Juvenile Idiopathic Arthritis

Consumer care guide



Arthritis AUSTRALIA

What is this guide?

This booklet is endorsed by the Australian Rheumatology Association, Australian Podiatry Association, Juvenile Arthritis Foundation Australia, and the Pharmaceutical Society of Australia

Australian Rheumatology Association

Apoda Australian Podiatry Association

Pharmaceutical Society of Australia

JAFA Juvenile Arthritis Foundation Australia

After a child is diagnosed with Juvenile Idiopathic Arthritis (JIA), many families find themselves in a world of unknowns, unsure of what will happen next or how to best support their child.

This guide was co-designed with JIA families to inform parents and carers about what to expect when a child is diagnosed with JIA. It includes useful information about the disease, what to expect at every stage, tips for every age, and extra resources for more information and support. We hope that this guide empowers young people with JIA and their families to advocate for their care, making informed decisions throughout their journey.

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what's inside

1 The basics

What is JIA? 5

Why does my child have JIA? 5

Types of JIA 5

A-Z of terms 6

2 What to expect

Standards of care 8

JIA timeline 9

Priority populations 10

Early care 11

Active disease 13

Flare-ups 15

Remission 16

Transition to adult care 16

3 Tips for every age

Early childhood (0-4) 18

Childhood (5-12) 18

Adolescence (12-18) 19

Adulthood (18+) 19

4 What you can do

Advocating for your child 21

Support communities 22

Extra resources 23

The basics

This section covers the basics of JIA. It includes an explanation of what JIA actually is, why your child has it, what types of JIA there are, and an A-Z of common terms that you will see throughout the rest of the document.

What is JIA
Why does my child have JIA
Types of JIA
A-Z of terms

What is 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 the cause is unknown



Arthritis

conditions that cause joint inflammation

Why does my child have JIA?

It's not your fault that your child has JIA.

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

Types of JIA

There are five main types of JIA each with its own set of symptoms. The type of JIA that your child has can change over time. The main types are:

Oligoarthritis *from 'oligo' meaning few*

This is the most common type of JIA and occurs when up to four joints are affected, usually the large joints such as the knees and ankles.

Polyarticular *from 'poly' meaning many*

This type involves five or more joints, with the same joints on each side of the body affected, including fingers, toes, wrists, ankles, hips, knees, neck and jaw.

Systemic onset JIA *also known as 'Still's disease'*

This is the least common type of JIA. It not only affects the joints, but the entire body. It causes widespread inflammation, resulting in high fevers, rashes, swollen glands, aching limbs and fatigue. Inflammation can also develop in and around the organs. It can be difficult to diagnose because early symptoms can be confused with other childhood diseases such as measles or glandular fever.

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 the joints themselves. It most commonly affects the spine, heel, hips, knees and ankles.

Psoriatic arthritis

This type of JIA can affect any number of joints and is usually associated with the scaly skin rash of psoriasis. Like other forms of JIA there is a risk of developing uveitis (eye inflammation).

A–Z of terms

There are many long and potentially unfamiliar words that you will encounter on your JIA journey. Here are some of the most important for you to understand.

A — Active disease

When the symptoms of JIA, such as sore joints and other signs of inflammation are present.

B — Biological Agents (bDMARDS)

Biologics are a type of DMARD that suppress the immune system by blocking natural substances called cytokines. Children with JIA have increased levels of cytokines, which cause inflammation and the symptoms of JIA. 'Biologics' are used when JIA hasn't fully responded to first-line treatments like methotrexate.

D — Disease Modifying Anti-Rheumatic Drugs (DMARDs)

A group of medicines that are used to treat JIA, slowing down the progression of the disease. DMARDs help reduce damage to the joints as well as relieving symptoms. They include biologics (mentioned above) as well as other medicines.

F — Flare / flare-up

A period of increased disease activity/ symptoms, that may last days or weeks.

I — Intravenous Infusion

When medicines or fluids are given through a drip or central line, directly into the veins.

J — JAK inhibitor

JAK inhibitors, such as Tofacitinib, are an oral form of DMARD. It works by blocking the signals that cause inflammation.

J — Joint injection

A procedure where a long-acting 'steroid' medicine is injected directly into an arthritis-affected joint to reduce pain and inflammation.

M — Methotrexate

The DMARD medication most commonly used to treat JIA. Methotrexate is given at a very low dose once a week, as either a tablet or an injection under the skin.

O — Ophthalmologist

A specialist eye doctor. Children with JIA are at risk of uveitis and may need to be assessed by an ophthalmologist.

P — Psoriasis

A skin condition characterised by patches of inflamed, thickened and scaly skin. It is associated with psoriatic arthritis.

R — Remission (inactive disease)

A period where there are no signs or symptoms associated with a disease.

R — Rheumatologist

A doctor who specialises in the diagnosis and treatment of conditions of the bones and joints including arthritis.

U — Uveitis

An inflammatory condition affecting the eye that can have no obvious symptoms but can cause damage if not treated. Children with JIA may develop uveitis.

What to expect

This section offers a breakdown of what you can expect JIA care to look like at different stages, from referral and diagnosis through to the transition from childhood to adult care. It is based on the JIA Standards of Care, with added information and suggestions from other JIA families.

Standards of care
JIA timeline
Priority populations
Early care
Active disease
Flare-ups
Remission

Standards of care

In Australia we have a **Standard of Care (SoC)** for JIA. This is a document that describes the type of care that health services should be delivering to all people with JIA and their families, regardless of where they live. It is used to advocate for better care and improve services across Australia.

It includes **6 guiding principles**, which are the general principles that should always apply to your care. It also includes **30 quality statements**, which describe what high quality JIA care looks like in more detail.

Each quality statement has a number. We'll be including these numbers throughout this section of the consumer care guide so you can point to relevant parts of the standards when speaking to your child's healthcare team and advocating for high quality care.



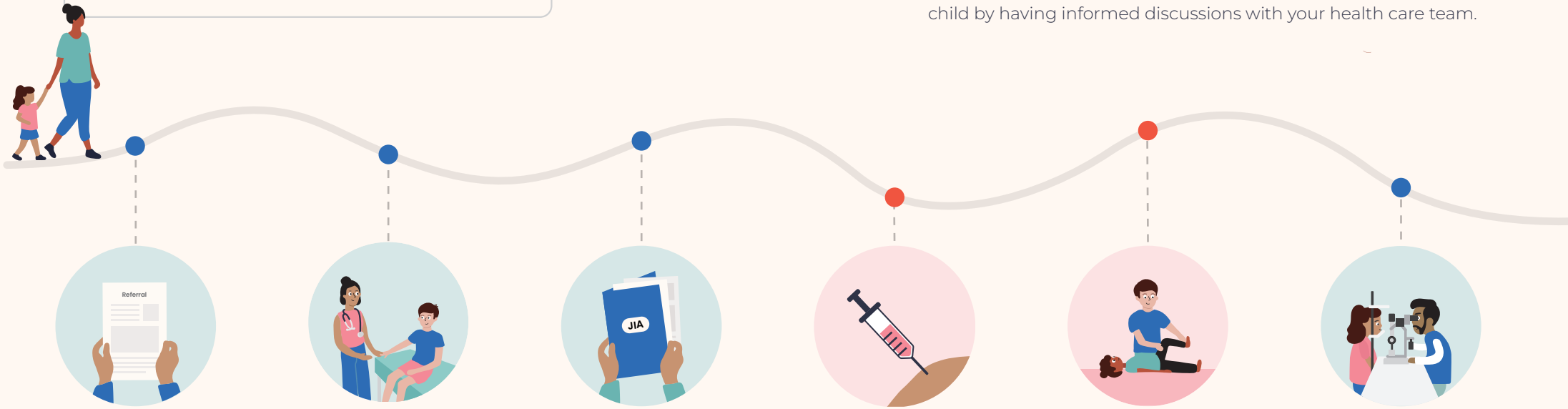
JIA timeline

Timeframes are relevant to:

All families Some families

It's normal to feel a bit overwhelmed when your child is diagnosed with JIA, and it's important to know what to expect. This timeline includes any specific timeframes that are provided in the Standards of Care for JIA, giving you a snapshot of what care should look like in the first 6 months. The JIA journey often begins many months or years before referral. However, this timeline begins at the moment a child is suspected of having juvenile arthritis and referred to a rheumatology service.

While these timeframes indicate what paediatric rheumatology teams across Australia are aiming for, many JIA journeys do not currently look like this. Use this timeline to help advocate for your child by having informed discussions with your health care team.



Referral

When you bring a child with JIA symptoms to see a health professional like a doctor or paediatrician, they should be able to identify that JIA is a possible diagnosis and promptly arrange a referral to a paediatric rheumatology service.

Quality statements: 1

Rheumatology appointment

If your child is suspected of having juvenile arthritis and referred to a public rheumatology service or private paediatric rheumatologist, they should be seen within **30 days** of referral. A rheumatologist will be able to assess and potentially diagnose your child with JIA.

Quality statements: 2

Education + care plan

Your family should receive education about JIA from your rheumatology team within **2 weeks** of diagnosis.

You should also receive a written care plan in the mail within **2 weeks** of diagnosis. This letter will be sent to your child's GP and other doctors as well, and will explain the diagnosis and next steps.

Quality statements: 3 4

Treatment

Your child should have timely access to treatment, which may include infusions within **2 weeks** of prescription and joint injections within **4 weeks** of prescription.

Your child should have timely access to Disease Modifying Anti-Rheumatic Drugs (DMARDs) and other medications as needed, based on the clinical guidelines.

Quality statements: 10

Allied health

Your child may need support from allied health professionals for issues ranging from movement, to mental health or cultural support. If your child is referred to a member of the multidiscipinary team, they should be seen within **30 days** of referral.

Quality statements: 7

Eye health monitoring

Uveitis is an inflammatory eye condition that is common among people with JIA. All children with JIA should be seen by a specialist eye service who can screen them for uveitis within **6 weeks** of referral. If they have symptoms of eye disease, they should be seen sooner – within **1 week** of referral.

Quality statements: 16 17

Priority populations

The following section will cover general information about what you can expect at different stages of JIA. Everyone has the right to respectful and personalised care at every stage. However, we know what there are groups with different needs or who may be at risk of worse health outcomes and need additional support.

This includes Aboriginal and Torres Strait Islanders, Culturally and Linguistically Diverse (CALD) people, Lesbian, Gay, Bisexual, Trans, Intersex, Queer (LGBTIQ+), people living with disability and those who live in rural or regional areas.

If you need extra support, speak to your rheumatology team about your needs and any concerns, and what additional assistance or support may be available, including translation services or support from an Aboriginal Health Worker.

Health services should have a commitment to providing culturally safe care, and health professionals should develop their cultural competence, listening to the individual cultural needs of each person as part of their assessment and using culturally appropriate language.

Quality statements: 28 29 30

Early care

The first few months after a child is diagnosed with JIA are full of many new experiences and emotions. These early days are crucial – both for families who are beginning to navigate what JIA means for them, and for their paediatric rheumatology team as they work to control the disease. This section summarises some of the most important actions for you and your care team to take during this time.



Initial education

Many people haven't heard of JIA until their child is diagnosed. Your care team should support and educate you about the condition and treatment options, providing culturally appropriate resources.

What you can do:

If you haven't had access to a JIA education session with a member of your rheumatology team within 2 weeks of diagnosis, ask your team if you can schedule a session. If you have not been given educational resources about JIA, see **Section 4** of this guide for our top picks.

Along with education about JIA more broadly, your family should receive specific education around each treatment option so that you can make informed, shared decisions with your team. Depending on your treatment plan, you may also have access to information and in-home support from pharmaceutical companies.

Quality statements: 4 5 6



Care team

In the first few months you and your child will be meeting and familiarising yourselves with your paediatric rheumatology team.

All families should have access to the health professionals they need. Members of your multidisciplinary team may include:

- General practitioner
- Rheumatologist
- Specialist nurse
- Physiotherapist
- Occupational therapist
- Administrative support
- Ophthalmologist
- Aboriginal Health Worker
- Psychologist and other mental health professionals
- Hospital; school services/teacher
- Orthotist and/or podiatrist
- Dietician
- Social worker

What you can do:

If you feel that your child needs additional support and would benefit from seeing members of the rheumatology care team that you do not currently have access to, speak to your paediatric rheumatologist. They will be able to determine if your child is eligible for a referral to another specialist or allied health professional.

Quality statements: 3



School support

The support that a child receives at school can play an important role in their JIA experience, both in the classroom and in school sports.

What you can do:

If your child is currently attending school, it is important to inform their school of the diagnosis. You may also need to educate the school about JIA, ensuring they are aware of reasonable adjustments that can be made. We've included specific school tips for every age in **Section 3**.

Quality statements: 6



Questions/concerns

Many families have questions or concerns within the early days of JIA and beyond. It's important that you know who to call, when and why.

What you can do:

Make sure you know who is your first point of contact to ask questions or seek support. If you don't know, ask your paediatric rheumatology team. It is also important to have a regular GP who knows your child and can communicate with your rheumatology team. Many families also find it useful to connect with other JIA families for advice and support. We have included a list of JIA communities on **page 22**.

Quality statements: 13

Emotional support

It's normal to feel stressed, overwhelmed or worried when your child is unwell – many families find this to be a challenging time.

What you can do:

The mental health and emotional wellbeing of you, your child and your family should be monitored by the paediatric rheumatology team on an ongoing basis. If you feel like you need more emotional or mental health support, speak to your care team.

You can also speak to your GP about the possibility of getting a mental health plan for any member of your family, giving you access to psychology services. Connect your child with their school's guidance counsellor/psychologist, or access your hospital's social work and/or Aboriginal Liaison Service if these are relevant to you.

Many families also find it useful to connect with other JIA families for emotional support – organisations like Arthritis Australia and JAFA have active Facebook support groups. We have included a list of JIA communities on **page 20**.

Managing phobias

JIA is a condition that involves the use of needles – for blood tests, joint injections and injected medications. Some children develop anxiety around needles as a result. Getting on top of this early is important, and support options are available.

What you can do:

If your child is developing fears or anxieties around needles, speak to a member of your paediatric rheumatology team as soon as possible. They may be able to offer support or direct you to an occupational therapist, child life therapist or psychologist who can work directly with your child to prevent ongoing procedural anxieties. There are adjustments that can be made to support your child during procedures, for example using distraction devices.

Tests and scans

Your child may need to undergo a number of scans and tests, including MRIs, x-rays and blood tests.

What you can do:

It is important to emotionally prepare your child for scans and tests. If sedation has not been offered and you feel that it may help your child, you have the right to request what sedation options are available. Some clinics may ask you to remain outside of the room during scans and tests. However, your child can request that you remain in the room if they need your support.

Financial support

Many families are concerned about the financial cost of JIA, and are unaware that support options may be available. Depending on your circumstances, your family may be eligible for a number of state and federal payments.

What you can do:

GPs are an important advocate and coordinator for your care. Speak to your GP about financial support options that you may be eligible for. These may include a **General Practitioner Management Plan** and/or a **Team Care Arrangement**, which will give you access to subsidised allied health services.

Some children may be eligible for financial support from the NDIS, for example through **Early Childhood Intervention.**

Centrelink offers a **Carer Allowance** for some parents of children with a disability or serious illness, as well as a **Health Care Card** to reduce the cost of medications and other expenses.

Each state has some form of **Travel Subsidy Scheme** to support families who need to travel and access accommodation for appointments.

Your state may also offer additional payments. For example, low-income Queensland residents can access a **Medical Cooling and Heating Scheme** intended for medical conditions like JIA that may worsen due to hot or cold weather.

Information about each of these federal and state payments can be found online.

Active disease

This section covers what you can expect during periods of active disease where symptoms of JIA are present.



Review appointments

All young people with JIA should be seen at least every 6 months, however your child may need to be seen more regularly depending on the type and severity of their JIA.

What you can do:

Remember that you know your child better than anyone else. Review appointments are the best opportunity to bring up any questions or concerns that you have about your child's treatment, symptoms or side-effects. Don't be afraid to ask for more information if you need it. You can also ask for a medication review if you are unsure if the current treatment plan is working for your child.

Many parents find it useful to prepare questions and priorities for the appointment in a notepad or on their phone. You may also want to take notes throughout the appointment. If you know that you will be taking in a lot of new information, you may want to bring a support person like a friend or family member to listen, record and process everything that's being said.

Quality statements: 11



Managing symptoms and side effects

On top of the symptoms of JIA, your child may experience side effects from their medicine. It can sometimes be difficult to know whether what you observe is a symptom or side effect. It is important to track changes in your child and share this information with your treating team.

What you can do:

Your child may experience side effects from their medicine like headaches, nausea, stomach pains, weight changes, mood changes, sleepiness, insomnia or irritability, depending on their treatment plan.

Some parents find it useful to keep a diary of symptoms and side effects alongside questions for their next appointment. It can also be useful to document the emotions that you and your child are experiencing alongside their physical condition, making sure to seek emotional support if needed. If your child is old enough, they could also keep a diary to document their own physical and emotional experiences. They could write and draw in the diary and share it with their rheumatologist or log their journey for their own benefit.

If your child is experiencing new symptoms, for example pain or swelling around an additional joint, it is important to keep an eye on these changes. If you are concerned, speak to your paediatric rheumatology team and discuss whether an urgent review appointment is required.



Pain management

Pain can be a common symptom of JIA, even when children are on medicines that are effectively treating their condition. If this is the case for your child , you may want to explore other pain management options.

What you can do:

Children should have access to a range of medicines and other treatments to relieve pain, such as hot and cold treatments, relaxation and distraction techniques, deep breathing, massage, gentle stretching and exercise. Speak to your care team about interventions to address your child's pain. Helping your child communicate their pain can also assist your child in developing skills in self-management.

Quality statements: 14



Blood tests

If your child is taking medicine for JIA, they will need to have regular blood tests to monitor the effect of the drug on their body.

What you can do:

Follow your paediatric rheumatology team's guidance for the frequency of blood tests, stay up to date with the schedule and check that they are receiving the results. It is common for children undergoing treatment for JIA to require blood tests approximately every 3 months, however this will be tailored to your child.

Eye care

Uveitis is an inflammatory eye condition that is common among people with JIA. Your child should be screened for this condition by an eye specialist at the point of diagnosis, and continue to be screened regularly if required.

What you can do:

If your child hasn't been screened for uveitis or it has been more than 6 months since their eyes were checked by an ophthalmologist, discuss this with your rheumatologist. They will be able to give you a referral to the ophthalmologist if required. Most people with uveitis don't have many symptoms, so regular screening is important. It may be the case that your child is not at risk of uveitis, which your rheumatologist will be able to determine.

Quality statements: 16 17 18

Exercise + healthy eating

There is no reason why your child can't live a full and active life with JIA. Many families choose to make diet and exercise changes to support their child. You may need additional support from your care team to explore evidence-based options as you consider lifestyle changes.

What you can do:

Many families feel unsure about the amount and type of physical activity that would be best for their child. You can speak with your paediatric rheumatology team about physical activity recommendations and ask for guidance about options that align with your child's capabilities, interests and health goals.

If your child has difficulty eating, or has lost or gained a lot of weight since the diagnosis, or you would like information about diet options, speak to your paediatric rheumatologist. They may be able to refer you to a dietitian or other relevant health professional if additional support is needed.

Quality statements: 21

Ongoing education

As your child's treatment plan changes and adapts to their changing body, your family should receive ongoing education about new treatment and care options so that you can make informed and shared decisions with your treating team.

What you can do:

If you are unsure about any aspect of your child's treatment, or need more information to make an informed decision, speak to your paediatric rheumatology team. Relevant members of the team can meet with you and/or give you educational resources.

Some pharmaceutical companies also offer complimentary in-home support and education – ask your care team if this is available to you.

Quality statements: 12

Flare-ups

Your child will experience flare-ups throughout their journey – temporary periods of time when the symptoms of arthritis such as pain and swelling get worse. Depending on the severity of the flare, they may need extra treatment and support during this time.

Daytime emergencies

If you are concerned about your child's symptoms during office hours, it is important that you know who to contact for rapid access to care.

What you can do:

If you are concerned about your child but it is not urgent, email your paediatric rheumatology team.

If you feel the problem is more urgent and you have direct phone contact to your rheumatology nurses, this may be an option for rapid support. Alternatively, you could visit your GP for advice and contact your paediatric rheumatology team to request an urgent review appointment.

In situations where you are very concerned about your child's condition and feel that it is an emergency, you may want to take your child to the Emergency Department at your local hospital for assessment. Make sure to carry a list of your child's medications with you, as the doctors and nurses will need to know what medications they are currently taking.

After hours emergencies

Sometimes emergencies happen late at night or on a weekend. It can be challenging to know where to turn. It's important to have a plan in place, knowing who to contact and why.

What you can do:

It is important to create an after-hours emergency plan with your care team, asking them who you should contact in an emergency. Generally, if your child is experiencing a flare but it doesn't feel like an immediate emergency, you may feel comfortable contacting your care team or booking a GP appointment and waiting until the next business day. Alternatively, if you are very concerned about your child's condition and feel that it is an emergency, you may want to take your child to the Emergency Department at your local hospital for assessment. Make sure to carry a list of your child's medications with you so that staff are aware of the risk of possible drug interactions.

Uveitis flares

If your child has uveitis, they may also experience significant flares in their uveitis symptoms, with blurred vision, red eyes and/or eye pain.

What you can do:

It is important that you contact your ophthalmologist as soon as possible to request an urgent review appointment if you do not already have a treatment plan in place.

Additional imaging

Your paediatric rheumatology team may request further scans or tests to better understand the flare and rule out causes other than JIA.

What you can do:

Be aware that your child might need extra imaging during a flare. You can also speak to your paediatric rheumatologist about the potential need for additional imaging.

Pain relief

If your child is experiencing significant pain during their flare, it can be important to reduce pain as quickly as possible. Several pain management options will be available to you.

What you can do:

If your child requires extra pain relief in between appointments, contact your paediatric rheumatology nurse for guidance around how to minimise your child's discomfort.

Pain management options may include heat/ice packs, anti-inflammatory creams, compresses and pain relief medications. You could also try pain relief strategies such as distraction or deep breathing. To prepare for periods of pain, it can be useful to create a "grab bag" of supports for self-care. This could include heat packs, meditation apps, games, your child's favourite music, etc.

Remission

The goal of JIA treatment is to achieve and maintain remission for as long as possible, where symptoms subside or disappear for a period of time. It is important to know what to do if your child has a flare after a long period of inactivity, as well as how to manage the period of inactivity.

Flare-ups after inactivity

Some people with JIA will have long periods where their disease is inactive, then suddenly experience a flare. They may no longer have a direct point of contact with their previous paediatric rheumatology team, and it can be challenging to find care quickly.

What you can do:

Be aware that it is possible the condition may flare up again in the future, and have a plan in place as well as a point of contact within your rheumatology team if you are no longer maintaining regular appointments. It may also be helpful to make an appointment with your GP who can re-refer you for appropriate care. Ensure you tell them your child has previously been diagnosed with JIA.

Maintenance during inactivity

Some people with JIA continue on a maintenance dose of their treatment, while others are able to go off medicine entirely. Some continue to attend review appointments and remain connected to their care team, while others go many years without JIA care.

What you can do:

Depending on your child's situation and the advice of your treating team, you may want to continue regular 6-monthly or yearly review appointments to maintain a point of connection with your team and monitor their condition.

Transition to adult care

By the age of 18, your child should be transitioning from paediatric care to adult care. This can be a challenging time for families, and it is important to plan for this transition in advance. As your child enters adolescence, you may also want to have conversations around sexual health and risk-taking behaviours.

Transition planning

As your child enters their teen years, it's important to start thinking about their transition to adult care, developing a plan with your care team and empowering your child to advocate for themselves.

What you can do:

Begin having discussions about the transition by the age of 16, two years prior to transition. It is important to put a plan in place with your rheumatology team, discussing what appointments will look like in the lead-up up to their transition.

Quality statements: 15

Sex and risk-taking behaviours

As adolescents consider becoming sexually active and are potentially exposed to risk-taking behaviours like consuming alcohol and drugs, it is important that they understand how these factors will interact with their condition and medication so they can make informed decisions.

What you can do:

Sexual health and risk-taking behaviours should be addressed by your rheumatology team as part of comprehensive adolescent care. If these discussions are not occuring, you may want to raise the topic during your next review appointment. You can find tips for adolescents in **Section 3**.

Quality statements: 22

Tips for every age

This section contains tips from other JIA parents to help you navigate JIA at every stage of life, from early childhood to adulthood. It offers practical actions that you can take to support your child and advocate for their care.

Early childhood (0-4)
Childhood (5-12)
Adolescence (13-18)
Adulthood (18+)

Early childhood

0-4



Developmental milestones

Children with JIA might be delayed in meeting expected developmental milestones. For example, they may be delayed in crawling, hopping, jumping or practicing fine motor skills (like picking up small objects or using cutlery). If you notice that your child is not meeting these milestones, it is important to let your paediatric rheumatologist know as this may prevent avoidable damage as their joints continue to grow.

Vaccinations

Children whose immune systems are suppressed due to JIA treatment cannot receive certain vaccinations. It is important to discuss your vaccination schedule with your paediatric rheumatology team. You may also need a special letter to permit your child to attend daycare without vaccination.

Protocols for illness

If your child becomes unwell while undergoing treatment for JIA and you are unsure what to do, it is important to contact your paediatric rheumatology team immediately. Protocols will need to be put in place for high-risk scenarios, for example if your child is exposed to chicken pox. If your child develops a fever or appears unwell, your doctor may advise that they stop taking their medication for a period of time.

Informing daycare

If your child is attending daycare, it is important to let daycare know that your child takes a medicine which suppresses their immune system. Speak to your rheumatologist in case special safety or hygiene measures are necessary for your child. As JIA treatment causes sun sensitivity, it is important that your child wears a hat and plays in the shade during outdoor time, as well as following the Cancer Council sun safety guidelines.

Procedural anxiety/needle phobia

If your child is showing signs of anxiety during treatments or phobia towards needles, it is important to speak to your rheumatology team as soon as possible. They will be able to refer you to an occupational therapist, child life therapist, psychologist or other practitioner who can support you and your child.

Childhood

5-12



Notifying schools

The support that a child receives at school can play an important role in how they adapt to living with JIA. Your child may miss days of school, need special adjustments to accommodate their needs, or turn up to class with visible side effects like bruises from treatment. Ask your paediatric rheumatology team for a hospital letter that you can give to their school to explain the diagnosis and any adjustments that could be made. It is also important to ask for a meeting at the school as soon as possible. The school should create an Individualised Education Plan, which they will update at the start of each teaching period.

In some cases, you may be able to access an occupational therapist or physio who can visit the school and recommend possible adjustments. In the classroom, wedges for writing can help reduce pressure on the wrist, and swivel chairs can minimise the force placed on their body. Portable chairs can be taken outside or to assembly if sitting cross-legged is uncomfortable. Your child may also need more time for exams, allowing them to stretch and walk periodically. Sports activities should be undercover where possible, and if your child has chronic uveitis they will need to wear goggles while swimming. The best thing you can do is to communicate with the school regularly, keeping the office and your child's teacher up to date with appointments and treatment changes.

School camps and excursions

It's important to speak to your school about any upcoming school camps or excursions. Your child should be supported to participate in school activities, but you will need to plan ahead so that you understand what type of physical activity is involved. You can consider if your child is capable of participating and whether adjustments can be made to help them. This will be particularly important if your child requires treatment while on the trip, as they may require additional supplies like sharps containers for needles. You may wish to be a parent volunteer to attend camp days and excursions to assist the teaching team with the care of your child.

Meeting others with JIA

Navigating JIA can be an isolating experience for both children and families. Arthritis Australia's affiliate organisations, along with groups like JAFA, MSK Kids and Zoe's Angels, have online and face-to-face support services where parents can connect, ask questions and offer support. There are also opportunities for young people with JIA to connect in a safe and supportive environment, including camps and initiatives like JAFA's KidsConnect with moderated Minecraft sessions. See **page 20** for a list of support communities.

Adolescence

13-18



Notifying high schools

Many of the adjustments that are useful for children in primary school also apply in high school. However, high school also presents new challenges, as there are more teachers who need to be educated about the condition. If your child is about to transition to high school, it is important to set up a meeting with the school in advance. Some high schools have a medical pass that students can wear, which allows them to leave the classroom at any time without explanation. You may need to apply for special exam provisions, especially during their final years of high school, and provide documentation for days of absence.

Preparing for the transition to adult care

By the age of 18 your child will need to transition from paediatric care to adult care. This means changing their care team and playing a more empowered and engaged role in their own care. It is important to prepare them for this transition as soon as possible, and these conversations should be happening with your rheumatology team at least two years prior.

Consent, decision-making and personal autonomy

As children with JIA progress through adolescence they will be more actively involved in decisions about treatment and develop greater autonomy over their bodies. It is important to encourage them to make decisions about their own care and advocate for their own care, especially as they near the age of 18.

Social media

As adolescents start using social media, it is likely that they will come across other people with JIA who recommend treatments and lifestyle changes that may or may not be evidence-based. It is important to have a conversation with them about social media, explaining that some of this information has the potential to be harmful.

Sexual health and risk-taking behaviours

As adolescents consider becoming sexually active and are exposed to risk-taking behaviours such as consuming alcohol and drugs, it is important that you and your rheumatology team have a discussion with them about how these actions will interact with their condition and medicines, so they can make informed decisions. Your child may also want to discuss contraception with their rheumatology team.

Adulthood

18+



Transitioning to adult care

Beyond the age of 18, people with JIA should be seen by an adult rheumatology service. The transition from paediatric to adult care can be challenging for many, as they will need to re-build their care team and adjust to advocating for their own care. In some states, transition clinics are available to assist in this process. In others it is important to work with your paediatric and adult rheumatology service, to make sure they will receive the support they need during and after the transition.

Work and study

Many of the adjustments that apply to primary and high schools are also useful at university or in the workplace. If your child intends to go on to further study (university or TAFE), they may be able to contact their study area coordinator or member of the faculty to discuss any concessions that could be made around exams and attendance. If your child gets a job, help them to consider how their condition may impact their work and what they may be comfortable telling their employer. For example, they may need to take time off for medical appointments or treatment, as well as times when they may be unable to work due to a flare. Their GP or rheumatologist should be able to provide a letter to their employer if they need to take sick leave, however it is not required that they disclose to the employer what their health condition is.

Fertility

Many people with JIA and their parents express concerns about fertility and contraception while on medication and in the longer term. Having JIA and undergoing treatment does not mean that your child will be unable to conceive, however some medicines are not suitable for pregnancy. It's important to initiate a conversation with your rheumatology team about fertility and contraception if you have any concerns.

Travelling and studying abroad

There is no reason why a person with JIA cannot travel or study abroad. However, it is important to plan ahead, confirming the travel dates with your child's rheumatology team prior to make sure the timing will not impact treatment. You will also need to ensure your child has all of the medication they need for the duration of the trip prior to leaving, and they may need a letter from their doctor in order to bring their medicines into different countries. Depending on the length of the trip, you may want to book in their next appointment for when they return, ensuring that the trip does not interfere with their regular appointments.

What you can do

This section covers all of the next steps you can take after reading this guide. It includes ways that you can advocate for improved care, support communities that can connect you to other JIA families, and extra resources to support you and your family as you continue to learn more.

Advocating for your child
Support communities
Extra resources

Advocating for your child

Advocating means speaking up for something or someone.

When you advocate for your child's care, you are asking for your family's rights and opinions to be respected by your care team.

We know that this is not always easy but the Standards of Care can help to make it clear what your rights are.



What do I do if my care is not meeting these standards?

Even when health professionals are trying their hardest to deliver good care, there may be times where the care described in the Clinical Care Standard is not fully met. If you have questions or concerns about your child's care, here are some things you can do:

In the first instance, it is best to raise any questions or worries with a member of your healthcare team.

If your concerns haven't been resolved, there are other paths you can take. If your care is through a public clinic, the hospital should have a process in place. You can usually find this on their website.

If you see a private rheumatologist, talk first to your GP. They can advocate on your behalf, or refer you to another rheumatologist for a second opinion.

How can I advocate for my child?

Both JIA families and health professionals want to see better care for children and young people with JIA. There are ways that you can get involved in advocacy, including:

Get involved with consumer advocacy groups such as Arthritis Australia.

Write to your local MP, advocating for better JIA services in your area.

Use this guide as a conversation starter, working with your rheumatology team to align your care with your needs.

Support communities



Australia

‘JAFA (Juvenile Arthritis)’ Facebook group

JAFA

A facebook group for parents of children with JIA to ask questions, share advice and offer support.

KidsConnect Minecraft game

JAFA

A fun, safe and interactive online platform where JIA kids can play Minecraft.

Teen Talk Chat Room

MSK Australia

A safe and secure online chatroom for teens aged 13-20 currently living with musculoskeletal conditions

Arthritis infoline

Arthritis Australia

A free infoline staffed by specially trained volunteers who are able to answer your questions about living with arthritis.

WA

JIA camps

AOWA

An annual camp for children with musculoskeletal conditions, giving children the opportunity to learn about their condition in a safe and fun environment.

The Arthritis Getaway (TAG)

AOWA

A weekend getaway for young adults (18-35) with chronic rheumatic conditions, ideal for those transitioning to adult care.

QLD

‘Juvenile Arthritis Parents and Families’ Facebook

Arthritis QLD

A facebook group for parents of children with JIA to ask questions, share advice and offer support.

Camp Courageous

Zoe’s Angels

A camp for children with JIA to connect with each other and learn from each other about how to thrive with their condition, including activities like kayaking, archery, trivia and games.

NSW

JIA camps

Arthritis NSW

Arthritis NSW deliver two annual camps for children affected by juvenile arthritis: Camp Footloose and Camp Twinkletoes.

ACT

Canberra JIA Support Group

Arthritis ACT

A facebook group for parents of children with JIA to ask questions, share advice and offer support.

SA

Kidsflix

Arthritis SA

Morning events that are free and inclusive for children living with JIA, including entertainment such as face painting, a new release children’s movie and complementary snacks.

VIC

Kidsflix

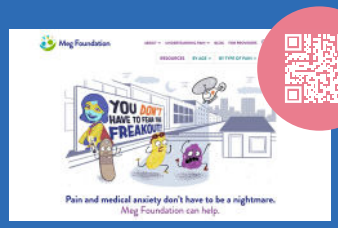
Arthritis VIC

Morning events that are free and inclusive for children living with JIA, including entertainment such as face painting, movies and snacks.

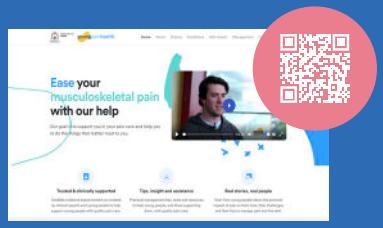
Extra resources

We've compiled some of our favourite resources on a range of JIA topics, created by organisations across Australia.

Pain management



Pain and medical anxiety resources
Meg Foundation



youngpainHEALTH
WA Department of Health

Procedures



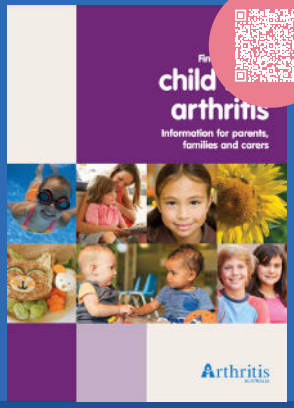
A child's guide: Joint Injection
RCH Melbourne

Families + carers

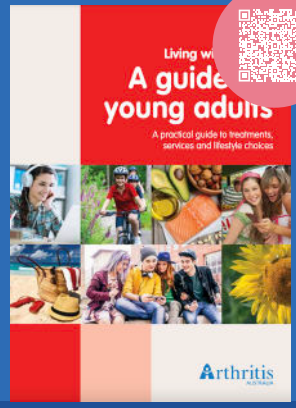
Young people

Teachers + schools

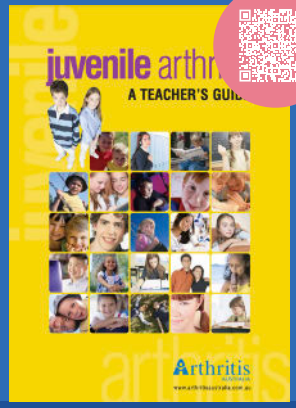
Transition to adult care



Finding out your child has arthritis
Arthritis Australia



Living with arthritis: A guide for young adults
Arthritis Australia



Juvenile arthritis: A teacher's guide
Arthritis Australia



Caring for a child with arthritis
MSK Kids



Preparing for your transition
Trapeze

We would like to thank all of the people who made this guide possible.

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Arthritis AUSTRALIA