



# Juvenile Idiopathic Arthritis

>>> Information for teachers

This information sheet provides an overview of the symptoms and treatments of Juvenile Idiopathic Arthritis, answers common questions teachers may have, and gives some ideas about how to help a child with arthritis cope well at school.

## What is Juvenile Idiopathic Arthritis?

Juvenile Idiopathic Arthritis (JIA) is a chronic disease in children and adolescents under 16 years that causes inflammation in one or more joints which lasts for 6 weeks or more. JIA is an umbrella term that covers different forms of arthritis, depending on how many joints are inflamed and what other tissues are affected. "Juvenile" means that it affects young people, "idiopathic" means that we don't know what the cause is, and "arthritis" means inflammation of the joints.

JIA affects approximately one in every 1000 children in Australia. This means that it is not really common, however it is estimated that there are at least 5000 children in Australia with arthritis.

## What are the symptoms of JIA?

JIA can appear in many different ways and can range in severity. JIA mostly affects the joints and the surrounding tissues, although it can affect other organs like the eyes, liver, lungs and heart. Some of the signs of an inflamed joint are joint swelling, pain, stiffness (especially in the morning) and warmth. However, a child may not have all of these signs in every joint that is inflamed. Children may also be unwell with fever, rash, loss of appetite and loss of weight.

## What causes JIA?

JIA is an autoimmune disease, which means that the body's immune system mistakes a normal part of the body for something foreign (like an infection), and starts attacking the body itself. In JIA the immune system attacks the tissues in the joints. It is not understood precisely how, or why, this happens. What we do know is that JIA is not hereditary, nor caused by being too cold, living in a cold climate or eating particular foods.

## How is JIA treated or managed?

Because JIA can affect each child differently, treatments are tailored to each individual child. The main ways of treating JIA include:

- medications to control the inflammation
- exercises to keeping the joints moving well
- splints to support the joints
- joint injections to reduce inflammation in particular joints
- pain management strategies to help children cope with pain

## What to expect from a student with JIA

The symptoms of JIA can change over time, and may even change from day to day. There may be periods when the arthritis gets better and then periods when it gets worse, which is called a flare or flare-up. As a teacher, this is the critical thing to know about JIA, because it means that children's physical abilities, pain and mood can change from day to day. This means that it is always best to be guided by children and their parents about what children can do at any particular time. In general, children are more likely to ignore their symptoms in order to fit in with their peers than to overplay their symptoms in order to avoid activities.

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## Common difficulties children with JIA may have at school

- Difficulty getting to school on time due to morning stiffness
- Difficulty holding pens, or with hand activities such as writing, drawing, cutting
- Difficulty writing fast enough to copy notes or complete tests in allotted time
- Difficulty completing homework on time due to tiredness and slow writing
- Difficulty opening things e.g. taps, jars, doors, lunchbox and its contents (e.g. packet of chips)
- Difficulty carrying things in their hands or over one shoulder
- Raising a hand to ask and answer questions may be difficult or painful
- Staying in one position for an extended period may cause pain and stiffness e.g. prolonged sitting
- Back and neck pain from bending over the desk when doing written work
- Difficulty getting on/off toilets and re-dressing self
- Difficulty getting up/down from the floor and sitting on the floor
- Walking long distances may be painful, or slow, causing lateness to class
- Walking up/down stairs is slow and they may need a rail to hold onto, or be unable to do this at times.
- Difficulty participating in physical education and playground activities
- Difficulty changing clothes for physical education
- Difficulty rehearsing fire drills as they may be unable to run and at risk of being knocked over
- People not believing they have arthritis because they look “normal”
- Being absent from school due to illness or hospital appointments
- Being teased by peers for looking different or getting “extra attention”
- Irritability due to pain, fatigue, discomfort and medication
- Tiredness as a result of the condition or lack of sleep due to pain

## How can teachers help?

Because of the unpredictability of JIA there are no hard and fast rules about teaching a student with JIA. The best sources of information about the child’s abilities and needs are the child and their parents, however the following ideas and guidelines may assist you to help your student do well at school despite JIA.

### **1. Pain or stiffness from sitting, standing, or leaning over the desk for a long time**

Everyone gets stiff when they stay in one position for too long and this is especially true for children with arthritis. Changing position frequently for brief intervals reduces joint pain and stiffness. This may mean the child needs to get up and move around 2-3 times per hour for a couple of minutes, or simply have a brief change of activity. You can:

- Periodically call on the student to perform a task involving movement.
- Let the child know that it is OK to move about when they need to.
- Make a plan with the child about how they can move regularly in the classroom without calling attention to themselves. For example, some children plan to walk to the bin across the classroom every hour.
- Arrange for extra time or rest periods during activities where there is a time limit, like exams.
- Provide accessible seating both inside and outside the classroom.
- The child’s seat should be arranged so that their ankles and knees are at a 90 degree angle and hips are at a 70 – 90 degree angle. The base of the chair should not slope backwards.
- The child should be able to rest their feet on the floor. If the chair is too high, give them a book, box or something else to put their feet on.
- The desk should be just above elbow height when sitting.

## **2. Morning Stiffness**

The immobility of children's joints while they sleep often results in increased pain, stiffness and slowness to move in the mornings. You can:

- Understand that it may be difficult to be on time every morning.
- Program a passive activity at the beginning of the day. Physical movement may be more achievable as the day progresses.

## **3. Fatigue**

Pain and discomfort can often result in disrupted sleep, leaving children tired and affecting their mood and concentration. You can:

- Alternate active and passive activities over the course of the day.
- Arrange a "time out" space within the activity area, ideally one which doesn't isolate the child, and allows them to still be included in some way.
- Understand that completing classroom activities and homework may be difficult at times, such as during a "flare".
- Watch out for signs of fatigue, grumpiness or uncharacteristic behaviour. These may mean that the child is in more pain than usual, or struggling with their arthritis. It is helpful to talk to the child at this time so you can plan together how best to deal with the day.

## **4. Difficulty with hand activities**

- Allow extra time for classwork and homework
- Allow rest periods during written work for the child to stretch their hands and fingers to minimise stiffness and pain
- Allow the child to use pen grips or special pens or scissors as required
- Provide the class with handouts instead of asking the child to copy lot of notes
- Arrange for a friend to share notes with them
- Record class lessons e.g. on a Dictaphone
- Older students could use a lap-top where appropriate

## **5. Walking and Balance**

Depending on which joints are inflamed, and especially during a flare, walking and balance can be difficult for children with JIA. You can:

- Program activities in the same area if possible.
- Allow adequate time for the student to move from one area to another.
- Build in a strategy to decrease the chances of the child being knocked over during "bustling" changeover times.
- Arrange for hand rails to be installed where appropriate.

## **6. Carrying books / equipment**

Children with JIA may be instructed by their treatment team to avoid carrying heavy things, especially during a flare. You can:

- If possible, organise two sets of textbooks, one for home and one for school. Old class texts are sometimes available for this.
- Allow an intra-school backpack to carry needed items.
- Ensure the student's designated locker is accessible, for example, does not require them to climb stairs regularly.
- If other students are designated to assist carrying books, ensure the task is rotated through the roll to avoid any resentment.

## **7. Peers and emotional wellbeing**

JIA can disrupt all aspects of a child's life, however the impact it has on a child's schooling, socialising and mood are potentially the most damaging. As mentioned earlier, most students want to be "normal" and part of the group and the student with JIA may therefore downplay their pain and difficulties to avoid isolation, or even 'innocent' questions from interested students. You can:

- In partnership with the student, educate their peers about JIA and the impact of an invisible chronic condition.
- Be aware of any special needs but always aim for inclusion rather than exclusion.

- Allow the student to do things for themselves to develop a sense of independence and competence. They will generally ask for assistance if they need it.
- Have the same expectations and rules for the whole class. JIA should not be used as an excuse to avoid deadlines and specific activities, and time allowances should be negotiated as with any other student. It is also important that children with JIA realise they will not be treated differently because of their condition, and that they are not defined by their illness.
- Be aware that the emotional and physical stress of the condition may mean the student can be emotionally volatile or fragile at times. This may also be the case for siblings you are teaching, who are also affected by concerns about their sibling's health.

### **8. Absence**

The management of JIA requires regular visits to a range of treatment providers, which in most cases occur during school hours. During a flare, the child may also be too unwell to attend school. The aim is to reduce the impact of absence on a child's learning and peer relationships. You can:

- Arrange for the child to attend for reduced periods of time, or for core subjects only.
- Liaise with hospital education advisors or rheumatology team if required. The hospital education advisors are experts in assisting chronically ill children to return to school, or develop an appropriate plan for their schooling.
- Keep the student updated of what's been happening both socially and academically to avoid further isolation.
- Use various methods of ICT to keep the young person linked into school even when they are not attending.

### **9. Extra-curricular activities**

You may find that the student prefers to avoid activities such as camps, extended excursions or sports days. The student may be anxious that the activity will be too much for them, or that their peers may see splints, or exercises that are usually done at home which will make them "different" to their peers. You can:

- Discuss the activity well in advance with the student and their parents to determine if there are any concerns.
- Think about the following issues when planning activities, or adapting them for the student with JIA:
  - Is the program physically demanding? Will it require walking long distances or standing for long periods?
  - Will it highlight their difference within their peer group?
  - Are the facilities accessible?
  - Will there be the opportunity to "opt out" if they are in too much pain?
- Be aware that children are likely to need to carry medication with them, and make arrangements for this to be stored and dispensed safely.

## Who to ask for further information

- The student and their family
- The rheumatology nurse or child's rheumatologist

### **Acknowledgments**

Arthritis Victoria: *Information for Teachers and Child Care workers*

Starship Children's Hospital: *Information Package for Schools*