

# Juvenile arthritis



Most of us know someone with arthritis...a family member, friend or colleague. Perhaps even you have arthritis. Arthritis is a condition that doesn't discriminate. Some of those most hard-hit are children. As you read this at least 5000 children will be affected by arthritis. At times, these symptoms can be debilitating. One child in every 1000 in Australia is diagnosed with juvenile arthritis.

## Arthritis

Arthritis is a name that's used for more than 100 different medical conditions.

Osteoarthritis, rheumatoid arthritis, gout, Ross River virus, lupus, and ankylosing spondylitis are all different types of arthritis that affect adults.

Although genetics and environmental factors can play a part, the cause of arthritis is largely unknown.

Many forms of arthritis – including juvenile arthritis – are believed to be the result of the body's immune system, for some reason, losing its ability to tell the difference between good and bad cells. This means the body attacks healthy cells in, for example, its own joints.

Common symptoms of arthritis can include pain, swelling, and stiffness in one or more joints.

Almost 3.5 million Australians have some form of arthritis and most of these people are of working age.

The belief that arthritis is something that only affects older people is a myth.

## Juvenile arthritis

Juvenile idiopathic arthritis or JIA – generally known as juvenile arthritis – refers to all types of arthritis that affect young people less than 16 years of age.

JIA is one of the most common, as well as serious, persistent medical conditions of childhood.

More girls than boys have juvenile arthritis and it is rare for more than one child in any family to be affected.

While some forms of JIA appear to be similar to some forms of adult arthritis, how it develops, parts of the body

affected, and ways in which it is treated can be quite different.

Juvenile arthritis was first diagnosed more than 100 years ago and, while a cure is yet to be found, there are now many successful approaches to treating and managing JIA.

Even though it's not possible to tell how long juvenile arthritis will last, its severity, or how often it might swing between being almost symptom-free to quite disabling, the good news is that many children or adolescents with JIA do not develop lasting complications.

Some instances of JIA last a few months, others years.



## Living with JIA

Living with juvenile arthritis can be challenging not only for the child or young person with JIA, but for their families and friends.

School and sporting activities, partying and playing aren't too much fun when mobility is compromised and painful flare-ups take so much enjoyment away.

Depending on the type and severity of JIA, pain and discomfort experienced as well as the joints affected can change not only on a daily basis, but from one hour to the next.

And the pain of juvenile arthritis is not only physical.

JIA can impact on friendships, self esteem and confidence. The sense of adventure, motivation to try new things, feelings of belonging as well as academic achievement, artistic expression, and athletic prowess can be undermined.

Puberty can be delayed by some medications, and stiff joints and altered growth patterns can affect self image.

Support is vital; as is understanding.

With accurate early diagnosis and ongoing treatment, going to school, playing sport, partying with friends, learning a musical instrument, and holidaying with the family can be everyday activities for the young person with JIA.

## Diagnosing

As with adult arthritis, there are different types of juvenile arthritis or JIA. It usually takes an arthritis specialist – a rheumatologist - to diagnose this medical condition.

Paediatric rheumatologists specialise in treating children with JIA and some general rheumatologists also have a strong interest and expertise in juvenile arthritis.

Indications of JIA include swollen, painful joint/s; heat or redness in the area; and stiffness, often after rest periods, lasting for at least six weeks. A fever or rash can also be present.

If JIA is suspected, a general practitioner or paediatrician can write a referral to a rheumatologist. Blood and/or urine tests, x-rays and sometimes scans are needed to confirm the diagnosis.

## Treating

Treating JIA is a team effort with the team leader being the young person diagnosed with juvenile arthritis or if the child is very young, the parent or carer.

Children with JIA are best encouraged to develop self management skills very early. Cooperation is also vital to ensure the efforts of the juvenile arthritis treatment team are effective.

The job of the team is to reduce symptoms, manage pain, and ensure quality of life.

Treatment depends on the type of JIA diagnosed. Some forms of juvenile arthritis can affect the skin, internal organs, eyes, and bones as well as the joints.

Team members can include:

- specialists such as an eye doctor or ophthalmologist; skin expert or dermatologist; bone and joint or orthopaedic surgeon
- physiotherapists who work to help increase mobility and reduce pain by strengthening muscles and improving flexibility; occupational therapists who can identify ways to make everyday

activities possible; and podiatrists to advise on making walking easier

- nurse educators and social workers who can help arrange access to services such as the government's Health Care Card, parking permits, carer allowances, and other concessions.

Arthritis Offices throughout Australia can also offer information and support. Arthritis Helpline 1800 011 041.

Some major hospitals have paediatric rheumatology units that enable a one-stop-shop approach to treating juvenile arthritis.

Medicare will help to pay for a range of services such as specialist doctors, general practitioners, blood tests, and x-rays.

Private health insurance can help meet some of the costs of physio- and occupational therapy, podiatry, special equipment, counselling, dentistry, and medicines that are not fully-subsidised by the Pharmaceutical Benefits Scheme as well as complementary therapies such as remedial massage.

## Managing

### At home and school

#### Be positive

Shift focus away from what can't be done or is difficult to do Encourage a *can do* attitude.

#### Get ready for change

JIA can be marked by painful flare-ups. If this happens, current treatments might need to be reviewed, medications changed, and splints or extra physio recommended.

#### Encourage independence

Everyday tasks can be made easier with a little planning If there's morning stiffness, lay clothes out the night before Velcro fastenings, large buttons and looser styles can make getting dressed easier Specially-adapted kitchen and eating utensils are available as are modified pens, pencils and paint brushes Lever taps can make turning water on and off easier and bathrooms can be readily modified Hand and grab rails can also be installed A range of adjustable furniture is also available.



### Start the day a little later

JIA can interfere with early morning activities • Starting the day with a warm shower can ease stiffness as can placing a hot water bottle in bed 30 minutes before it's time to get up • Tasks attempted first thing might be easier later in the morning • Catching up with friends in the afternoon can be preferable to spending a whole day at home alone.

### Move it or lose it

Strength and mobility is built and maintained through movement • Swimming and aquarobics are excellent as is just paddling in warm water, tai chi, introductory yoga or even air guitar on slower days • Bending and stretching every joint everyday is recommended as is avoiding being in one posture, especially sitting, for too long • A health professional can advise if it's safe to exercise during severe flare-ups.

### Mood and movement

Mood can be as much as an indicator of being in pain as limited or slow movement • Being unusually quiet and withdrawn or appearing tense or even being a bit difficult can signal pain • Keeping a joint such as a knee or finger bent can also show there's discomfort.

### Diet is important

Reducing exercise and everyday physical activities can lead to weight gain • Some medications also stimulate appetite • Extra weight puts extra pressure on bones and joints • Foods low in fat and sugar are advised, and fast foods minimised • Appetite can also be lost. If this happens, small frequent meals can help maintain weight.

### Inform others

Let the school principal, teachers, sports coaches, and group leaders know about JIA • Use Arthritis Australia's School advisory form from Juvenile arthritis - a teacher's guide [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

### Be assertive

Ask that JIA be considered in everyday situations • For example, arrange to be able to stretch or walk around during exams and ask for extra time to complete assignments • Know it's ok to wear splints and use things like writing boards, adjustable chairs, and modified computers at school.

### Monitor the meds

Monitor all medications and inform health professionals of any over-the-counter preparations from chemist shops, supermarkets and health food stores that are also being taken for JIA or any other condition.

### At play and away

#### Go camping

JIA camps provide a valuable opportunity for children and young people with juvenile arthritis to have fun, meet others and share experiences in a supportive environment. Dedicated team leaders and staff, including health professionals, attend camp and guide participants through a range of exciting activities and fun education. Camps are held during the school holidays and these annual events are organised by State and Territory Arthritis Offices • Call 1800 011 041 for details.

#### Roll on

Pull-along school and travel bags on wheels are now widely available • Wheelchairs can be hired on a one-off basis to ensure very special events can be attended.

#### Avoid the rush

If balance and coordination are a problem, try avoiding peak hour pedestrian crushes or moving through large crowds.

#### Take it with you

Travel with medicines, a copy of prescriptions as well as medical notes



• Check with travel companies for special arrangements for carers as well as wheelchairs and other aids.

### Down the aisle

Book seats or sit near the aisle • Find out in advance the location of things like toilets, food outlets, and alternative entrances and exits.

### Have a go

JIA can be predictably unpredictable so sometimes it's best to get in and have a go rather than wait on the sidelines • Playing goal keeper rather than centre or being on court for just the first and third quarters can encourage participation as can taking on new roles such as umpire, score keeper, costume and set designer, meeter and greeter, coach, special helper or ticket seller.

### Words of the well meaning

There are perhaps as many myths about arthritis as there are people with it! • And with one in five Australians having some form of arthritis that means there is a lot of misunderstanding about its causes and supposed cures • Despite the good intentions of many, there is no scientific proof, for example, that not eating tomatoes, wearing copper bracelets or using magnetic underlays will prevent or improve any form of arthritis, including juvenile arthritis.

**And most importantly: Talk about JIA. Talk about fears, concerns and frustrations as well as discoveries, adventures and triumphs!**

# 10 steps for living well with arthritis



- 1 Take control by knowing your disease
- 2 Don't delay, see your doctor
- 3 Work with your healthcare team and be an important part of it
- 4 Know about your treatment options
- 5 Find new ways to stay active
- 6 Learn techniques to help you manage pain
- 7 Acknowledge your feelings and seek support
- 8 Make food choices that count
- 9 Balance your life
- 10 Call your local State or Territory Arthritis office

For a free copy of the booklet  
**10 steps for living well with arthritis**

visit

[www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)  
or call 1800 011 041



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**Arthritis Helpline:** 1800 011 041

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#### **Arthritis ACT**

Level 2A Grant Cameron  
Community Centre  
27 Mulley Street Holder ACT 2611  
PO Box 4017 Weston Creek ACT 2611

#### **Arthritis New South Wales**

Suite 1.15 32 Delhi Road  
North Ryde NSW 2113  
Locked Bag 2216 North Ryde NSW 1670

#### **Arthritis Northern Territory**

Shop 18 Rapid Creek Business Village  
48 Trower Road, Millner NT 0810  
PO Box 452 Nightcliff NT 0814

#### **Arthritis Queensland**

1 Cartwright Street  
Windsor QLD 4030  
PO Box 2121 Windsor QLD 4030

#### **Arthritis South Australia**

118-124 Richmond Road  
Marleston SA 5033

#### **Arthritis Tasmania**

19A Main Road  
Moonah TAS 7009  
GPO Box 1843 Hobart TAS 7001

#### **Arthritis Victoria**

263-265 Kooyong Road  
Elsternwick VIC 3185  
PO Box 130 Caulfield South VIC 3162

#### **Arthritis Western Australia**

17 Lemnos Street  
Shenton Park WA 6008  
PO Box 34 Wembley WA 6913

#### **Support services**

Carers Australia [www.carersaustralia.com.au](http://www.carersaustralia.com.au) 1800 242 636

Human Services [www.humanservices.gov.au](http://www.humanservices.gov.au) 136150

Kids Helpline [www.kidshelp.com.au](http://www.kidshelp.com.au) 1800 551 800

Medicare [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au) 132 011

Livewire [www.livewire.org.au](http://www.livewire.org.au) (02) 8425 5971

#### **More online about JIA**

Arthritis NSW [www.arthritisnsw.org.au](http://www.arthritisnsw.org.au)

Arthritis SA [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

Arthritis Victoria [www.arthritisvic.org.au](http://www.arthritisvic.org.au)

Canada The Arthritis Society [www.arthritis.ca](http://www.arthritis.ca)

UK Arthritis Care [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

USA Arthritis Foundation [www.arthritis.org](http://www.arthritis.org)