Musculoskeletal
Health Australia
Knowledge. Choice. Connection.

JUVENILE IDIOPATHIC ARTHRITIS (JIA) SELF-CARE PLAN

A plan to help your child understand, manage and live well with JIA

Juvenile idiopathic arthritis (JIA) self-care plan

A plan to help your child understand, manage and live well with JIA

Musculoskeletal
Health Australia
Knowledge. Choice. Connection.

Table of contents

This plan was made possible through a generous grant from AbbVie

What is a self-care plan and how can it help me and my child?

Learning that your child has juvenile idiopathic arthritis (JIA) is the beginning of a long expedition into unfamiliar territory, and you're sure to have dozens of questions swimming around in your head.

Your child has no doubt had lots of tests, seen many doctors and they have possibly already started treatment. But where do you and your child fit into this plan? What are the steps that you, guiding your child, can take every day to help them live an active and healthy life where they can learn, play and have fun like any other kid, while managing their pain and other symptoms too?

That's exactly where this self-care plan comes in. With the collective wisdom and experience of other parents and their children living with JIA, and guided by the latest research, our medical advisors and MHA staff, we've created a plan that puts you and your child at the centre of managing JIA.

We've designed this plan to put you back in the driver's seat, providing you with the information, tools and support systems you need to become actively involved in managing your child's arthritis. Over time, this will mean that many of the resources your child needs for their self-care will already be in place for them as they transition to adulthood. At every stage, the more involved you, your child and your family can be, the more opportunities your child will have to live with less pain and with an improved quality of life.

This plan will guide you through understanding your child's condition and its treatments, through to the vital role of exercise and healthy eating, practical ways to manage pain, participating fully in school life, and supporting good emotional health – all the way through to navigating your child's transition to becoming a young adult, where you'll experience exciting and challenging times together, and your child will gradually take on more responsibility for their own healthcare. Importantly, this plan will remind you to take good care of yourself as a parent, ensuring you find extra support when you need it too.

While this plan is designed to be a practical resource that puts you and your child at the centre of their care, remember that it doesn't mean all the responsibility for managing JIA rests with you. Your child's healthcare team and MHA are always here for you, ready to provide you with information, guidance and support whenever you need it.

Using your self-care plan: The self-care plan isn't intended to be read from front to back – although you could certainly do that. We think the most helpful way to use it is to dip in, scan the contents and choose where you'd like to start. Each section is its own unique guide with information, hints, tips and links for more information.

Make notes and add your own thoughts, insights and experiences. This self-care plan is for you and your child – so make it your own. And if you have feedback on how we can improve this plan for others, please let us know.

Important note: This information is a guide only. Speak with your doctor about what's right for your child and their specific set of circumstances.

1.Learning about juvenile idiopathic arthritis

Things to remember

- JIA is a group of inflammatory joint conditions that affect children and teens under the age of 16. There are many different types of JIA.
- We don't know the exact cause of JIA, but we do know it involves the immune system mistakenly targeting healthy tissue in and around the joints, causing ongoing inflammation and pain.
- JIA is not hereditary and no one is to blame for your child getting it. You or your child could not have done anything to prevent it.
- Learning as much as you can about JIA is one of the main steps to managing your child's condition as well as you can.
- It's normal to experience a wide range of different thoughts and feelings you're your child is diagnosed with JIA. These will usually soften over time, but there's always help available if you need it.
- There's no one test that can diagnose JIA – it's diagnosed based on a combination of your child's symptoms, a physical examination, blood tests and scans.
- Learning about what each member of your child's healthcare team does, asking questions, and keeping track of your child's test results and symptoms helps you to be more actively involved in their healthcare.
- Family and friends and peer support groups can make all the difference in how both you and your child adjust to living with JIA.

Knowledge helps put you in control

Living with and managing your child's JIA well begins with learning as much as you can about it – because the better you understand their condition and what is happening in their body, the better you can manage it together.

With the right knowledge, you'll be able to ask your healthcare professionals clearer questions, become more involved in decisions about your child's treatment, understand how lifestyle affects their symptoms, and therefore play a more active role in managing their JIA daily and over the longer-term.

Finding out your child has JIA

If you've recently found out that your child has JIA, you're probably experiencing a whole range of thoughts and feelings.

You may be feeling shock, confusion and anger. Some people have a sense of disbelief or denial, especially if it wasn't a diagnosis they were expecting.

Many parents experience grief as they come to terms with what the diagnosis means for how they imagined their child's and their family's future.

You may also be feeling a sense of relief, especially if it has taken some time to get a diagnosis and finally have a label for what your child is experiencing. With a clear diagnosis, you may feel that you have a way forward with a treatment plan. Or, you may still be feeling that you have more questions than answers.

Depending on your child's age and ability to understand their diagnosis, they're likely to be experiencing a wide range of emotions too. As a parent, you need to acknowledge and validate their feelings, and be a source of stability and certainty for your child. This can be really hard while you're processing your own emotions.

It's helpful to know all of these thoughts and feelings are normal. Sharing how you feel and building a support network around you can help you cope – now and in the future.

Over time, your emotions will change and will usually soften. Life may have changed, but you'll begin to adapt and experience a new way of living as a family and managing your child's health.

Where to get help

It's important to recognise that as well as impacting your child's health and wellbeing, a diagnosis of JIA impacts you and everyone in your family. As a parent of a child with JIA it's important to remember the line we hear on the aeroplane all the time – "Please fit your own oxygen mask before helping others." Why is this an important message? Because if we don't look after ourselves, we can't help anyone else. Finding out your child has JIA can be tough and you need to make sure that your own mental health is a priority at this stage. If you feel you are struggling, please reach out and speak with your GP or call one of the many reputable mental health helplines.

The mental and physical wellbeing section of this self-care plan includes lots of information and links to support both your and your child's mental wellbeing at any stage of living with JIA.

Ava - 10yrs

"Mum took me to lots of doctors who looked at my swollen fingers and told me I should just play with Playdough. It was only when I was taken to a paediatric physio that they recognised my symptoms to be juvenile arthritis and immediately sent me to a rheumatologist. I was then diagnosed with polyarticular juvenile arthritis. I had over 40 joints with arthritis. It was scary because I didn't even know what arthritis was. I didn't know how it would change my life".

What is JIA and who does it affect?

JIA is a group of inflammatory joint conditions that affect children and teens under the age of 16.

Most people think that arthritis only affects older people. The truth is one in 800 Australian children has a form of JIA. It's one of the most common chronic health conditions that affects children.

If we break the words up, it provides some clues about juvenile idiopathic arthritis:

- **juvenile** – it affects people under the age of 16
- **idiopathic** – we don't know what causes it to occur
- **arthritis** – inflammation of the joint.

This tells us that JIA is a group of conditions that cause joint pain and swelling in children and teens under 16, for some unknown reason.

Other names for JIA include juvenile rheumatoid arthritis (JRA), juvenile arthritis (JA), juvenile chronic arthritis, and Still's disease.

We don't really know what causes JIA. But we do know that it occurs because of a malfunctioning immune system.

Our immune systems are designed to look out for and attack foreign bodies – like bacteria and viruses – that can make us sick. However, in JIA, the immune system mistakenly attacks healthy tissue in and around the joints, causing ongoing inflammation and pain.

JIA isn't hereditary, which means that it's not passed from parent to child. It's also very rare for two children from the same family to develop JIA, although that can sometimes happen.

It's really important to remember that no one is to blame for your child getting JIA. We don't know what causes JIA, and you or anyone else could not have prevented it. There are some factors that impact the development of JIA, and you could not have controlled or changed any of these.

While there's currently no cure for JIA, there are many things that can help control the symptoms – which is what this self-care plan is all about.

What are the symptoms of JIA?

The symptoms your child experiences will depend on the type of arthritis they have. Common symptoms include:

- pain, swelling and stiffness in one or more joints
- skin over the affected joints may be warm or red
- mental and physical tiredness, often called fatigue.

Any joint in the body may be affected – the most common are joints in the knees, hips, hands and feet.

Less common symptoms include:

- fever
- skin rashes
- feeling generally unwell
- eye inflammation, called uveitis, which we've covered a bit later in this section.

The symptoms of JIA vary from child to child, and are likely to change as they get older.

At times, your child's symptoms can become more intense, which is known as a flare. Flares can be unpredictable and often seem to come out of nowhere. Learning more about flares and how to manage them will be an important part of the self-care plan for your child.

There may also be times when your child experiences a remission – where their symptoms go away for a while.

Ava - 10yrs

"There is one nurse named Leanne and she helps me every time I go to a rheumatology appointment or need to take a blood test. She's really important to me. At school lots of my friends know about my arthritis and will be helpful and ask if they can get me a chair because I can't sit on the floor"

What are some of the common types of JIA?

There are many different types of JIA including:

- oligoarticular JIA
- polyarticular JIA
- systemic JIA
- enthesitis-related JIA
- psoriatic JIA
- undifferentiated JIA.

Let's look at each of these types in a bit more detail.

Oligoarticular JIA

This is the most common type of JIA – about half of all children with JIA have the oligoarticular type2. It's also sometimes called pauciarticular JIA. 'Oligo' and 'pauci' mean not many or few – so few joints are affected. Children with this type of JIA are more likely to develop inflammation of the eye, called uveitis.

Polyarticular JIA

Polyarticular JIA affects five or more joints. 'Poly' means many. Around 30% of children with JIA have polyarticular JIA3. There are two types of polyarticular JIA, based on whether rheumatoid factor (proteins produced by the immune system that can attack healthy tissue in the body) is found in the blood.

We have fact sheets that explain more about the two different types of polyarticular JIA:
- polyarticular JIA—rheumatoid factor positive
- polyarticular JIA—rheumatoid factor negative.
- Systemic JIA

Systemic JIA can affect many areas of the body, such as the skin or internal organs. It's the least common type of JIA.

Enthesitis-related JIA

Entheses are the tissues that attach tendons and ligaments to the bone. This type of JIA affects the entheses as well as the joints. You'll find more detailed information about enthesitis-related JIA in our fact sheet.

Psoriatic JIA

Children with psoriatic JIA have inflammatory arthritis in their joints as well as having the skin condition, psoriasis.

Undifferentiated JIA

This is where a child's arthritis doesn't quite fit into any of the specific types of JIA.

Other types of musculoskeletal conditions that affect children

There are other musculoskeletal conditions that can also affect children, including Perthes' disease, fibromyalgia, scleroderma and lupus.

Uveitis and JIA

Uveitis means inflammation of parts of the eye, and can be experienced by children with JIA. The inflammation is caused by the immune system mistakenly attacking the eye as part of the auto-immune disease process.

Uveitis is more common in children with oligoarticular JIA who have a positive blood test for antinuclear antibodies (ANA positive), and affects about 15-20% of these children. Uveitis affects about 5% of children with polyarticular arthritis4.

It's important to know that the most common type of uveitis has no symptoms (sometimes called silent uveitis). This means that it doesn't hurt, and you won't be able to tell if your child has uveitis just by looking at their eyes. Some children do have symptoms such as blurred vision, light sensitivity and in rare cases, eye redness and pain.

If uveitis isn't treated, it can cause permanent vision loss. This means that all children with JIA need to have regular check-ups with an ophthalmologist (specialist eye doctor) to check for uveitis and to start treatment if needed.

How is JIA diagnosed?

JIA can be difficult to diagnose because the symptoms differ between children, and many symptoms are similar to those experienced with other illnesses.

There isn't one single test that can be used to diagnose JIA, and your doctor will usually use a combination of tests to confirm your child's diagnosis, including:

- a physical examination to assess joint tenderness, flexibility, and stiffness
- blood tests to check for inflammation associated with JIA, which can also help to work out which type of JIA your child has
- scans such as x-ray and MRI (magnetic resonance imaging) to check for joint inflammation and damage.

- an eye examination.

If you visit your family doctor (GP) and your child has symptoms that suggest it might be JIA, they'll usually order some of these tests and refer you to a paediatric rheumatologist, in a paediatric rheumatology department at a public hospital. The rheumatologist may order more tests to help them make a diagnosis.

What does the future hold?

Every child's JIA is different, and every child responds differently to treatment.

You may be feeling very confused but the outcome for most children diagnosed with JIA is good.

JIA is considered a chronic condition because the affected joints are inflamed for 6 weeks or more and because treatments, although effective in relieving symptoms, can't actually 'cure' JIA.

Your child may have JIA for months or years, and many children will go into remission, where their symptoms go away for months, years, or forever. About 95% of children with JIA go into full remission before they become adults.

It's also really helpful to know that our understanding of and treatments for JIA are improving all the time.

The best thing you can do as a parent is to learn as much about JIA as you can and be there for your child as you navigate this journey together.

More to explore

- The MHA Kids page on our website has lots of resources that you may find useful including resources for school, past webinars, an illustrated children's book and accompanying video, and links to our teen chat group, Teen Talk.

- The Royal Children's Hospital Melbourne has lots of detailed information for parents about JIA, including information sheets and diagrams.

- Versus Arthritis (UK) has an interactive website with information on JIA, including information for parents and information for young people. You might find the table under 'different types of JIA' on the left navigation bar particularly helpful.

- Irish Children's Arthritis Network (ICAN) has a storybook for children that helps parents understand how their child with JIA may be feeling and provides practical tools to help children cope with many of the challenges of JIA.

- Arthritis Australia has a useful booklet, Finding out your child has arthritis and has an information sheet with more information on uveitis in JIA.

Keeping track of your child's test results

When your child is first diagnosed with JIA, your GP and rheumatologist will order quite a few different tests and you'll quickly start to learn a whole new language!

Your rheumatologist will order tests periodically to keep an eye on your child's JIA, how it develops over time and how it responds to treatments.

One of the ways that you can be actively involved in managing your child's condition is by asking for copies of test results and keeping them in a safe place. This can help you to:

- see how your child's JIA changes over time
- understand how your child's condition responds to different treatments and lifestyle changes
- have test results at your fingertips to share with other healthcare professionals.

Tips for keeping track of test results

- At each doctor's appointment where you receive your child's blood test results, ask if you can have a copy of these. Don't be shy about asking – it's your right to have a copy.

- Keep blood tests in date order where they're easy to find: a clear plastic folder works well. Or you may prefer to scan and upload the results to an app (see the tips box about health tracking tools later in this section).

- Most scans are now stored electronically, but you may be given physical copies of the scans to keep. These can be quite large, so a large clear plastic bag that's used to carry artwork or a large plastic storage box can be handy for storing these.

- Remember to take these test results and images along to any new healthcare appointment – such as when your child sees a physio or exercise physiologist for the first time.

Keeping track of your child's symptoms

When you go to medical appointments, do you find it difficult to accurately answer questions about how your child has been since your last visit? How they've been sleeping, how their symptoms have been, how physically active they've been, or how many flares they've had?

When you try to remember, it's very easy to get things wrong. Our memories aren't always reliable, and can be influenced by many other factors, including our emotions.

To help provide your doctor with a clearer picture of what's been happening – and so your child's treatment plan is based on facts – you may want to keep track of your child's symptoms.

To get started with tracking symptoms, you can simply grab a notebook and start jotting things down, try one of the apps suggested below, or download a blank template.

As your child gets older, keeping track of symptoms is something they can do for themselves, giving them a greater sense of independence and control of their health.

Note: If you feel like the focus on tracking your child's symptoms is making their pain worse, ease off or make your notes without your child's input.

Tips for health tracking tools

You might like to try a smartphone app or online tool to keep track of test results, exercise, eating, medicines, symptoms and more:

- Versus Arthritis (UK) has a free Arthritis Tracker app for iPhone and Android. It was originally designed for teens and young adults, but it's popular with adults too.
- You can also track symptoms simply by adding them to the free 'Notes' app on your smartphone – where you can also upload and save copies of test results.
- If you'd prefer to keep track of your symptoms on your computer or with pen and paper, try an internet search for a "symptom tracker template". You'll find many free templates that you can either use on your computer or print off and fill in by hand.

Working with your child's healthcare team

Your child's healthcare team may be made up of different healthcare professionals, with you and your child at the centre of the team.

You may see some of these healthcare professionals regularly, and you may see others only when you need help in managing a specific issue.

You'll be able to work best with the team and get the greatest benefit from their skills and your visits when you understand a bit more about the role they can play in your child's care.

If you live in a metropolitan area, most children with JIA are managed by a paediatric rheumatology clinic at a public hospital. Through this clinic, you'll have access to paediatric specialists including a paediatric rheumatologist, paediatric rheumatology nurse, paediatric physiotherapists (physios) and occupational therapists (OTs), child psychologists, play therapists and more.

There are often long waiting lists for these specialists in public clinics, and so you may see some of these health professionals (such as a physio or OT) in their private clinics.

If you live in a regional or remote area, you may need to travel to the closest major centre with a paediatric rheumatology department. Your GP will be able to connect you with other options, such as visiting specialists, local physios and OTs, and general rheumatologists.

Doctors and specialists

Your general practitioner (**GP**), **also called a family doctor,** is an important partner in managing your child's JIA and is likely to be the healthcare professional you see most often. They can help you to:

- manage their condition day-to-day
- manage any other health conditions your child may have
- make sure your child's health screens and vaccinations are up-to-date
- access other health professionals and services – including coordinating your child's care.

Paediatricians are doctors who specialise in children's health. You may already have a paediatrician, or your GP may recommend someone they think will be a good fit for your child and family.

Rheumatologists are doctors who specialise in diagnosing and treating problems with joints, muscles, bones and the immune system. Paediatric rheumatologists are doctors who specialise in diagnosing and treating children with arthritis.

Usually, you'll be referred to a paediatric rheumatologist to diagnose JIA. Your paediatric rheumatologist will be involved in the ongoing care of your child, including monitoring progress and side effects of treatment.

Ophthalmologists diagnose and treat eye problems, like uveitis. Your GP, rheumatologist or optometrist will refer you to an ophthalmologist to check your child's eyes for symptoms of uveitis.

Pain specialists are doctors who have done extra training and can provide medicines and other tools to help manage your child's pain. They may work with other people in your child's healthcare team, like physios and psychologists.

Allied healthcare professionals

Rheumatology nurses have specialised knowledge about different types of arthritis and can provide education and counselling, as well as help to monitor disease progression and coordinate other parts of your child's care. Paediatric rheumatology nurses have specialist training in musculoskeletal conditions that affect children, such as JIA.

Physiotherapists, often called physios for short, use physical therapies – like exercise, massage, heat and cold – as well as education and advice to help keep your child moving and functioning as well as possible. A physio can design an exercise program for your child and show you pain relief techniques.

Paediatric physiotherapists specialise in working with children and may use methods such as play therapy to make exercises and treatment more accessible (and fun!) for children.

A physio is likely to be an essential part of your child's healthcare team. Read more about how they can help in Section 2: Treatments for JIA and in Section 3: JIA needs exercise.

Exercise physiologists, also called EPs, can help to improve your child's health and fitness through exercise programs tailored to your child's specific needs. They can also support your family to make healthy lifestyle changes.

Occupational therapists or OTs can help reduce your child's pain, improve physical function and help them become more independent in their daily activities.

OTs can help you and your child learn better ways to do everyday activities such as bathing, dressing, eating and playing.

Paediatric OTs will also consider how your child can function best at school, playing sports, and in social situations. They can help with aids and equipment to assist with everyday tasks and at school – like pencil grips, writing wedges, wrist supports, an ergonomic mouse and keyboard, and seat or back support cushions.

Podiatrists specialise in foot care and can assess, diagnose and treat foot and lower limb problems, including problems with toes and ankles, and with walking.

A podiatrist can also advise you about supportive footwear and shoe inserts, called orthotics, which are made by an orthotist.

Hand therapists are OTs or physios who have had extra training and can help to treat and manage arthritis symptoms in hands, fingers, wrists and elbows.

Dietitians provide information and advice on food and nutrition. They can develop a healthy eating plan for your child and your family, helping you to get the different nutrients they need.

If needed, a dietitian can also support your child to lose or gain weight in a healthy way.

Psychologists can help you and your child work through your feelings, especially if your child is feeling anxious or depressed.

Some psychologists specialise in working with children and young people, and help them manage social, emotional or behavioural challenges.

A psychologist can provide different types of talking therapies, including cognitive behavioural therapy (CBT), and can help children learn ways to manage pain.

Your GP or hospital rheumatology clinic can recommend psychologists that will be a good match for your child.

Pharmacists can help you to understand more about prescription and over-the-counter medicines – and how to use them correctly and safely.

More to explore

We have a series of articles that provide more information about the different types of healthcare professionals and therapists who'll help your child to live well with JIA. These articles are written for people of all ages living with any type of musculoskeletal condition, including children with JIA:

- read more about the different specialists involved in your care
- learn more about different types of physical therapists and how they can help you
- find out about the different types of support available for mental and emotional wellbeing.

- Here are direct links to professional associations where you can search for a healthcare professional in your local area who has the expertise you need:
  - Find a rheumatologist
  - Find an orthopaedic surgeon
  - Find an ophthalmologist
  - Find a psychiatrist
  - Find a physio
  - Find an EP
  - Find an occupational therapist
  - Find a podiatrist
  - Find a hand therapist
  - Find a dietitian
  - Find a psychologist

Most of these links will include an option to search for a paediatric healthcare professional. This should be your preference if there's one available in your area, as they will have expertise in working with children and will often have experience with JIA.

Tips for getting the most out of your child’s healthcare appointments

- Write down your questions – and leave space to write down your answers.
- Ask the most important questions first.
- If you have a lot of questions or several issues to address in one appointment, ask to make a double or long appointment.
- Remember to take your child’s scans and test results with you.
- You might like to take another family member or a friend to your appointment (checking first that your child is comfortable with that). The other person may be able to help you ask questions and to chat with you afterwards about what your healthcare professional said.
- If you don’t understand something your child’s healthcare professional has said, ask them to explain it again.
- You generally don’t need to make treatment decisions on the spot. If your healthcare professional has suggested a new treatment for your child, it’s fine to tell them you need some time to think and talk about it with your family.
- Ask as many questions as you need to about any new treatment your healthcare professional suggests – including the benefits, side effects, risks and costs.

Questions to ask your child’s healthcare team

Sometimes, it can be difficult to know where to start with questions for your child’s healthcare team – especially if your child has been recently diagnosed with JIA or they’re starting a new treatment. Here are some questions that might help to get you started – many of these are most relevant for your paediatric rheumatologist and GP.

You might like to print this list and add extra questions of your own. Remember, there’s no such thing as a silly question!

- How severe is my child’s JIA?
- Do you know what type of JIA my child has?
- Do they have any damage to their joint/s?
- How often will they need to have blood tests and scans to check on the progress of their JIA?
- How will their condition likely progress?
- How will their condition change at different ages?
- What type of exercise program do you recommend?
- Can you recommend a paediatric physio, OT or exercise physiologist with experience in JIA?
- What treatment/s – including medicine, exercise and lifestyle changes – do you recommend and why?
- Does my child really need this test, treatment or procedure?
- What are the risks?
- Are there simpler, safer options?
- What happens if we don't do anything?
- What are the costs?
- What written information can you give me about these treatments?
- How will I know if the treatment is working?
- Will the dosage of my child’s medicine be changed throughout treatment?
- Will they need to have extra blood tests on this medicine?

- What should I do if my child develops a new or worsening side effect or symptom while on this treatment?
- What should I do if my child is already taking or needs to start taking any other medicines?
- What local healthcare services do you recommend for additional support?
- Are there specific symptoms you want me to track for future appointments?
- Does your practice have a paediatric rheumatology nurse I can talk with?

Involving your child in their care

If your child with JIA is very young, you'll be entirely responsible for their care, including leading doctor's appointments.

As your child gets older and becomes more independent, it's important that they become more involved in their own care. Instead of speaking for them, you can encourage them to ask questions, and to answer questions from doctors and practitioners about their symptoms, health and wellbeing. From around 11 years' of age (but this will vary with every child), it's ideal for your child to gradually become more involved in decision-making about their treatment. This will help them understand the side effects and risks of medicines, and can help them to develop responsibility for sticking to their treatment plan, including exercise and healthy eating.

Teens and young adults with JIA might like to attend appointments with their healthcare team on their own. This is an important and safe space for them to practise independence, and it may help them to discuss topics they feel hesitant to be completely open about with their parents.

Section 8 of the self-care plan, Growing up, includes more information about moving onto adult healthcare.

Keeping things as normal as possible – JIA doesn't define your child or your family

A diagnosis of JIA is going to have a significant impact on your child and your family's life. It can be a challenging condition as it can be unpredictable and vary from one hour or day to the next.

Depending on your child's age and level of understanding of what's happening, it can be confusing and upsetting for them and for you.

One of the most important things you can do is to try and keep your child's life as normal as possible. Of course, there will be times when things feel far from normal. During diagnosis, or through flare-ups, it's likely your child will need to take time away from school, and there may be lots of appointments to attend.

As much as possible, do your best to keep your child in school, playing, socialising and developing as a normal child or young adult.

Being a constant source of support, understanding and stability will be essential, as your child navigates their own journey with JIA, learning (and probably pushing!) their limits, and overcoming challenges around fatigue, pain and school.

Support from your family and friends

Support from your family and friends is important – not just for your child – but also for parents. Being responsible for your child's care is demanding and tiring. Having a reliable support network around you is one thing that can make everything a little easier.

To be able to offer support, your family and friends will need to learn more about JIA. They'll also rely on you being honest with them: so don't be afraid to let them know when you're struggling and need extra help.

Tips for talking to your family and friends about JIA – and asking for help

- Your family and friends are on a big learning curve with you and, just like you, will need to understand what JIA is, how it's treated, the ways it will affect your child, and what the future might have in store. You might like to email or print parts of this self-care plan to help them understand more. You may also like to take a close family member or friend to doctor's appointments.
- It's important that everyone can be honest about their feelings. Let your family and friends know how you're feeling – and ask them to share how they're feeling too.
- Let your family and friends know what type of support you would like from them. It can be difficult to ask for help and it can be difficult for others to know how to offer help – so be as specific as you can. Here are some examples to get you thinking about the type of support you might need and how you could approach these conversations with family and friends:
    - "I can get overwhelmed by the amount of information I need to remember in rheumatologist appointments. Can you come to an appointment with me and help me ask the questions I need answers to?"
    - "My child is experiencing a flare at the moment, and I'm struggling to find time to cook healthy meals. Do you think you could help by bringing over a dinner one night a week for the next few weeks?"
    - "Could you take my other children out for some one-on-one time with an adult on the weekend? I want them to have the support and attention they deserve, and I don't have the bandwidth to provide it to them all at the moment."
    - "Having someone else help with the housework would be the best possible thing for me right now."
- You may also need to tell family and friends what you don't want help with! If you have set up honest two-way communication from the start, this will be much easier.

More to explore

- The Royal Children's Hospital has a helpful resource on Managing the impact of JIA on your child's life. It covers topics including managing school and absences from school, mood, hobbies and sleep.
- The Royal Children's Hospital also has a fact sheet on how others can help a family who has a child with JIA.
- Arthritis Australia has a page on Living with JIA, which covers caring for your child and your whole family.

Support groups

There's nothing like talking with someone who knows what caring for a child with JIA is like. If you don't know anyone else who has a child with JIA, you might want to look into joining a peer support group. They're available all over the country. Some meet face-to-face, while others connect through social media and websites.

If you're interested in online support, you're not just limited to Australian groups. There are some very interesting forums, social media pages and blogs all around the world.

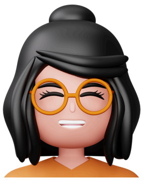
If you find some you like, remember to bookmark their page or join them so that you can get back in touch when you need to.

It can also be helpful and validating for your child to connect with other young people living with JIA. This can help them feel less alone, and have someone they can casually talk to about their symptoms or experience. Local peer support networks might have a kids and parents group, or even playgroups for children with JIA.

You'll find links for many of these groups under 'More to explore' on the next page.

Chloe - 10yrs

"What I love most about Teen Talk is being able to access it any time and any place. I love connecting with people from all over Australia. Because of its digital format, Teen Talk doesn't have to stop when we move into lockdown and it's accessible by everyone, having broken down the barrier of location and the struggle that can come with getting out of the house. Teen Talk is anonymous, allowing our group to talk freely and to feel more comfortable in putting ourselves out there".

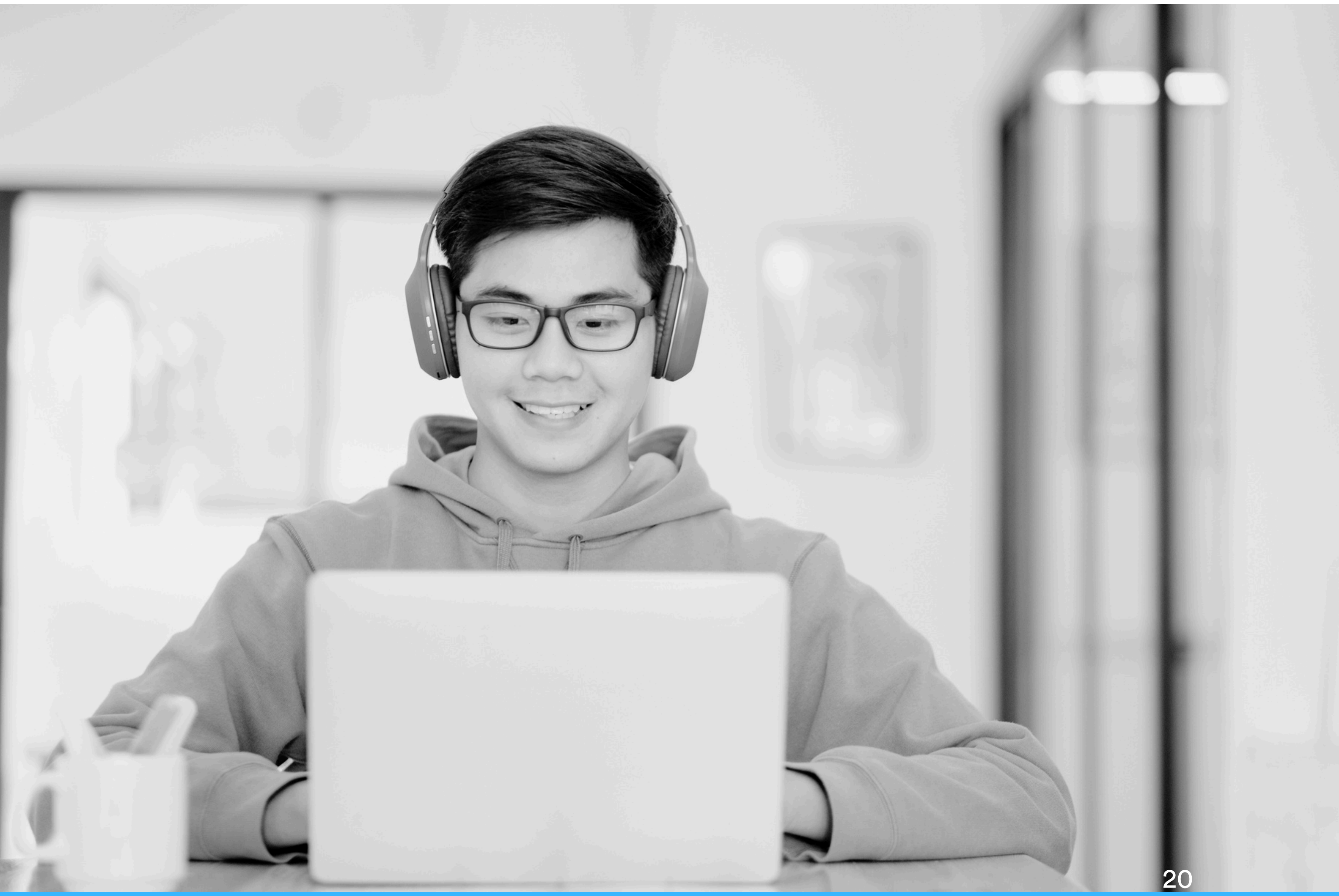


Georgina - Mum of Teen Talk User

"My son has been dealing with lupus since he was 2 years old; he's now 14. There is not much support available. He was so happy that as soon as he signed up for Teen Talk, someone asked how his day was. He also seemed to feel a sense of empowerment offering someone else encouragement".

More to explore

- We have a periodicMHA Kids newsletter that you may like to sign up to. It will help keep you up to date with everything happening at MHA Kids.
- You may also wish to follow us on our MHA Kids Facebook and Instagram pages
- Find out more about our network of support groups here.
- Call the MHA Help Line on 1800 263 265 to find out more about support groups in your area and that fit with your needs.
- We have an online chatroom for teens with arthritis and other musculoskeletal conditions called ‘Teen Talk’. The chatroom is for young people and run by young people. You can share this link with your teen.
- The Royal Children’s Hospital has links to Australian Support groups.
- Your hospital’s paediatric rheumatology clinic can also tell you more about local support groups.
- Creaky Joints Australia has good information about how peer support groups work.



2. Treatments for JIA

Things to remember

- There are many different treatments that can help manage your child's JIA so they can live a healthy and active life.
- Your doctor will prescribe medicine to help manage your child's symptoms. These medicines will vary depending on your child's symptoms and may change over time.
- Many children with JIA experience anxiety about taking medicines, and some may have a phobia (fear of) needles used to give injections or to take blood. Don't worry: we have lots of tips that can help.
- Physical therapies are an important part of your child's treatment plan. They include hands-on therapies to help relieve pain and stiffness and to improve mobility, movement and joint function, and exercises to keep joints moving and strengthen muscles.
- Your child's physiotherapist may use splints to help rest and support sore, inflamed joints and to stretch joints that are at risk of losing movement.
- Many parents are interested in trying complementary therapies for their child. There isn't as much evidence for these as for conventional therapies, but the evidence is increasing. Always talk to your doctor before trying any complementary therapy.

There are many effective treatments to help manage JIA

While there's no cure for JIA, there are many different types of treatments to help manage the condition and its symptoms so your child can continue to lead a healthy and active life. Because every child's experience of JIA is different, treatment will be tailored by your healthcare team to best meet the needs of your child.

Finding the right combination of treatments may take time, and is likely to change as the JIA symptoms change or your child grows. For most children and young people, treatment will include exercises to keep joints moving and muscles strong, medicines to reduce inflammation and pain management strategies.

Goals of treatment

Your healthcare team will talk with you about the specific goals of treatment for your child.

Generally, these goals are to:

- reduce inflammation
- reduce pain
- prevent or slow down any damage to joints
- make sure joints keep working as best they can
- help your child get back into their normal activities and prevent arthritis from interfering with a full and active life.

Medicines

Most children with JIA – regardless of the type – will need to take some form of medicine at some time. The medicines that your rheumatologist prescribes for your child will depend on their symptoms, including how much pain and inflammation they have.

It's likely that your child will need to take more than one medicine – because different medicines work in different ways.

Your rheumatologist will always start with the simplest medicines at the smallest doses and work their way up to more complex medicines and larger doses depending on how your child's condition responds to the treatments.

The main types of medicines used to treat JIA and help manage its symptoms include:
- pain relievers (also called analgesics) for temporary pain relief
- creams and ointments (also called topical analgesics and topical anti-inflammatories) applied to the skin over a painful joint to provide temporary pain relief
- non-steroidal anti-inflammatories (NSAIDs) to control inflammation and provide pain relief
- corticosteroids a short does of corticosteroids may be required to quickly reduce inflammation whilst other drugs kick in
- disease-modifying anti-rheumatic drugs (DMARDs), which control your child's overactive immune system
- biological disease-modifying medicines (bDMARDs), which are also called biologics and biosimilars. These also work to control the immune system, but in a much more targeted way
- joint injections to reduce inflammation in specific joints
- eye drops to treat eye inflammation (uveitis).

The medicines your rheumatologist prescribes may also change over time. It's common to need to try different medicines to find out which will work best for your child, or they may need another or a different medicine if their condition changes.

Ava - 10 yrs

"The medicine is scary at first but then you work out that it's actually helping you and you feel the difference. It then makes taking the medicine easier and worthwhile".

Kate - Mum of child with JIA

"As a parent it's really difficult to see your child in terrible pain and then have to take daily medication to manage it. My daughter has to take weekly injections, which is terribly challenging every week, however, I'm incredibly thankful that such medication exists because it allows her to enjoy a love of sport and playing with her friends".

Side effects of medicines

All medicines have possible side effects. These can vary a lot from child to child and may be mild or more serious. It can be worrying to read through the list of potential side effects for a medicine, but it's helpful to be aware of them, and talk through any concerns with your child's doctor.

This is one of the reasons why it can be useful to keep track of your child's symptoms, it helps keep you in tune with what's usual for them and to quickly notice any changes, which may be due to medicine side effects. If you have a younger child, you may be the main person who needs to watch for side effects, because they may be too young to notice or name the changes themselves.

Ask your doctor about the more common side effects of the medicine prescribed for your child, and what you should do if your child experiences any of these.

Biologics and DMARDs can increase the risk of infections. For children and young people, it's particularly important to be aware that these medicines can increase the risk of experiencing severe chickenpox. Make sure you let your rheumatologist know if your child has not had chickenpox. And speak with your child's childcare centre or school so you can be notified immediately if someone in your child's class develops chickenpox.

Some of the medicines prescribed for JIA can cause visible side effects, including weight gain and delayed puberty. Most teenagers are self-conscious about their body image, so these side effects can be upsetting, especially if your child isn't developing at the same pace as their peers. Being sympathetic and boosting their confidence with genuine compliments will help.

If your child is prescribed certain medicines, they'll need to have regular blood tests that check for side effects and monitor their disease activity.

As your child gets older, or if they're already a young adult, it's important that they have accurate information about the potential interactions between prescribed medicines and alcohol, drugs and contraception. We've covered this in Section 8 of the self-care plan.

Vaccinations for children with JIA

Some vaccinations can interact with medicines prescribed for JIA.

If your child is taking any of the following medicines, they should not have any LIVE vaccines:

- methotrexate
- anakinra
- etanercept
- adalimumab
- infliximab
- tofacitinib
- rituximab
- tocilizumab.

Live vaccines include:

- rotavirus vaccine
- MMR (measles, mumps, rubella) vaccine
- chickenpox (Zoster) vaccine
- BCG vaccine
- Yellow Fever vaccines.

If you're not sure whether a vaccine is live or not, talk to your child's rheumatology team. Your child should have all other recommended (non-live) vaccines, including a yearly flu vaccine. You may also wish to talk with your doctor about whether your child needs the meningococcal and/or pneumoccocal vaccines.

It's important to know that none of the COVID vaccines are live, and they're safe and important for children with JIA. All children 5 years and older are eligible for free COVID vaccinations in Australia.

How we can help

You can call the Back Pain | Arthritis | Musculoskeletal Conditions Helpline and speak to one of our friendly team to learn more about treatments for JIA and ask questions about your child's treatment.

Call 1800 263 265 (Monday to Thursday 9 am to 5 pm) or email helpline@muscha.org

More to explore

- The Royal Children's Hospital has a helpful Medication overview factsheet, which goes through each of the medicines commonly used to treat JIA.·This factsheet from the Royal Children's Hospital explains more about joint injections.
- We have created an infographic all about biologic treatments for JIA.
- Arthritis Australia has an information sheet on uveitis in JIA, which includes information on its treatment.

Our community's tips for dealing with medicine anxiety and needle phobia

Many children with JIA experience anxiety about taking medicines, and some may have a phobia (fear of) needles used to give injections or to take blood.

Helping your child to manage this anxiety or phobia is an important part of learning to live well with JIA. Here are some tips from our community that have helped their children to cope:

- Avoid unnecessary medication reminders I feel this can create anxiety
- Have everything you need prepared before alerting your child to what's coming up. Be organised
- Play inspirational music on repeat
- Encourage calm, relaxation and slow steady breathing
- If you feel your child has developed a significant issue around needles, please speak with their GP or rheumatologist about a referral to a psychologist who specialises in treating needle phobia.
- Place a favourite (or really strange) object in the room that your child can look at when taking the injection
- Remind your child they are safe and comfortable
- Build trust by reminding your child they have "awesome parents" who are trained/brilliant at giving an injection
- Provide your child with some control, such as counting down 3,2,1 before giving the injection
- We always ensure the medication is at room temperature as this apparently helps avoid a cold sting
- Always ensure the moisture from the antibacterial cleaning wipe dries before giving the injection to the area.
- Having something to look forward to always helps, but probably shouldn't be relied upon, e.g stamp on the hand, stickers or choice over family game.
- Our daughter likes to listen to a quick story while receiving the injection. The story starts when the injection does.
- Our daughter gets a metallic taste in her mouth and so chewing gum has helped with that.
- Room spray helps to reduce the scent of the antibacterial cleaning wipes
- We've started naming her injection "super juice". This puts a positive spin on the injection, experience and how it helps our daughter.
- When our daughter is receiving her injection, I like to comment in that moment that the experience isn't painful or as bad as she thought.
- Praise, praise, praise! Talk about anything positive from the experience, such as an improvement in how long it took to take the injection, using breathing techniques etc.

Physical therapies

Physical therapies are an important part of your child's treatment plan for JIA. Keeping your child active and mobile is very important for their physical and mental wellbeing, and is possible with the support of the right experts.

These therapies use a hands-on approach to help relieve pain and stiffness and to improve mobility, movement and joint function.

The most common therapies include physiotherapy, occupational therapy, massage, myotherapy and osteopathy.

Physiotherapy for JIA

Physiotherapists, or physios, are an essential part of your child's healthcare team.

When your child is first diagnosed, you'll ideally be referred to a paediatric physio, or a physio who has experience working with children and managing JIA.

Your physio will be able to assist by:
- assessing and monitoring joint range and function
- developing exercises to help keep your child's joints moving and make sure they're developing strength in their muscles
- suggesting adaptations to sports and activities that your child enjoys
- using hands-on therapies like ultrasound, mobilisation, massage and acupuncture to help with joint pain and inflammation
- provide advice on equipment to help protect joints
- give advice on splinting, and apply splints to joints.

How a GP chronic disease management plan can help

You may have heard people talking about having a management plan from their GP to help manage a chronic (ongoing) health condition like JIA.

These plans include five visits a year to other healthcare professionals – like a physio, OT or psychologist – and Medicare will pay for part of the cost. These five visits may be to one healthcare professional or be spread between several professionals.

If you're interested in this service, book an appointment with your GP, and let the receptionist know you want to create a chronic care plan for your child. You'll usually need a long or double appointment to do this.

More to explore

- Our article Physical or manual therapies tells you more about different physical therapies used to manage musculoskeletal conditions.
- The Royal Children's Hospital has a fact sheet about physiotherapy for JIA, as well as a specific resource for adolescents with JIA.

Daily care and hygiene

Both JIA and many of the medicines used to manage it can affect the way your child's immune system works, which means that they may be at increased risk of picking up infections. It's important to keep your child's skin clean with a daily shower or bath, regular handwashing, and careful wiping after using the toilet.

How this is managed will depend on your child's age – younger children will need your help to make sure they're maintaining good hygiene, and as they get older, they'll be responsible for these tasks on their own.

Thorough hand washing is important to help prevent the spread of diseases, especially after your child has used the toilet or been in contact with other people – at childcare, school or anywhere that they're likely to be exposed to germs.

For children and young people with more severe JIA or during a flare-up, these seemingly simple everyday tasks of showering, washing their hands and using the toilet can be a bit more challenging.

If your child is having difficulties in any of these areas, please ask your physio or occupational therapist (OT) for suggestions based on the specific challenges faced by your child, including ways to make using the toilet at school easier.

Section 6 of this self-care plan includes more information about aids and equipment that's helpful for children at school.

More to explore

- Find an occupational therapist here.
- Freedom Solutions is a not-for-profit organisation that makes and modifies equipment needs for people with a disability.
- You may be eligible for assistance with the cost of aids through the Victorian State-wide Equipment Program (SWEP). This can sometimes help with the cost of aids such as wheelchairs or alterations to bathrooms. Have a chat to your GP or OT about this program and your eligibility. It's important to note that there may be a long wait for items available through this scheme.

Complementary therapies

Complementary therapies include a wide range of medicines, products or practices that are not currently considered to be a conventional or mainstream medical treatment.

These therapies include acupuncture, supplements, herbal medicines, meditation, massage, aromatherapy and naturopathy.

Many parents are interested in exploring complementary therapies to try and help their child with JIA to:

- manage symptoms such as inflammation, pain and fatigue
- deal with anxiety and stress
- improve sleep.

While many people feel that using complementary therapies benefits health and wellbeing, there isn't as much evidence to support their use for JIA as there is for conventional treatments.

For many complementary therapies, there aren't enough well-designed randomised controlled trials to show whether or not they're effective.

More and more research is now focusing on these therapies, but because the evidence is still lacking, it's wise to be cautious.

If you're interested in using any complementary therapy, it's very important to remember that they may have side effects and they can interact with your child's other treatments. That's why it's so important to talk with your doctor about any complementary therapies you're interested in trying for your child.

More to explore

- Our article Do your research includes detailed tips to consider before starting a new complementary therapy, including helpful suggestions for doing your research and questions to ask.
- Our resource Complementary and alternative treatments includes brief information about many of the popular types of complementary therapies and links to professional associations for their therapists.

Surgery

Most cases of JIA can be managed using a combination of exercise and physical therapies, medicines, splints and other devices, and self-management like healthy eating and caring for your child's mental and physical wellbeing.

That means most young people with JIA won't need surgery. However if your child does, your rheumatologist will explain what is required.

3. JIA needs exercise

Things to remember

- Exercise is essential for all growing, healthy children and even more important for children with JIA.
- Exercise can help to improve your child’s stiffness, pain and fatigue, as well as increasing flexibility, building muscle and bone strength and improving independence and overall wellbeing.
- Exercise can also help your child stay at a healthy weight.
- A physio or exercise physiologist (EP) with experience in JIA can help develop an exercise program for your child.
- It’s ideal for your child to remain as active as possible every day, integrating play as part of exercise.
- You might be surprised to find that, with some adaptations, it’s possible for your child to participate in and enjoy nearly all sports and activities.
- Providing your child’s PE teacher with some guidelines will help them to adapt activities for your child where needed.

Why exercise is so important for JIA

Exercise is essential for all growing, healthy children, and even more important for children with JIA. Exercise can improve symptoms including stiffness, pain and fatigue. It helps maintain and increase flexibility and range of movement, build muscle and bone strength, and improve independence and overall wellbeing.

Exercise will also help your child maintain a healthy weight, as extra weight can put additional strain on already sore joints. Additional weight can also increase the risk of them developing heart conditions later in life.

As soon as possible after receiving your child’s diagnosis, they should ideally begin a personalised exercise program developed by a physio or exercise physiologist (EP).

The aim is for your child to remain as active as possible every day. For most children and young people, that means integrating exercises into play, and making them fun. With some adaptations, it’s possible for children to participate in sports and activities that they enjoy without causing too much discomfort.

Cat - 16yrs

“I find exercise amazing for me as it gives me a way to connect to other people even when I’m still in pain. I adapt the moves. I do karate so I just do what I can”.

Different types of exercise for JIA

If managed well, and supported by a physio or EP, children with JIA can safely do all types of exercise and play almost any sports they enjoy. It's important for you and your child to know that exercise won't damage joints, even joints that are inflamed and sore.

Children with JIA need to include exercises that improve their strength, but the exact types of exercise will depend on their age, how controlled their pain is, and what they enjoy. You're unlikely to get your child to do exercises that they don't enjoy!

The exercises, sports or activities your child does should ideally include a combination of:

Flexibility – stretching and range of movement exercises help maintain or improve the flexibility of joints and nearby muscles. They'll help keep your child's joints moving properly and ease joint stiffness.

Strength – to build muscle strength, provide stability to joints, improve bone strength, and improve your child's independence to perform daily tasks.

Overall fitness – exercise that gets your child moving and increases their heart rate – like brisk walking, swimming or cycling – will help improve heart and lung health and help with endurance, weight loss, and prevent other health problems like diabetes. This type of exercise is also called aerobic exercise, cardiovascular exercise or 'cardio'.

Some of the best activities for children with JIA are lower impact ones, and include:

Swimming and water activities – water supports your child's body and reduces the impact on joints. Swimming improves overall fitness and strength. Your child doesn't need to be swimming laps to get the benefits, they can be playing with friends or siblings, or taking part in a water play lesson.

Cycling is low impact and helps improve coordination, balance and overall fitness. Your child can join the whole family for a ride or cycle with friends. Make sure the bike fits properly to reduce the impact on their joints.

Yoga helps improve flexibility and strength, and lots of modifications can be made to accommodate stiff or swollen joints. You might like to find a local kids yoga class or find free videos online.

Ultimately, your child will want to do the type of sport, exercise or activity that feels good for them and they enjoy. As their parent, it's important to encourage them to move – even when they don't want to or they feel stiff, and help make it feel fun and not like a chore. Your role in encouraging exercise will change depending on your child's age and how involved in their own care they are able to be.

Remember that you're a part of a team, and your physio and EP can help you and your child find ways to integrate more movement into their life.

Ava - 10 yrs

"I love sport, and I being active is really important to me. I love to play cricket, which is great because it's low impact on my joints and is extremely fun and social too. I also play basketball. It's a great team sport and it keeps me fit. Every week I do swimming lessons and this is really great for my joints and to move them when they might be a bit stiff".

Tips from our community on balancing exercise and rest

Sometimes, children with JIA can find it difficult to exercise or participate in sports due to pain. An inflamed, hot or painful joint needs rest, but too little exercise and movement can cause muscle weakness, pain and stiffness.

It's important to help your child find the right balance of rest and exercise. As a parent, it can often be difficult to know what your child needs. Talking openly and honestly with your child and involving them in their care is one of the best ways to work out when rest is needed and when they should be encouraged to play or move their joints.

If you're not sure what the right balance is for your child, talk with your doctor, physio or exercise physiologist for some advice.

Here are some tips from our community that may help your child:

- Don't feel your child has to keep up with what all the other children are doing.
- Be a good example to your child on balancing exercise and rest.
- Check in with your child on how they are feeling. Maybe create a chart.
- Teaching your child that they'll have good days and bad days, and to adjust their activity levels accordingly.
- Provide your child with a variety of fun ways to rest – e.g. drawing, laying on the grass watching clouds, writing songs.
- Traffic light wrist bands – Red – pain; orange – some pain, but manageable; green – feeling great.

Sports safety for kids with JIA

Children with JIA can, and should, play sports. It's safe for their joints and overall health and is important for their broader social and physical development. Depending on the severity of their condition and which joints are affected, your child might need extra support to participate and enjoy playing sport.

It will be important for you to speak with your child's physical education (PE) teacher and sports coach to make sure they're aware of your child's specific needs and limitations, and how to best support them to participate.

Additional safety devices, such as splints or braces, may help your child take part in sports they want to and make it more enjoyable. Your physio can help with suggesting devices for your child.

The importance of play for kids with JIA

It's essential to encourage and support young children with JIA to play.

Playing is important for all children's physical, emotional and social development, and children with JIA are no different. In fact, play is even more important because it encourages children to move their joints and help to distract them from pain and fatigue.

Play for your child might include:

- **Playing in warm water** – Warm water can help soothe achy joints, so the bath is a great place for play. Plastic household objects like sieves and bowls make fun bath toys, and you might like to try bringing music into bath time too.
- **Finger puppets** will move your child's fingers and hands without it feeling like exercise. Ask them to act out a scene from their favourite book or TV show.
- **Play with friends** – Sometimes pain might prevent your child from participating in play, so when they're having days with less pain, getting together to play and have fun with friends is especially important.
- **Dancing** – Put on some great music and dance with your child. If they have sore joints this might look like just moving one part of their body, or sitting down to dance.

Ava - 10 yrs

"Exercise is very important for my body and it helps me have fun with my friends. I like to be involved".

More to explore

- Our MHA Kids school resource includes a section for your PE teacher to help them understand what your limitations may be and give them tips about how to adapt sessions to keep you involved.
- We have a really useful webinar Being active with pain that covers the benefits of kids with JIA staying active and tips on how to keep them moving.
- The Royal Children's Hospital has a helpful resource to share with sports teachers and coaches about small adaptations to sports and activities that can make a big difference to your child's ability to participate.
- Arthritis Foundation has lots of great information about children with JIA. You might find these articles on Sports Safety for Kids with Arthritis and Best Exercises for Children with JIA helpful.

4.Healthy eating for your child with JIA

Things to remember

- Even though there isn't a miracle diet for JIA, eating a wide range of healthy, unprocessed foods can help them feel as well as possible.
- An ideal eating plan for a child with JIA includes plenty of vegetables, fruits, wholegrains, legumes and beans, lean meat/tofu, along with nuts, seeds, fish and oil.
- Children with JIA are at increased risk of developing osteoporosis (brittle bones), so it's important to make sure they get enough calcium and vitamin D.
- Omega-3 fats found in oily fish, flaxseeds, chia seeds, walnuts and fortified foods have been shown to help reduce inflammation that's part of JIA.
- Sometimes finding the time to prepare healthy food for your child can feel overwhelming. We have lots of tips that can help.
- Maintaining a healthy weight is very important for children with JIA as being overweight can put additional strain on their joints and make symptoms worse.

What is the best eating plan for JIA?

Your body works best when you eat a wide range of healthy foods.

While there's no special diet or miracle food that can cure arthritis, most people find that they feel better if they enjoy a balanced eating plan filled with fresh, unprocessed foods, while limiting processed, fatty, salty and sugary foods.

What does this type of eating plan look like?

A healthy eating plan for JIA looks a lot like a typical Mediterranean diet and includes:

- foods that are as unprocessed as possible
- a rainbow of fresh whole vegetables and fruits (not juices),
- wholegrains like brown, black or red rice, quinoa, buckwheat, oats, as well as whole grain breads and pastas
- legumes like chickpeas, lentils, cannellini, red kidney and other beans
- raw, unsalted nuts and seeds
- fish, seafood, poultry and tofu
- healthy oils such as olive and flaxseed.

This type of eating generally includes eating less:
- red meat
- foods high in sugar, salt and fat
- highly processed foods.

Eating in this balanced way and drinking enough water can help your child to:

- keep up their energy levels
- maintain a healthy weight
- sleep better
- improve their mood
- have a greater overall sense of wellbeing
- prevent other health problems, like heart disease and diabetes.

And all of these effects may help to improve their symptoms – like pain, stiffness, inflammation and fatigue. It will also support your child's overall growth, bone, tissue and joint health.

Ava - 10 yrs

"Exercise and eating healthy really helps. I find it makes me feel stronger and more able to do things and not be in as much pain".

Cat - 16 yrs

"When I eat well and don't eat rubbish it makes me feel physically and mentally better".

This type of eating isn't just good for a child with JIA, it's the ideal way for all children and adults to eat for overall health and wellbeing. It's also important that your child with JIA isn't singled out or put on a 'special diet'. As much as possible, eating a well-balanced diet should be a goal for the whole family.

If your child has strong eating preferences, or struggles to eat well because of side effects of medicines, allergies or intolerances, you may want to work with a dietitian who can support you to develop a healthy eating plan that works for your child and your family.

Fad diets

As your child becomes a teenager and young adult, you'll have less and less control over what they eat (and most things!). Teenagers are particularly susceptible to restrictive diets, and being influenced by social media to try eating fads – such as eliminating gluten from their diet.

Having open and honest communication with your teenager with JIA is important, so that they understand the importance of their diet on their symptoms and can make good decisions for themselves.

If you're concerned about your child's eating habits, have a chat to members of your child's healthcare team: possibly their doctor, dietitian or psychologist. Depending on your child's age, they might like to attend a dietitian appointment by themselves to ask questions and address their concerns.

More to explore

- The type of eating plan we've described is sometimes called an anti-inflammatory diet. We've written an article about anti-inflammatory diets, the evidence for them, and tips to move your eating plan in this direction.
- Have a look at our webinar about nutrition for young people with JIA and musculoskeletal conditions.
- Arthritis Foundation USA has a blog post that explores the pitfalls of headline grabbing diets that you or your child might be hearing about through mainstream and social media.
- Our Handy tips for eating well with arthritis includes helpful tips for keeping your family's eating plan in balance.
- For healthy meal ideas, have a look at our Healthy meals on a budget and recipes.
- Arthritis Foundation's The ultimate arthritis diet looks at the different parts of the Mediterranean diet and how they may benefit joint health.
- If you need help in making changes to your family's daily eating, it's a good idea to chat with an accredited practising dietitian.

Eating for healthy bones

Childhood is a time when children are building their bone mass; creating strong bones for their future. Staying active, getting enough calcium in their diet and having regular, safe sun exposure is essential for growing bones.

Some children with JIA may be low in vitamin D. Steroids, which are often prescribed for JIA, can contribute to vitamin D deficiency.

Discuss with your child's doctor if this may be an issue for your child, and if they should be have their vitamin D levels checked. If they're low, you should work out a plan to manage this.

If your child doesn't have a vitamin D deficiency, the best way to make sure they're getting this essential vitamin is through safe exposure to sunlight for 10-15 minutes per day. Oily fish are also a good source of vitamin D.

Calcium is found in milk, yoghurt, cheese, soy milk, leafy dark green vegetables and almonds.
Find out how much calcium and vitamin D children need and learn more bone health tips in our resources.

What about omega-3 fats?

You've probably heard people talking about omega-3 fats (often called omega-3 fatty acids, or simply omega-3s) for joint, heart and brain health.

Foods and some supplements that are rich in omega-3 fats have been shown to help reduce inflammation that's part of JIA.

Omega-3s don't reduce inflammation as much as medicines, but when they're eaten through food sources, they don't have side effects and may have other health benefits.
So, it makes good sense to add a few servings of omega-3-rich foods to your weekly eating plan.

Foods rich in omega-3s include:

- oily fish and seafood including salmon, tuna, mackerel, sardines, anchovies and oysters
- flaxseeds and flaxseed oil (also called linseeds and linseed oil)
- chia seeds
- walnuts
- foods that fortified with omega-3s, including some dairy products, eggs and margarines.

Fish that are rich in omega-3 can have a strong taste, which means some children might not like them so much. You might like to try breaking up flakes of tuna or salmon in a pasta sauce, or in homemade fish patties with mashed potato, which children usually enjoy.

Fish oil supplements

If your child won't eat fish, you might want to chat to your child's doctor about trialing a flavoured, chewable fish oil supplement that's a rich source of omega-3 fats.

Your doctor will be able to advise on the correct dose for your child's needs and make sure it won't interfere with any other medicines they're taking.

It's also important that you don't confuse fish oils with fish liver oils – like cod liver oil and halibut liver oil. Fish liver oils contain vitamin A, which can cause serious side effects in large amounts.

Our community's tips for healthy snacks

Sometimes it can feel like it's impossible to prepare enough food to satisfy a growing child!

When your child has JIA, you want to make sure they're following a healthy diet, and that they also have snacks and treats like all kids.

Healthy snacks that can be alternatives to packaged or high sugar treats (which can cause increased inflammation and pain) include:

- carrot and cucumber sticks with dips like hummus
- popcorn without added sugar
- muesli bars that are low in sugar
- 'pizza toasts' – made by spreading tomato sauce or paste on toasted bread and topping with grated cheese and then grilling
- apples, bananas
- smoothies
- bread sticks
- carrot sticks
- berries on porridge

Healthy eating when your child has lost their appetite

Sometimes, the pain and fatigue of JIA can make it difficult for your child to eat enough and to eat well. They might have lost their appetite during a flare, or a new medicine might be causing nausea as a side effect and making eating difficult. With young children in particular, this can be a really challenging time for you as a parent.

When your child has lost their appetite, focus on encouraging them to eat nourishing foods that you know they enjoy and won't upset their stomach. It's often helpful for children to eat smaller meals or more frequent healthy snacks to keep their nutrients and energy up, even if they don't feel like a full meal. Remember that this will pass, but if it doesn't and you're concerned about your child's appetite, chat to your doctor or dietitian.

Helping your child stay at a healthy weight

Being overweight is linked to increased pain in children with JIA, so helping your child stay at a healthy weight is important.

Extra weight puts more pressure on already sore joints, and can increase the risk of your child developing other chronic health problems, including diabetes.

Some children will be prescribed steroids for their JIA, which can lead to weight gain. This can be challenging for young people, and especially for teenagers who are often very conscious of their body image.

As your child gets older and they have more independence over what they eat, you're likely to find that there's an increasingly delicate balance between encouraging a healthy and active lifestyle and your child becoming preoccupied with weight and body image. This can be a tricky area to navigate, and health professionals like a dietitian or psychologist can offer the support and guidance you and your child may need.

We've covered body image in more detail in Section 7 of this self-care plan: Your child's mental and physical wellbeing.

Quick and healthy meal ideas for all the family

Some weeks, preparing healthy meals for the family might be really difficult. As a parent with a child with JIA, you're juggling so much, and it's okay for some things to feel out of reach.

These tips might help you for the times when cooking a healthy meal feels hard:

- **Prepare meals** in advance and freeze them when you have more time and energy. This way you'll know that you have some extra meals ready for times when you don't have the time or energy to cook.

- **Look up options for healthy food delivery services** and consider using one of these for a short time.

- **Home-delivered food kits** can be a huge help when you're juggling a lot. There are many healthy options to choose from, and these kits can provide a good way of getting children involved with preparing meals.

- **Ask for help.** Family and friends always want to help but often don't know how to be useful. Asking for healthy meals and snacks to be prepared is a simple way people can help, and will make a big difference for you.

- **Seek advice.** If you need help planning meals, or finding simple ways to prepare nutritious meals, chat with a dietitian for information and advice.

Tips for low-effort meals

There are lots of healthy ingredients you can stock up on and store in your pantry or freezer to make low-effort meals easier when you have a lot to juggle. Here are some simple ingredients and ideas to try:

- **Low-salt baked beans** served on a baked potato or baked sweet potato.

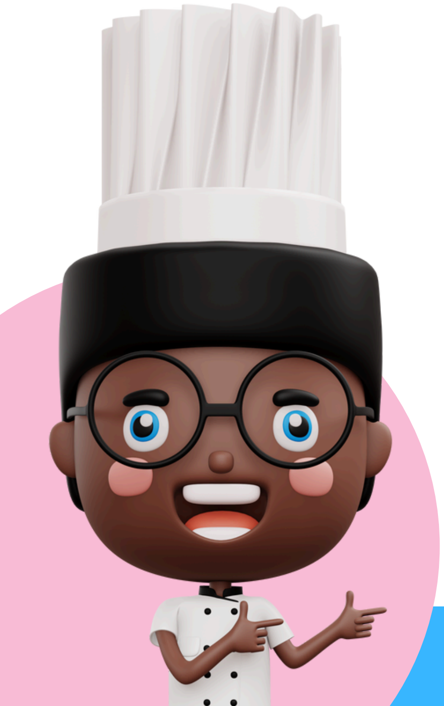
- **Frozen veggie burgers** cooked and served in a wholemeal pita bread pocket with any of your favourite burger toppings (like sliced cheese and tomato and crunchy lettuce).

- **Canned chickpeas or other beans and canned chopped tomatoes**, simmered with veggie stock and any veggies you have on hand to make a quick minestrone.

- **Free-range eggs** (which usually keep well in the fridge for weeks) scrambled, boiled or poached and served on top of wholegrain toast and baby spinach with some sliced avocado on the side.

More to explore

- Our article Now we're cooking! includes lots of tips for preparing meals with less stress.
- Try any of these 17 healthy no-prep recipes for the days when you just can't.
- Versus Arthritis' Five easy ways to eat well with arthritis includes some great tips and quick recipes for a super-simple breakfast, lunch and dinner.



5. Managing your child's pain

Things to remember

- Experimenting with and finding new ways to manage ongoing pain is an essential part of helping your child manage JIA.
- Your child's treatment plan, staying active and eating well will all contribute to managing their pain – and there are lots of additional strategies and tools you can use as well: from soothing heat and cold, to distraction, and using hydrotherapy.
- As a parent, you have an important role to play in helping your child to manage their pain – this includes not asking about their pain all the time while also validating how they feel and encouraging action.
- You can also help your child to learn relaxation techniques to help them manage pain during medical procedures.
- Helping your child to balance activity and rest using a strategy called pacing can help to reduce their risk of pain, flares and fatigue.
- Poor sleep, fatigue and pain are closely tied together, with each one making the other worse. You can help your child to break this cycle with good sleep habits.
- Flares are part of the unpredictable nature of JIA. Having a plan to manage them, including creating a care package with your child, can help give them more control.
- Staying connected with friends and activities that your child enjoys will help to distract them from pain and promote wellbeing.

Helping your child live well with ongoing pain

Experiencing and learning alongside your child to help manage their pain is a major part of living with JIA, and an important part of your child's self-care plan.

Living with the chronic pain of JIA can affect your child's daily activities, exercise, sport, sleep, energy levels, mood and friendships. In turn, these effects can then increase their experience of pain.

For example, chronic pain can make it difficult for your child to sleep well, which can make them feel more fatigued during the day. The inflammation of JIA that causes pain can also make them feel fatigued. When your child is more fatigued, their pain may feel worse and limit their activities more than usual.

Depending on the age of your child, they may not be able to understand or articulate this cycle of pain and fatigue, which can be frustrating for them and for you.

The good news is that there are many simple, practical ways to manage pain and the impact it can have on your child's life.

Having plenty of different strategies and tools that you can turn to when you need them can help give you and your child more control over their pain and make life with JIA easier to manage. As a parent, modelling and supporting your child to manage their pain is really important.

More to explore

- Our booklet Managing Your Pain provides an A-Z kit of pain management tools that you can dip into whenever you need them. It includes lots of practical suggestions that you can easily try out to see if they work for you. Some of the tools in the booklet are covered in this section, and there are many more in the booklet.
- You'll also find that a lot of the info in Section 7 of this self-care plan: Your child's mental and physical wellbeing, like mindfulness and using relaxation techniques, can help to manage your pain.

How JIA causes pain

In section 1 of the JIA self-care plan, you learnt how the immune system targets the joints in a child with JIA – resulting in the main symptoms of inflammation and pain. Your child's misdirected immune system causes fluid to build-up in joints, and the synovial membrane that lines joints to become inflamed and thicker than usual – all resulting in joints that become swollen or puffy, stiff and painful to move.

The way that each type of JIA affects the immune system and causes pain is slightly different, but in general, the pain of JIA is considered chronic pain. This distinction from acute or short-term pain is important to understand, because our brains and bodies respond to ongoing pain in different ways.

More to explore

When you understand what's really going on behind the scenes with pain signals and the way the body reacts to them, it can help you to see pain differently and perhaps be a little more open to trying new things that can help your child manage their pain.

You might like to have a look at:

- Our webinar Being active with pain that covers the benefits of kids with JIA staying active and tips on how to keep them moving.
- Pain, the brain and your amazing protectometer – The MSK 2018 Koadlow Lecture
- Treating pain using the brain – MHA Koadlow Lecture
- Our information sheet Persistent pain.
- PainBytes there's a whole section for young people. It includes some great videos from young people who share their experience of living with pain.
- Check out these strategies for coping with pain and this article from Arthritis Foundation USA for tips and strategies to help you manage.
- Younger children will enjoy our illustrated story book, The worst pain in the world.
- MHA Kid's Pain page – where you'll also find some additional pain resources and a list of paediatric pain clinics in Australia.

Tiana - 16 yrs

"You can be fine one day but in absolute agony the next. People don't understand that it can change so suddenly, so you don't get the help that you need because nobody actually knows how to help". Tiana, 16

Your role in helping to manage your child's pain

It's every parent's instinct to do everything they can to prevent their child from experiencing pain. When your child lives with a chronic pain condition like JIA, it can make you feel helpless and like you can't protect them as you'd like to.

Although it's not always possible to take away all of your child's pain, almost all pain can be reduced. There's a lot you can do as a parent to help your child understand and manage their pain, as well as things you can control to make periods of extreme pain less likely.

The ultimate goal of pain management for children with JIA, is to help them live a vibrant, joyful childhood like any young person.

Some practical things you can do to help your child's pain management include:

- **Learn their cues.** Depending on the age of your child, it might be difficult for them to understand and communicate their pain. It may show up in non-verbals ways such as being irritable, angry or very fatigued. Learning these non-verbal cues will help you be proactive in managing their pain, and reduce frustration for you and for them.

- **Healthy eating**. Maintaining a healthy eating plan for your child is something parents often have control of, depending on the age of the child. Eating an anti-inflammatory diet may help reduce the frequency and severity of JIA pain.

- **Sleep hygiene**. Support your child to practise good sleep hygiene by sticking to a consistent bedtime, and putting a relaxing wind-down routine in place for them. Good sleep is essential for pain management.

- **Don't ask about their pain all the time.** Try to not ask about your child's pain all the time, as this may make them become fixated on it. There's a delicate balance here with being aware of how they're feeling so you can help them, but still be able to report accurately to your child's healthcare team. So it might take some time to get this balance right.

- **Validate and encourage action**. If your child is experiencing pain, it's important to validate how they're feeling and be empathetic, but then to suggest solutions that might help. For example, if they're feeling too unwell to meet friends out, suggest they invite their friends over to watch TV or play some video games together. This will help your child learn that they do have control over many things, despite living with JIA.

In general, being positive and not becoming overwhelmed or upset about your child's pain is an important part of helping you all navigate this new reality for your family.

More to explore

- This article provides more practical strategies from doctors to help you respond to your child's pain.
- Arthritis Foundation USA has a helpful article on how parents' attitudes can influence a child's experience of pain.

Helping your child to manage pain during procedures

As part of their ongoing treatment for JIA, your child will have procedures, like blood tests and joint injections. This can be a scary time for children, and if they're anxious and tense it will increase the pain they experience.

There are lots of ways you can help your child relax and feel more comfortable with common procedures, including preparing them by being honest, being confident and calm during the procedure, and giving positive feedback.

This resource from the Royal Children's Hospital has lots of practical tips you can use to help for children of different ages.

Medicines

The medicines your child is prescribed for JIA all play a role in helping to manage their pain. At different times, your child's doctors and healthcare team may use different types of medicines to help manage their pain in different ways.

It's always important to balance the benefits of medicines with the side effects they may have. Also remember that medicines are just one part of the pain management tool kit, and they'll have the most benefits when you can support your child to combine them with other strategies like exercise, distraction, relaxation, healthy eating and getting a good night's sleep.

More to explore
- Section 2 of this self-care plan: Treatments for JIA includes an overview of the medicines used to manage JIA.
- Medications for pain in our Managing Your Pain booklet explains more about the different types of medicines used for pain and tips for using these.

Physical therapies

Physical therapies like physio, massage and occupational therapy use a hands-on approach to help relieve pain and stiffness and to improve mobility, movement and joint function.

Two treatments that children may find helpful for managing JIA pain include hydrotherapy and using a TENS machine.

Hydrotherapy is specialised exercise therapy run by a health professional such as a physio or exercise physiologist in a warm water pool. The exercises are tailored to your child's specific needs. Being in warm water and floating without impact on joints, can help manage pain.

Transcutaneous electrical nerve stimulation – otherwise known as a TENS machine or unit is a small, battery-powered device with leads that connect to sticky pads that are placed on painful parts of the body. It delivers very small electrical currents to the skin that stimulate nerves to relieve pain. You can often hire a TENS machine through your chemist so you can see if you like it before you buy.

While there's insufficient high-quality evidence to say if TENS is effective for treating JIA symptoms or not, there's evidence to suggest that some people do find it helpful in reducing pain and fatigue, and they're quite low-cost.

Have a chat with your physio about whether a TENS machine might be helpful for your child. Many physios have TENS units available for hire, so your child can try it out for a week or two before deciding if you'd like to buy one.

You can read more about many of these different types of therapies in Section 2 of the JIA self-care plan under Physical therapies.

Complementary therapies

Complementary therapies are widely used by parents to help their children with JIA manage their symptoms, including pain.

Read more about complementary therapies and explore other resources in Section 2 of the self-care plan: Treatments for JIA.

The importance of exercise

Being physically active is such an important part of managing JIA, we have dedicated a whole section of the self-care plan to it!

Read JIA needs exercise to learn all the different ways that being active, and continuing to participate in sports, play and activities, can help with the pain, stiffness, and fatigue of JIA.

Soothing heat and cold

Applying heat or cold to painful, stiff joints and painful muscles, tendons or ligaments (called soft tissue) can help to relieve your child's pain.

Some children prefer heat, others prefer cold – and some types of pain prefer either heat or cold. As a general rule, heat can relieve joint stiffness, muscle spasms and tension. Cold can reduce swelling and may be especially helpful for a hot, tender joint.

Depending on where your child is – at home, school, or out and about – there are many different ways you can use heat and cold: from hot showers, heat packs or an electric blanket, through to ice packs and cooling gels.

It's important to make sure that heat and ice packs are wrapped in a barrier layer such as a towel so that they don't damage your child's skin. Young children should only use heat and cold treatments under supervision from an adult.

When your child is experiencing pain, you may like to try:

- a warm shower or bath – for young children, play and toys in the bath will help distract from pain
- an electric blanket to help with night-time pain (make sure you turn the blanket off before they go to sleep, and follow any safety instructions)
- a hot pack placed on sore and stiff joints.

Helping your child become aware of whether heat or cold feels better for them, and equipping them to use this treatment independently when they're at an appropriate age will help them manage their pain when you're not around.

Your child might like to store a heat pack in their locker, or with the school nurse or an understanding teacher so they can use it at school when they're having a painful day or flare.

More to explore

- Our resource Heat and Cold Therapy includes more examples of heat and cold as well as important safety tips you need to keep in mind when using them.

Ava - 10 yrs

I love to play cricket and often my shoulder will hurt from throwing the ball during a game or training. I find a long heat bag is helpful to relax my shoulder and reduce pain. I also like the weight of the bag on my body too".

Balancing activity and rest: The art of pacing

It's easy for children with JIA to over-do things when they're feeling good. On the other hand, if they're experiencing pain, they may avoid activity and movement. Both ends of the spectrum – overdoing and avoidance – aren't helpful for managing chronic pain and can actually make their pain worse.

Pacing can be an effective strategy to help your child do the things they want to do by finding the right balance between rest and activity (both physical and mental). This can help to reduce the risk of pain, flares and fatigue.

Learning to pace themselves can be particularly challenging for children and young people. Children are likely to want to keep playing or participating in activities, even if they know it may result in pain or fatigue later on.

But it's also important that your child feels they have control and autonomy over their body, and that they aren't being overly managed in a way that makes them feel different from their siblings or peers.

As a parent, communicating openly with your child to help them work out their limits will support them to understand the rhythm of activity and rest that works best for them.

Steph - 15 yrs

"You just change things in a way that can be managed, so in P.E at school, if I have to run three laps of the oval, I would change it to pace myself and walk one lap and jog some of the rest. The teachers are aware that I have arthritis and know that I will always try my best, but sometimes need to pace myself to be able to get through the class".

Our community's tips for pacing

- We like to avoid overdoing our afterschool/weekend activities. Our aim is to keep a manageable balance.
- Meet with coaches and provide examples of how your child may need to modify tasks.
- Praising a child who makes a decision about their body based on how they're feeling.
- I think it's important that teaching staff at school are reminded of the need to trust the child with JIA and their judgement about their body.
- Provide some education to coaches and teachers about JIA. And be available to support coaches/teaching staff while your child is under their care.
- For school, my daughter uses traffic light coloured wrist bands to indicate how she's feeling throughout the day. Red – pain; orange – some pain, but manageable; green – feeling great. This is a quick and subtle way to let those around her know how she's feeling and what they can expect from her.

More to explore

- The first 15 minutes of the presentation Being active with pain explains the boom-and-bust cycle of pain, and the role that pacing plays in managing pain.
- Read our blog post to learn more about pacing.

Managing sleep and fatigue

Sleep problems, pain and JIA

It's common for children with JIA to have trouble falling asleep and staying asleep, often because of joint pain and inflammation.

Sleep is important for people of all ages, and it's especially important for healthy growth and development in children.

Unfortunately, there's a vicious cycle linking pain and sleep. If your child isn't getting enough quality sleep, it can lower their pain threshold. This in turn affects the quality of your child's sleep. Pain can affect their ability to be active – affecting their quality of sleep and pain levels. This can make your child feel anxious or stressed – which again can impact their quality of sleep and the amount of pain they experience.

The diagram on the right helps to visualise how this happens.

Helping your child develop good sleep habits is the first step in helping to beak this cycle.

The pain-sleep-cycle

Good sleep habits for kids

To help your child build habits around bedtime that can contribute to quality sleep, you might like to try:

- **Creating a calming bedtime routine**. This might include having a warm bath, reading a book together, and playing relaxing music. Your child can help design a routine that they enjoy.
- **Stick to a consistent sleep schedule**. Ensuring your child gets up and goes to bed at the same time every day, even on weekends, can help with quality sleep.
- **Reduce screen time before bed**. Encourage your child to stop their screen time 1 hour before bed – that includes TV, phone, tablet or computer screens.
- **Talk to your doctor about your child's medicine schedule**. Some medicines your child may be prescribed can make sleep more difficult. Talk to your doctor to see if those medicines can be taken early in the day to prevent them from disrupting sleep.

More to explore

- The Arthritis Foundation USA's article How JIA can affect sleep tells you more about the link between JIA and sleep problems.
- Arthritis Australia's information sheet Good sleep habits has helpful ideas on encouraging quality sleep for kids.

Fatigue and JIA

Fatigue can be one of the most challenging symptoms for children with JIA. The fatigue from a chronic condition like JIA is different from the everyday tiredness that people without an autoimmune disease might experience.

The fatigue of JIA can be described as an extreme, and sometimes overwhelming feeling of physical and/or mental tiredness – even exhaustion. And even though sleep and fatigue are linked, this type of fatigue often doesn't improve a lot with rest or sleep.

Several different factors that can contribute to JIA fatigue, including:

- autoimmune disease activity that causes inflammation throughout their body – the inflammatory process releases chemicals, called cytokines, that result in fatigue
- sleep problems – which may be due to pain or other things
- the emotional impact of living with JIA, which can cause physical symptoms like fatigue
- anaemia (low red blood cell count), which can be common in children with JIA
- side effects of some medicines.

Our community's tips for staying on top of fatigue

Like everything else when it comes to managing JIA, it's often the combination of self-care tools that you use that can help you better manage fatigue.

Many of the strategies that you use to help your child manage their pain can be used to manage fatigue – and therefore to manage the complex relationship between the two. These include:

- encouraging your child to keep moving – exercise can give them more energy and stamina and promote better quality sleep
- helping your child to learn relaxation techniques
- eating a healthy diet
- pacing activities
- getting a good night's sleep
- talking with your child's doctor about their treatment plan – your child may need better control of their pain and inflammation to improve their fatigue, or some medicines may be causing fatigue as a side effect. You and your doctor can discuss this and decide if a change to your child's treatment plan may help.

More to explore

- Check out our webinar on dealing with pain, flares and fatigue from occupational therapists Zoe and Huong from Supporting Kids in Pain (SKIP).
- The Arthritis Foundation USA's article Helping Kids with JA Fight Fatigue includes helpful tips for parents.
- Versus Arthritis (UK) has a comprehensive guide to Managing fatigue on their website, including a helpful fatigue chart that you'll find under 'Lists and charts'.

Flares and how to manage them

A 'flare' or 'flare-up' is a period of time when pain and symptoms are worse. Most children with JIA will experience flares.

We don't always know what causes a flare – they can sometimes appear for no reason.

Other times, a flare may happen because your child has been more active than usual, sleeping poorly, coming down with a cold or other virus, under increased stress (e.g. school exams) or changing their treatment.

Flares are temporary, but can be frustrating and painful while they last. Every child with JIA will experience flares differently: they may involve extra-painful joints, as well as flu-like symptoms, extreme fatigue and rashes.

As a parent, flares can be difficult to live with, because you can feel helpless while your child experiences increased pain and symptoms.

You have an important role to play in helping your child manage flares:

- **Develop a flare plan for your child with their doctor**. This may include many of the suggestions in the rest of this list.
- **Medicine**. Talk with your doctor about any changes to your child's treatment they might suggest during a flare. Your doctor will want to make sure that they keep your child's inflammation under control so it doesn't cause joint damage or affect their growth. Remember that you should not make any changes to your child's medicines or dose without speaking to their doctor.
- **Write down** what your child was doing before the flare. This can help you identify if there was something specific that triggered the flare. If there was a trigger, hopefully they can avoid repeating it. As children get older, this is something they can keep track of themselves, which will give them greater control over their JIA and its symptoms.
- **Manage stress** – as stress can increase your child's pain levels. This might mean reducing your child's workload at school for a little while, or speaking with a teacher if your child needs special accommodations during the flare period.
- **Pull out all of your pain management strategies**. Use heat or cold packs, play games to distract your child, sing songs … use all the tools that you know can help manage their pain.
- **Manage rest**. It can be tempting to keep your child in bed and limit their movement when they're having a flare and are in pain. But this can make pain and fatigue worse. Continue to encourage your child to move, but at a lesser intensity than usual.

- **Move gently**. Movement will help with the stiffness in your child's joints and muscles. Playing in a warm bath, a gentle trip to the playground, or a light walk around the block can help.
- **Splints** at night can help support joints and stop them from moving and causing additional pain. Talk to your doctor or physio about splints or braces.
- **Have a plan for school**. During a flare, your child might need to miss school. Speaking with teachers in advance about how they can accommodate your child's needs, like sending schoolwork home, can help to reduce disruption to learning. Section 6 of this self-care plan is all about managing school with JIA.

If you're concerned about the flares your child is experiencing, speak to your doctor. There may be other things contributing to the intensity or frequency of flares and extra things they can suggest to help.

Josh - 13 yrs

"It's sometimes frustrating when I can't do an activity because I'm in pain...like this year so my ankle doesn't hurt too much, I won't do cross country. I know this will help so I can do other fun activities".

Create a care package

When a flare strikes, imagine how it would feel to open a care package that you and your child have created ahead of time?

A care package is a collection of items that can help distract your child from pain and boost their mood.

Creating a care package with your young child can be a good way to talk to them about pain and flares. It can also be soothing for them to feel like there's something they can turn to when they're experiencing pain. Older children are likely to enjoy making a care package for themselves.

What's in their care package is entirely up to your child. Depending on your child's age, it may include a favourite magazine or comic book, a soft toy, puzzles, colouring books, crafts, photos of favourite memories, bath bombs, and your child's pain playlist. Your child might like to save episodes of a favourite TV show to watch when they're having a flare [AB1]Links to 'Create a pain playlist' box below.

Our community's tips for things to include in your care package

- Squishy ball
- Playlist on Spotify
- Soft toy to hug when having injections
- 'Well done' stamp
- Heat bag
- Inspirational cards/poster

- Reward chart
- Grip pen
- Massage voucher for parents who help manage their child
- Room spray

More to explore

- Our blog post on Coping with flares has tips that are relevant to people of all ages with any type of musculoskeletal condition, including children with JIA.

Create a music 'pain playlist'

There's plenty of evidence to support the use of music for managing pain. Listening to music has been shown to reduce anxiety, fear, depression, pain-related distress and blood pressure. And when we listen to our preferred style of music, it has an even greater positive effect.

It's not exactly clear how or why music can have such an effect on pain, but it may be that enjoyable music triggers the release of opioids in our brains (which is your body's own morphine).

Or it may be that music distracts your mind from focusing on your pain.

Whatever the reason, it's an easy, cost-effective and enjoyable way to get some relief from pain.

If you have a younger child, you can have some fun creating a pain playlist together – choosing songs that distract them, make them happy, or get them dancing and moving.
Older children and teenagers can create their own pain playlist and load it onto their phones or music player.

Read more about the power of music here

Staying connected: Helping your child focus on the people and activities that make them happy

Staying connected and involved with school, friends, sports and hobbies helps to engage your child's mind and energy and distract them from pain.

As a parent, one of your roles will be to help your child maintain their routine, and help them continue to do the things that bring them joy – sport, playing with friends, music, attending social events and any hobby they enjoy.

Some of these activities might need to be modified if they're not feeling well, but the most important thing is to resist the temptation for your child to withdraw from these activities altogether, which can leave them feeling disconnected and more focused on their pain.

More to explore

- Arthritis Ireland has a helpful information page for parents on JIA pain, including a list of things to do, and not to do, to help manage your child's pain.
- Section 7 of the JIA self-care plan is all about looking after your child's mental and physical wellbeing.

If your child is struggling with negative emotions and finding it difficult to stay connected, it's important that they talk with someone they trust. In some situations, that might be you. At other times, and depending on their age, they might feel more comfortable talking to someone else – a close friend or another family member, or a member of their healthcare team.

Being open and honest with your child about mental wellbeing and modelling good mental health management is an important part of your role.

Being a parent of a child with JIA can be challenging, so remember to look after yourself as well, and ask for extra support when you need it.

You can read more about mental health professionals here.

If you're concerned that your child is thinking about suicide or experiencing a personal crisis, call Lifeline on 13 11 14.

6. School

Things to remember

- Like all children, school is a vital part of your child's educational, social, emotional and physical development.
- Your child's school and teachers are essential members of your child's support team. You'll need to help them understand more about JIA and how it affects your child. We've provided lots of tips and resources to help you do this.
- An occupational therapist (OT) can help your child with aids and equipment that make schooling easier.
- With some simple planning, your child will be able to participate in PE and school camps.
- Sometimes, children with JIA can be targets of bullying. We have strategies and online support that can help.
- Moving onto high school can be challenging for some children with JIA. Exploring your child's new campus and talking to teachers before they start high school can help them work out solutions to any challenges.
- Children with JIA may need extra support to manage the stress around exams and may be eligible for special consideration. It's important to ask for the support your child needs.

The importance of school for children with JIA

Like any child, ensuring your child with JIA is in school as much as possible is critical for their educational, social, emotional and physical development.

When your child is first diagnosed they may be out of school for some time as your family comes to terms with living with JIA, and as you build a healthcare team and set up a treatment plan.

A primary focus of your child's treatment plan is managing their pain so they can participate in school and other activities as much as they can.

There may be times, such as during flares, when being at school every day is too difficult for your child. And that's okay. With a good support network, including teachers that understand how JIA impacts your child, children with JIA adapt quickly and can have a relatively normal schooling experience.

Speaking with your child's school and teachers

Your child's school and teachers are essential members of their support team.

In primary school and during school term, your child's class teacher is likely to be spending more awake hours with your child than you are, so it's vital that they understand your child's JIA.

It's ideal to meet with your child's teachers to help them understand JIA, and the steps they can take to help your child to participate in school life as fully as possible.

If your child is older, they might like to come to the meeting with you. Children in later years of high school might prefer to have that conversation with teachers by themselves.

You might want to talk to your child's teacher about:

- **General information about JIA**. You can print off or email resources to them from the 'more to explore' section below.
- **What a good day and bad day looks like**. As JIA affects every child differently, this will help the teacher understand the symptoms and impacts of JIA on your child. This includes the physical and mental implications of JIA.
- **Your child's biggest challenges**. Tell the teacher about the areas where your child has the greatest difficulty, and then discuss potential modifications the teacher might make to overcome these. For example, some children find that sitting for long periods can be painful, so the teacher might consider having stretch breaks for the whole class (which will benefit everyone!).
- **What to do when your child is experiencing pain**. This should be informed by their treatment plan and with support from your doctor. This could involve the teacher suggesting a hot or cold pack, or visiting the school nurse.
- **Signs that your child is experiencing symptoms and pain**. Children often try to hide their symptoms at school, so your teacher can look for subtle signs that your child is in pain and find discrete ways to check in with them.
- **An easy way to share a lot of this information** with your child's teacher is through an individual health care plan, which we've covered in the next section.

Individual health care plan

We've created an Individual Health Care Plan to help you share information about your child's JIA and the support they need at school. You can print the form and fill it in with input from your child's healthcare team, including their doctor, physio and occupational therapist.

Depending on your child's age, you might like to involve them in creating their care plan. This is an important step in your child becoming more independent and having autonomy over their care. It can also help them feel more confident about raising issues at school themselves.

Because JIA changes as your child grows and develops, you might like to revisit and update their health care plan each year to ensure the information is up-to-date.

More to explore

- Our booklet Caring for a child with arthritis has a whole section dedicated to how teachers, coaches and school coordinators can support children with JIA at school.
- This information sheet from The Royal Children's Hospital is a very helpful resource to print off and share with your child's teacher.
- Versus Arthritis (UK) has a page for older children, which includes tips for having conversations with their teachers about their JIA.
- Watch our recording of a presentation from Leanne Czerniecki, former Paediatric Rheumatology Nurse at Monash Children's Hospital on Communicating effectively with your child's school.

Aids and equipment

There's a huge variety of aids, equipment and gadgets that can make school activities easier for your child.

These include an ergonomic mouse and keyboard for your child's computer, a supportive chair or back support cushion, and foam rubber to make pencils, pens, brushes and cutlery handles easier to grip. Wrist supports and writing wedges can be helpful as older children write more.

You may want to buy your child a lunchbox and water bottle that's easy to open and Velcro shoes that are simpler to put on and take off.

An occupational therapist (OT) can give you advice on available equipment, and techniques to reduce strain on joints from common school activities.

PE

Your child can safely participate in most physical education classes (PE) and sports. Depending on their symptoms, your child might need small modifications to their PE classes so they can be fully involved.

Speaking with your child's PE teacher is a great first step. You might like to encourage them to check in with your child before class to understand their symptoms and pain level that day. Most PE teachers are experienced in adjusting activities to help everyone be involved.

Read more about the benefits of exercise and sports for kids with JIA in Section 3 of the self-care plan.

School camps

Like most children, your child with JIA will be keen to go on school camps and excursions. JIA shouldn't be a reason that your child misses out on fun school activities, but you may need to make special arrangements to make sure they can safely and fully participate.

Some things you might like to think through and communicate with their teacher include:

- How will your child's medicines be stored? Most biologic medicines need refrigeration.
- Can your child inject themselves, or will a staff member need to be trained to do this?
- What equipment or aids do they need to take with them?
- What is the plan if your child becomes unwell and needs to go home?
- If walking is a challenge for your child, and there'll be a lot of walking, is there an alternative?
- Will there be a quiet and private area your child can go to rest if they're feeling especially tired?

More to explore

- The Royal Children's Hospital has a helpful information sheet to share with PE teachers, including specific modifications they can make to support full participation for children with JIA.
- Versus Arthritis have some great resources too

Bullying

Parents, caregivers and teachers need to be aware of whether children are being bullied. The symptoms of JIA aren't just physical; many children struggle with self-confidence, anxiety and other mental health impacts. Bullying can add to these feelings and further impact your child's wellbeing.

Many children with JIA need to take medicines that can cause weight gain and have other side effects. Children who were previously able to keep up with their peers may now need to sit out or take a rest. They may at times walk with a limp. Changes in behaviour, mood and appearance may lead to bullying.

Preventing bullying is part of every school's duty of care towards all students, and schools must pay particular attention to ensure that a child with an illness isn't targeted.

- The National Centre Against Bullying has some great strategies to help out if your child is being bullied.
- Arthritis Foundation USA's article When kids with JA get bullied has helpful information on recognising the signs of bullying at different ages.
- It's often helpful for young people with JIA to talk with and get support from other young people who have similar health issues and 'get it'. Our Teen Talk is an online chat room that's a safe space for people aged between 13 and 20 with a musculoskeletal condition or chronic pain to connect with each other.
- Younger children might like to have a chat in class about JIA and how it affects them: knowledge is power and when other kids understand what's going on, it may help with acceptance. Some facilitators can give classroom talks with a model skeleton and sticker activities to get kids really involved. Get in touch with MSK by emailing info@msk.org.au if you'd like to organise a talk for your child's school.

Friendships

There may be times when your child feels like their friendships are being affected by JIA. This could include when they have absences from school, aren't able to participate in social events, or feel self-conscious because of changes to their body.

As a parent, you can't control your child's friendships, but you can support them to talk with their friends about JIA and how it impacts them. Children are naturally empathetic and are likely to be supportive and understanding.

If your child is younger, you might want to speak to their friend's parents to see if playdates and activities can be low impact and inclusive, especially when your child is experiencing more pain or a flare.

All children (and adults!) want to feel included and develop friendships. If you're concerned about your child's friendships, they might need extra support with their emotional wellbeing. It could be a good idea to chat with your school's student counsellor or your child's doctor about extra mental health support that's available.

Missed days

Children with arthritis will need time off school from time to time to attend appointments, and may need time off when they're unwell. If this time stretches beyond a couple of days, you'll need to make arrangements to ensure they're not falling behind with schoolwork.

This is important academically and ensures your child feels involved and motivated with their studies. It's also important that they don't start feeling isolated from their friends and classmates. You might like to invite a close friend or two over to boost your child's spirits and help them feel connected to what's happening at school.

These days, most schools have virtual learning arrangements in place, so it's worth asking your child's teacher or school coordinator if your child can attend some lessons virtually when needed.

Managing fatigue

Fatigue can be one of the biggest challenges for children with JIA. Fatigue can result in missed school days, and difficulty participating in sport, music and other hobbies.

It can be difficult to balance your child's need to stay engaged with school and friends with times when they need more rest or quiet time. This is where the art of pacing comes in, which you can read more about in Section 5 of this self-care plan. A few techniques that might help for managing fatigue at school include:

- **Later starts** – If your child struggles with fatigue and stiff joints in the morning, you might like to try a later start to the school day to give them time to warm up their joints.
- **Half days** – A reduced schedule, such as doing half school days, can be a useful technique especially when returning from a prolonged period of absence.
- **Using the sickbay** – Working with the school nurse and your child's teacher, your child might like to have quiet time each day where they can have a rest in the sick bay or another quiet area.
- **Indoor activities** – If playing outdoors or on the playground is challenging for your child due to fatigue or pain, their teacher could set up an indoor activity such as watching a movie or playing board games and encourage other students to participate so they're not singling out your child.

Moving onto high school

High school is an exciting and challenging time for all young people, but it may be particularly so for children with JIA. It's a good idea to start thinking early on about specific challenges your child might face, and how best to deal with them.

If moving onto high school means starting at a whole new school, you may wish to organise a meeting with staff at the new school so that you can fill them in on all the important information – and give them a copy of your child's individual health care plan.

One of the biggest differences between primary and high school is that high school involves different teachers for different subjects, so there'll be more people to keep informed. That's why it's really helpful to have a good relationship with one key person at the school. They can be the person on the ground who can advocate for your child when you're not there.

If your child is starting at a new campus, they might feel anxious about getting around, and if there are large distances or sets of stairs between classes. You might like to contact the school and organise a day you can come in over the summer holidays to have a tour and discuss ways they can get around in a low-pain way. Moving between different classrooms can present challenges for young people with JIA, as they might need to be carrying heavy bags of books between classes, and if they have aids such as their own chair, it will be difficult to take it between rooms.

These are all issues you can discuss with your key teacher. Because your child is also getting older, they're likely to want to be more independent and involved in their own care. This is a good thing, and your role as a parent will constantly be changing as you work out where they need you to step back, and where they need your support.

Year 11 and 12 exams and special allowances

When the time comes for sitting year 11 and 12 exams, your child may be eligible for special consideration, such as longer exam times, taking breaks, using a keyboard instead of handwriting, and having a support person with them.

Take a look at the Curriculum and Assessment Authority in your state or territory for more information. Your child's school will be able to help you with this. And read our blog 'Special provisions for Senior Secondary Certificates of Education (SSCE)' for more info.

Managing stress around exams

Stress can trigger pain and flare-ups, so managing the normal stress that many students experience around exam time is important for young people with JIA.

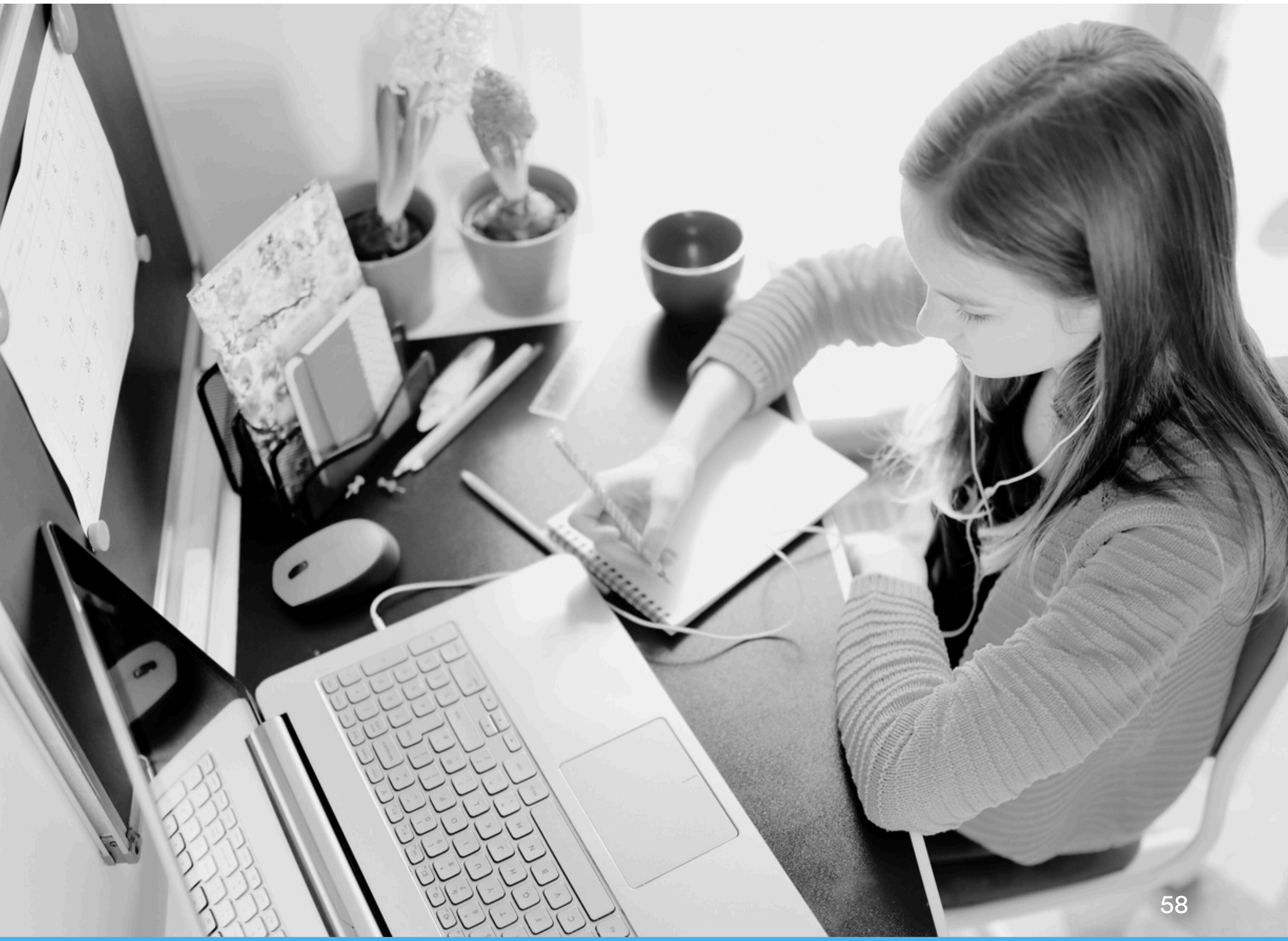
As a parent, you can support your teenager to develop a plan to help manage stress around exam time. This can include:

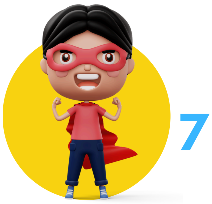
- taking regular study breaks
- keeping up exercise and movement
- implementing relaxation strategies such as breathwork and meditation
- helping them set up an ergonomic and comfortable study space
- ensuring they're eating well (lots of healthy study snacks!)
- support them to maintain good sleep habits.

If your child needs additional support managing stress, or you're concerned about the level of stress they're experiencing, you might like to talk to your doctor, and they can suggest mental health supports available to your child. It can also be helpful to speak to teachers and school counsellors, who will have experience supporting students with exam stress.

More to explore

- Read our blog post on exams and JIA, which includes our community's tips about applying for special exam allowances and managing stress around exam time.
- Headspace has resources for all young people to help manage exam stress.
- Versus Arthritis (UK) has a guide for young people on managing exams with JIA (select 'Exams' from the left navigation bar). You might like to share this guide with your teenager.





7. Your child’s mental and physical wellbeing

Things to remember

- Understanding the link between mind, body and symptoms can help you support your child’s mental and physical wellbeing, often making small changes can significantly impact how they feel.
- Caring for a child with JIA can be hard work and it’s really important to look after your own mental and physical wellbeing – and ask for extra support when you need it.
- One of your roles as a parent will be to provide your child with regular opportunities to chat openly with you about how they’re feeling.
- Many young people have challenges with their body image. Having JIA can make the way your child sees their body even more challenging. You can help by modelling positive self-talk about your own body and praising your child about non-physical traits.
- Mindfulness meditation and different types of relaxation are helpful ways to relieve stress and improve your child’s mood.
- All of us, including children, have times when we feel anxious or down. Sometimes, anxiety and low mood can be more intense and long-lasting. These may be signs of an anxiety disorder or depression, which are real and treatable illnesses that affect children and young people as well as adults.
- There are many effective treatments for anxiety and depression, including talking therapies, prescription medicine and self-help.

Managing the impact of JIA on your child’s life

Our minds and bodies are so closely linked. The physical symptoms your child is experiencing – like pain, stiffness and fatigue – often have a direct impact on how they feel emotionally. And then, how they feel can impact their physical symptoms. Depending on their age, your child might not be aware of how JIA is affecting their emotional health, and it may present as moodiness and tantrums.

Recognising and acknowledging how the mind and body interact with each other – and that emotional challenges are part of living with an ongoing health condition – can help you find ways to support your child’s mental health, and help them build good habits around emotional wellbeing.

This section will help you explore the relationship between mind and body to better understand how one influences the other. We’ll introduce tools that can help support your child’s mental and physical wellbeing, often helping both at the same time. You’ll also find that many of the ideas in the Managing your child’s pain section of this plan – like pacing and getting better quality sleep – can help your child’s overall sense of wellbeing.

Looking after yourself: Caring for your own mental and physical wellbeing

Caring for a child with JIA impacts everyone in the family – parents, caregivers, grandparents and siblings – and can affect your own mental and physical wellbeing.

A big part of being able to support your child’s mental and physical wellbeing involves looking after your own. As well as modelling good habits to your child, caring for yourself will ensure you have the energy, and the emotional and physical capacity to support your child.

All the tips for health and wellbeing in this self-care plan can be used to support you as well as your child. These include getting good sleep, eating well, exercising, reducing stress, enjoying hobbies, and having a support system of friends and family.

Joining a local support group for parents and other family members of children with JIA, or connecting with them online, can be a great source of support. Speaking with people who know first-hand what you're going through and can offer tips and advice is invaluable.
Many parents will also need external support to help maintain their mental health. Your GP can help by providing a referral to see a counsellor or psychologist.

It's common for siblings of children with a condition such as JIA to experience their own emotional challenges. Siblings might experience fear, confusion, anger, jealousy and isolation, and may feel like they need to fight for attention. It's important that these feelings are acknowledged and validated, and that siblings also get the support they need to be physically and mentally well.

More to explore

- The Royal Children's Hospital has an information sheet on Finding the support you need, which has ideas on where to find support for the whole family.
- Arthritis Foundation's article Impact of juvenile arthritis on siblings has helpful tips to avoid sibling rivalry.

Talking to your child about arthritis and their feelings

It's normal that, from time to time, your child will feel sad, frustrated, anxious or angry about having JIA. Try to provide regular opportunities for your child to talk to you openly about JIA and how they're feeling. Being honest about your child's JIA, and letting them know that it's normal to feel sad sometimes will help your child understand that they can talk to you.

Depending on your child's age, how you do this might look different. For younger children, you could use coloured or emoji stickers and they can let you know how they're feeling without having to use words. It might also be easier to talk to them about their feelings while doing an activity or playing. Older children and teenagers might feel embarrassed talking about their feelings, so modelling your own vulnerability and discussing mental health can help break that stigma.

You might like to try asking open questions like:

- I've noticed you've been a bit flat lately, can you tell me a bit about how you're feeling?
- I know your joints have been hurting more this week, and it's normal if that is making you feel sad. How are you feeling at the moment?
- I know this week has been tough for you. I wonder if you have any ideas of things we can do together to help you feel brighter?

More to explore

- The Royal Children's Hospital's resource Managing the impact of JIA on your child's life has a helpful section on mood on page 2.
- Watch our video Encouraging good mental health in children with a chronic musculoskeletal condition, presented by psychologist, Megan Davies.

Body image

Body image is how we see our bodies, and how we feel and think about them. It can be positive, negative or neutral, and can change over time. It's very common for all young people to have challenges with their body image. For children with JIA, additional factors may affect the way they see their bodies.

JIA may cause some of your child's joints to look swollen or red, and different from how their friend's joints look. Some common medicines for JIA can cause weight gain and make your child's face puffy. These body changes, combined with the regular body changes young people go through, can compound and make body image issues a common challenge for children with JIA.

As a parent you can:

- **Model positive self-talk**. Children pick up on behaviours and attitudes and learn from them. As a parent, avoid criticising your own or other people's appearances in front of your children. Instead, say positive things about your body – and focus on what your body can do rather than how it looks.
- **Be honest about changes**. If you know your child is experiencing body changes, be honest about them and talk about them together. Ignoring changes won't help your child accept them, and might make them feel like they can't talk to you about them.
- **Praise your child**. Use positive reinforcement often and always comment on non-physical traits such as their generosity, kindness, intelligence and creativity.
- **Encourage connection**. Children with JIA can benefit from speaking with other young people living with the same condition. They can understand their experiences in a way that other friends might not be able to.

It's important to monitor body image issues your child might be experiencing. If they're not managed, they can lead to anxiety, depression and disordered eating. If you're concerned about your child, speak to your doctor who can refer you to a counsellor or psychologist who specialises in young people and body image.

More to explore

- The Butterfly Foundation has great resources and support services to help young people develop a positive body image. They also have a national helpline and online chat that both you and your child can access.

Bullying

Like all children, bullying can significantly impact on the mental wellbeing of kids with JIA. Because some children with JIA develop differently from their peers, and may need special accommodations at school, it can make them targets of bullying.

You'll find more information in Section 6 of this self-care plan about what to do if you think your child is being bullied at school.

Mindfulness and relaxation

Mindfulness and relaxation techniques can help your child manage the pain and fatigue of JIA, and help reduce the stress, anxiety and fear that can occur around procedures and flare-ups. These techniques can also help your child develop a greater overall sense of acceptance of life as it is in the present moment, help them manage everyday stresses, and experience a greater sense of overall wellbeing.

Mindfulness is a way of focusing the mind on the present moment, paying attention to thoughts and sensations, and accepting them without judgement.

Research has shown that regularly practising mindfulness meditation can help to improve mood, relieve stress, improve sleep, improve mental health, and reduce pain in children and adults.

Relaxation includes techniques such as deep breathing and visualisation that can help ease stress and muscle tension, reduce pain levels, and create a better sense of overall wellbeing.

Mindfulness and relaxation techniques are an important part of the toolkit for your child's physical and emotional wellbeing. These tools are free, you can do them anywhere, and they don't have any side effects. There are a lot of resources available online and at your local library to help get you started.

If you have a younger child, you might like to guide them through mindfulness and relaxation exercises. You can teach them simple techniques such as deep breathing from their bellies that they can use when they feel pain or anxiety. Mental health professionals can also help with finding the right techniques for your child.

You might like to try mindfulness and relaxation techniques before bed, appointments, school, during flares, or any other stressful situations that make your child anxious.

If your child is older, they'll benefit from reading about and practising many of these techniques themselves.

More to explore

- The Royal Children's Hospital's resource Breathing and relaxation strategies to use with your child includes a step-by-step guide to exercises you can guide your child through. They also have a guide specifically for teenagers.
- To learn about the changes and other effects mindfulness has on our body, watch this short Smiling Mind video featuring Associate Professor Dr Craig Hassed from Monash University.
- Our Mindfulness meditation resource explains more, and includes great tips on getting started and how to do a simple body scan.

Ava - 10 yrs

"I find having my injections really very hard. Breathing and wiggling my toes works well when I'm having my injection. I also like to have positive songs playing. Sometimes I like to put an object in the room so I can look at it and feel better".

Our community's tips for including mindfulness and relaxation in your day

- I have a timer on my watch and when it goes off, I think of what I'm most grateful for.
- Ithink being organised is helpful, especially whenflares can strike unexpectedly. We have bags, uniforms and lunches prepared the night before a school day. This means there's less stress and we can take the mornings slower if we need to.
- I like to include lunchbox notes with inspirational messages to my daughter.
- I have designed her some t-shirts that remind her what a warrior she is.
- I think it's important for children to see their parents value mindfulness and practise relaxation.

Part-time work

Having a part-time job is often an important part of growing up for any child. Part-time work can provide young people with a sense of independence, help them connect with others, and give them a focus outside home and school.

All of these benefits can have a positive impact on a young person's mental and physical wellbeing – and this can be especially so for children with JIA, where it provides a focus outside their arthritis and pain, and allows them to feel just like any other kid who's growing up and spreading their wings. Having JIA can sometimes interfere with your child's part-time work, and so you'll both need to be realistic about what is and isn't manageable. Your child may need to learn for themselves what happens when they push too hard and become fatigued or have a flare.

Talk openly about these issues with your child and encourage them to talk to someone in their healthcare team or a school counsellor if they need more guidance and support to find a part-time job that works for them. Your child might also want to talk about how much they do or don't tell their employer about their JIA.

Fortunately, there are many things you can do to help your child in their part-time job – including using the pain management techniques in Section 5 of this self-care plan, modifying a workspace, using helpful aids and equipment, and having some flexibility with the hours worked.

More to explore

- Our workplace tool, WorkWise, provides tips, strategies and resources to help people of any age with musculoskeletal condition to manage symptoms at work, continue to work, change jobs, understand their rights and more.

- Our articles about Musculoskeletal conditions and work – part 1 and part 2, include many more helpful tips and links to provide support at work.

- The Royal Children's Hospital resource on Finding a job with a chronic health condition includes useful tips for young people.

Sleep and why your child needs it

Sleep helps our bodies recharge mentally and physically.

While asleep, our bodies are busy doing important jobs to help us wake up refreshed and healthy. Our brain is cleaning itself of waste products and consolidating memories. Our muscles, bones, and organs are repairing themselves. Sleep also helps keep our immune systems healthy.

For children, sleep is where they do most of their growing and developing. Getting a good night's sleep both in quality and quantity, is essential for attention, behaviour and their learning.

The amount of sleep children need changes depending on their age.

- 0-3 months: 14-17 hours
- 4-11 months: 12-16 hours
- 1-2 years: 11-14 hours
- 3-5 years: 10-13 hours
- 6-12 years: 9-12 hours
- 13-18 years: 8-10 hours.

Some children may need more or less than these guidelines, and the amount of sleep they need may also change depending on their symptoms at the time.

Not sleeping well can contribute to mental health conditions like anxiety and depression, and be a symptom of these conditions. It's common for children with JIA to have challenges with sleep, so supporting them to sleep well is a key role for you as a parent.

Managing sleep and fatigue in Section 5 of the self-care plan explains more about the connection between pain, sleep and fatigue and includes a comprehensive guide for supporting your child to get enough quality sleep each night.

Living with flares

Flares - periods where your child's pain and symptoms are worse - are part of the unpredictability of JIA, and can have a big impact on their mental and physical wellbeing.

That's why it's really important to plan in advance and have a system and care package ready for when flares strike.

Learn more about flares and how to manage them in Section 5 of this self-care plan, which is all about managing the pain of your child's JIA.

Anxiety and depression: When your child needs extra support for their mental health

Anxiety

Most of us will have times when we feel fearful, stressed and anxious. These are normal responses to stressful situations.

For children with JIA, there's a link between chronic pain and anxiety. Your child might feel anxious about upcoming school events, social activities or sports – and whether their pain or fatigue will stop them from participating. They may feel anxious about procedures and medical appointments, and this might stop them from being able to sleep or do everyday activities.

These anxious feelings can become a more serious problem when they begin to interfere with everyday life, making it difficult for your child to relax, concentrate or make decisions – or resulting in constant feelings of irritability and panic.

These may be signs of an anxiety disorder, which is a real and treatable illness, and is more than just feeling stressed.

Depression

All of us feel sad, lonely, unhappy and miserable at times. These are also common, normal feelings for a child living with JIA to experience from time to time.

Being concerned about friendships, not being able to do the things they enjoy, living with pain and feeling a lack of control and uncertainty about the future can all contribute to these feelings.

There's a difference between experiencing periods of sadness and having depression. Children experiencing depression experience these emotions frequently and intensely for longer periods. They may lose interest and motivation in their lives and the world around them – and in the activities and people that normally make them feel good. These may be signs of depression, which is a real and treatable illness that is more than feeling low.

More to explore

- Beyond Blue's website Healthy families, includes information for parents on what anxiety and depression looks like in children of different ages and includes a mental health checklist.
- Headspace's information on Understanding depression in young people and Understanding anxiety in young people includes signs of depression and anxiety, and what you can do to help.
- Arthritis Foundation's article Juvenile arthritis and depression looks at the relationship between depression and JIA.

Getting help for anxiety and depression

If you're concerned that your child is displaying signs of anxiety or depression, it's important that you get them the help they need.

Talking to your child and letting them know that you're concerned about them, and creating a space where they feel comfortable to open up and speak to you is an important first step. Ask your child questions about how they're feeling and make sure you respond without judgement and with empathy. Ask how you can help, and what support they need from you.

It's also important to get professional help for your child. There are effective treatments that can help them feel much better:

- If you think your child has signs of anxiety or depression, talk to a healthcare professional as soon as you can. If you're not sure if you need to be concerned about your child's symptoms, you can use this Beyond Blue checklist as a guide.
- Chatting to your GP is often a good place to start. Your GP can then recommend and link you with a mental health professional who specialises in working with children. For older children, you might encourage them to attend an appointment with their GP on their own, or you can ask them if you can go together. If needed, your GP can work with you and your child to create a mental health treatment plan, which means that Medicare will pay for part of the cost to see certain mental health professionals.
- A psychology team is often part of your hospital paediatric rheumatology clinic that your child attends. Doctors and nurses at the clinic will have experience with mental health challenges in children with JIA.
- Our article Support for mental and emotional wellbeing explains more about the different types of mental health professionals, tips for choosing which type of health professional might be a good fit, and the types of support available.

Treatments for anxiety and depression

There are many different types of treatment options available for anxiety and depression. The important thing is to find the right treatment and health professional that works for your child.

Psychological or talking therapies

Psychological therapies (sometimes called talking therapies) can help change thinking patterns and help people cope better with life's challenges.

These therapies are often the most effective types of long-term treatment and prevention for anxiety and depression. As well as helping with recovery, they build coping skills and reduce the risk of anxiety and depression coming back.

There are many different talking therapies; two types that are often used with both adults and children are:

- **Cognitive behaviour therapy** (CBT), helps your child understand how the way they think and act affects the way they feel. The aim is to help them think about, assess and change their thought patterns and how they react to different situations.

- **Interpersonal therapy** (IPT) focuses on your child and their relationships with other people to help improve relationships, increase social support and resolve symptoms.

Medicines

If your child's anxiety or depression is severe, their doctor may suggest including treatment with prescription medicine.

If they think prescription medicine may help your child, they'll do a full health check and talk to you and your child about how the medicine can be used as part of their treatment plan together with talking therapies and self-help.

Your doctor will talk to you about the medicine's possible side effects and what to expect from treatment.

More to explore

- Beyond Blue's Healthy Families page on Supporting children and young people and How to talk about mental health with young people includes examples of practical support you can offer and questions to ask.
- Listen to our recording of a presentation by psychologist Megan Davis, Encouraging good mental health in children with a chronic musculoskeletal condition.

Don't delay in asking for help

If you or your child is struggling with anxiety or depression, remember that you don't need to manage by yourself – there's always someone available to help:

- **Beyond Blue Support Service provides one-on-one calls and chats with a trained mental health professional and are completely confidential. They can provide you with brief support and point you in the direction of the help you need.**
    - **You can call them 24 hours a day/7 days a week on 1300 22 44 36 or chat online between 1pm and 12am 7 days a week.**
- **If you need urgent help at any time of the day or night, call the Lifeline 24-hour telephone counselling service on 13 11 14.**
- **Kids Helpline is a free 24/7 online and phone counselling service for young people aged 5 to 25. Call on 1800 55 1800 or chat online.**

8. Growing up

Things to remember

- As your child grows up and transitions into their teenage and young adult years, there'll be many exciting and challenging times ahead for both of you. It helps to be prepared well ahead of time.
- Your child will begin to move from being under the care of a paediatric team to adult care. You can help make this transition easier by gradually increasing the responsibility your child takes for their health.
- A young person with JIA will have extra factors to consider when making decisions about uni, apprenticeships and working life. There are many great guides to help them with this.
- During this stage of growing up, intimate relationships will be a new area for you to help your child navigate. It's important that your child feels comfortable to have conversations with someone they trust about safe sex, birth control and any concerns about how JIA might affect their intimate relationships.
- Alcohol and other drugs will most likely cross paths with your teenager. Your child will need to understand the general risks of alcohol and other drugs and the dangers of mixing them with some medicines and how they can impact JIA symptoms.
- Smoking has specific impacts on the body that are particularly risky for young people with JIA. There's lots of support for kids at risk of smoking or who need help to quit.
- Protecting themselves from the sun is especially important when taking certain medicines. Check our list and make sure your child is prepared.
- There are extra safety considerations to be aware of if your child is keen to have tattoos or piercings and they'll need to discuss these with their doctor.
- Music festivals are something that many young people look forward to. Careful planning can help make these special events safe and manageable for your child with JIA.

A time of change

As your child transitions into their teenage and young adult years there are many changes – new schools, universities, workplaces, healthcare providers, relationships and experiences await them. This is an exciting and challenging time, especially for parents of children with JIA.

Children will begin to have greater autonomy and will be making more decisions for themselves – experimenting more, and making positive as well as imperfect choices.

As a parent, it's also a period of transition for you. You'll have been very involved in all aspects of your child's life and care for many years. Now you'll experience your own challenges as you have less control and find new ways to support your child.

Because every child is different, the ages at which they'll experience some of the topics covered in this section, including alcohol, drugs, tattoos, will vary. It's a good idea to read this section before you think you'll need it, so that you can start preparing for some of the issues in advance.

A lot of the information in this section is equally for you as a parent and for your child. You might like to share sections with them, and they might like to read many of the 'More to explore' resources themselves.

Transitioning from paediatric to adult care

A big milestone in a young person's JIA treatment pathway is transitioning from being under the care of a paediatric team of healthcare professionals to seeing specialists that treat adults.

This transition is a process that ideally should take place over several years as your child learns to be more independent and responsible for their own care.

Your paediatric healthcare team will start this conversation with you and your child around the age of 15, and support them to ensure they have the knowledge, skills and confidence to navigate and advocate for themselves in an adult care setting. Most young people 'graduate' to adult care between the ages of 16 – 20 depending on their specific needs.

Depending on where you live, this might mean seeing an entirely new team of healthcare professionals. If your child has been cared for by the same people and has become comfortable with them over many years, this could be a challenging change for them.

As a parent, you can help in this transition period by supporting your child to have increasing responsibility for their own care from as early as the age of 10, depending on your child. This will help set them up for success for their transition to adult care, as they'll have already started building awareness of how JIA affects them, and the practical skills they need to navigate the medical system.

This transitioning process might include:

- learning how to make their own appointments
- being responsible for keeping track of their test results or knowing when a new script is required
- talking to your child about options for care and involving them in decision-making
- attending healthcare appointments on their own.

Being involved in their own care can also support positive mental and emotional wellbeing for your child, as it can help them have a sense of control and autonomy. This is important for young people with chronic conditions like JIA, where they can feel a lack of control which can contribute to poor mental health.

More to explore

We've brought together what we think are some of the best transition resources for you and your young person here. And, of course, speak with your child's rheumatologist about what services they offer.

- The Royal Children's Hospital has detailed information on transitioning to adult care. We recommend:
    - Guide for parents Helping your teenager become more independent in their healthcare
    - Guide for teenagers Becoming more independent in your health care, which you might like to share with your child.
    - A table that outlines the differences between paediatric and adult healthcare.
    - Transition Readiness Checklist you can go through with your child.

- Our webinar with Jamie McCarthy, the Transition Support Coordinator at the Royal Children's Hospital – Transition from paediatric to adult care.
- There's a great podcast episode on Transitioning from paediatric to adult care in rheumatology from the limbic.

Moving onto high school

High school is an exciting and challenging time for all young people, but may be particularly so for those with JIA.

For a young person with JIA, high school likely means new teachers to explain their condition to, new friends, and a campus that might be challenging to navigate with joint pain.

You can read more about the transition to high school in Section 6.

Getting ready for uni, apprenticeships and working life

There are lots of pathways your child might consider after high school, including university, a technical college, apprenticeships, and work.

We recommend starting the conversation early about how JIA might be a factor to consider in their decision-making and then creating a plan that will set them up for success.

There are many great resources to help you and your child get ready for their next life adventure.

More to explore

- Versus Arthritis (UK) has a comprehensive guide on making decisions about university written for young people with arthritis. Select 'University' from the left navigation bar. This is a good resource to share with your child, and is also helpful for parents.
- Arthritis Foundation's (US) guide on Juvenile arthritis on the college campus.
- Arthur's Place (UK) has written a University survival guide and Work survival guide with lots of helpful tips for young people with arthritis.
- The Royal Children's Hospital resource on Finding a job with a chronic health condition includes useful tips for young people.

Keep in mind that UK and US resources will include information about specific services, apps and legal rights that will be different in Australia.

Body image

Body image issues may become particularly intense during adolescent years for young people with JIA. You can read more about this in Section 7 of the self-care plan.

Personal relationships and intimacy

As they grow up, your child will become more confident about developing new friendships and relationships. They'll also become clearer about what they do and don't want to share with others about their health condition. There are likely to be lots of new people in your child's life as they navigate high school, university, workplaces and new social circles.

During this stage of growing up, intimate relationships will be a new area for you to help your child navigate.

As part of the natural conversations you'll be having with your teenager about safe sex, you can encourage them to be open with you about any concerns they have about their JIA and how it might affect their intimate relationships. Your child may be worried about their joints or pain when having sex, or the effects of medicines.

Talking about safe sex and birth control is especially important for young people with JIA, as some medicines prescribed for JIA can interfere with birth control and some can cause serious harm to an unborn baby. Your child's doctor can tell you more about the specific precautions that apply to any medicines.

If your child doesn't feel comfortable having this conversation with you, it's something you could encourage them to raise with their GP or someone they trust in their care team. They may prefer to have an appointment to discuss sexual health on their own. The important thing is that they do talk about these issues with someone – ignoring them doesn't make them go away!

More to explore

- Kids Helpline has a helpful guide on talking to your teen about safe sex. While not written specifically for young people with JIA, it includes helpful tips to help the conversation go smoothly.
- Arthur's Place (UK) has some terrific blog posts that young people might find helpful, including When to tell your date you have arthritis as well as a blog on chronic pain and sex.

Alcohol and other drugs

Alcohol and other drugs cross paths with most teenagers, and are a challenging area for all parents to navigate.

There are many great resources to help parents have conversations with their teenagers. It's important that your child understands:

- the general risks associated with alcohol and other drugs
- the potential dangers of combining alcohol and drugs with some medicines
- how their JIA symptoms can be impacted by alcohol and other drugs.

Most teenagers will try alcohol and other drugs at some stage, so an approach of "don't ever drink or take drugs" is very unlikely to work.

Instead, focus on ways your child can minimise harm, options to consider if they're feeling pressured to drink or take drugs, and support them to make good decisions.

Some of the specific impacts of alcohol and drugs to be aware of include:

Lower alcohol tolerance – Some medicines prescribed for JIA, including steroids and methotrexate, can lower alcohol tolerance. This is important for your child to be aware of, as binge drinking is common among teenagers, and alcohol will affect them differently from their peers.

Interaction with medicines – Alcohol can interact with commonly used medicines such as non-steroidal anti-inflammatories like ibuprofen, where the combination can cause problems like ulcers, bleeding in the stomach and liver damage.

Talk with your doctor or pharmacist about how alcohol and drugs can interact with any of the medicines your child is taking, or encourage them to have that conversation.

Liver damage – Drinking alcohol while taking steroids and methotrexate can increase the risk of developing long-term liver damage.

Sleep – Alcohol and drugs affect the quality of sleep. Getting enough quality sleep is vital for the health and wellbeing of young people with JIA.

Injury – Alcohol and drugs can cause a loss of coordination and balance and increase the risk of falling and injury. Young people with JIA can already be more prone to injuries because of stiff and inflamed joints, and an injury can be more challenging to recover from.

Mental health – Drinking and using drugs can add to feelings of depression or anxiety that young people with JIA may already be experiencing.

Illegal drugs can be extremely dangerous for young people taking medicines for JIA, especially as it's not possible to know what's in them. As well as recreational drugs such as cocaine, marijuana and amphetamines, teenagers may be tempted to take prescription drugs including strong pain-killers or stimulants such as Adderall or Ritalin.

It's critical to have an open conversation with your child about the dangers of these drugs.

Smoking

Most young people are aware of the health impacts of smoking cigarettes. Smoking has specific impacts on the body that can be even worse for the health of a young person with JIA:

- **Smoking increases the risk of osteoporosis**, which young people with JIA are already at a higher risk of developing.
- **Smoking makes being active difficult** as it impacts lungs, breathing and circulation. Because exercise is so important for managing pain and maintaining mobility in young people with JIA, anything that makes that more challenging will impact their wellbeing.
- **Smoking can make it more difficult to manage pain.** It causes fatigue and slower healing, which can make pain worse.
- **Smoking can impact medicines**, such as biologics, making them less effective.

If your child is smoking, you're worried that they're at risk of developing the habit, or they need support quitting, talk to your GP about specific support services available.

It's also important to be aware of the rising popularity of e-cigarettes (also known as vaping), especially amongst young people. Many young people believe that e-cigarettes are a 'safer' way to smoke, but this isn't true. Find out more about the risks associated with e-cigarettes.

More to explore

- The Victorian Government's Better Health Channel has helpful guides for parents on navigating smoking, alcohol and drugs with teenagers.
- About Kids Health (Canada) has a detailed article about drugs, cigarettes and alcohol and the impact on JIA.
- The Royal Children's Hospital has information about e-cigarettes and teens.
- The Royal Children's Hospital has information on drugs and alcohol on page 2 of these information sheets – there's one for parents and one written for teenagers themselves.

Sun protection

Some medicines used to treat JIA, as well as other more general medicines, can cause your child's skin to become sensitive to sunlight. This can result sunburn and skin rashes, even after a very small amount of exposure to the sun. This is called photosensitivity.

Medicines that can increase sun sensitivity include:

- non-steroidal anti-inflammatory drugs (NSAIDS) – like diclofenac and ibuprofen
- disease-modifying anti-rheumatic drugs (DMARDs) including azathioprine, cyclosporin, leflunomide, hydroxychloroquine and methotrexate
- antidepressants
- oral contraceptives
- tetracycline-based antibiotics.

Your doctor or pharmacist can tell you more about medicines that are likely to increase your child's sun sensitivity.

If you have a young child with JIA, you'll need to be particularly aware of the impact of sun exposure and ensure that they're well protected from the sun by seeking out shade, covering up with clothing, wearing a hat, and using a minimum SPF30+ sunscreen on any areas of skin that can't be covered up.

As your child grows up and goes out on their own with friends, they'll need to become more responsible for their own sun protection. Talk to your child about the importance of sun protection and the impacts of photosensitivity, and make sure they're equipped with sunscreen.

More to explore

- Our article Enjoying the sun safely includes more practical tips to protect your child in the sun. You could share this with your older child to read themselves.
- We all need to balance the need for sun protection with the need for vitamin D. This info will help you to find that balance for your child:
  - Our article on Calcium and vitamin D
  - Healthy Bones Australia's Vitamin D & bone health page, which includes a map to work out how much daily or weekly sun is needed for vitamin D in each area of Australia.

Body art: tattoos and piercings

Once considered edgy, piercings and tattoos are forms of body art that have now become mainstream. It's almost more difficult to find a young person who hasn't got one than someone who does!

Young people who are spreading their wings and exploring their identity are often interested in piercings and tattoos. But there are a few extra things to consider when a young person also has JIA.

Because JIA is a condition that affects the immune system, and young people with JIA are often taking medicines that suppress their immune system, they're at risk of developing an infection any time their skin is broken – like when they get a tattoo or piercing. JIA and these medicines may also affect the time it takes to heal. These risks are generally more of an issue with tattoos than piercings.

Before you and your child can make a decision about a tattoo or piercing, it's worth exploring the articles below and then having an open discussion with your child's doctor or specialist to decide whether or not this is safe for your child, with their specific condition, and at this time.

More to explore

- Arthur's Place (UK) has a really detailed article Is it safe to get a tattoo if you have arthritis? that focuses on the issues to consider for young people with arthritis and includes expert input from an adolescent and adult rheumatologist.

Festivals

Music festivals are something many teenagers and young adults look forward to. As a parent of a child with JIA, it's normal to feel anxious about their first festival.

Festivals include the regular risks associated with alcohol, drugs, smoking, sex and sun exposure, and it's unlikely that your child will be getting quality sleep and eating a balanced diet while camping in a field!

Talk to your child about how you're feeling, discuss the safety precautions they'll take, and trust them to make good and safe decisions. You might like to help them ensure they know where the first aid tent or van is located, and that they have their medicines safely stored.

The general information on alcohol and other drugs, safe sex, smoking and sun exposure earlier in this section is worth going over together before a festival.

You and your child might like to have a plan in case their pain or other symptoms get worse while at the festival, including what you should do if they need support from you.

More to explore

- Arthur's Place is a digital resource for young adults with arthritis, and has a lot of blogs your teenager might like to explore, including their Festival Survival Guide.

MHA
KIDS

muscha.org.au/msk-kids

TEEN
TALK

muscha.org/msk-kids-teen-talk

Musculoskeletal
Health Australia
Knowledge. Choice. Connection.