juvenile arthritis

A TEACHER'S GUIDE



Arthritis AUSTRALIA

www.arthritisaustralia.com.au

School advisory form

attach photo here

Parents and caregivers, please complete this form...

Dear Principal

NAME OF STUDENT

DATE OF BIRTH

IN CLASS

has Juvenile Idiopathic Arthritis or JIA.

SYMPTOMS

Her/his symptoms include (eg morning stiffness and/or pain, slow walking, skin irritations, muscle weakness, poor coordination, fatigue, etc)

ACTIVITIES AFFECTED

These symptoms can affect activities such as (eg holding a pen, standing for more than 20 minutes, sitting on a stool or cross-legged, getting up from the ground, carrying books or sporting equipment, playing contact sports, etc)

MEASURES TO BE TAKEN

Measures that will help alleviate discomfort and/or minimise symptoms include (eg using a pen grip, specially-angled desk or other aids; avoiding stairs; being able to use a pull-along trolley; not being asked to wear shorts or swimwear; etc)

UNEXPECTED EVENTS

In the event of a flare-up of the condition, action that can be taken includes (eg allowing student to rest, being flexible with due dates for homework, allowing pain relieving medication to be taken, calling a parent/caregiver, etc)

MEDICATION

She/he needs to take medication at school. ☐ YES ☐ NO

If yes: I therefore seek permission from the school to have the following medicines administered by

☐ staff and delivered to the school by

☐ OR self-administered by the student.

NAME OF MEDICINE	DOSAGE	TIME/S TO BE TAKEN

CONTACT

NAME OF CAREGIVER 1	PHONE	MOBILE
NAME OF CAREGIVER 2	**PHONE**	**MOBILE**
DOCTOR	**PHONE**	**MOBILE**

Thank you for your support.

If you require more information or would like to arrange a time to meet, please do not hesitate to contact me.

SIGNED

NAME

RELATIONSHIP TO CHILD

DATE

MOBILE

Please attach additional page/s if needed.

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how you can **help**

Most of us know someone with arthritis...a family member, friend or workmate.

One in five Australians has arthritis. And it's a condition that doesn't discriminate. Some of those most hard-hit are children.

At least one child in 1000 in Australia has juvenile arthritis.

School and sporting activities, and partying and playing aren't too much fun when mobility is compromised and painful flare-ups take so much enjoyment away.

Everyday tasks such as tying shoelaces, sending SMS messages, learning a musical instrument, turning on a tap and even carrying school books can prove extremely difficult – if not impossible - for those with severe juvenile arthritis.

Teachers and schools can play a major role in helping children and adolescents with arthritis to manage their condition and get the most out of their lives.

The pain of juvenile arthritis is not only physical.

It can impact on friendships, self-esteem and confidence. The sense of adventure, motivation to try



new things, feelings of belonging as well as academic achievement and sporting prowess can be undermined.

Support is vital; as is understanding.

Juvenile arthritis can affect every child and adolescent differently. In fact arthritis is predictably unpredictable! It is not a static condition. The pain and discomfort experienced as well as the joints affected can change not only on a daily basis, but from one hour to the next.

arthritis australia

Arthritis Australia is the peak arthritis organisation and is supported by affiliate offices in every state and territory.

More than 3.4 million Australians – mostly of working age – have some form of the more than 100 different types of the condition.

Arthritis costs the community $19.25 billion each year and is Australia's major cause of disability and pain.

Arthritis Australia aims to:

- promote community awareness of the problems confronting people with arthritis
- provide support, advice and information for those with arthritis and their families
- educate medical and health professionals in the treatment of arthritis, and
- fund research into the causes of and cures for arthritis.

With limited government funding, Arthritis Australia relies mostly on public donations.

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what is juvenile arthritis

Arthritis is the inflammation of a joint or joints. It makes the affected joint swollen, stiff and painful.

Juvenile arthritis is one of the more common, persistent medical conditions of childhood. More girls than boys are affected and its severity differs from child to child.

There is no known cause and often no apparent link to a family history of the condition.

Most forms of arthritis are thought to be a reaction of the body against its own joint tissues.

While there is no current cure, innovative strategies for managing juvenile arthritis are meeting with success.

Today joint inflammation and pain can be better addressed by new medications. This combined with treatment by a rheumatologist and occupational therapist or physiotherapist can readily improve the condition.



Even though it's not possible to tell how long juvenile arthritis will last, which joints will be affected or its severity, the good news is that many children and adolescents will gradually recover.

the **most common forms** of juvenile arthritis

There are more than 100 forms of arthritis and the types that affect people under 16 years of age are grouped under the term *Juvenile Idiopathic Arthritis* or JIA.

Here are the most common forms of Juvenile Idiopathic Arthritis or JIA:

Oligoarthritis usually affects larger joints such as knees, ankles and elbows but can also manifest in wrists, fingers and toes. It is the most common form of JIA and occurs when up to four joints are affected. Children with oligoarthritis are at substantial risk of eye inflammation and their eyes need careful monitoring.

Polyarticular arthritis literally means " many joints" and involves five or more joints. Small joints such as fingers can be affected as well as the hips, ankles, feet, shoulders, neck and jaw. Five per cent of those with polyarticular arthritis show rheumatoid factor positive in tests. This means their blood contains an antibody similar to that found in adults with rheumatoid arthritis. Early treatment is vital to help prevent long term damage and deterioration of the joints.

Systemic arthritis, the least common form of JIA, not only affects the joints but causes widespread inflammation with high fevers, rashes, aching limbs, and fatigue. It can be difficult to diagnose because early symptoms can be confused with other childhood diseases such as measles and meningococcal infection.

Enthesitis-related arthritis most often affects boys 8 years or older. Along with having arthritis in several joints, there is usually swelling at the point where a tendon attaches to the bone. Enthesitis-related arthritis initially affects lower limbs such as the hips, knees and ankles and then the spine in later years.

Psoriatic arthritis can affect several joints and is usually associated with the scaly skin rash of psoriasis. Children and adolescents with psoriatic arthritis, like those with oligoarthritis, need regular eye checkups.

how teachers can **make a difference**

Pain associated with juvenile arthritis (JIA) as well as the inability on some days to join sports or social activities can lead to isolation, depression and a loss of self-esteem.

Intelligence levels are not affected by JIA. Like almost everyone else, children and adolescents with juvenile arthritis thrive on interaction and learning, but their condition can slow them down.

In the classroom symptoms can include difficulty writing because of pain in the fingers, neck or back. The pain can also be the result of stiffness from sitting in one spot for too long or from standing for a long time.

Moving easily from room to room, climbing stairs, and carrying text books can also prove difficult, and on some days, impossible.

Chronic pain can mean homework is not done on time. Lateness can be unavoidable as stiffness and pain are worse in the morning before joints have had a chance to move and unlock. Absences can be attributed to flare-ups, visits to health practitioners, even hospital stays. At times some with JIA need a wheelchair.

Seeing strengths in every student is something at which teachers excel.

Ensuring the pupil or student with juvenile arthritis is included, and feels included, in school activities is one of the best ways to help overcome feelings of not belonging. This in turn can boost confidence.

Being at one with peers instead of being defined by a medical condition can encourage a *can do* attitude that shifts focus away from what can't be done or is difficult to do.

Like all kids, those with JIA don't like being singled out or thought of as different. With a discreet helping hand and a bit of creative thinking their path can be made easier so they too get the most from everything school has to offer.

> "I had to do a writing test with no break. At the end of 20 minutes my hand was so sore I couldn't grip or hold a cup." Katie, 12

more **copies**

To download additional copies of:

- this booklet
- school advisory form, and
- other JIA resources

visit www.arthritisaustralia.com.au



JIA camps

Camps for children and adolescents with JIA are a great way for young people to get together and share experiences.

For more information call 1800 011 041

working with the **whole family**

Parents and caregivers of those with JIA are often in an ideal position to work with teachers to overcome school-based challenges.

Caregivers are encouraged to provide the school with a comprehensive written list detailing, for example, how arthritis affects their child, symptoms to watch for, emergency contacts, abilities such as hand skills and mobility, suitable sports, and other recommended activities. A form for this purpose can be found on the inside cover of this booklet.

Attaching a recent photograph of the child or adolescent to the form will help all staff to more readily identify them as someone who may need extra help.

Meetings between staff and caregivers are recommended. Details of medication, therapy programs, and the availability of special aids such as slope-boards, special scissors and pens, height-adjustable chairs, desks and footrests as well as small trolleys that make carrying easier, can be identified and discussed. Some occupational therapists and physiotherapists are also willing to attend such meetings.

Alternate transport to and from school may also need to be organised, particularly if bus stops or railway stations are overly-crowded or not close to the home or school. State government education, disability, transport or health departments can assist with special transport needs.

> “Over protection can be as bad as not protecting at all. If a teacher’s over protective you feel really bad, as if you’re not grown up enough to look after yourself.” Benjamin, 11

listening to the child

As the impact of arthritis can change on an hourly basis it’s perhaps best to respect the wishes of those who say they are unable to do something.

Few with juvenile arthritis have outward signs of the condition but this does not mean all are free of pain or fatigue.

Most often they are not trying to get out of things or as some might say, skive off. It may be that they are just not up to participating in that particular activity at that particular time.

A child or adolescent with JIA is likely to be in more pain and less capable of various activities in the morning. By midday and early- to late- afternoon they can be more mobile and comfortable, and able to do what they could not accomplish earlier in the day.

Rather than be left out though, those who are eager-to-please might try and join in activities despite being in pain. For this reason it’s important for teachers to monitor pupils’ movements closely and assess if they really are capable of participating.

If the child seems unusually quiet and withdrawn, moves slowly, limps or appears tense, this can signal they are in pain, and despite their insistence, not up to the activity suggested.

Learn to detect the signs and perhaps find other ways to involve the child such as appointing them umpire or timer; any activity that keeps them part of the group.

If someone with JIA is inadvertently forced into an activity - even something like writing for 15 minutes or sitting cross-legged on the floor – when they are not up to it, they can experience excruciating pain and possible absence from school the next day.

So be guided by the child.

Giving them a degree of control can help further the teacher-pupil relationship.

arthritis at **pre-school**

Teaching pre-schoolers can be demanding and even more so when children have special needs.

Suggested guidelines for teachers with pre-schoolers with juvenile arthritis (JIA) in their care include:

- Ask a parent or caregiver to complete the form on the inside cover of this booklet.
- Double-check with parents or caregivers about medications that need to be taken.
- Find out if any additional pain relief might be needed and the appropriate dosage.
- Have emergency phone numbers, including the mobile numbers of caregivers, at hand.
- Sitting on the floor can be difficult for the child with JIA. Small chairs can help but rather than having just one chair in isolation, group some chairs together to reduce the likelihood of the child feeling isolated from others.
- Pencils, crayons and paint brushes can be harder to hold for the pre-schooler with juvenile arthritis. Thick-handled brushes are recommended and handgrips for pens might be necessary. As standing or sitting for long periods could be difficult, allow them to move unobtrusively around the room rather than stay still for too long.
- If there is an activity the child is not capable of on a certain day, involve them by giving them another task such as handing out papers or being the teacher's special assistant.
- Pain means interrupted sleep so tiredness can be a problem. Encouraging rest periods rather than playtime can help.
- Introduce a voluntary buddy system where other children help the child with JIA by carrying books, opening lunchboxes and other day-to-day tasks they might find difficult.
- Try to ensure hooks for hanging coats and bags as well as lockers are at a suitable height.
- Place toys on tables and shelves so the pre-schooler with restricted movement doesn't need to get on the floor to play with them.
- A child with JIA needs understanding, but in terms of classroom management, should be treated no differently from others if they are misbehaving.



"I have trouble bending so when they say take off your shoes and socks, I have real trouble and take ages to get them on again." Sam, 14

"Instead of my teacher asking me how I felt and stopping the whole class, I'd hold up red, yellow or green cards. Red meant I didn't feel very good. Yellow meant I was pretty okay and green meant I felt excellent." Annelise, 13

arthritis at **primary school**

Much of what applies to a pre-schooler also applies to the 5 to 12-year-old child with juvenile arthritis (JIA).

As they get older most children will better understand their condition, what they are capable of, and when it's time to slow down.

Be guided by the child about what they can and can't do.

Ideas for assisting pupils with JIA include:

- Create a volunteer buddy system of not just one special buddy but four or five pupils who take it in turns to help their friend with JIA with things like lifting, carrying books and equipment, and getting around the school building. These buddies can also be asked to alert staff if they think the child with JIA is being bullied or in increased pain.
- Organise a special session to talk about JIA and other chronic conditions such as asthma and diabetes. Pupils with these conditions will hopefully be able to gain a sense of empowerment by contributing to the discussion.
- Further increase awareness of these conditions by holding a fund-raiser for a related charity.
- Broken sleep resulting from pain can mean the pupil with JIA is fatigued and/or cannot always meet deadlines for homework and projects. Giving leeway is encouraged as is assessing the quality of, rather than the quantity of, work presented.
- Absenteeism can be high so extra tutoring might be needed. Some state government departments of health, disability or education can assist.
- Even if the child can only manage to attend school for an hour or two in an afternoon, there can be benefits gained from them being able to be with friends, and for a brief period, distracted from pain.
- On school excursions the pupil with JIA might need help to carry a backpack, walk distances, climb stairs and get on or off a bus.



- Coordination, balance, weak muscles and restricted mobility can be problems for the child with JIA. Some days they will want to participate in sport or other class activities. Other days they won't. Flexibility can be key to helping the primary school pupil reach their potential.
- Encourage a parent or caregiver to complete the form on the inside cover of this booklet.

"I can't kneel and my knees look too big for my legs, and when I can't play sport I feel really bad." Rachel, 14

"I hate telling anyone I hurt so I don't. I don't like telling them I've got arthritis either." Wendy, 8

arthritis at **high school**

Juvenile arthritis (JIA) and the side effects of its treatment can be associated with growth problems and puberty can be delayed.

For an adolescent this can be distressing and can reinforce a negative self-image and a sense of being different from others their age.

Having twisted and inflamed joints can make them feel unattractive so it's often best to avoid insisting that, for example, shoes are removed or shorts or swimming costumes worn.

Special consideration can also be needed during exams. As students with JIA might be unable to sit for long periods, it's advisable to seat them near a door or at the back of the room so they are able to get up and walk around for a few minutes during the exam without disturbing other students.

More suggestions for high school teachers include:

- Ensure information provided by a parent or caregiver about the student's condition is up-to-date. The form on the inside cover of this booklet can be used.
- Continue to focus on strengths. If the student with JIA doesn't excel at sport, acknowledge and encourage passions such as music, science, ecology, singing or acting.



> "My teacher didn't think I should pass my School Certificate because I hadn't done enough sport. She didn't understand what arthritis was." Melissa, 18

- Ask classmates to volunteer for a buddy system.
- If the student with JIA is willing, let them tell the class about their condition and how it affects them.
- If possible arrange for all classes to be in rooms where access is stair-free. Also allow extra time for students with JIA to move from room to room.
- Reduce the amount the student needs to carry by providing two sets of text books; one for home, one for school.
- Investigate, if possible with the school's counsellor and the student's therapist, aids and tools that could be useful. These range from pens with grips to spring-lock scissors, height-adjustable chairs and desks, to laptops and note-taking devices.
- Make special arrangements for external exams well ahead of time in conjunction with a caregiver and appropriate authorities such as the state's Board of Studies.

top tips from kids and parents

The backpack seat School excursions can be difficult as pupils and students with JIA can need to stop and rest. A backpack that comes with a collapsible seat can be a boon on excursions.

A small cabin bag on rollers is a great way to carry everything needed for school as it can be pulled along the ground.

Orthotics insoles can help make walking easier and put less stress on the joints. Using orthotics can mean the school might have to relax strict guidelines on regulation footwear.

Arthritis camps Run by state and territory arthritis offices, juvenile arthritis camps provide a valuable opportunity for children and adolescents with JIA to have fun and meet others their own age, and share experiences.

Modified kitchen implements can be used at home as well as in cooking classes at school.

Back support Some classrooms such as science labs are furnished with stools. Adolescents with JIA may need to sit on something that offers back support.



Avoid the rush For high-schoolers with JIA the rush between classes and the jostling that can occur in crowded corridors can be a major challenge, particularly as teens with juvenile arthritis often have problems with balance and coordination. Allowing such students to leave class a little early or later to avoid the rush is recommended.

Sport The unpredictability of arthritis can limit participation in regular team activities. It's advised though that children and adolescents with JIA, who love their sport, should be encouraged to participate without the game being modified. They will usually know what they are capable of at any given time.

Extra information Parents and caregivers are not always sure what aids, tools, special concessions and other assistance are available from schools as well as government departments and agencies. Teachers can help by offering caregivers information on what they know is available.

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