

Finding out your child has Juvenile Idiopathic Arthritis (JIA)

Information for parents, families and carers



ARTHRITIS 
NEW ZEALAND

ENABLING A BETTER QUALITY OF LIFE

KAIPONAPONA AOTEAROA

Te whakapiki i te kounga ora



Jetstar Flying Start Ambassador Steve Price with Tamsin Taylor and Jennifer McNaughton

Did you know?

- **Juvenile Idiopathic Arthritis (JIA)** is a relatively uncommon condition. It **affects around 1 in 1,000 children.**
- JIA is **more common in girls** than in boys.
- At least half of children with JIA won't have any symptoms by the time they become adults.

What is Juvenile Idiopathic Arthritis (JIA)?

JIA is a type of arthritis that occurs in children aged 16 or younger. 'Juvenile' means that young people get this type of arthritis. 'Idiopathic' means that we don't know what the exact cause is. 'Arthritis' means inflammation of joints; it causes joint swelling, stiffness and pain. JIA is a chronic condition and it lasts more than six weeks.

Causes of JIA

The cause of JIA is unknown. JIA is not considered hereditary and rarely involves more than one family member. Research suggests that some genes and environmental triggers, such as an infection can play a role in the development of JIA.

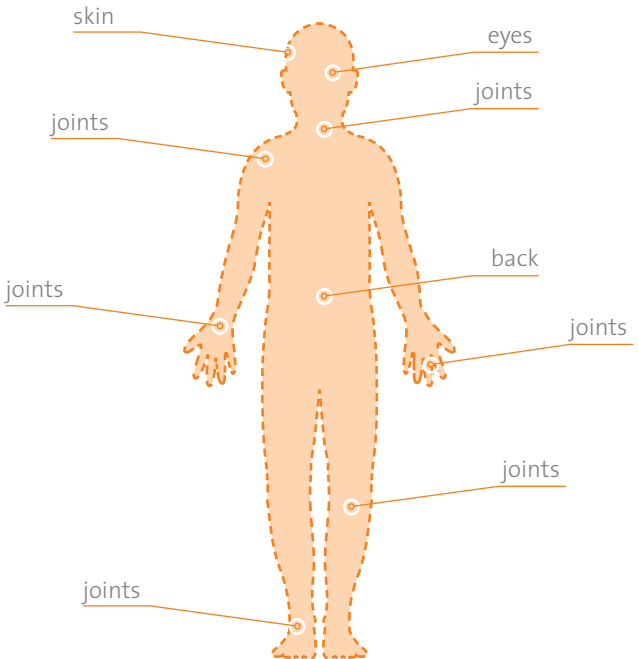
Contents	Page
▪ <i>What happens in Juvenile Idiopathic Arthritis?</i>	4
▪ <i>Types of Juvenile Idiopathic Arthritis</i>	6
▪ <i>Symptoms of Juvenile Idiopathic Arthritis; What is uveitis?</i>	8
▪ <i>Diagnosis</i>	9
▪ <i>Management and treatment options</i>	10
▪ <i>Medications</i>	12
▪ <i>Exercise; The importance of rest</i>	14
▪ <i>Pain Management; Nutrition</i>	15
▪ <i>Psychological support</i>	16
▪ <i>Questions to ask your rheumatologist</i>	17
▪ <i>How I can help my child; Key points</i>	18
▪ <i>Where can we get more information and support?</i>	19

What happens in Juvenile Idiopathic Arthritis?

JIA is an autoimmune condition where, for unknown reasons, the immune system becomes confused and attacks normal healthy cells of the body.

In healthy joints, synovial membranes surrounding the joints produce fluid that provides nutrition to the cartilage as well as lubrication and cushioning to the connecting bones. In JIA the synovial membranes become inflamed, producing more fluid and joints may become swollen, painful and stiff. If inflammation is not treated, it can damage the joint, the cartilage and the bone. Muscles around the joint can become weak and the joint may not be able to move as well as usual.

Common areas affected by JIA



*Over 1,000
children in
New Zealand
have JIA.*



Types of Juvenile Idiopathic Arthritis

JIA includes eight different types of arthritis, the most common are: oligoarticular and polyarticular.

Oligoarticular JIA:

- Most common type of JIA affecting about 50-60 percent of children with arthritis
- Often begins between 2 and 4 years of age
- Is more common in girls than in boys
- Initially can affect four joints or less. About 20-30 percent of children will develop more than 4 inflamed joints after 6 months
- Children with this type of arthritis can develop eye inflammation (iritis or uveitis). This usually has no symptoms, so regular eye checks are important.

Polyarticular JIA:

- Affects 20-30 percent of children with arthritis
- Is more common in girls than in boys
- Can begin at any age
- Affects five or more joints.

There are two types of polyarticular JIA based on whether the Rheumatoid Factor (RF) is found in the blood.

About 5 percent of children with polyarticular JIA are RF positive. This form more commonly affects teenage girls and is more likely to continue into adulthood.

Less common types

Systemic JIA:

- Affects about 10 percent of children with arthritis
- Effects boys and girls equally
- It usually involves fevers and rashes
- May cause inflammation of the internal organs.

Psoriatic arthritis:

- Is associated with psoriasis – a scaly skin condition which may also involve the nails.
- The arthritis may be in any number of joints.

Enthesitis-related arthritis (ERA):

- Involves both arthritis and inflammation in the spine.
- Joint pain can be without obvious swelling
- Children may complain of back pain and stiffness.

Need a caption here as these are 'real people'.



Symptoms of Juvenile Idiopathic Arthritis

Signs and symptoms of JIA change over time, sometimes even day to day. Times without symptoms (remissions) followed by a reappearance of symptoms ('flare-ups').

Symptoms may include:

- pain, stiffness, swelling, especially in the morning, and a joint that feels warm to the touch
- limping or "going off their feet"
- fatigue
- loss of appetite
- loss of weight
- high fever and skin rash (systemic JIA)
- swelling in lymph nodes in the neck and other parts of the body.

JIA can also cause bones to grow unevenly.

What is uveitis?

Uveitis is inflammation of parts of the eye, including the iris (the coloured bit of the eye) and the muscles and tissues that focus the eye. It doesn't hurt, and it is hard to tell if there is inflammation just by looking at the eye. However if uveitis is not treated it can cause vision loss.

It is very important to have regular check-ups with an ophthalmologist (specialist eye doctor) to check if there is inflammation in the eyes.

Diagnosis

If JIA is suspected, the child should be referred to a Paediatrician, who will liaise with a Paediatric rheumatologist. There is no single test to confirm a diagnosis of JIA, and reaching a diagnosis may take time. This can be very frustrating for families.

The diagnosis of JIA is based on medical history, physical examination, laboratory tests, x-ray and other tests.

Medical investigations may include:

- **Blood tests:**
 - **FBC** (Full Blood Count) – a blood test to check for anything abnormal that might be important in diagnosis and managing the illness.
 - **RF** (Rheumatoid Factor) – an antibody detected by a blood test. This can be useful in deciding on treatments for JIA.
 - **Erythrocyte Sedimentation Rate** (ESR) and **C-Reactive Protein** (CRP) are tests that show how much inflammation there is in the body.
 - **ANA** (Anti-Nuclear Antibody) is an important indicator for your child’s risk of developing eye problems.
- **X-rays** of the affected joints are usually needed to allow the doctor to look for any joint damage.
- **Ultrasound and magnetic resonance imaging** (MRI) scans are other ways to look at the soft tissue structures of the joints for signs of inflammation.
- **Aspiration of a joint** is where the fluid from a swollen joint is removed to be tested in a lab, to check for possible infection.

Some tests maybe ongoing or have to be repeated several times. This helps the doctor look for changes to your child’s symptoms over time.

Management and treatment options

The overall goal of managing JIA is for your child and family to lead as normal a life as possible. A team of health professionals will provide a range of treatments and support to make sure that your child leads an active and enjoyable life. The make-up of your child's team will depend on how the illness is impacting on your child's well-being.

Your child's Paediatrician will coordinate this team.

This team may include:

- Paediatric rheumatologist or adult rheumatologist
- GP
- Physiotherapist
- Nurse
- Occupational Therapist
- Ophthalmologist (specialist eye doctor)
- Podiatrist/orthotics service
- Dietician
- Pharmacist
- Arthritis Educator
- Social worker
- Psychologist or counsellor
- Teachers.

Take guidance from all members of the team so together, you can make the best decisions for your child.



*I couldn't
believe the
GP's diagnosis!*



Treatment for JIA

Treatment for JIA might include:

- medications to control the pain and inflammation
- exercises to keep the joints moving well and muscles strong
- strategies to help with pain
- social and psychological support.

Medications

1. Pain relievers (analgesics)

Pain relievers or analgesics include paracetamol (Panadol). Other stronger pain relievers are also available and can be prescribed by your GP or specialist when required. Pain relievers can help your child feel more comfortable, be more active and sleep better. Pain relievers do not reduce inflammation, and can be used with other drugs like **Non-steroidal anti-inflammatory drugs** (NSAIDs).

2. Non-steroidal anti-inflammatory drugs

NSAIDs such as Naproxen, Indomethacin and Celecoxib reduce inflammation and help control the symptoms caused by JIA, such as stiffness and swelling. They can make your child feel better but they don't cure JIA. The most common side effect of NSAIDs is stomach upset. Do not give your child any additional over-the-counter NSAIDs, only those prescribed.

3. Disease modifying anti-rheumatic drugs (DMARDs)

DMARDs such as Methotrexate, can slow or stop the progression of JIA by reducing the activity of the immune system, which is overactive in JIA. They are often used in combination with an NSAID. These medicines can take several months to reach their maximum effectiveness. Your child will be monitored for side effects while taking this medicine.

Because DMARDs reduce the activity of the immune system, some children are more likely to catch infections. Because of this, live virus vaccinations e.g. oral polio, varicella (chicken pox) and measles, mumps, rubella) should not be given while your child is on DMARDs.

4. Corticosteroids

Corticosteroids are hormones that are produced naturally in the body by the adrenal glands. When given as a medicine, corticosteroids can provide rapid and powerful reduction of pain and inflammation in children with JIA. Steroids can be given in various forms. In JIA they are most commonly given by injections into the inflamed joints.

5. Biological Therapies (biologics)

Biological Therapies is a name given to some newer very effective drugs that have been available for about 10 years. Etanercept, Adalimumab and Tocilizumab are funded for JIA in New Zealand. These medications are only used for children with JIA that is not controlled by DMARDs. Biologics slow down the progress of arthritis, and reduce pain, swelling and stiffness. Like DMARDs they work by suppressing the immune system, and

inhibiting the body's over production of inflammatory substances such as TNF alpha. Children on biologics are monitored for side effects. Some children are more likely to catch infections, live virus vaccines should not be given while your child is on this therapy.

**Remember to let your doctor know about other prescribed medications or natural therapies that your child is taking as they may interact with their arthritis medications.*

Exercise

Exercises are important to keep muscles and bones strong. Exercise can also help to reduce the pain of JIA. Your child's physiotherapist can advise on suitable exercises for your child. Swimming is excellent, it allows greater freedom of movement and it's fun.

The importance of rest

JIA can cause tiredness, so it is important that your child gets a good night's sleep and maybe some rest during the day. Alternating between active and passive activities such as listening to music, reading a book may help to reduce fatigue.

Pain management

There are many strategies that can help children cope with pain. It is important for you and your child to learn these strategies such as deep breathing, imagery and relaxation and practice them regularly. You can also try hot and cold packs, massage and distraction.

Nutrition

Children with JIA can have trouble with their appetite, so make sure your child is eating enough to maintain a healthy weight and good energy levels. A balanced diet is key, so include plenty of fresh fruit and vegetables, as well as calcium-rich foods like milk, cheese and yogurt in your meals.



Psychological support

Most children with JIA grow up to be well rounded people living active lives. However if JIA is a challenge for your child and your family it may help to be referred to a psychologist or other support services to learn skills and strategies to cope with feelings, pain, or relationships.

There are support groups that provide information and support to families with children with JIA such as *Arthritis New Zealand* and *Kids with Arthritis New Zealand* (KWANZ).

Questions to ask your rheumatologist

Having good information and understanding of JIA and medications is important in managing this condition and supporting your child. If you don't feel that you are fully informed or have concerns about the medicines being used for your child don't be afraid to discuss these with the doctor who prescribed the medicine. It may be helpful to write down your questions as you think of them, rather than trying to remember them at the next appointment. If you are well prepared you will gain the most information from each appointment.

Questions to ask your Doctor:

- Why is this medicine needed and how it can benefit my child?
- How does it work?
- How should the medicine be taken (the dose, frequency, etc.)?
- What side effects can it have and what to do if they occur?
- What tests (if any) are needed while taking this medicine?
- How long does it take to achieve the maximum benefit?
- How long will my child need to stay on the medicine?
- When and how will you (the doctor) review the progress of the medicine?

How I can help my child?

Well informed, supported and supportive parents are great role models and advocates for their children with arthritis. They will, together with the treatment team, help their child learn about their illness, form healthy routines with medications and think positively about life, family relationships, friendships, their education and growing up.

Key points:

1. **JIA can vary from child to child**; your doctor will create a treatment plan tailored specifically for our child.
2. **Be prepared for 'flares'** – know how to recognise and manage a flare.
3. **Encourage your child to participate** in normal activities e.g. sports, crafts, music.
4. **Explain to family, friends and teachers at your child's school what JIA is** and how it might impact on your child's daily life.
5. **Encourage maintenance of school attendance** and normal childhood routines.
6. **Write down questions as you think of them**, ready for the next time you talk with your child's healthcare team.
7. **Most importantly, don't be afraid to reach out for help and support.**





Where can we get more information and support?

- Arthritis New Zealand – www.arthritis.org.nz and Toll free 0800 663 463
- KWANZ – Kids with arthritis support group – www.kidswitharthritis.org.nz
- Royal Childrens’ Hospital Melbourne – www.rch.org.au/rheumatology/information_about_rheumatological_conditions/
- Arthritis Research UK – www.arthritisresearchuk.org/arthritis-information/conditions/juvenile-idiopathic-arthritis.aspx
- Arthritis Care – www.arthritiscare.org.uk/@3235/Youngpeopleandfamilies

Where can I learn more?

www.arthritis.org.nz

Regional offices

Northern (Auckland) 09 523 8900

Midland/Central (Wellington) 04 472 1427

Southern (Christchurch) 03 366 8383

National office

Level 2, 166 Featherston Street

PO Box 10020, The Terrace

Wellington, 6143

Phone 04 472 1427

Fax 04 472 7066



ARTHRITIS NEW ZEALAND

Tollfree 0800 663 463



Proudly sponsored by:

