My JIA

A booklet about living with Juvenile Idiopathic Arthritis

JAFA Juvenile Arthritis Foundation Australia
www.jafa.org.au

JAR Juvenile Arthritis Research
www.jarproject.org

Acknowledgements

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How to use this booklet

My JIA is an information booklet for children and young people, parents, carers and schools about managing life with Juvenile Idiopathic Arthritis (JIA).

Being diagnosed with JIA can be scary and daunting. You might not have even heard of the condition before. But you are not alone. JAFA is here to support you on your JIA journey.

This booklet will give you an outline of your condition and what to expect. It is written for 'you' – a child or young person with JIA. Your parents, carers, family and school will also need to read it. Electronic copies are available on our website to share with them.

Remember that your doctor, nurses and whole healthcare team are the experts. Ask them for specific advice when it comes to your treatment and medications, or if you need some support. When looking for more information, be careful what you read and who you listen to, including social media. Look for trusted sources, such as our website www.jafa.org.au especially the video's on talks by leading Australian paediatric rheumatologists at: www.jafa.org.au/jafa-symposia-series/

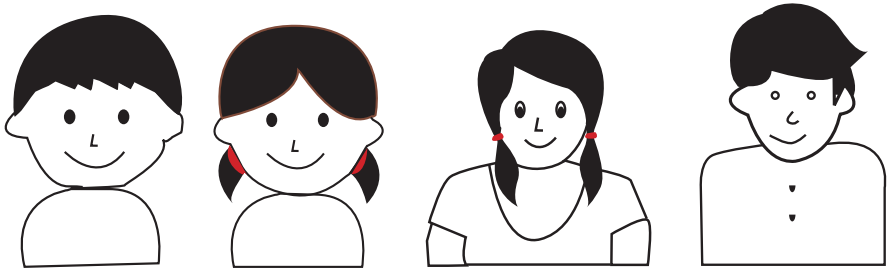
Above all, remember that you are not alone. Your paediatric rheumatology team and JAFA are here to support you.

Contents

What is Juvenile Idiopathic Arthritis (JIA)

Juvenile Idiopathic Arthritis (also called JIA) is an autoimmune disease. This means the body's natural defences (called the immune system) which are designed to fight off viruses, bacteria and infection get confused and start to attack your joints. This can cause pain, swelling, discomfort, fatigue, and reduced mobility.

- ***Juvenile*** – the arthritis began before the age of 16. When a young person with JIA turns 16, they still have 'JIA' because the condition is different from adult types of arthritis
- ***Idiopathic*** – means that the cause is unknown (which means we know it is not caused by injury or infection which will have been ruled out by your doctors)
- ***Arthritis*** – means that one or more joints are inflamed, usually for at least six weeks.



Signs and symptoms of JIA

For some children and young people, the first signs of JIA can be hard to spot. In others, they can be quite obvious. Not everyone with JIA has all of these symptoms, and they can change on a day-by-day basis. Sometimes they develop gradually, but sometimes they can be very sudden.

Children and young people with JIA have inflamed joints. Their **joints are sometimes swollen or warm** to the touch, but sometimes inflammation is hard to spot.

Their **joints may be painful**, and they may have reduced mobility and stiffness, particularly in the morning.

Some children and young people change how they move to avoid pain.

Many children and young people with JIA also experience **fatigue** (extreme tiredness that sleep does improve). Some develop a **fever**; some have a **rash**.

Some children and young people with JIA develop **inflammation inside the eye**. This is called uveitis. Symptoms of uveitis can be very hard to spot, so it is essential you see an eye specialist soon after you are diagnosed with JIA and regularly after. There is more information about uveitis later in this booklet.

Types of JIA

Your doctor will tell you which type of JIA you have. You don't need to know all about the different types, but you might find it helpful to know that there are different types – particularly when you meet other people with JIA. Each person with JIA is affected in a slightly different way. You are unique in every way, including your JIA.

Oligoarticular JIA

Also known as 'oligo JIA', this is the most common type of JIA. Oligo JIA is where 4 or fewer joints are affected in the first six months. In some children, it may spread to involve more joints (this is called 'extended oligo JIA'). It is more common in girls and often begins in young children (under 5 years). Oligo JIA carries a risk of developing uveitis (inflammation of the eye).

Polyarticular JIA

Also known as 'poly JIA', this is where 5 or more joints are affected in the first six months. This type of JIA is divided into 2 groups, rheumatoid factor (RF) negative or RF positive. Most children with poly JIA are RF negative. A smaller number of children are RF positive, more likely in teenage girls and sometimes considered early onset adult rheumatoid arthritis.

Enthesitis-related arthritis

In this form of JIA, also known as ERA, inflammation is in the places where the tendons attach to the bone. Children with ERA often suffer pain in the spine and hips.

Psoriatic arthritis

In this type of JIA, children may have a skin rash called psoriasis, which looks like a dry scaly rash, or they may have a relative with psoriasis. They may also have changes to their nails, which looks like pitting.

Systemic-onset JIA

Around 1 in 10 children with JIA have systemic-onset JIA (also known as SJIA). Children with SJIA usually have a non-contagious fever and rash. Inflammation not only affects the joints, but sometimes other parts of the body including the heart, liver and lungs. Some children with SJIA develop a rare but very serious condition known as macrophage activation syndrome (MAS) that may require urgent treatment. SJIA is different to other types of JIA because it is considered 'autoinflammatory' rather than autoimmune. This means a different part of the immune defence is involved.

Undifferentiated arthritis

This is where the arthritis does not fit neatly into any of the other categories. Arthritis can be part of other inflammatory diseases or post infection illness.

Uveitis

Some children and young people with JIA can develop inflammation inside the eye as well as their joints. This is called uveitis.

Uveitis can occur at any age, but the symptoms can be very hard to spot – especially in younger children. It is very important that, as soon as possible after a diagnosis of JIA, you are seen in an ophthalmology clinic. This is the specialist eye team who can check for uveitis. At your first appointment they will tell you how often you need to have your eyes checked.

At the appointment, you will usually be given a sight test first by reading a chart with letters, pictures or symbols. Then the eye health professional will use a special microscope (called a slit lamp) to look for any inflamed cells inside the eye which could indicate uveitis.

If you have uveitis, the doctors will talk to you about medication. It's important to treat uveitis, because it can lead to eye damage and sight loss if it is not treated.

By the time you notice there is something wrong with your eyes it might be more difficult to fix the problem. Also, you can develop uveitis even when your 'joint' arthritis in remission.

So make sure that you keep going to your eye clinic appointments even if you feel OK.

Getting diagnosed

You will normally be given a diagnosis of JIA by a paediatric rheumatologist. This is a doctor who specialises in JIA and similar conditions. They work within a team of other specialists (called a 'multi-disciplinary team') to ensure every child and young person gets the best possible care and support.

There is no single test for JIA. To reach a formal diagnosis, you will have a complete medical history taken and a physical examination. Most people will also have blood tests at this stage, and some will have X-rays or scans. This is done so the healthcare team can be sure that this really is JIA and not something else. Be aware that blood tests and X-rays can appear 'normal' in children with JIA. It can take some time to get all the results of tests back, so it might take a while to get a diagnosis. Your doctor will make a diagnosis of JIA based on their examination and your symptom history.

Being diagnosed promptly is really important, so that your treatment can begin as soon as possible. The aim is to get your JIA to stop being active (this is called remission) and with prompt and effective treatment this can happen for many children.

When you go to see your paediatric rheumatologist, they will want to check your joints. It helps if you wear comfortable but loose fitting clothes that make it easy for them to check your joints, or maybe take a pair of shorts to change into.

Sometimes there are unavoidable delays at appointments, so take some snacks and activities to keep busy.

Why me?

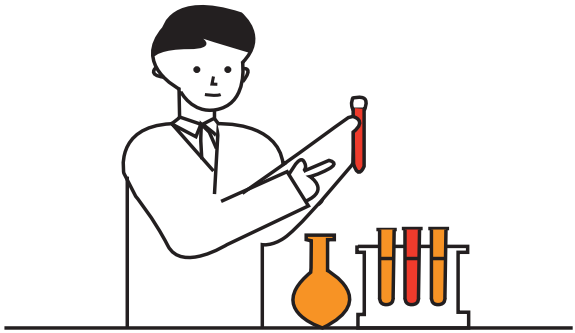
We do not yet know exactly why someone gets JIA. But one thing we do know – it is not your fault. There is nothing that you have done to cause the JIA, and nothing you could have done differently to stop it from developing.

JIA is not contagious. You did not catch it from someone else, and nobody can catch it from you.

Research has shown that a number of factors have to happen for someone to develop JIA. It appears you have to have a certain combination of genes, for example, and may need to experience a 'trigger'. But not everyone who has those genes and the same trigger will develop JIA. We simply do not know why some people develop it, and others do not.

Some people with JIA also have other autoimmune conditions themselves, or other people in their family may have similar conditions, but not everyone does.

Research is being done to understand the cause of JIA.



Your healthcare team

Once you have a diagnosis of JIA, your healthcare team will talk to you about treatment, medication and support. Your treatment and care plan will be specific to you, so it might be different to someone else with JIA. This is because your treatment will be based on the type of JIA you have, which joints are affected, whether you have uveitis, and a number of other things your doctors will need to consider.

Your ongoing care will usually involve medication, physiotherapy, a good healthy balanced diet, and exercise. You can find out more about these later in this booklet.

The exact members of your healthcare team will vary, depending on your JIA. It is important to note that although each member of the team has a specific role, they work together to give the best possible care to each child or young person with JIA. Here are some of the people you might meet:

Paediatric rheumatologist

This is a doctor who specialises in JIA and similar conditions. They will assess your needs and make decisions with you about treatment, and prescribe your JIA medications. You will have regular appointments with your paediatric rheumatologist.

Paediatrician, or other local hospital doctors

If you have 'shared care' between two hospitals, you will also see a doctor at your local hospital. This will usually be a paediatrician, and they will work closely with your paediatric rheumatology team to give you the best possible care.

Rheumatology Specialist Nurse

This is a nurse who specialises in paediatric rheumatology. They will often be a first point of contact if you have any questions or concerns about your JIA and treatment. You can usually contact them by phone or email between appointments with your doctors.

Specialist eye team

This is the team that check your eyes for uveitis. You may see an ophthalmologist (specialist eye doctor), an orthoptist (vision and eye heath specialist) or an optometrist (specialised optician).

Physiotherapist

A physiotherapist will assess muscle strength and joint movement and give specific exercises to target muscles that need extra support. Doing these exercises at home between appointments is an important part of your physiotherapy treatment. There is more information later in this booklet.

Occupational Therapist

Occupational therapists (OTs) can help children and young people with JIA participate more fully in everyday activities at home, school or college, and with hobbies and social activities. They can give recommendations to help make things easier, and advice on making changes to what you do or your environment. For example, if your fingers, wrists or arms are affected by JIA, they can give support to help with handwriting (such as recommending pencil grips, sloped desks or splints). They will assess your needs specifically, as each person with JIA experiences different challenges. If you feel you would benefit from seeing an OT, ask your doctor about this.

Other specialist doctors

Depending which joints are affected, you may also see other specialist doctors. For example, orthopaedic specialist doctors look after the physical structure of joints and bones. If your jaw is affected you may see a maxillofacial specialist. If you have psoriatic JIA, you will need to see a dermatologist (skin specialist).

Phlebotomist

This is the person who is an expert in taking blood. You may need to have regular blood tests. We know this can be difficult, but they really are important. The phlebotomist will have a number of strategies for making it less stressful.

Orthotist / Podiatrist

This is an expert in foot health. Many children with JIA have joints in their legs affected – hips, knees, ankles and feet. A podiatrist /orthotist assesses how your JIA affects your walking. You can ask your paediatric rheumatologist/ specialist rheumatology nurse if they think seeing an orthotist or podiatrist could benefit you.

Psychologist / Counsellor

It is quite common for children with JIA to feel a range of emotions including anger, fear, anxiety and loneliness due to their JIA. Psychologists help people deal with the emotional side of having to live with JIA. They can help children overcome their fear of particular treatments, for example. If you feel you would benefit from seeing a psychologist, ask your paediatric rheumatologist about this. You may want to ask your GP if there is any option for a Mental Health Plan to subsidise the cost of mental health consultations.

Radiographer

This is the specially trained person who takes images of the inside of your body. These can include ultrasound scans, X-rays, CT scans and MRI scans. If you are asked to have any of these scans, the radiographer and their team will be able to answer any questions about what the scan is looking at, although they will give the results to your doctor who will explain them to you (as the doctor will use that information along with other information they have about your condition).

GP

Your GP (general practitioner) remains an important part of the team. They will sometimes be involved in prescribing medication, referring you for scans, requesting blood tests, and keeping an overall eye on your JIA and health. They will also be the person you see for other health issues and concerns. Your GP can provide you with a chronic health plan if you need physio or OT in the community along with a mental health plan to access psychology or counselling services.

Pharmacist (chemist)

The pharmacist is the person who prepares and issues your medication. If you have any questions about how to take your medication, or any concerns about them, you can speak to your pharmacist.

Child Life /Play Therapist

Some hospitals and clinics have a 'child life' or play therapist. This is someone who is specially trained to assist children through play (including craft, colouring, imaginative play, stories and interactive games). They can help ease anxiety before an appointment or scan, before and during blood tests, or if you have an injection and are worried about it. If your hospital or clinic does not have a child life/ play therapist, you might want to inquire if your OT can help with this.

Medications

We know that it can be scary to start medication, particularly when you read or hear about the side-effects. But medical evidence has shown that not taking medications can lead to permanent damage. And this can lead to more pain, discomfort, disability and more medical treatment.

Your healthcare team will advise you on which medications they think are best for you. Sometimes it will be one medication, sometimes a combination of medications. They will make sure you know which ones to take, how to take them, and any side-effects to look out for. They will also monitor you regularly to check for side-effects.

To get the best outcomes, it may be necessary to take medications for several years. Just be aware that, over time, the combination of medications and the dosage may change as you grow, as your JIA changes, or if you experience side-effects.

Also remember that most medication can take a while before the benefits can be felt, so stick with it even if it doesn't appear to be working straight away.

Whilst research is continuing to help find the right treatment for each child every time, unfortunately it can sometimes take a while to get the right medications or right dosage. If you feel your medication is not working well enough, or you are unhappy with the side-effects, speak to your healthcare team straight away – don't change dose or stop taking medication without speaking to them.

When you are taking a medication, keep taking it even when the symptoms are gone - until you are advised by your healthcare team to stop. The aim is to get your JIA into remission and keep it there so you can lead a normal pain-free life. It can take a while for this to happen. Your paediatric rheumatologist will be able to advise when they are happy you have reached the stage to reduce or stop your medications.

This table shows the main groups of JIA medications, but remember that new medications are being developed all the time and your healthcare team will be able to give the latest advice. Many medications have several different names, depending on which company produces them. If in doubt, speak with a member of your healthcare team.

Type	Example	Purpose
Pain Medication (analgesics)	Paracetamol	Helps to control mild to moderate pain, and reduce fever. Does not reduce inflammation.
Non-steroidal anti-inflammatory drugs (NSAIDs)	Naproxen Ibuprofen Celebrex Piroxicam	Reduces pain, stiffness and inflammation.
Steroids (corticosteroids)	Prednisolone	Reduces inflammation and eases pain. They usually work quickly and are short- term treatments. May be injected into the affected joint, given orally or by infusion.
Disease-modifying anti-rheumatic drugs (DMARDs)	Methotrexate Sulfasalazine Hydroxycholoriquine Leflunomide	Reduces the immune system which is overactive. They take time to work (weeks or months) and control the disease over the long-term.
Biologics	Etanercept Adalimumab Tocilizumab Abatacept Rituximab Tofacitinib Secukinumab	These target specific chemicals or cells in the immune system. Sometimes given alongside DMARDs.

Things to remember about medications

Some of these medications work by turning down your immune system. The reason is to stop your immune system overreacting and attacking your joints. Depending on the medication, this can sometimes make you more susceptible to certain infections. Your healthcare team will be able to advise you and explain what you need to do to protect yourself, and what to do if you become unwell.

Vaccinations are an important part of protecting you from particular illnesses; some medications used for JIA can make certain types of vaccination unsuitable. For example, you may not be able to have 'live' vaccines if your immune system is reduced by certain medications. In some circumstances additional vaccination may be offered or a 'catch-up' vaccination program may be required to complete your routine vaccinations. You can check this with your healthcare team.

Guidance does change, based on up-to-date research and evidence, and your rheumatology team will know the latest guidance and how it affects you. Your GP may not be as familiar with this specialist guidance.

Certain medication may make you more likely to burn in sunlight. We recommend you follow standard "sun smart" recommendations.

"Slip, Slop, Slap, Seek and Slide"

Blood tests

Before you are diagnosed you may have a range of blood tests. There is no blood test for JIA, but these results help add to the overall picture for your doctor. Often, blood tests can appear 'normal'. You may also have regular blood tests to monitor your JIA and identify any possible side-effects of your medication. Below are some of the common things that you may see in blood test results. You do not need to understand these in detail as your doctors will be checking the results of your blood tests, but for those of you who want to know what all the acronyms stand for, here is an overview:

WBC – White Blood Cell Count

White blood cells help your body fight infection, and you have more of these cells if you get an infection. A high WBC can indicate an infection, although in some forms of JIA, you may have a higher WBC.

Haemoglobin is part of your red blood cells and helps carry iron and oxygen. A low level can indicate anaemia. Anaemia can sometimes occur in children with JIA or in other long-term conditions where there is ongoing inflammation but this is rarely severe in children with JIA.

This is a marker of inflammation. A higher ESR indicates that there is some inflammation, although it does not say where in the body it is or why. Colds, infections, illnesses and inflammation in conditions such as JIA can increase the ESR.

This is also a marker of inflammation. It tends to rise and return to normal more quickly than ESR. A high level indicates inflammation or infection.

Some medications can affect your liver, so your healthcare team will look at these results to identify any signs of side-effects.

One-off indicators

Certain indicators may be measured only once or occasionally as they are used to categorise patients, help doctors understand treatment options, and identify possible long-term outcomes. These include:

HLA – Human Leukocyte Antigen. This helps your body's immune system recognise your own cells. There are many subtypes, but doctors tend to look at HLA-B27 which has been linked with enthesitis-related arthritis (a type of JIA) in some patients.

RF – Rheumatoid Factor. This is used as an indicator of the subtype of JIA and can help doctors understand treatment options. RF is often negative, or absent, for most children and young people with JIA.

ANA – Anti-Nuclear Antibody. This looks for certain autoantibodies in the blood. These are proteins in the immune system. Being positive for ANA (sometimes shown as ANA+) may increase the risk for children with JIA for developing uveitis.

CCP - Cyclic Citrullinated Peptides. Like RF, these are indicators used by doctors to help understand the type of JIA and treatment options.

Physiotherapy

Physiotherapy, or physio, can be a very important part of your treatment. However, not every child with JIA will need physiotherapy so it's a good idea to talk to your paediatric rheumatologist about your particular needs.

If you do need physiotherapy, your physiotherapist will assess you to check the strength of different muscles, and to monitor joint movement.

Every joint in your body has a group of muscles to control its movement. Often in JIA certain muscles become weaker, which makes controlling the movement of the joint harder. If this is not corrected, your body will naturally try to compensate without you even thinking about it – but that can lead to a limp, or twisting, or bending to avoid using a joint that hurts.

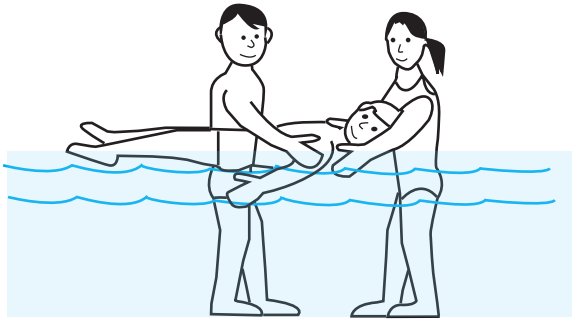
The physiotherapist will assess you and may give you specific exercises to target those muscles that need a bit of extra strength, to help balance the joint again. This will lead to greater control, better movement, and reduced pain. The set of exercises you are given will often be specific to you because they are designed to help your joints. Your physiotherapist will show you which exercises to do, tell you how often to do them, how many repetitions each time, and whether you need to use weights.

If an exercise ever hurts, contact your physiotherapist or a member of the healthcare team for support.

Physiotherapy helps build specific muscle strength, as well as improving and maintaining your flexibility, range of movement, stamina and fitness. Your physiotherapist will work with you, taking your goals and aspirations into account.

Hydrotherapy

You may be advised to have hydrotherapy too. With the help of a therapist, during hydrotherapy you will do exercises in a warm-water pool (like a swimming pool, but usually warmer). The water supports your weight and keeps your joints and muscles warm while you exercise (which can ease any pain you may have). The water also gives resistance, so moving against the water helps build up your muscles.



Remember that regular exercise is an important part of everyday life and will help your overall health and fitness as well as your JIA.

Bad days: 'flares'

One of the challenges of JIA is that each day can be different. You will have good days and, bad days where your JIA symptoms are worse. This can include pain or fatigue. Most people won't realise how you are feeling, and we know it can be hard to tell them. However, it is important to make sure people around you – those you know and trust – know how you are doing. Parents and carers can help, friends can support you, and teachers can make things easier for you – but only if they know you need an extra bit of help. But occupational therapy can be most helpful when everyday activities are affected – learning how to adjust to tasks or getting adaptive equipment to help make things easier and reduce fatigue.

A flare is a worsening of disease activity. That means your symptoms get worse and you need extra help.

During a flare one or more joints may become painful or tender, you may become fatigued and exhausted. Things that seem so easy most of the time can gradually become more difficult and affect any activities – combing hair, walking up steps, and doing up buttons. If this starts to happen, you can contact your paediatric rheumatology team.

Children with JIA may develop a temperature and rash or joint pain. A flare can happen at any time but is more likely after an illness or infection.

If you are having a flare, you may need to contact your rheumatology team.

Top tips if you experience a flare:

- Tell someone! People can only help if they know. You don't have to tell your whole class or announce it on social media (unless you want to), but make sure your family and teachers know so they can support you
- Keep moving! This will reduce stiffness and protect the joint but remember not to overdo it
- Be kind to yourself! Don't try to do everything that you can do on a good day but give yourself the time you need. This is sometimes called "pacing" yourself so that you don't overdo things when you are feeling good and then trigger a "bad" day the next day
- Use non-drug treatments! Heat and cold packs can help ease pain and reduce inflammation. Warm showers or baths can help with morning stiffness. Ask your healthcare team or pharmacist for advice
- Relax! Ok, telling you to relax doesn't work by itself, but find something that does work for you. Deep breathing, meditation, stretching, yoga, listening to music, and colouring can all help. It can be hard to relax, so it is best to practise these things when you are having good days, too, so they become easier when you really need them
- In addition to the prescribed medications you take as part of your treatment, you may find that creams with massage are effective for you. When taking any medication, always read the label and speak to your doctor or pharmacist
- Ensure that any medications are taken under the advice of your healthcare team so that they can check for interactions.

General health

JIA is very treatable and remission is achievable when you work with your rheumatology team. As well as medication and physiotherapy, there are some key things you need to do. Life with JIA isn't always easy, but it can still be rewarding.

Food and diet

Your body needs a range of different nutrients to be able to work properly. Healthy eating is all about getting the right amount of the right balance of nutrients.

A healthy diet is low in sugar, processed foods and unnecessary fats. It will provide you with a mixture of vitamins, minerals and other nutrients (such as calcium, which is important for bone health).

You may hear and read about diets claiming that eating or avoiding specific foods or food types can improve and even drive JIA into remission. There is currently little evidence about this and no specific recommendations about the benefits or harms of particular foods in managing JIA. But please be aware that a well-balanced diet is important for general health and normal growth and development. Some medications, such as steroids, can increase your appetite. Maintaining a positive attitude toward body shape is important as body shape may change as part of a normal treatment program. This may be different for each child. Please discuss with your paediatric rheumatology team if you have concerns about your body shape.

Eating well and exercising supports general well-being.

Sleep

When we sleep, our bodies use that time to grow and repair. Having enough sleep is also really important for every child and young person and helps with mental performance (how well you think) as well as physical health. If you do not get enough sleep, you may find your tiredness affects your physical health. You might find you ache more, or your joints are more sensitive than usual. And, because sleep helps your body fight infection, you might be more likely to become unwell.

Top tips for sleep:

Devices off! We love our gadgets just as much as you do, but switching off gadgets such as phones, tablets and games consoles an hour before going to bed helps you sleep. It's also best to not have gadgets in the bedroom if possible, as it can be very tempting to check that last message or play one more game.

Bedtime! Try to set and stick to a regular bedtime. This helps your body adjust to sleeping at a certain time.

Wind down! Use relaxation techniques to relax at the end of the day. This could include a warm bath, dimming the lights, breathing exercises or quiet music.

Keep it dark! It is usually easier to fall asleep if the bedroom is dark, well ventilated, and quiet.

Exercise helps! We talk about exercise in a moment, but it also helps you sleep.

Sensible mealtimes! Eating too much or too little before bedtime can make it hard to sleep.

If you struggle to fall asleep or stay asleep, speak to a member of your healthcare team for other suggestions.

Exercise

It is really important to keep active if you have JIA. Your muscles and joints need to be used regularly to maintain their function. Using them keeps them strong, which can reduce aches and pains associated with your JIA. Exercise helps your overall health.

You do not have to give up sport or activity because you have JIA. If you need advice on starting or building up exercise levels, your physiotherapist will be able to advise you. If starting something new, start gradually and build up slowly to help with your fitness and stamina levels.

Exercises and sports that are lower-impact can be particularly useful, like cycling, swimming or dance. But there is no reason that JIA should stop you from taking part in the sports you love either – martial arts, football and netball are all carried out at a high level by people with JIA. In fact, it is important to maintain an active lifestyle and take part in weight-bearing activities when you are able to for healthy bone development. Speak to your healthcare team if you need any advice.

Pace yourself and know your limits when it comes to your JIA. Make sure PE teachers at school and college are aware of your limits so they can support you too.

When you are first diagnosed with JIA, you may feel that you are in too much pain to do your favourite sports and activities ever again. Rest assured that once treatment plans are in place with the right medication, most children with JIA go on to lead very full and active lives.

School information

School plays a big part in the lives of children and young people. Some children and young people with JIA may face more challenges than their peers, so it is important for school staff to understand JIA and how to best support you.

It is not always obvious that someone has JIA. On some days they will look and act like any other child. But on other days they might struggle. JIA can cause pain, fatigue and reduced mobility, which can be worse on some days than others.

Teachers and other school staff will want to support you in school, and this section of the booklet is full of tips for you and them to make it happen. Letters to give to your school can be provided by your rheumatology team as required.

Give a copy of this booklet to your school. It is also available online at www.jafa.org.au.

Who needs to be involved at school?

At school there will be a number of people who can help you.

Class teacher

Your class teacher is usually the person who you will see most days at school. They will want to know how your JIA affects you so that they can help you and learn to recognise when you are having a difficult day. Make sure you talk to them about your JIA, so they know how your JIA affects you and any changes the school needs to make to support you.

Learning support

The learning support teacher or team at your school will be able to assist with adjustments for certain tasks and can provide guidance about the supports that can be accessed. They can also speak with your teachers about agreed adjustments and apply for adjustments for formal exams like NAPLAN and the final high school exams.

Other teachers, and teaching assistants

Depending on how old you are and the arrangements at your school, you may have a number of other teachers and teaching assistants that you come into contact with each week. Every teacher who teaches you should see a version of your healthcare plan so they can support you in their lessons.

Principal / Deputy Principal, and head of year

The Principal and Deputy Principal are in charge of running the whole school. In high schools where there is more than one class in each year, the role of the Head of Year is to co-ordinate and support the teachers and children across all the classes in the same year. They all need to know about your JIA so they can help support you. If you need changes made to your school day or special arrangements, they will be able to make them happen. This is particularly important in high school where you have lots of different teachers instead of one. The support of the Principal, Deputy and Head of Year can make your life a lot easier.

PE and sports teachers

It is important that your PE and sports teachers are aware of your JIA so they can support you, particularly as JIA can vary day-by-day. They may wish to speak with your physiotherapist for advice and ideas.

School nurse

Some schools have a school nurse, or a member of staff who is responsible for health matters. They keep records of children with long-term health conditions and information about your medications and treatments. If your school has a nurse it is a good idea to let them know that you have JIA.

School office

You may have a lot of appointments to see doctors, physiotherapists, podiatrists, ophthalmologists, and a wide range of medical professionals. The team in the school office will probably get to know you as you leave school for appointments, or come in late after an appointment, or if you have special arrangements to access the building before or after other children to avoid crowds.

Your friends and classmates

You don't have to tell your classmates about your JIA if you don't want to, but you might find it helpful to tell a close group of friends. They will then be able to support you throughout the day and look out for you when you have a bad day, just as you can support them when they are feeling low. That's what friends are for.

Learning Plans

Individualised learning plans need to be discussed with your school. They identify agreed goals, adjustments, considerations and supports required by the student in each education area. These should be developed in conjunction with the teaching and well-being support staff and updated regularly.

Healthcare plans

Some children may benefit from an individualised healthcare plan. We recommend that you and your family work with the school to put a healthcare plan in place. The school may have a template that you can use together. The healthcare plan should focus on:

- Your teacher listening to you and how you feel and understanding that how you feel may change from day to day, morning to afternoon
- Adjusting activities to allow you to continue to participate in school activities.

Read through this section and use it as a list of suggestions to consider.

Your healthcare plan will be shared with teachers and other staff at the school who have a role in supporting you. This is so they know what they need to do to enable you to learn effectively and participate fully in school.

Remember that you may be the first child in your school with JIA so it is important to tell your school all the information that will help them to help you.

Your medication

If you take medication during school hours, you will need to include these medications in your healthcare plan. If you do have side effects of your medication during school, then include this in your healthcare plan.

Vaccinations

Many children receive their routine vaccinations while at school. Your family will need to provide consent before you can have a vaccine at school. Your family will receive a letter telling them about the vaccination. If you are on medication to treat your arthritis, you may have to avoid live vaccines. If you aren't sure, check with your paediatric rheumatology team.

Impacts of medication

Many of the medications used to treat JIA turn down the immune system and can make you more likely to catch bugs and illnesses. This makes it very important for your school to encourage good hygiene practice in the classroom and the playground.

- Anyone with sickness (a cold, cough, or 'flu or diarrhoea should be off school for until better
- Good hand washing is essential for everyone
- Anyone with infectious illnesses should not attend school.

If you have not had chickenpox before, ask your school to let you know if someone you have been in contact with gets chickenpox, as it can be more serious if you are on certain medications.

Sitting

Depending on how your JIA affects you, you might find sitting on the floor difficult or painful. If that is the case, make sure your teacher knows so they will be able to make arrangements for you to sit on a chair when your classmates sit on the floor. This can make things a lot easier and less painful for you. If you sit on a chair, or ask to use a chair, ask the teacher to allow you to have a friend alongside you.

Shoes

Some children with JIA may find it difficult to wear particular types of shoes. Others may be advised by their podiatrist not to do sport or PE in bare feet as they need support from their shoes. If this applies to you, add it to your healthcare plan so your school knows how to help you.

Movement breaks

Sitting for long periods of time can sometimes make your joints stiffen up. It is really important that you move regularly to stop this from happening. Many schools build movement into lessons, but there are often times when the class will be sitting for a long time.

Speak to your school about movement breaks - this doesn't mean a big run around the building, or even leaving the classroom… just standing up and having a stretch can really help, or assisting the teacher to hand out papers or run messages to the office.

A discreet signal

We know that most people do not like to be different, and children with JIA often don't want to draw attention to themselves because they need something different from their classmates. We've found that having a discreet signal to tell the teacher you need a movement break, or some other form of extra support, can make it easier for you and them. This could be a card you put on your desk, which you turn over if you need a break, or something really subtle like putting your pencil a particular way round on top of your pencil case, or a hand signal that you can show without putting your hand up.

Whatever works for you and your teacher, use that and record it in your healthcare plan so other staff know, too.

Flares

Earlier in this booklet we spoke about flares. These are the times when your JIA is worse, and you may feel pain and discomfort. Many people also feel fatigued - this is extreme tiredness that doesn't get better with sleep, and it makes it hard to concentrate. When you put your healthcare plan together, make a note that sometimes you might have a flare. And it is best to tell your school when you have one. If you can go to school during a flare, your teachers need to know you are having one so they can support you.

They need to understand how a flare is affecting you. If you are not able to attend school during a flare, tell the school why you are off. They will need to put things in place to help you catch-up anything you have missed. Sometimes you might not be able to attend due to a flare but are still able to learn - your school may be able to help with remote learning so you don't miss out. Sometimes a flare can take a while to settle, and you may need new medication before it does. This may mean you miss school for a while, so keep in contact so they can help with remote work.

Your paediatric rheumatology team may provide you with a specific plan if you are experiencing a flare to help you manage the flare at home. But if you are concerned about how the flare is going or need additional help, you should contact your paediatric rheumatology team.

Appointments

Your doctors and healthcare team will need to see you regularly to monitor your arthritis and your medications. It is particularly hard for kids who live in regional areas. You will have appointments to see different specialists and these are often on different days. So, make sure your school is aware that you have appointments and put this in your healthcare plan. You can't help missing school so and ask them how they can help. Your school may request a medical certificate for your absences, ask your doctor or nurse for the certificate before you leave your appointment.

Physiotherapy

Sometimes you may need to have physiotherapy during the day at school as well as at home in the morning or evening. Your physiotherapist will explain what you need to do and how often. This would usually only be if you are in a flare and unable to take part in sports, or after another procedure or treatment. Speak to your school to make arrangements if this applies to you.

Other adjustments

You may find you need other adjustments to help you fully take part in school life. If you have an occupational therapist they will have some suggestions, too. Some examples might be that you need a pencil grip or sloped desk, or you may need to be able to move between lessons outside of busy times to avoid being bumped in a crowd, or you may need to do work on a computer rather than writing on paper. You may also need extra time to complete assignments or tests in class or have someone scribe for you.

If you need aids to help you move or find stairs difficult, you may need to use alternative routes around the building. Often schools will not only help you with these adjustments, they will usually allow a friend to join you too - that way you aren't alone and you have the support and friendship you need.

Classroom set up

If you are in primary school and have the same classroom every day, you could ask to have an OT do an assessment of the classroom and provide advice to your teacher about how to best set it up to suit your needs.

Carrying heavy school books

If carrying books or a backpack is difficult for you, please discuss this with your school to find a solution eg if lockers are available. Many schools have thought of creative ways around this, and with more digital resources becoming available over time, there is less need to carry so many text books.

School trips, residential trips and visits

Before any trip or activity, your school will complete a risk assessment and detailed planning. This may include any changes you need to support you with your JIA. Exactly what they need to do will depend on the activity or trip as well as your JIA. The school should speak to you and your family during the planning of the trip to make sure you know what is happening and how they will support you.

School attendance awards

Children and young people with JIA are more likely to have time off school than their peers because their JIA can make them miss school sometimes, especially:

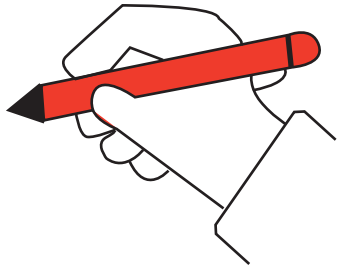
- During a flare
- Their medication may cause side-effects sometimes
- They may have a lot of medical appointments to attend
- They may be more likely to catch colds and other illnesses due to their JIA and medication.

As a result, children with JIA are almost never going to get 100% attendance. If your school issues attendance awards, you could ask them to exclude absence due to your JIA (flares, medication issues, appointments, or sickness) and base your attendance on the rest.

Homework

Talk to your school about managing homework levels so you don't have too much to do in one go.
Talk to your school about having a scribe for homework (someone writing for you). This could be a parent or family member.

Handwriting tips and other things that can help



For some children with JIA, handwriting can be a challenge, particularly if your fingers, hands, wrists, elbows or shoulders are affected. Here are some tips that might help, and remember an occupational therapist will be able to advise you further:

- Use pencil grips
- Use a sloping desk at school and home if that is more comfortable
- Use workbooks, don't rewrite the questions
- Talk to your school about typing instead of writing if that helps you
- Reduce the amount you write – your school will be able to help make this possible (for example, writing 3 sentences instead of 5)
- Have rest breaks
- Check your posture and ensure you have good supportive equipment
- Prioritise what is important – writing, not colouring, for example
- Speak to your school about whether extra time for exams would help.

Everyday life with JIA

As well as the symptoms of JIA, many children and young people may also feel isolated or alone. Sometimes your friends and peer group don't understand what life with JIA is like, and you may experience negative reactions from them. This is not your fault, but it can make you feel frustrated and alone. Sometimes you might not be able to join in because of your JIA and that can make you feel different, too.

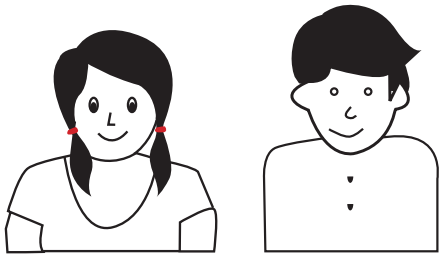
Most children don't like to be different. Most children don't want to stand out. Being the person with JIA in your school can sometimes make you feel like you stand out. It's important to find someone you trust to tell them how you feel. If you have a close friend or group of friends, talk to them and explain what JIA is like for you and how you feel. Otherwise talk to a member of your family. If you need someone else to talk to, ask a member of your healthcare team for advice.

As you grow older, you will want to do different things and become your own person. This is completely normal. But there are some things you have to remember if you have JIA. For example, you have to keep taking your medication. If you ever want to stop or change your medication, speak to your healthcare team first so they can support you. Remember, too, that physiotherapy and exercise are really important.

It's important to find someone you trust to tell them how you feel.

Teen issues

Life as a teenager is never truly simple. And JIA can add a layer of complexity to it. Your healthcare team will be able to advise you on specific issues and how they affect you, but there are a few things you need to think about in advance.



Transition to adult care

As you get older, the specialists and healthcare team that look after you will change. In some cases, you may also change hospital (from a children's hospital to an adult one). This is because you will gradually move to be under the care of a team of specialists who look after adults, rather than children. You will also become more responsible for your own care and treatment, rather than your parents or family taking the lead.

Most hospitals now start the transition process quite early and gradually, so you get used to the changes and how they will affect you. The exact age, and how they support you through the changes, will vary between hospitals and will depend on you, too. Through this your team will help you take a greater lead in your appointments, to give you the confidence to see members of your healthcare team independently, as well as being able to take on responsibility for your own medication and treatment when the time is right for you.

If you have any questions, you can ask your healthcare team about how this process works in your hospital, to help you all prepare for it. They will be able to reassure you. Remember, everyone in your healthcare team is there to help you.

The future

As yet, there is no cure for JIA. But whilst some people have symptoms of JIA for life, many children and young people find their JIA becomes inactive after a while (we call this remission). This can sometimes take several years, and you will need to continue with your medication and other treatments as recommended by your healthcare team until they advise that you can stop. Just be aware that, even when you are an adult your arthritis will remain as juvenile onset JIA because your symptoms started when you were under 16. Other types of arthritis that are diagnosed in adulthood are not the same as JIA.

JAFA is committed to fostering and funding research to understand and improve treatment and care of JIA, reduce pain and disability, and to find a way of preventing and, ultimately, curing JIA. We want everyone with JIA to achieve remission, and not need to keep taking medication. Unfortunately, achieving this may take a long time so, until then, we want to support you on your JIA journey. And we will continue to raise awareness that children and young people get arthritis and advocate for better access to services and support for you and your family.

It's really important for you to know right now that whilst you may have JIA, it should not control your life. There is no reason why you cannot live a full and active life despite your JIA. We know of people with JIA who are sports people who play competitively for their country; children competing in netball, cricket, football, karate and judo competitions. And young adults who are media professionals, researchers, scientists, politicians, radio announcers, motor bike racers, magicians, mums and dads. JIA may be something you have, but it doesn't have to be who you are. As one child with JIA told us:

"We are not our disease… we are our dreams!"

JAFA Juvenile Arthritis Foundation Australia

KIDSCONNECT

Connecting kids with juvenile arthritis

Join up for some online fun and games playing Minecraft

Meet other kids with juvenile arthritis

Hang out and chat

Safe, secure and moderated platform

Open to kids aged 7-17yrs

Visit www.jafa.org.au/kidsconnect to find out more and sign up for a welcome pack, or scan the QR code

Meet new friends and join in the fun

JAFA Juvenile Arthritis Foundation Australia

ABOUT JAFA

The Juvenile Arthritis Foundation Australia (JAFA) is the primary organisation for children and young people with arthritis. It is a registered charity, established in 2019 in response to the urgent need for a national voice dedicated exclusively to addressing the needs of children and young people with juvenile arthritis and childhood rheumatic diseases and their families and carers.

What we do

- Support, connect and inform families
- Political advocacy to improve services and support
- Raise and leverage research funding for better treatments, prevention and, ultimately, a cure

Connect with JAFA

- We invite you to Join the JAFA community via our website.
- JAFA has no formal membership and no fees – people are free to come and go as they please.
- JAFA is committed to connecting and informing you on upcoming events, programs, campaigns, new treatments and advances in treatments and our Online Symposia Series.

Join JAFA @ www.jafa.org.au/join/

Register for Australian Juvenile Arthritis Registry (AJAR)

If you have a child aged 0-17yrs with JIA or CRD or are a young adult aged 18-25yrs you can change tomorrow by registering with AJAR today.
Click here to see more and register: https://bit.ly/3P10fcM

Join the JAFA Private Facebook Group of parents, grandparents and older children from all over Australia

Email your questions or feedback to us at: info@jafa.org.au

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