Finding out your

child has arthritis

Information for parents, families and carers









Arthritis AUSTRALIA

How can this booklet help

Finding out that your child has arthritis can be a confusing and anxious time. Naturally, you will have a lot of questions.

This booklet:

- has been written for parents, families and carers of children with arthritis
- includes information to help you understand the condition and the key challenges that may face children, and their families, affected by arthritis
- provides information about treatments and practical advice for children and their families living with arthritis
- can help you find support and additional information to cope with the impact of the condition.

A panel of parents and carers of children with arthritis and medical experts have reviewed the information to make sure that it is current and relevant to your needs.

This booklet may contain some medical terms that are new to you. We have provided a glossary at the back of the booklet to describe some of these terms. Remember to ask members of your child's healthcare team to explain any terms that you are not sure about.

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What is juvenile idiopathic arthritis (JIA)?

Juvenile idiopathic arthritis (JIA) is the name given to a number of types of arthritis that occur in children. The name comes from:

Juvenile: referring to children under the age of sixteen years.

Idiopathic: meaning it has no known cause.

Arthritis: conditions that cause joint inflammation and pain.

You may have thought arthritis is a condition that only affects older people but there are many different types of arthritis, some of which affect babies, children and teenagers.

In Australia about 6000 children are affected by arthritis, making it as common as Type 1 diabetes.

Over time, in Australia and overseas, different terms have been used when referring to arthritis in children, some of which you may still hear or read. These include:

- Juvenile arthritis (JA)
- Juvenile chronic arthritis (JCA)
- Juvenile rheumatoid arthritis (JRA)
- Still's disease
- Juvenile idiopathic arthritis (JIA).

These different names all refer to types of arthritis that occur in children under the age of 16.

We will refer to the condition as JIA throughout this booklet.

> In Australia, the types of arthritis that affect children are commonly referred to as Juvenile idiopathic arthritis (JIA for short).

What are the main symptoms of JIA?

Your child may have experienced one or more of these symptoms:

- joint pain, swelling, tenderness, stiffness, redness and warmth
- fatigue (tiredness and lack of energy), fevers, loss of appetite or weight, and generally feeling unwell

- skin rashes
- inflammation of the eyes (uveitis) and other organs of the body in some forms of the disease.

Any joint in the body may become inflamed but the joints most commonly affected are the knees, hips, hands and feet. Any number of joints might be affected from just one to several.

Many people only associate arthritis with damage to joints. JIA can affect other parts of the body, such as the eyes, skin and internal organs.

JIA symptoms can fluctuate – meaning they may vary from day to day, week to week.

> JIA symptoms may fluctuate, with periods of increased disease activity called 'flares' or periods of remission.

There will be times when symptoms are worse – these are called 'flares' – and then times when they are in remission.

Many children develop symptoms after having a viral infection such as a cold. The original infection resolves itself but if any of the symptoms listed above continue for more than six weeks seek advice from a doctor.



What causes JIA?

The causes of arthritis in children are not yet fully understood.

Research suggests that in some types of JIA genetics may be involved. However, these conditions are not regarded as hereditary (passed from parent to child). If you have one child with JIA, it does not mean that your other children will also develop the condition. Genetics are only one part of the puzzle and researchers continue to look for other factors.

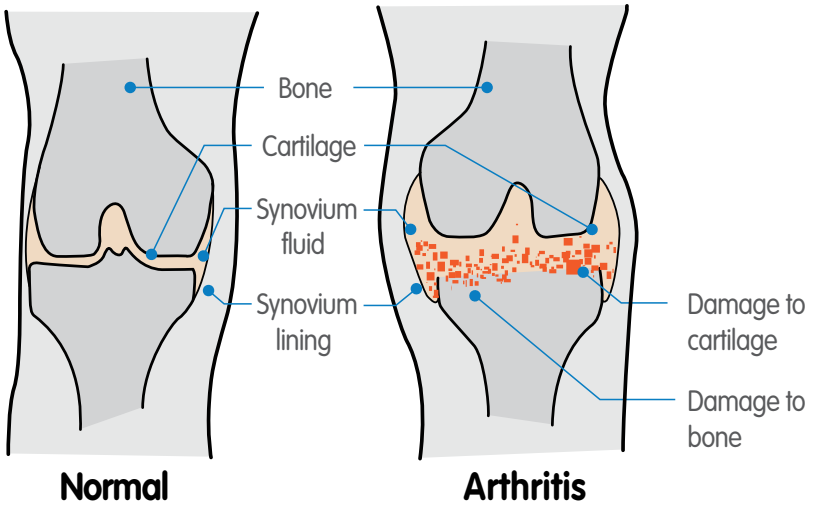
Climate, diet or emotional factors do not appear to play a role in the development of arthritis in children.

We do know that JIA is an autoimmune condition. This means the body's immune system (its protective mechanism against infection) starts to mistakenly attack healthy cells of the body. This happens for reasons we don't yet understand, possibly after being triggered by a virus or bacterial infection. The immune system fails to 'turn off' when the infection has been cleared producing ongoing joint inflammation called JIA.

The immune system mistakenly attacks cells in the connective tissues, including the lining of the joints (synovium). JIA can also affect connective tissues in other parts of the body.

JIA is not an infectious condition so it cannot be spread from one child to another.

Figure 1 - comparison



> While the cause of JIA is still unknown, there is nothing that you did to cause it or could have done to prevent your child developing it.

How is JIA diagnosed?

There is no single test to diagnose JIA. Instead, it involves a number of steps. These may include:

- detailed health and medical histories of the child and their biologically related family members (where known)
- physical examination of affected joint/s
- laboratory tests e.g. blood tests (see next page)
- other tests such as X-rays, ultrasound and/or scans of the joints
- eye tests.

The results of these tests will help in confirming a diagnosis of JIA, or rule out any other possible causes for the symptoms your child is experiencing.

Sometimes all of the test results will be normal. This does not necessarily mean your child does not have JIA – it just means that the tests will need to be repeated, possibly when your child has symptoms.

Ongoing testing will also help the doctor look for changes in your child's symptoms/condition over time and to make adjustments to their treatment/s as necessary.

If your doctor suspects JIA, your child should be referred to a rheumatologist (ideally a paediatric rheumatologist who specialises in children with arthritis) who would confirm the diagnosis and start treatment.

Reaching a diagnosis can take time due to the fluctuating nature of the condition. The 'waiting period' can be a very anxious and frustrating time. These feelings are understandable, but it is important to keep on with the process until the diagnosis is made.

Once JIA is diagnosed, your child can be started on treatment to manage symptoms and to reduce potential damage.

> Remember, diagnosis is the important first step in addressing your child's health needs.

Medical tests

Your child will be asked to have a number of tests, both for diagnosis and for the ongoing management of their arthritis.

Some of the more common tests include:

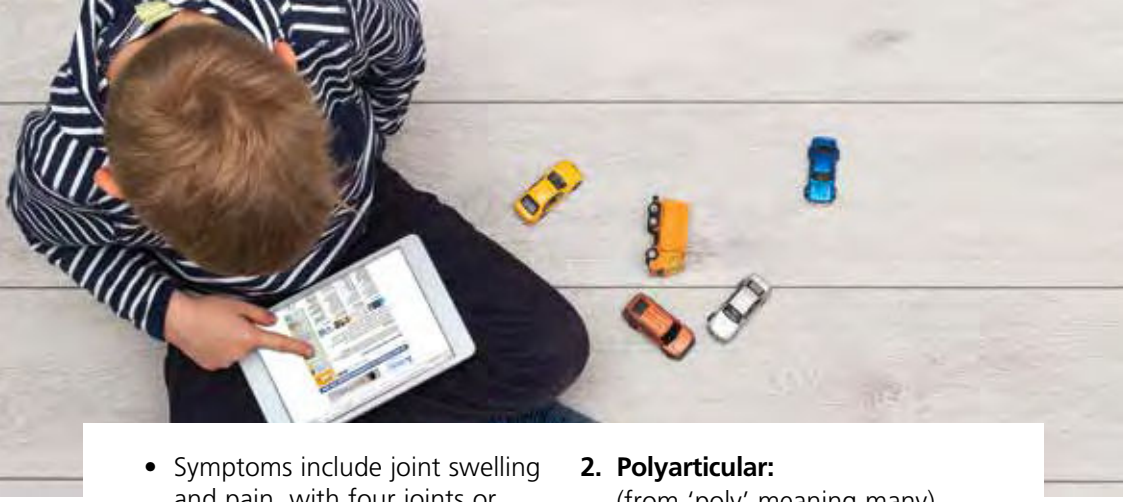
- FBC - full blood count. A blood test to check for anything abnormal that might be important in managing the illness.
- RF - rheumatoid factor. An antibody detected by a blood test. This is an indicator of the type of JIA your child has.
- ESR - erythrocyte sedimentation rate. A blood test that detects how much inflammation there is in the body.
- CRP - C-reactive protein. This is also a test that detects inflammation.
- ANA - antinuclear antibody. This test is used to do two things. It helps identify the type of arthritis your child has and it is an important indicator for your child's risk of developing eye problems.
- HLA-B27 - A blood test that helps to determine the type of arthritis that your child may have.
- X-ray - Takes pictures of your child's joints to see any damage and how they change with time.
- MRI or CT scans. They do much the same as X-rays but in greater detail. They can also show changes in non-bone structures around the joints (like ligaments and tendons).

> Medical tests can be daunting for you and your child. However these tests are routine and will assist with both diagnosis and effective ongoing management of your child's condition.

The different types of JIA

There are five main types of JIA, each with its own specific set of symptoms. These main types are:

1. **Oligoarthritis:**
   (from 'oligo' meaning few)



- Symptoms include joint swelling and pain, with four joints or less affected.
- It usually affects large joints such as the knees and ankles, and typically does not affect the same joints on both sides of the body.
- There is a risk of developing uveitis (inflammation of the eye).
- The child's general health is not normally affected.

This is the most common type of JIA, affecting 50-60% of children. It often begins in young children (under 5 years) and is more common in girls.

Fortunately, oligoarthritis is often mild and is the most likely type to go away leaving little or no joint damage. Uneven growth may occur when arthritis affects joints on one side of the body more than the other. Approximately a quarter of children with oligoarthritis will go on to have extended oligoarthritis, meaning more joints become inflamed after six months and they have a higher risk of joint damage.

2. Polyarticular:
(from 'poly' meaning many)

- Symptoms include inflammation of many joints, affecting the same joints on each side of the body including fingers, toes, wrists, ankles, hips, knees, neck and jaw.
- Onset of symptoms may be sudden and typically the child feels unwell, tired, listless and may develop a slight fever.
- Affects between 20-30% of children with JIA and is more common in girls.

This type is divided into two groups, depending on whether the test for rheumatoid factor (RF) is negative or positive:

- RF negative (RF-): most children with polyarticular JIA are RF negative.
- RF positive (RF+): a small number of children are RF positive (RF+), often teenage girls. It is sometimes thought of as early onset of adult rheumatoid arthritis.



3. Systemic onset JIA:

This is the least common type of JIA. The early symptoms appear as a general illness involving:

- fevers that occur once or twice a day
- pink-coloured rash anywhere on the body, which comes and goes
- swollen glands in the armpits, neck and groin
- feeling tired with widespread aches and pains, although swollen joints may not appear for several weeks.

Sometimes it may cause inflammation of the liver and spleen, and very occasionally the covering of the heart (pericarditis). These early symptoms of JIA have also been called 'Still's disease', named after Dr George Frederick Still who identified the condition.

It can be confused with other childhood illnesses such as measles or glandular fever.

4. Enthesitis-related arthritis (ERA)

Enthesitis refers to inflammation of the ligaments and tendons, which are attached to bones. This type of JIA:

- causes pain and inflammation in the tendons and tissues around the joints rather than in the joints themselves
- most commonly affects the spine, heel, hips, knees, and ankles
- is linked with an increased risk of acute uveitis, an inflammation of

> Your child's diagnosis will depend on which symptoms they experience, as well as the number of joints affected during the first six months of the disease.

the eye that causes it to become red, painful and sensitive to light

- is associated with the genetic marker called HLA-B27, detected by a blood test. HLA-B27 can also be found in people who do not have any form of arthritis
- may also be called juvenile spondylitis, juvenile spondylarthropathy, or seronegative-enthesopathy-arthropathy syndrome.

5. Psoriatic arthritis:

The symptoms of psoriatic arthritis include joint pain in any number of joints. In addition this form of JIA also involves the skin. This is usually seen as patches of scaly skin, called psoriasis. These may affect large areas of the body and/or along the scalp-line, behind the ears or knees, on the eyelids or in the belly button.

The skin symptoms can appear before or well after the joint symptoms develop, which may mean your child is initially diagnosed with a different type of JIA.

Psoriatic arthritis will typically only be diagnosed when both the rash and joint pain are present although the doctor may suspect this type of arthritis, and look closely at your child's fingernails and toenails for early signs, if close family members have psoriasis.

Like other forms of JIA, there is a risk of developing uveitis (eye inflammation).

What is the outlook for your child?

Every child's JIA is different and responds differently to treatment. It is very difficult to predict how long JIA will last, its severity or how often it might swing between being almost symptom-free to quite disabling.

The treatments for JIA are constantly improving and the good news is that many children with JIA who receive early diagnosis and good treatment, both during and between flares, will grow up without any lasting effects of their arthritis.

There is still no cure for JIA but many children go into remission, meaning symptoms disappear for long periods, sometimes forever.

For some, JIA can cause longer-term problems, especially if they do not receive early diagnosis and treatment.

Arthritis-affected joints that are not kept mobile can stiffen into abnormal positions and then will no longer work properly. This can also lead to joint damage and severely restrict your child's ability to do most normal daily activities for the rest of their life. With the improvements in treatment options for young people with JIA, this is much less frequent than in times gone by.

Some children with JIA may need to continue taking the medicines to control their arthritis into adulthood. Some will be able to do so intermittently but some will need to do so all the time.



"The outlook for children with JIA is usually very positive. The good news is that most children with JIA will not have active symptoms by the time they become adults.

How is JIA managed?

> Management of your child's JIA will require a multi-faceted approach. It will need to target the underlying disease process, any presenting symptoms and focus on their growth and development.

Early diagnosis and active, long-term management provides the best chance for positive outcomes for the child with arthritis.

Management of JIA will be specific to each child, depending upon:

- which type of JIA they have
- how/where it is affecting them – how many joints, which joints, which non-joint symptoms eg uveitis (eye inflammation) are present
- how active the condition is – whether it is 'flaring' or in remission
- how well the child tolerates and responds to the medicines prescribed to treat the condition and other management interventions.

The management of your child's JIA will need to be monitored closely and changes made to their treatment plan from time to time to be responsive to any issues as they arise.

Any management plan for children with JIA will need to be multifaceted.

It will involve medical and physical therapies and need to ensure that all aspects of the child's health, growth and development are monitored.

Medical management of the condition will require medicines that are targeted at working on the underlying disease process (even if the child is seemingly symptom free, they may still have underlying disease activity that needs to be treated.)

There will also need to be ongoing management that responds to presenting symptoms of the condition - during periods of disease 'flare'. Good overall care, during and between disease flares, can minimise the effects of the condition and help

to keep your child's life as 'normal' as possible, now and in the future.

Remember, your child's body is still growing so they need to do the things that all children do to grow big and strong such as exercise, have a healthy diet and lots of fresh air and sunshine. Like all children, they also need lots of fun and laughter.

Who can help to manage your child's JIA?

To achieve the best possible health outcomes, the management of your child's JIA will involve a team effort over a long period of time.

It is important that you and your child are at the centre of the care team, involved in all aspects of health management and decision-making. This means having open, honest discussions with team members and asking any questions that you have along the way.

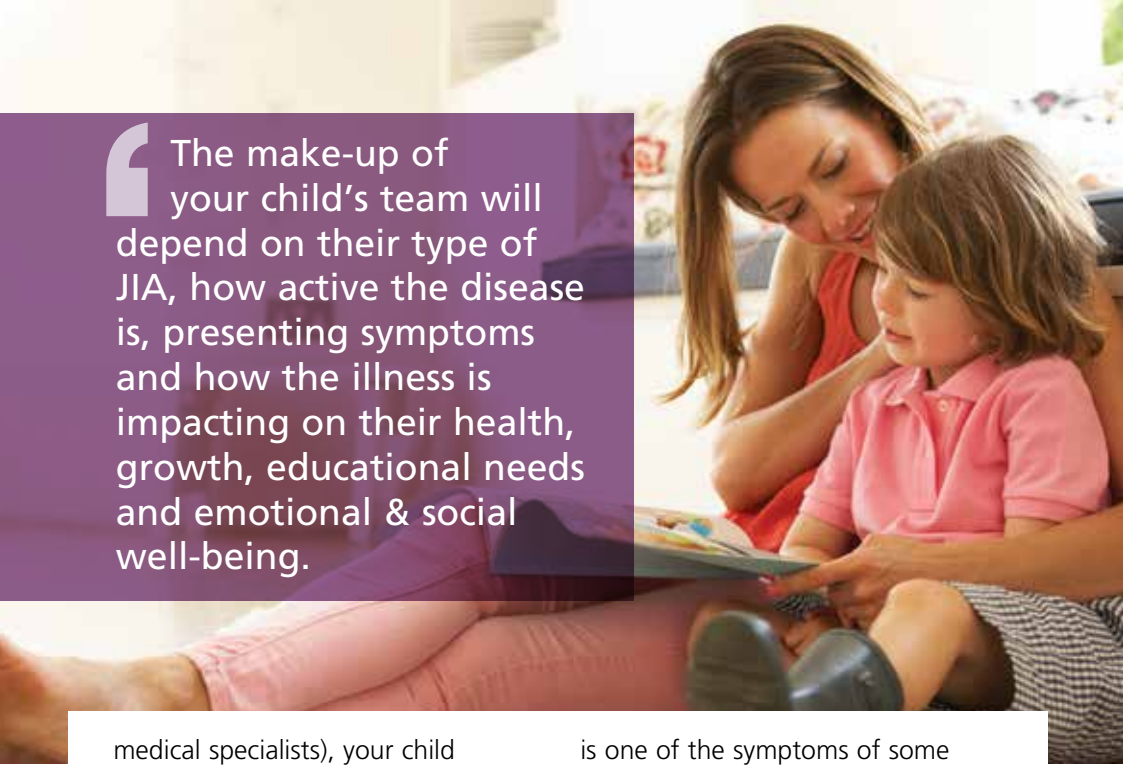
Depending on the child's individual needs, the team may include:

- Rheumatologist (paediatric rheumatologist if available)
- Paediatrician
- General practitioner (GP)
- Rheumatology nurse (if available)
- Physiotherapist
- Occupational therapist (OT)
- Ophthalmologist (specialist eye doctor)
- Podiatrist, Orthotist
- Dentist
- Pharmacist
- Child psychologists/Counsellors/ Play therapists/Social workers
- Teachers and school support staff
- Other family members – siblings, grandparents and carers.

If JIA is suspected, your child is likely be referred to a rheumatologist (possibly a specialist in paediatric arthritis if available) who would confirm the diagnosis, discuss treatment options with you and start your child on therapy.

The rheumatologist can then make sure that your child receives the best treatment to manage symptoms and reduce damage by targeting the underlying inflammation. Remember, if you feel it is needed, you can seek a second opinion by asking your GP for another referral.

If you are not able to access a rheumatologist (some rural and regional areas do not have these



> The make-up of your child's team will depend on their type of JIA, how active the disease is, presenting symptoms and how the illness is impacting on their health, growth, educational needs and emotional & social well-being.

medical specialists), your child may be referred to a paediatrician (doctor who specialises in diseases of children).

It is important that your child is supported to be as physically active as possible. Exercise will help to strengthen muscles, keep the joints flexible and encourage normal limb function and skeletal development.

A physiotherapist can play a key role in keeping your child as mobile and independent as possible by recommending exercises and/or providing physical treatments. You can request a referral for your child to see a physiotherapist.

You should also ensure that your child has regular eye examinations with an ophthalmologist, as uveitis (inflammation of parts of the eye) is one of the symptoms of some types of JIA and can be present without your child having noticeable symptoms. If chronic uveitis isn't treated it can lead to permanent vision loss. Uveitis is treated with special eye drops or other medications.

Dental health is also very important so ensure that your child has regular checks with their dentist and that the dentist is aware that the child has JIA. Increased inflammation in the body can cause problems and sore hands may not be able to brush teeth as well as necessary.

An occupational therapist can assist with ensuring that your child has any aids and/or equipment they need. They will also be able to advise on how to overcome any issues that your child has with school.



Developing a relationship with members of the health care team is vitally important. Remember that you know your child best and this information will be invaluable for members of the health care team.

Sometimes children with JIA will benefit from having a tailor-made splint. Splints are made of plastic which is moulded around your child's arm or leg. Resting splints worn at night hold the joint in a good position. This helps with the shape or alignment of the joint and prevents deformities. Splints worn in the day are called working splints, and these support a painful joint so your child can stay active for longer.

Some children may need splints for a period but long-term use is rare nowadays.

Orthotics in the shoes may also be important to support foot alignment and/or strain on other leg joints. They will need modification as the child grows and alignment and function improve. If one leg is longer than the other because of arthritis affecting one leg, a heel raise or shoe

raise may be important to correct alignment of the pelvis and back and prevent problems in the future.

Consultations, medicines and equipment can come at a cost. Be sure to ask about costs associated with interventions when they are being suggested. If you are having difficulty paying for things, speak to your child's team about eligibility for subsidised services or other entitlements.

Every child with JIA is different and will need individual assessment, treatment and monitoring from members of the health care team. Be sure to mention the things that your child wants to do, any goals that they may have so that the care team can offer assistance in reaching these goals.

> Every child with JIA is different and will need individual assessment, treatment and monitoring from members of the health care team.

What are the aims of treatment in JIA?

There are many different treatments available for JIA. What works for one child may not work for another and finding the right treatment for your child can involve a process of trial and error. While this can be frustrating for all involved, it is important that you stick with the process to ensure that your child gets the best possible treatment for their particular type of arthritis.

The overall treatments used for JIA aim to:

- prevent or slow damage to joints and/or progression of the illness
- reduce symptoms including inflammation, stiffness and pain
- assist your child's normal growth and development, and ensure that they are able to get back to their usual activities and lead the most normal life possible.

Medicines will play a major role in the management of JIA. As a parent you may feel anxious about the prospect of your child taking these medicines. This is natural and understandable but they are very necessary for the best long-term outcomes for your child.

It is important that you have the opportunity to discuss any worries or questions that you have about the medicines with the prescribing doctor.

Your child may not want to take these medicines, particularly if they feel that their symptoms have improved. However, many of the medicines used today not only reduce the symptoms but also slow the progress of the condition by targeting underlying inflammation, so long-term compliance with therapy is essential.

For these medicines to be effective, it is important that they are taken exactly as your child's doctor prescribes. Many of them will need to be taken long term, continuing even when the child's symptoms improve so that they maintain the improvement and lessen the risk of permanent damage to the joints and other parts of the body.

While your child is taking JIA medicines, the doctors will be closely watching for disease progression and any side effects. To make sure that any potential problems are detected and rectified as early as possible, your child will need to have regular tests, such as blood tests.

> Medicines are a major part of the treatment of JIA and your child may need to take more than one type of medicine.





What types of medicines are used to treat JIA?

The most common types of medicines used to treat JIA are:

Pain relievers (analgesics)

Analgesics are medicines that can relieve mild to severe pain. They work by blocking pain signals from being sent to the brain or by preventing the brain from receiving or working out what these signals mean.

They typically take effect within an hour of taking the dose, with each dose usually providing relief for between 4 and 6 hours. Common pain relievers for mild to moderate pain include paracetamol, codeine or combinations of these. Analgesics for milder pain are available as non-prescription (over-the-counter) brands. In the case of severe pain, your doctor will prescribe a pain relief medicine.

These medicines do not reduce the inflammation present in JIA.

Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs relieve both the inflammation and consequently the pain around the joint. However, NSAIDs do not slow the progression of the illness or reduce the risk of joint damage. Examples of the many NSAIDs include ibuprofen, naproxen and diclofenac.

DMARDS (disease-modifying anti-rheumatic drugs)

DMARDs can slow the progression of JIA. Although researchers don't fully understand how some DMARDs work, they believe they dampen the immune system's attack on joint tissues. Methotrexate is the most commonly used DMARD in JIA throughout the world.

DMARDs are only used if your child's JIA is not well controlled or is unlikely to be well controlled, by NSAIDs and/or joint injections alone.

DMARDs can take several weeks to reach maximum effectiveness. Providing there are no serious side effects your child will need to stay on



the medicine at least that long before its success can be assessed.

DMARDs are given as a tablet, liquid or as an injection under the skin. Some are given every day; others are given once a week

Corticosteroids

Corticosteroids, or cortisone-like drugs, are a man-made form of naturally occurring hormones produced by the body. They can provide rapid and powerful reduction of pain and inflammation for children with arthritis.

They can be given as tablets, as eye drops, by injection into a joint or by a drip into a vein.

Steroid injections can be given into an affected joint during a flare. Most children notice that the joint is a lot less sore and inflamed with a few days after the injection, and this improvement can last for months. In younger children these injections will be done under general anaesthetic, but as they get older injections may be done under sedation (medications to help them feel relaxed and sleepy). As children approach transition to adult care, sedation will be reduced or not used at all.

Steroid tablets are prescribed at the lowest possible dose and used for short periods (for a few days to a week) to reduce the risk of side effects.

Biologic DMARDs

'Biologics' subdue the immune system by blocking natural substances called cytokines. These are substances found in excessive amounts in the blood and joints of children with JIA. The increased levels of cytokines cause inflammation, which results in the symptoms of JIA, and can lead to joint damage. By blocking particular cytokines called tumour necrosis factor (TNF), interleukin-1 or interleukin-6, biologics reduce inflammation, lessen the symptoms and help stop further joint damage.

The biologics available in Australia under the PBS scheme to treat JIA

include adalimumab, etanercept and tocilizumab. Anakinra and infliximab may also be prescribed occasionally.

These are given as an injection under the skin once or twice a week, fortnightly or sometimes daily, depending on which medicine has been prescribed. Some medications can also be given as an infusion into a vein by an intravenous drip every 2, 4 or 6 weeks. These medications can only be prescribed by a rheumatologist.

Live vaccines

If your child is taking methotrexate or any of the biologics, he or she should not have any LIVE vaccines. This means no rotavirus, MMR (measles, mumps, rubella), chickenpox (Varicella), BCG or Yellow Fever vaccines (among others). It may be advisable that the child has no contact with family members who have recently had any of these vaccines. If you're not sure whether a vaccine is live or not, contact your rheumatologist to check. Your child is encouraged to have all other (non-live) vaccines, including a yearly flu vaccine.

What you need to know about your child's medicines

Your child's rheumatologist/prescribing doctor will explain the different types of medicines to you and outline the treatment plan specific to your child's needs.

For each of the medicines prescribed, your child's doctor/s should outline:

- what the medicine is called
- why it is needed, how it will benefit your child
- how it works (what does it target eg inflammation)
- how the medicine is taken (dose, frequency, method eg tablet)
- what possible side effects it may have and what to do if they occur
- what tests (if any) are needed while taking the medicine
- how long it may take to achieve maximum effect
- how long your child may need to stay on the medicine
- when and how the doctor will review the progress/effect of the medicine.

If you don't feel that you have the answers to these questions or if you have other questions or concerns about the medicines your child is prescribed don't be afraid to discuss these with the doctor who prescribed the medicine or a pharmacist.

For additional information on specific medicines, see your pharmacist or go to the Australian Rheumatology Association website www.rheumatology.org.au

> Medicines in JIA today not only treat symptoms but also target the underlying disease, slowing down the progression of the condition. The goal of treatment is disease remission.

Managing pain

Pain is a very common symptom of JIA, even when children are on therapies that are effectively treating their underlying condition.

High levels of pain can result in children with JIA being less physically active and may reduce their participation in school, social and family activities.

It can also result in sleep disruption and poor sleep quality, which in turn can cause daytime fatigue, reduced mood and increased sensitivity to pain – essentially creating an ongoing pain cycle.

A range of interventions including medicines, use of hot and cold treatments, relaxation and distraction techniques, deep breathing, massage, gentle stretching and exercise can assist in relieving pain.

Children with sore joints may be reticent to move but staying in one position for too long, including lying down or resting, can cause pain so children should be encouraged to move regularly to alleviate stiffness and pain.

As a parent, you are well placed to pick up on cues that your child is in pain, even if they can or do not articulate it. These may include the



> Parents play a key role in assisting children to practise and develop self-management skills and implement pain management strategies.

child becoming quiet, withdrawn or more clingy, sad or irritable, or changes in appetite, play, sleep patterns or behaviour.

Parents play a key role in assisting children to accurately describe their pain (its location, type and its intensity), communicating this to the care team and assisting the child to develop skills in self-management of their pain.

Members of the JIA healthcare team can offer suggestions and interventions that actively address your child's pain. A comprehensive, multidisciplinary approach will provide you and your child with techniques and skills aimed at limiting the impact that pain is having on your child's physical and psychological health and their social and educational development.

Pain is never pleasant however the good news about pain in JIA is that pain intensity is not necessarily proportional to joint damage.

Physical activity and exercise

Physical activity is essential for good health and wellbeing in all children, and even more so for children with JIA. It assists to:

- relieve stiffness, improve joint mobility and range of movement
- maintain/enhance muscle and bone strength
- improve physical function and independence.

It is important that your child remains as active as possible, every day. This may mean finding physical

activities or sports that they enjoy but that do not cause too much discomfort. Generally, non-contact sports will be best for children with JIA to reduce the risk of joint injury or damage. Low impact activities such as cycling, yoga or dance are ideal, as they do not place too much stress or strain on joints.



Swimming or water based activities are also excellent as the buoyancy provided by the water takes most of the weight off the joints, and allows greater freedom of movement. Swimming can improve muscle strength, lung function and general health. Added to this, in water your child may not feel as if they are exercising. It's fun and they can do it with friends and family. Warm water pools or spas are best, as the warm water also helps muscles to relax.

Ensure that sport teachers and coaches are aware of your child's condition and that they warm up and cool effectively before and after activity. Also ensure that your child wears good shoes that absorb impact and joint protectors as necessary.

In addition, your child should have an individually tailored exercise program that they do every day. Your child's physiotherapist or exercise physiologist can advise you on suitable exercises. Try to build exercises into their daily routine and make them fun – this may mean involving your child's siblings and friends or doing exercises to their favourite music.

> Exercise has significant physical benefits for children with JIA and also boosts mood, body image and confidence.

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.

With accurate early diagnosis and ongoing treatment, going to school, playing sport, being with friends, learning a musical instrument, and holidaying with the family should still be part of normal life for children with JIA.

> Overall, your child should be encouraged to keep their life as normal as possible – to just do the things that kids do. This helps to increase their self-esteem and also their feelings of control over their illness.

Sleep and rest

Children with JIA can struggle with tiredness and fatigue.

It is important, therefore, that your child gets sufficient rest. This includes a good night's sleep and possibly a rest period during the day particularly if they are young, are having a 'flare' of their JIA or have previously had a poor night's sleep.



Rest does not necessarily mean lying in bed. Rest can be sitting on the lounge listening to music, reading a book, colouring in, playing a game, chatting to friends or family, or any other non-physical activity that they enjoy doing.

While they are resting, attention should be given to maintaining good joint and limb position, as well as posture.

Alternating between active and passive activities throughout the day can help your child to participate in their normal daily routines without



too much difficulty. This may mean that they have a rest before attending a party or playing sport.

An important skill for children with JIA to learn is that of 'pacing.' This means actively managing their activities and activity levels to avoid unnecessary symptoms of their JIA. An occupational therapist can assist with pacing strategies or by developing a Fatigue Management Plan with strategies for coping with fatigue.

Healthy eating

Children and teenagers need a healthy, balanced diet for normal growth and development.

There is no evidence to suggest that any food or diet will cause or cure arthritis, or cause disease flares in JIA. Exclusion of certain foods or food groups may however may mean your child misses out on important nutrients, vitamins and minerals.

Your child will benefit from a nutritious diet offering calcium for bone strength and iron rich foods to help prevent anaemia.

> Maintaining a healthy, balanced diet is important for bone growth and development, and maintenance of a healthy body weight.

It is vitally important that your child maintains a normal body weight. Carrying extra body weight puts additional stress through weight bearing joints. Limited mobility and excessive fatigue can lead to being less physically active which may also result in weight gain.



Try not to offer your child sweet or fatty foods as treats for comfort or reward. Instead read them a story or have a star chart with a special activity of their choice as a reward. Comfort eating can also be an issue in older children.

Some medications can change your child's appetite and taste in foods so you may have to be a little creative in finding a menu that is appealing as well as healthy.

Try to engage your child in planning and preparing nutritious meals and snacks.

A dietitian may be able to assist if your child is having issues associated with diet and nutrition.

Play

For children, play is a vital part of physical, cognitive and social development. It promotes imagination and a positive sense of self. Playing with others encourages the development of social skills and friendships.

For the child with JIA, play can be a time to explore unfamiliar experiences or express feelings and anxieties associated with living with their condition.

If they are in pain, having a flare of symptoms or have physical limitations, you may need to invite a few children into their play circle rather than expect them to join the neighbourhood rough and tumble. This may need a word to the parents of the other children and a little ingenuity to make the fun flow.

If you are concerned about your child's emotional health or feel that they need assistance with 'just being a kid', ask your child's treating team for advice about seeing a play therapist or child psychologist.

> Play takes them away from their day-to-day for a while and provides an opportunity to be an astronaut or superhero even if for just a little while!

> Attending appointments takes time and effort - get the most out of appointments by being focused and prepared.

Preparing for your child's appointments/consultations

Attending appointments, consultations and therapy sessions takes time, energy and effort but they are a very important part of the JIA management plan.

Try to remove the angst as much as possible by being prepared, organised and focused:

- Know where you need to be (and where there is likely to be parking).
- Prepare a list of questions that you wish to ask, before you go.
- Ask your child if they have any questions and add these to the list – older children can be encouraged to start to ask their own questions.
- Always remember to ask for an explanation of technical words or concepts that you do not understand.
- Ask a friend or relative to attend the appointment as well – to listen, take notes, to drop you and park the car and/or just for support.
- Have a list of prescription repeats that are needed if you are visiting the prescribing doctor.
- Keep a file of all correspondence relating to your child's JIA so that you have easy access to documents when you need them – this includes referrals, letters, management plan documents etc.
- Take along photos of any symptoms (rashes, swollen joints etc) that your child has exhibited so that you can show them to members of the care team.
- Keep a diary of symptoms/side effects/issues so that you can recall them when you see the care team.
- Ask about referral/s to other services that you feel would be beneficial.
- Be honest with your child about what may be done at the consultation (if you know).

And have a ritual of doing something a little special after the appointment/ session – some time with your child that is not focusing on their JIA.

School

Your child's school plays an important part in their development, providing educational and social skills and opportunities, so it makes sense to partner with your child's school and teachers.

Actively communicating with your child's teachers can assist in ensuring that the child's individual needs are catered for.



Most teachers will not have had a child with JIA in their class so it is important to inform the school/ teachers about the condition, how it affects your child and any specific needs that they may have.

With this knowledge, teachers can assist in recognising issues and work with you and your child in trouble-shooting solutions.

Some areas that may need discussing could include:

- mobility – moving from class to class, around the school campus or on excursions may be an issue at times for your child.
- seating – prolonged sitting may cause stiffness and pain so finding an appropriate seat/seated position is important, eg. sitting cross-legged or getting up from the floor may be difficult so a chair may be a better option for floor or mat time in the classroom.
- managing absences/lateness – your child may need to have time away from school for illness or scheduled medical/allied health appointments or just if they are slow to get going in the morning.
- flexibility in doing tasks – sometimes children with JIA may need extra time to complete tasks, to use specialised equipment or adjustment to the task, eg. if handwriting for long periods is difficult due to sore hands, a laptop or writing buddy might be helpful for exams.
- participation in sports – sometimes your child may not be able to participate in sports due to their JIA but they should still to be engaged, eg they can act as the scorer or coach for an activity undertaken by their peers.
- school uniform – sometimes children with JIA may need to wear shoes or clothing that does not comply with the set uniform for the school.

Whether you and your child wish to tell their class-mates and peers about their JIA is entirely up to you.

> Talk openly with your child and give them a chance to express how they're feeling. Listen and help them with strategies to maintain friendships and deal with unkindness.

Helping your child to cope

The aim is for children to maintain their regular schedules and routines as much as their health allows. Here some ways you can help your child:

- Aim for your child to return to school, preschool or kindergarten, as soon as possible. A graduated return to school may be helpful and schools are happy to work with the team to achieve this. Setting goals which are achievable is better than "phone me when you can't cope anymore" which focuses on failure. There are great resources or supports available including

Arthritis Australia's *Juvenile arthritis - a teacher's guide*
www.arthritisaustralia.com.au

- Encourage and support your child to continue hobbies such as sports, music and other activities, or to develop new hobbies. Involving them in activities they enjoy can build their self-esteem and keep them connected with friends and peers. Talk to your child's physiotherapist or occupational therapist about suitable activities or sports for your child.
- Ensure your child shares in the 'chores' at home recognising that what your child does needs to be within their capabilities. Encourage your child to get a part-time job when older, if possible.



- Encourage your child to keep a diary. This can boost their feeling of control over the disease.
- As early as possible, involve your child in their treatment. Allowing your child to take part in some decisions related to his or her care, such as which medicine to take first or medication delivery method, is another way to encourage independence and a sense of control.
- It can be helpful to seek input from a psychologist or counsellor if they are struggling with their feelings, relationships, confidence or moods.

Teenagers and arthritis

Being a teenager can be challenging enough, without adding a chronic condition to the mix. It is important to remind your teenager that while their friends may not have arthritis, they may be living with other medical conditions, disabilities and/or challenges.

Issues of social interaction and relationships, body image, and personal and sexual identity will also likely be challenging for everyone within their friendship group.

Teenagers with JIA will need support and guidance to develop the skills to ensure they are confident (as possible) to deal with the challenges of living with their condition while 'setting their sails' for adult life.

As a parent, this includes supporting their increasing involvement in their own care planning, goal setting and decision-making, ensuring that they understand their condition and any implications associated with the decisions they make about their arthritis, its treatment and management.

This will take time and preparation as they develop the skills to manage their own health care. It is important to remember that, like learning any new skill, they could make some mistakes.

This period is called 'transition' and is a time for linking into adult services and programs, which will mean developing relationships with new care team members and taking an active role in seeking assistance when they need it.

It will also mean actively handing control over to them over time – which can be very hard when you have been so intimately involved in all aspects of their care.

The key message for parents of teenagers with arthritis to reinforce is that your child is not defined by their JIA but by who they are and what they can do and be. Since the expectation for the vast majority of children with JIA is that they will study, travel, work, marry and have a family, it is essential that these building blocks are in place.

As your teenager transitions into young adulthood, they will need information to support the next stages of their journey. Arthritis Australia has a booklet designed just for them. It is called *Living with arthritis – a guide for young adults*; a practical guide to treatments, services and lifestyle choices.

> Having JIA doesn't mean that teenagers can't follow their dreams and aspirations. Young people with this condition may need to make some allowances – but so do most people, in some way.



Caring for the whole family

A child being diagnosed with arthritis was never part of a family's plans. The condition not only impacts the child with arthritis, but also parents, siblings and extended family members. Managing JIA is likely to mean changes in the routines and organisation of your family. It may also mean that problems and feelings arise from time to time that need to be dealt with.

Shifting roles, new routines and responsibilities, and added financial and emotional stress can all take a toll. Family bonds may be tested, and siblings of children with more severe JIA may feel resentful and guilty. Try to give each child in the family some regular one-on-one time and to constantly reinforce that they're loved. You could also arrange one-on-one time or special time with their grandparents, extended family or friends.

Most importantly, parents of children with JIA need to take care of themselves too. Be sure to make time for things you enjoy, spend time with your partner and/or friends and find ways to deal with stress. Staying positive and making contact with other parents who share your experiences and have information and advice to share can also help.

It is also important for you to develop an informal support network – family and friends, neighbours or others - who can lend a helping hand, be there for a chat or to give a hug.

They could look after your child if they are unwell, or look after your other children if you have medical appointments or maybe they could take them all out for a while so that you can simply recharge your batteries or spend time with your partner and/or friends.

People will often want to help but they may not know how so be prepared to let them know what you need and when you need it.

Try to have a few meals in the freezer at any time so that if you are tired, you won't have to cook. And remember, taking a few moments out just for you or for a little family fun is more important than vacuuming the house.

If you feel that things are becoming a bit too much, seek professional assistance from a counsellor, social worker or psychologist. Your physical and mental health is important to not just you but the whole family.

If you work, juggling medical appointments and therapy sessions can be difficult, particularly in the early days while the team are establishing what works for your child. Consider speaking to your employer about options for a little flexibility.

This is not the time to make big decisions such as leaving work. The goal of the health team will be to get your child's JIA into remission, so give it a while and see how things work out.

> JIA is a chronic condition and will require long-term management – in other words, it is a marathon rather than a sprint, so remember to look after yourself too.

Glossary:

Analgesic:	Medicine used to relieve pain
Anaemia:	A condition where there are too few red cells in the blood causing tiredness
Antibody:	A blood protein produced in response to a foreign substance eg a virus
Anti-inflammatories:	Medicines that lower inflammation
Autoimmune condition:	A condition where the body's immune system mistakenly attacks healthy cells
C-reactive protein (CRP):	Substance produced by the liver in response to inflammation
Complementary therapy:	Those that are currently considered to be outside conventional medical treatment
DMARDs:	Stands for disease-modifying anti-rheumatic drugs which are used in JIA to slow down the progression of the disease
Erythrocyte sedimentation rate (ESR):	A test of blood that shows the level of inflammation in the body
Exercise physiologist:	Specialises in exercise and movement to prevent/manage chronic diseases
Flare:	A period of increased disease activity/ symptoms, may last days, weeks or months
Genetic predisposition:	Increased likelihood of developing a disease/condition based on genetic makeup
Immune response:	Reaction of the body to a 'foreign' substance such as an infection
Inflammation:	Reaction/response by the body to injury or infection causing symptoms of redness, pain, heat and swelling
Multidisciplinary:	Involving input from different health professional disciplines
NSAIDs:	Stands for non-steroidal anti-inflammatory drugs – a type of medicine used to lower inflammation

Occupational therapist:	Health professional providing assistance with aids/ equipment and strategies for activities of daily living, work and school
Ophthalmologist:	Specialist eye doctor
Pacing:	Strategy for managing activity levels
Paediatrician:	Specialist children's doctor
Physiotherapist:	Health professional specialising in assessment and treatment of conditions using physical methods such as manual therapy, movement and exercise
Podiatrist:	Health professional specialising in diagnosis/treatment of disorders of the feet
Psoriaisis:	A skin condition characterised by patches of inflamed, thickened and scaly skin. Associated with psoriatic arthritis
Remission:	A period where there are no signs/ symptoms associated with a disease
Rheumatologist:	Medical specialist working in the area of diagnosis and treatment of conditions of the bones and joints including types of arthritis and pain
Rheumatoid factor (RF):	Proteins produced by the immune system that can attack healthy tissue in the body
Synovium:	The membrane lining the inside of joints. Produces synovial fluid
Ultrasound:	A type of scan used to examine muscles, tendons, and internal organs
Uveitis:	Inflammatory condition affecting the eye that can have no obvious symptoms but can cause damage if not treated

Where you can find health professionals

For assisting in finding a health professional to be part of your child's JIA care team, see the following:

Rheumatologist:
Australian Rheumatology Association
www.rheumatology.org.au

General practitioner:
The Royal Australian College of General Practice
www.racgp.org.au

Physiotherapist:
Australian Physiotherapy Association
www.choose.physio

Occupational therapist:
Occupational Therapy Australia
www.otaus.org.au

Psychologist:
Australian Psychological Society
www.psychology.org.au

Dietitian:
Dietitians Association of Australia
www.daa.asn.au

Podiatrist:
Australian Podiatry Council
www.apodc.com.au

Exercise physiologist:
Exercise and Sports Science Australia
www.essa.org.au

Medication Information:

The Australian Rheumatology Association has excellent information sheets about medications used to treat arthritis, including side effects and precautions.

https://rheumatology.org.au/patients/medication-information.asp

Call Medicines Line, a telephone service provided by the National Prescribing Service and healthdirect Australia, for independent information about prescription, over-the-counter and natural medicines from a registered nurse. Your question may be answered on the spot, or you may be referred to your GP or pharmacist, or put through to a NPS pharmacist.

Phone: **1300 633 424** Monday to Friday, 9am to 5pm EST or go to www.nps.org.au

Where you can find information, resources and support

Your **State/Territory Arthritis Office** can provide you with information resources on a wide range of topics associated with living with arthritis.

Freecall: **1800 011 041** or visit www.arthritisaustralia.com.au

Arthritis Australia has an excellent resource *Juvenile Arthritis A Teacher's Guide* available at: www.arthritisaustralia.com.au

The Royal Children's Hospital Melbourne website provides a huge collection of information on managing the impact of JIA, treatment options, and resources for schools and teachers.

There are sheets written specifically for children and young people, as well as adults and were developed by all the Paediatric Rheumatologists in Australia in collaboration.

www.rch.org.au/rheumatology/information_about_rheumatological_conditions/

The Arthritis Foundation (US) has a website for juvenile arthritis called Kids Get Arthritis Too. www.kidsgetarthritistoo.org/

Arthritis Ireland has great resources, videos and other information for kids (2-8), tweens (9-12), teens (13-17) and parents. www.juvenilearthritis.ie/

Emotional support:

beyondblue provides information and advice about depression, anxiety, available treatments and where to get help. Visit www.beyondblue.org.au or call **1300 22 4636**.

Lifeline provides a 24 hour confidential telephone crisis support service for anyone across Australia experiencing a personal crisis. Call **13 11 14**.

Kids Helpline provides 24 hour support and confidential counselling for children and young people aged 5 – 25 years. Call **1800 55 1800**.

Notes

My contact details

My name: _____

Telephone: _____

My GP

Name: _____

Telephone: _____

My specialist

Name: _____

Telephone: _____

My support team

Name: _____

Telephone: _____

Name: _____

Telephone: _____

My medicines

Name	Dosage	Instructions

Arthritis Australia

Arthritis Australia is a not-for-profit organisation that provides support and information for all Australians affected by arthritis.

Arthritis Infoline: 1800 011 041 www.arthritisaustralia.com.au

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Building 18, 170 Haydon Drive
Bruce ACT 2617
PO Box 908 Belconnen ACT 2616

Arthritis New South Wales
Unit 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
WOTSO Chermside, Level 2 Westfield
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111A Welland Avenue
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