AIHW.
- AIHW 2011. The use of disease-modifying anti-rheumatic drugs for the management of rheumatoid arthritis. Arthritis series no. 16. Cat. no. PHE 138. Canberra: AIHW.

The Australian Institute of Health and Welfare is a major national agency which provides reliable, regular and relevant information and statistics on Australia's health and welfare. The Institute's mission is authoritative information and statistics to promote better health and wellbeing.

© Australian Institute of Health and Welfare 2013 (cc)

This product, excluding the AIHW logo, Commonwealth Coat of Arms and any material owned by a third party or protected by a trademark, has been released under a Creative Commons BY 3.0 (CC BY 3.0) licence. Excluded material owned by third parties may include, for example, design and layout, images obtained under licence from third parties and signatures. We have made all reasonable efforts to identify and label material owned by third parties.

You may distribute, remix and build upon this work. However, you must attribute the AIHW as the copyright holder of the work in compliance with our attribution policy available at <www.aihw.gov.au/copyright/>. The full terms and conditions of this licence are available at http://creativecommons.org/licenses/by/3.0/au/.

Enquiries relating to copyright should be addressed to the Head of the Communications, Media and Marketing Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

This publication is part of the Australian Institute of Health and Welfare's bulletin series. A complete list of the Institute's publications is available from the Institute's website <www.aihw.gov.au>.

ISBN 978-1-74249-393-0

Suggested citation

Australian Institute of Health and Welfare 2013. A snapshot of juvenile arthritis, January 2013. Bulletin no. 113. Cat. no. AUS 168. Canberra: AIHW.

Australian Institute of Health and Welfare

Board Chair

Dr Andrew Refshauge

Director

David Kalisch

Any enquiries about or comments on this publication should be directed to: Communications, Media and Marketing Unit Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

Tel: (02) 6244 1032

Email: info@aihw.gov.au

Published by the Australian Institute of Health and Welfare

Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.aihw.gov.au> for any amendments.

bulletin 113