Musculoskeletal Health Australia
Knowledge. Choice. Connection.

Caring for a child with arthritis

& other musculoskeletal conditions

This resource has been developed with funding from Gandel Philanthropy and AbbVie and produced by the team at Musculoskeletal Health Australia.

We would like to thank the following people for their contributions to this project:

- The Paediatric Rheumatology teams at Monash Children's Hospital and The Royal Children's Hospital, Melbourne.
- Parents, children and school staff involved in reviews.

Musculoskeletal Health Australia
Knowledge. Choice. Connection.

ISBN: 978-0-9925452-4-6

abbvie

GANDEL PHILANTHROPY

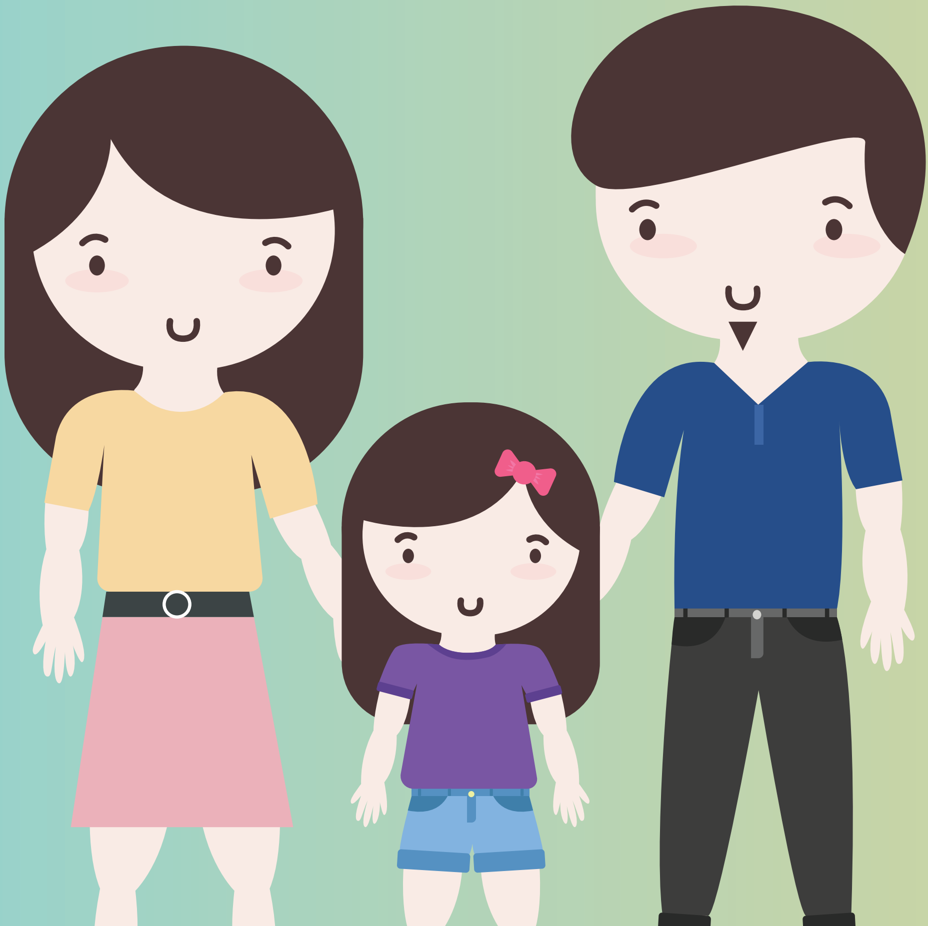
Contents

For parents and carers

If your child has juvenile idiopathic arthritis or another type of musculoskeletal condition (e.g. lupus, back pain, fibromyalgia) and you're wondering how they'll get the most out of their time at school, we can help.

We've developed this resource to help you work with your child's school so that the time they spend at school is as happy and productive as possible.

Note – *for ease of use, throughout this booklet we'll use the term arthritis, or JIA, to cover all juvenile forms of musculoskeletal conditions. We'll also use parent when referring to both parents and carers.*



Open communication is vital

One of the most important things you can do is to develop positive, honest and open communication with your child's school and teachers. Make sure they're kept in the loop about any issues that may arise. If your child is having a flare up, is in pain, or finds certain activities difficult, make sure their teachers are made aware of this.

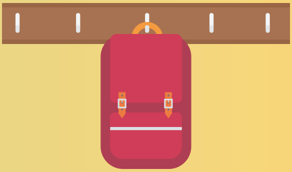
It's also extremely important to let your child's teachers know that arthritis is an episodic condition. That means that there will be times when your child may feel extremely well and able to do most things, while at other times they may have a lot of pain, and be restricted in their activities. This is the unpredictable and frustrating nature of arthritis.

Help your child at school - tips and strategies to discuss with their teacher

Sitting on the floor can be difficult for many children with arthritis. A strategy that may help address this situation, without making your child feel isolated or different to their classmates, is to ask the teacher to group a few chairs on the edge of the circle. Your child, and a few others, can then sit on chairs rather than the floor. Floor chairs are also an option to enable students to sit comfortably and well supported with their peers on the floor.

Pencils, crayons and paint brushes may be hard for some children with arthritis to hold. Thick brushes or special grips may help with this. Try adding hollow foam tubing (from the hardware store) to existing pencils, brushes etc. to save buying completely new equipment.

Ensure your child's school locker or peg is at a comfortable height – not too high or too low.



Place toys, blocks or puzzles on a table rather than on the floor to make them easier to play with.

Standing or sitting in one position for any period of time may be difficult. Encourage your child to move around and take small breaks. Perhaps they can scrunch up some paper and walk to the recycling bin – anything to keep them moving.

* * *

Lunchboxes can often be tricky for children to open, especially if they have arthritis in their hands. Shop around, and take your child with you and try out as many lunchboxes as necessary, until you find the one that works for them.

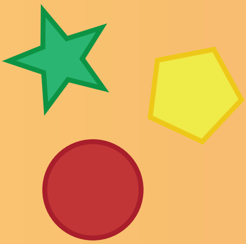
Modified uniforms with elastic waist bands instead of buttons or zippers may make clothing changes for PE/swimming easier. School shoes that are fastened with Velcro, rather than laces may be a better option at this stage.

* * *

Stickers, wrist bands and badges are an easy, visual way for your child to let their teachers know how they're feeling without bringing too much attention to themselves.

For example:

- a green sticker = Go, I'm feeling fine.
- a yellow sticker = Caution, I'm a bit sore.
- a red sticker = Stop, I'm having a bad day today.



* * *

Sharing information – It's up to you and your child to decide how much and what information you want to share with the school. But keep in mind that if staff aren't aware, they're less able to fully support your child. Decide who'll be responsible for sharing information with whom, in what way and when so that everyone is comfortable.

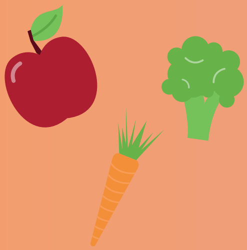
Managing your child's condition

As well as strategies for managing at school, there are many things you and your child can do to manage their condition. They will help your child's health in the long run, but will also help them manage living with a chronic condition and lessen the impact it has on them and their time at school.

Follow the plan that your health professionals have developed. That means taking medications as they've been prescribed, doing the exercises the physiotherapist and/or occupational therapist have provided and letting your doctor know of any changes to your child's symptoms and how they're feeling.

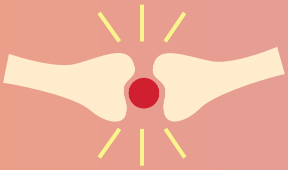
Stay active. Physical activity is really important for maintaining muscle strength, joint flexibility and managing pain. It's also vital for so many other reasons such as: growing strong bones, helping your child sleep, maintaining a healthy weight, improving mood and staying connected with their friends and schoolmates. A physiotherapist or exercise physiologist can help design an individual program for your child and can provide advice on how they can remain active and involved in school and extra-curricular activities.

Learn ways to manage pain. From heat and cold treatments, distraction, massage and medication, there are many ways your child can manage pain. Helping your child learn about these different techniques, and when to use them, will help them take control over their condition and their pain. Your doctor, physio, psychologist and the nurses on our MSK Help Line (**1800 263 265**) can help you.



Eat well. While there's no diet that can cure arthritis, a healthy and well-balanced diet is the best for good health. Keeping to a healthy weight is also important as extra weight puts added strain on your child's joints, especially load bearing joints such as hips, knees and ankles. Talk with your doctor or a dietitian if you need help with diet and/or weight management issues.

Protect joints. There is a huge variety of aids, equipment and gadgets that can make activities easier, from an ergonomic mouse for your child's computer, to walking aids and foam rubber to make pens, brushes and cutlery handles easier to grip. An occupational therapist can give you advice on available equipment, as well as techniques to reduce strain on joints.



Stay at school. Attending school is important for your child's health, wellbeing, education and connection to their peers. If your child is missing a lot of school, or having difficulties keeping up, talk to your doctor, allied health professionals and teachers about ways to help your child stay at school and keep up with school.

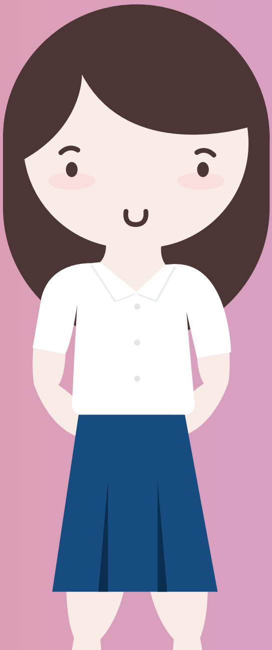
Some paediatric rheumatology departments in major hospitals have rheumatology nurses. They can come out to your school and present a fun talk to your child's class about what it means to be living with arthritis – they might even bring their spooky skeleton!

Transitioning to high school

High school is an exciting and challenging time for all students but may be particularly so for those with arthritis. It's a good idea to start thinking early about specific challenges for your child and how best to deal with them. You may wish to organise a meeting with someone at your child's new school so that you can fill them in on all the important info – and give them a copy of this booklet!

Unlike primary school, high school involves different teachers for different subjects so there'll be more people to keep informed and up-to-date. That's why it's important that you make sure you have a good relationship with one key person at the school. They can be the person on the ground who can advocate on behalf of your child when you're not there.

When the time comes for sitting final exams, your child may be eligible for special consideration. Take a look at the **Curriculum and Assessment Authority** in your state for more information. Your child's school will be able to help you with this.



For teachers, coaches etc.

What is juvenile idiopathic arthritis?

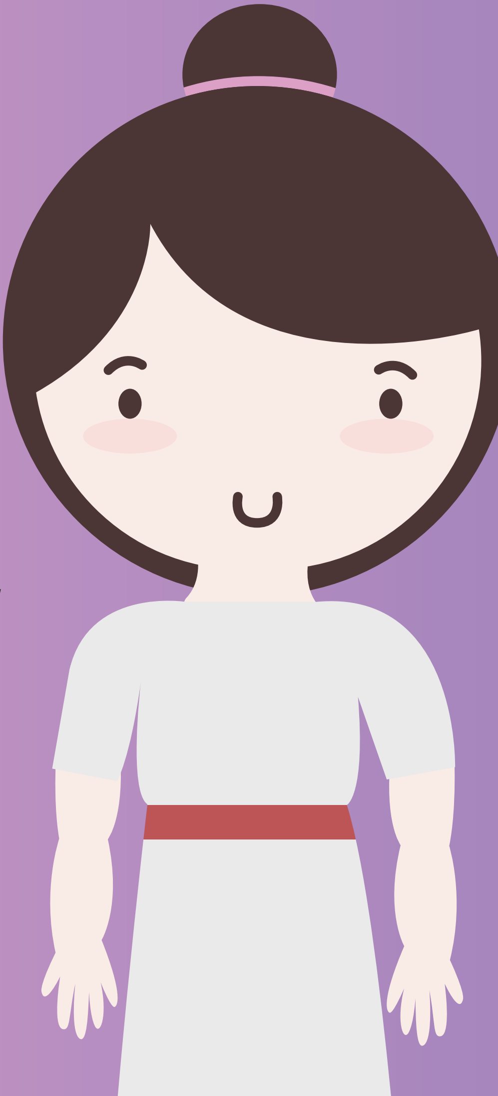
Most people think that arthritis only affects older people. The truth is one in 800 Australian children has a form of juvenile arthritis[1]. This figure is likely to be far higher if we take into account other musculoskeletal conditions that can affect children such as back pain, lupus and fibromyalgia.

They're some of the most common chronic conditions to affect children. But many people have never heard of arthritis affecting children.

If you break the name down, it provides a bit more information about the condition:

- **Juvenile**—it affects children under the age of 16
- **Idiopathic**—we don't know what causes it
- **Arthritis**—inflammation of the joint

Note – *for ease of use, throughout this booklet we'll use the term arthritis, or JIA, to cover all juvenile forms of musculoskeletal conditions. We'll also use parent when referring to both parents and carers.*

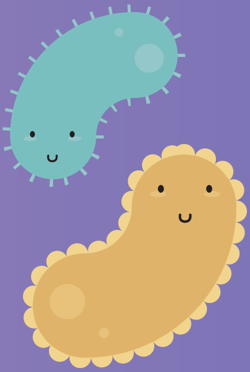


---

[1] Australian Institute of Health and Welfare 2016. Australia's health 2016. Australia's health series no. 15. Cat. no. AUS 199. Canberra: AIHW.

Causes

We don't really know what causes arthritis in children. We do know that in most types of JIA, it occurs as a result of a malfunctioning immune system.

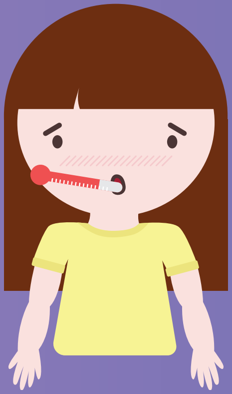


The immune system is designed to identify foreign bodies (e.g. bacteria, viruses) and attack them to keep you healthy. However in the case of JIA, the immune system mistakenly attacks healthy tissue in and around the joints, causing ongoing inflammation and pain.

Symptoms

The symptoms the child experiences will depend on the type of arthritis or musculoskeletal condition 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, or fatigue.



Less common symptoms include:

- fever
- rash
- feeling generally unwell
- eye inflammation (uveitis).

Remember, everyone's different and will have different symptoms. Some children will not experience all of the symptoms listed here. It's impossible to know.

It's important to know that arthritis is a fluctuating, or episodic condition. Children may feel different from day to day or even from hour to hour. When conditions are more active, it's called a flare, or flare up.

During this time their arthritis is more painful, and they may experience more inflammation and fatigue (or tiredness). We don't always know what causes a flare, but we do know that stress or an illness can trigger one. Flares are temporary and can be frustrating and painful while they last. A flare can make everyday activities like concentrating, getting dressed, writing and going up and down stairs very difficult or impossible.

Most children with arthritis look completely well, so you won't be able to tell from simply looking at a child how they're feeling or how they're managing. Having an open and positive relationship with your student and their parents is important so you can help the child get the most out of being at school.

Treatment

Unfortunately at this stage there's no cure for JIA, however there are many treatment options available.

Depending on the type of arthritis they have, your student will likely see a range of professionals including their rheumatologist, GP, nurses, physiotherapists, occupational therapists, dietitians, ophthalmologists, podiatrists, psychologists and social workers to help them manage their condition.

Medication

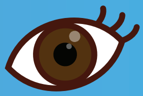
Most children with arthritis – regardless of the type – will have to take some form of medication at some time. It depends on the symptoms they're experiencing. There are many different types of medications that work in different ways.

The most common types of medications used are:

- pain-relievers (analgesics) – e.g. paracetamol – for temporary pain relief.
- creams and ointments – can be rubbed into the skin over a painful joint to provide temporary pain relief.
- non-steroidal anti-inflammatory drugs (NSAIDs) – e.g. ibuprofen or naproxen – to control inflammation and provide temporary pain relief.
- corticosteroids – e.g. prednisolone – are used to quickly control or reduce inflammation. They can be taken as tablets or given by injection directly into a joint, muscle or other soft tissue.
- disease modifying anti-rheumatic drugs (DMARDs) – e.g. methotrexate – work on controlling the immune system. These medications help relieve pain and inflammation, and can also reduce or prevent joint damage.
- biologics and biosimilars (bDMARDs) – e.g. etanercept or adalimumab – these newer medications are also a type of disease modifying drug. They also work on controlling the immune system. However unlike other disease modifying drugs, biologics target specific cells and proteins that are causing the inflammation and damage, rather than suppressing the entire immune system.

Complications

Uveitis: This inflammation of the eye can occur in approximately 10-30% of children with JIA. Unfortunately there are often no symptoms in the early stages so regular check-ups are essential. Left untreated, uveitis can result in loss of vision.



Immune suppression: Many children with JIA will be on some form of medication that suppresses the immune system. This means that they're both more susceptible to picking up infections and more likely to suffer from complications if they do. These children are particularly vulnerable to chickenpox, measles and parvovirus B19 and, if exposed, should seek medical advice promptly. It's important that someone at the school is responsible for contacting the child's parent if anyone in the class is unwell.

How teachers can make a difference

As a primary teacher you'll probably spend more waking hours with your student with JIA than virtually anyone else. For that reason alone, you have a very important role to play in the life of the young person in your care. Your positive attitude can go a long way to ensuring that their time at school is a happy one.

Children with arthritis and other musculoskeletal conditions often feel worse in the morning before their joints have had a chance to 'warm up'. Think of how you feel the morning after you've had a very active day – at the gym, playing sports or in the garden. Getting out of bed can be challenge when your muscles are sore and your joints feel stiff, and it takes a bit of time and movement before you feel better. This will give you a small insight into how your student likely feels most mornings. Bear this in mind when setting activities for early in the day. We've also included some really helpful tips and strategies to help you in the classroom on page 5.

It can be difficult, because of the fluctuating nature of arthritis, and the fact that there's often no visible signs, but you need to remember that pain is what your student says it is. No one else knows what it feels like for that child to live with their condition except for that child. Young people tend to downplay their pain, rather than exaggerate or embellish how they're feeling, so listen to them carefully. Children just want to fit in and be like their peers.

Living with chronic pain also causes increased fatigue, which can make school work difficult. Pain makes you tired and some students with arthritis will come straight home from school and need to sleep. This can affect their ability to get their homework done. Try and focus on the quality rather than the quantity of work done. And talk with your student and their family if you're concerned that they're falling behind. Being proactive and dealing with the situation as soon as possible will mean better results for your student. Pain and fatigue can also affect the ability to focus and concentrate, especially if their pain has impacted on the quality of sleep. This is not to say that children with JIA are in anyway less academically able then their peers, purely that when they're unwell, they may need additional time to complete their work.

Arrangements for when the child needs time off school

Children with arthritis will need time off school from time to time to attend appointments. They also may need time off when they're unwell. If this time stretches beyond a couple of days, arrangements will need to be made to ensure they're not falling behind with their schoolwork.

This is obviously important not just academically, but also to ensure your student feels involved and motivated with their studies. It's also important so that they don't start feeling isolated from their peers and classmates.

Consider discussing with the parents the possibility of having a close friend or two pop by to boost your student's spirits and keep them feeling socially connected with their peers.

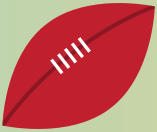
Camps and excursions

Like most children, children with arthritis will be keen to go on camps and excursions. However in some cases special arrangements may need to be made. For example, will your student need to take medications and how will they need to be stored? Most biologic medications need refrigeration. Does the child inject themselves or will a staff member need to be trained to do this? What equipment will need to be taken? What considerations will need to be made if the child is unwell and needs to go home? Start planning early and make sure your student and their parents are involved.

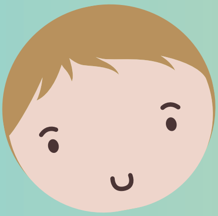
PE/Sport

If your student is unable to participate in sport for a period of time, make sure they don't feel left out. Give them another job to do. It might be scoring, time keeping or helping to set up the equipment – anything so they still feel part of the action.

At other times, you may need to look at using modified equipment so that the child can participate. Bean bags may be easier to catch than a tennis ball or try playing tennis with a balloon… focus on what the student can do rather than what they can't.

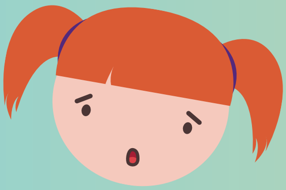


Some students may feel very self-conscious about their swollen joints or other body issues, so it's best not to insist that sports or swimming costumes are worn if it's going to cause embarrassment. You may also need to allow extra time for getting changed. Discuss this with your student and their parents.



Emotional support

Living with chronic pain and fatigue can be tough. If you feel your student is struggling, speak to their parents. They may wish to talk with their GP about the variety of options that are available, including accessing a mental health care plan which gives up to 10 subsidised appointments with a psychologist.



Bullying

Many children with arthritis have to take medications that can make them gain weight as well as having other side effects. Children that 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.

The prevention of bullying is part of the school's duty of care towards all students, but particular attention may be needed to ensure that a child with an illness isn't targeted.

The National Centre Against Bullying website has some great strategies to help out if you feel the child in your care is experiencing bullying.
https://www.ncab.org.au/who-we-are/

Sick bay

Sick bay for a child with a chronic illness is a bit different than for those with a head cold, a sprained ankle or a sudden bout of gastro. Instead of just being a place to go when sick, it may instead be a place for some quiet time and an area for the child to practice his or her own pain management strategies. That is, of course, providing there's not another child in there with an infectious illness!

A child with JIA or another musculoskeletal condition doesn't necessarily need to go straight home from school if they're feeling unwell. They might just need a little time to rest before they are able to join back in with their classmates. Speak to the child and their family and work out a plan. It's possible that after some rest, some heat or ice packs or even listening to some music that they're ready to get back into the school day again. After all, being at school as much as possible is the aim for all kids.

We are here to help.

Check out our website for more detailed information about specific conditions not covered here: **www.muscha.org**

We also have a free Helpline that can be called weekdays on **1800 263 265**. They can help you with information about arthritis and musculoskeletal conditions, management options, and strategies for helping children manage at school.

More to explore

Hospitals:

- **Monash Children's Hospital** – www.monashchildrenshospital.org/rheumatology
- **The Royal Children's Hospital** – www.rch.org.au/rheumatology

Arthritis organisations:

- **Arthritis Foundation USA** – Kids Get Arthritis Too www.kidsgetarthritistoo.org
- **Arthritis Ireland** – www.arthritisireland.ie
- **Versus Arthritis UK** – www.versusarthritis.org
- **Australian Rheumatology Association** – www.rheumatology.org.au
- **British Society for Rheumatology** – www.rheumatology.org.uk
- **National Rheumatoid Arthritis Society** – www.jia.org.uk

Pain:

- **PainBytes – Agency for Clinical Innovation** – www.aci.health.nsw.gov.au/chronic-pain/painbytes
  Information for young people about chronic pain, managing pain and school and much more.
- **Tame the Beast** – www.tamethebeast.org
- **The Worst Pain in the World** – www.youtube.com/watch?v=GWFaJzM_N7k&t=2s

General health:

- **Better Health Channel** – www.betterhealth.vic.gov.au
  Victorian Government health website.
- **Lab Tests Online** – www.labtestsonline.org.au
  Provides information on the many clinical lab tests.
- **Medlineplus (USA)** – https://medlineplus.gov/
  Information on health conditions and wellness issues. From the National Institutes of Health and the National Library of Medicine.

Mental health:

- **ReachOut Australia** – https://au.reachout.com
  Helps under 25s with everyday questions through to tough times.
- **Youth Beyond Blue** – www.youthbeyondblue.com/
  Beyond blue's dedicated site for young people.

Research databases:

- **Cochrane Library** – www.cochranelibrary.com
  Regularly updated collection of high-quality, independent evidence to inform healthcare decision-making.
- **Medline** – www.ncbi.nlm.nih.gov/pubmed
  Health and medical journal citations and abstracts from around the world.

Allied health professionals:

- **Australian Podiatry Association** – www.apodc.com.au
- **Australian Physiotherapy Association** – https://australian.physio
- **Australian Psychological Society** – www.psychology.org.au
- **Dietitians Association of Australia** – www.daa.asn.au
- **Exercise and Sports Science Australia** – www.essa.org.au
- **Occupational Therapy Australia** – www.otaus.com.au
- **Australian Society of Ophthalmologists** – www.asoeye.org

Individual Health Care Plan

Musculoskeletal Health Australia
Knowledge. Choice. Connection.

STUDENT DETAILS

Name

Date of birth / /

Current year level

Please attach a recent photo of your child to this document.

SCHOOL CONTACT INFORMATION

First school contact person

Second school contact person

Other relevant staff

FAMILY CONTACT INFORMATION

CONTACT ONE

Name

Relationship

Home phone ( )

Mobile phone

Work phone ( )

Email

FAMILY CONTACT INFORMATION

CONTACT TWO

Name

Relationship

Home phone ( )

Mobile phone

Work phone ( )

Email

MEDICAL CONTACT INFORMATION

GP

Specialist

Specialist nurse contact

Allied health contact eg: physio/occupational therapist

Please attach additional page if required

STUDENT'S HEALTH NEEDS

Condition

Main issues

JIA MANAGEMENT

The student’s usual JIA symptoms / symptoms during a flare may include:

- ☐ Joint stiffness *(especially in the morning)*
- ☐ Limping when in pain
- ☐ Fever
- ☐ Fatigue
  - ☐ Physical fatigue
  - ☐ Mental fatigue
- ☐ Joint pain, swelling and tenderness
- ☐ Eye redness or eye pain
- ☐ Rash
- ☐ Blurred Vision
- ☐ Redness and/or warmth in joint/s
- ☐ Loss of appetite/ weight
- ☐ Problems with balance
- ☐ Irritability
- ☐ Joints usually affected include
- ☐ Other (please specify)

MEDICATION

Does your child currently take any medications? ☐ Yes ☐ No

Is your child likely to require medication at school? ☐ Yes ☐ No

If yes, please detail below and make sure the medication is supplied to staff as needed:

Name of medication	Dose and route of administration	Time required

IMPACT ON STUDENT’S LEARNING

How is your child’s condition likely to affect their learning?

- ☐ Difficulty holding pens
- ☐ Difficulty opening things *E.g. laptop, packets*
- ☐ Difficulty staying in one position (e.g. sitting) for prolonged periods of time
- ☐ Difficulty writing fast
- ☐ Difficulty carrying items to class *E.g. books, bags*
- ☐ Being absent from school due to illness or hospital appointments
- ☐ Difficulty concentrating due to pain, fatigue, discomfort
- ☐ Other (please specify)

Difficulty raising hand to ask a question

☐ Yes ☐ No

Pain and/or fatigue at the end of the day affecting homework

☐ Yes ☐ No

Does your child require any further professional assessment to aid learning?
E.g. occupational therapist who can provide classroom aids, devices, splints etc.

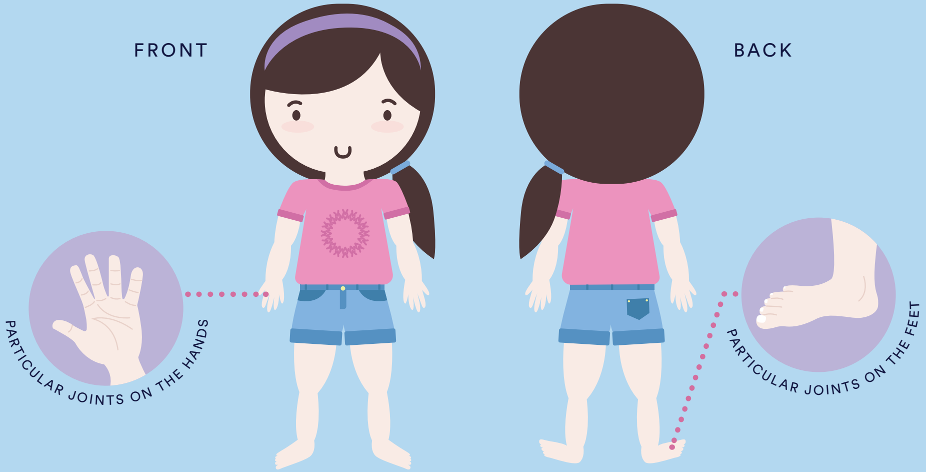
☐ Yes ☐ No

If yes, please specify:

PHYSICAL ACTIVITY

Are there any restrictions/limitations in movement? ☐ Yes ☐ No

If yes, which joints are affected by limited movement? Please list OR circle on the diagram below.



Has your child's treatment team recommended that any movements or activities be avoided or done with care? *E.g. avoid sitting cross legged.*

☐ Yes ☐ No ☐ Not at this stage

If yes, please specify:

Does the student have any specific concerns with physical activity?
E.g. are they worried about being knocked over?

☐ Yes ☐ No ☐ Not at this stage

If yes, please specify:

PHYSICAL ACTIVITY

Does the student require extra time or different equipment to be used?

☐ Yes ☐ No ☐ Not at this stage

If yes, please specify:

What special consideration needs to be made regarding sports carnival, cross country, swimming carnival etc?

SOCIAL AND EMOTIONAL NEEDS

Is this child likely to ask for help when needed? ☐ Yes ☐ No

Would this child benefit from a 'buddy' to help carry belongings etc.?

☐ Yes ☐ No

Is this child receiving additional emotional support from a psychologist?

☐ Yes ☐ No

Please specify any social/emotional needs that you feel should be acknowledged

SCHOOL ENVIRONMENT

What issues may arise from the school environment?
E.g.: stairs, seating, writing, laptops, bathroom, taps etc

SCHOOL ENVIRONMENT

What changes can the school make to deal with these issues?

What outside agencies may be of assistance?

IMMUNE SUPRESSION

Many children with JIA will be on some form of medication that suppresses the immune system. This means that they're both more susceptible to picking up infections and more likely to suffer from complications if they do.

Who is the staff member responsible for notifying parents of any communicable disease in the school?

CAMPS AND EXCURSIONS

What arrangements need to be made?

Who is responsible for these?

CAMPS AND EXCURSIONS

Will medication need to be taken? ☐ Yes ☐ No

If so, does it need refrigeration or special storage?

Will specialised equipment be needed? ☐ Yes ☐ No

Who will be responsible for the student on the trip?

What is the plan should the student need to come home/leave early?

Did any issues arise on camp that need following up?

SIGNATURES

Student ×	Healthcare professional ×
Parent/carer ×	School representative ×
Parent/carer ×	School nurse ×

Musculoskeletal Health Australia
263-265 Kooyong Road
Elsternwick VIC 3185
Telephone: 03 8531 8000
Helpline: 1800 263 265
info@muscha.org | muscha.org

Musculoskeletal Health Australia
Knowledge. Choice. Connection.

**Musculoskeletal
Health Australia**
Knowledge. Choice. Connection.

263 Kooyong Road Elsternwick 3185
PO Box 130 Caulfield South 3162
1800 263 265 www.muscha.org