Managing JIA in School

JIA at NRAS
JUVENILE IDIOPATHIC ARTHRITIS
www.jia.org.uk
About this document

Attending school is a huge part of a child’s life. It provides structure and stability, as well as helping children develop crucial social, emotional and behavioural skills.

- **Who is this for?** This document is for everyone who works in an educational setting with children 10 years old and above and for parents/carers who have education-related questions.

- Here at The National Rheumatoid Arthritis Society (NRAS) we have become “the voice” of people affected by rheumatoid arthritis (RA) in the UK. Our service for children and young people with all forms of juvenile idiopathic arthritis (JIA) is developing alongside our well-established rheumatoid arthritis service.

- The information contained here is deliberately concise; however more information is available on our website or please call us on **0845 458 3969**.
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What is Juvenile Idiopathic Arthritis (JIA?)

Signs and symptoms

There are approximately 12,000 children and young people across the UK living with JIA; that’s 1 in every 1,000 young people. This is a small number in comparison to the 690,000 adults with rheumatoid arthritis (RA) but nevertheless JIA is a long term condition affecting children and young people at a time when life should be an adventure; a time for learning and exploring, engaging and developing. JIA and RA are in a group of autoimmune conditions, where the body’s immune or defence system attacks the body’s own tissues, which can damage the joints and cause fatigue, pain and other symptoms.

The first signs of JIA, which can be subtle or obvious, may include a sore wrist, limping, or a swollen finger or knee. This may happen suddenly or develop more slowly over time.

JIA can be undetectable and then suddenly flare up, so it is important that all relevant members of staff are aware of this long term condition.

There are 7 different types of JIA. Having a greater understanding of the condition will help the school create an appropriate learning environment. Understand more (Types of JIA) at www.jia.org.uk/what-is-jia
Signs and symptoms include:

- Joint(s) that have remained swollen and painful for more than 6 weeks and that may be restricting movement (although symptoms can ‘flare’ for shorter periods of time)

- Stiffness in the affected joints. Additionally, this can affect co-ordination and make children and young people clumsier, especially first thing in the morning (at the start of a school day) or after sitting still for long periods

- Some children will alter their movements to avoid pain, rather than complaining of the pain. (eg not wanting to sit on the floor or limping to minimise weight bearing on a knee or hip)

- A child or young person may be particularly lethargic and not their normal self, particularly during a flare (page 6)

- In some cases children can develop a high fever that peaks in the evenings and settles to normal within hours, only to recur again each day. In these children rashes may suddenly appear in one area and then disappear, and then develop in a different area. This is specific to “systemic onset JIA”

- Uveitis (inflammation within the eye) is a condition which can be related to JIA; it can cause difficulty with vision and untreated can lead to blindness. Initially there are no symptoms and it is only picked up on routine clinic eye screening which children will automatically have following a diagnosis

Please be aware that as well as the physical challenges, confidence, self esteem and friendships can be affected when a child or young person has JIA.
What does a bad day look like? (flare up)

An increase in symptoms is often called a ‘flare’. A ‘flare’ usually means that the pain in the joints increases (sometimes with swelling of the joint) and often this can be accompanied by a feeling of being ‘tired’ and ‘washed out’

(extract from SusanOliver.com)

An arthritis flare may occur after an infection, or after a highly stressful situation; this could be school exam pressures, moving home or changing school, bullying and family splits.

However, what triggers a flare is often not clear. There may be long periods when the JIA is quiet, or in remission. Then, suddenly, the inflammation becomes more active and a child can have a flare.

During a flare the young person may be absent from school. In this instance it is important for the school to keep in contact and if appropriate enable the student to study whilst away from school.

If the arthritis is not controlled adequately, the flare ups are more frequent.
Meilla Earnshaw
Age 5
Managing JIA in School

Important information

Pain is what the patient says it is.

- Juvenile Idiopathic Arthritis (JIA) or more simply arthritis in children and young people is not always an obvious condition and young people don’t always want others to know about it, so please do not share information about individual pupil(s) with anyone unnecessarily unless you have been given permission.

- Search out as much information as is needed to ensure you are as knowledgeable as you need to be to support a child or young person with JIA in the learning environment.

- Try to think of some relevant questions:
  - How is your arthritis at the moment?
  - What medication do you take/ how and when is it taken? (check the school’s medication policy as they might need ibuprofen during the day)
  - Are there any triggers that we should know about that might lead to a “flare up”?
  - How can we make school-life easier for you if you are having a bad day with pain or fatigue?
  - What is the most comfortable seating arrangement? And would it help if you are able to move around in lessons?

- After the young person has settled in and become more familiar, ask them who they feel might be the best person in the school to discuss/share their issues/concerns about school life with, when and if they have any. This may be a question that you need to ask on more than one occasion during their time at school.
If/when a child or young person needs time off school, arrangements need to be made for school work to be carried out at home, or catch up sessions. Ask parents/carers if hospital appointments are possible at a time outside the normal school day. Increasingly, hospital clinics will be aiming to provide early morning or evening appointments for secondary school age children.

As and when PE comes up in the school day, please think about how the school can ensure the pupil is still included. JIA is a variable condition, some days for the pupil will be better than others. Please draw attention to this in the pupil’s IEP (individual education plan) if they have one.

Consider how included this pupil will feel at your school. Is there anything else that the school can do to support inclusivity for this pupil with this long term condition?

JIA in hip and lower body joints (legs etc) can cause particular problems with going up and down stairs.

JIA is an invisible disease; it can be very debilitating and is often more than you can see!

Useful website: http://medicalconditionsatschool.org.uk/

Children and young people with JIA are vulnerable to picking up infections.

The following information is taken directly from the government’s guidance on infection control.

Some medical conditions make children vulnerable to infections that would rarely be serious in most children, these include those being treated for leukaemia or other cancers, on high doses of steroids and with conditions that seriously reduce immunity (children with JIA). Schools and nurseries and childminders will normally have been made aware of such children. These children are particularly vulnerable to chickenpox, measles or parvovirus B19 and, if exposed to either of these, the parent/carer should be informed promptly and further medical advice sought. It may be advisable for these children to have additional immunisations, for example pneumococcal and influenza.

For guidance on infection control, visit www.gov.uk and search ‘infection control in schools’ for a downloadable PDF.

www.wiltshire.gov.uk/early-years-hpu-advice-re-infection-control.pdf

For more information and access to further resources please visit www.jia.org.uk
Important information

When children/young people move school, communicating with the new school is very important. Don’t assume that the schools have shared everything with each other. Some are very good and have a robust student information sharing process in place but it would still be a good idea to get in touch and keep in touch with the relevant people at the new school. Try to find out who is your new school contact and arrange to meet with them before the start date.

- Who are the key people in the school who will be responsible for sharing information to colleagues, as appropriate, about your child and JIA? Not all schools use the same titles for staff members in specific roles. Here are some roles that may be relevant:
  - The SENCO (special educational needs co-ordinator). Your child may not have special educational needs, however sometimes the SENCO’s remit includes supporting all students who may face additional physical or emotional challenges
  - The Deputy Head of Year (DHOY). Most schools have a member of staff in a pastoral role who supports the Head of Year (HOY) and they are responsible for supporting the students in that year group
  - Head of Year or Head of House has overall responsibility for a year group
  - School Nurse – They should be made aware of the health needs of students
  - Pastoral Manager -Pastoral Managers look after the welfare of students, supporting them and their families to maximize learning

- If you have not done so already, please share this document with your child’s school. JIA is not a common condition and many school staff will know nothing about the disease
Direct the school to us; give them our freephone number and website details and we can answer their questions

Try and arrange clinic visits out of school, many centres now offer evening appointments. This will ensure the young person feels less conspicuous disappearing during the day and they won’t miss out on valuable lessons

Wrapping your children in cotton wool and living every day as if the world is only full of hazards is unhealthy. No child goes through life without getting hurt; so encourage them and support them to engage in all aspects of school life and its social scene

The law doesn’t specify at what point local authorities should step in to offer education to children with medical needs who can’t attend their school. However, where it is clear that an absence is likely to be more than 15 days the local authority should arrange education by the sixth day. All local authorities should have freely-accessible written policies setting out what they will do for pupils unable to attend school because of a medical condition, and they should be flexible enough to meet the needs of individual pupils, whatever those needs are

There are more than a million children in the UK who have a long-term, or even lifelong, illness and need medicines for the foreseeable future. Children with medical needs have the same rights of admission to schools as other children.

Schools are legally obliged to ensure that all children with health needs are properly supported in school and have full access to education, including school trips and PE. Schools, local authorities, health professionals and other support services are advised to work together to ensure that children with medical conditions receive a full education.

– NHS livewell
Most young people with JIA will not need to take medication whilst at school. The table below is a guide to the drugs used to treat and ease the symptoms of JIA after diagnosis.

<table>
<thead>
<tr>
<th>Type</th>
<th>Example</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analgesics, also known as painkillers</td>
<td>Paracetamol, <em>(suitable for all ages)</em>; Co-dydramol &amp; co-codamol <em>(not suitable for children under 12 years)</em></td>
<td>Help to control pain.</td>
</tr>
<tr>
<td>Non steroidal anti-inflammatory drugs</td>
<td>Ibuprofen, <em>(suitable for all ages)</em>; Meloxicam <em>(not suitable for children under 12 years)</em>; Naproxen <em>(not suitable for children under 5 years)</em></td>
<td>Ease pain and stiffness by reducing inflammation.</td>
</tr>
<tr>
<td>Corticosteroids, also called steroids</td>
<td>Prednisolone</td>
<td>Reduce inflammation and ease pain.</td>
</tr>
<tr>
<td>Disease modifying anti-rheumatic drugs or DMARDs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard DMARDs</td>
<td>Methotrexate, Sulfasalazine, Hydroxychloroquine</td>
<td>Usually the first DMARDs prescribed on diagnosis. These reduce the immune system ‘attack’. They take time to work (weeks, even months). DMARDs provide a way of controlling the disease over the long term.</td>
</tr>
<tr>
<td>Biologic therapies</td>
<td>Etanercept, Adalimumab, Tocilizumab, Abatacept</td>
<td>These drugs work by targeting particular chemicals or cells in the body’s immune system. They may be prescribed together with a standard DMARD</td>
</tr>
<tr>
<td>Newly developed biologic drugs</td>
<td>Canakinumab</td>
<td>A biologic drug which is currently only available from some specialist centres.</td>
</tr>
</tbody>
</table>
Types of medication

- For some, pain relievers like ibuprofen (eg Nurofen) or diclofenac (eg Voltarol) may be the only medication needed. These can reduce fever, pain and inflammation.

- Steroids are often used as an injection into the joint to suppress the inflammation quickly. They are also occasionally prescribed as tablets.

- Disease modifying drugs [DMARDs], such as methotrexate, which is the anchor drug for many other medications, work by suppressing the disease process. Methotrexate can be taken by mouth or by injection and importantly is only a 'once a week' medication.

- There is also a group of drugs called Biologic therapies. These work by blocking specific parts of the immune system which may be causing the problem.

- There is always the possibility that children and young people may suffer from side effects to their medication.

- Children and young people can develop needle phobia, a phobia of the colour yellow (relating to methotrexate) and nausea.

- Should any new symptoms or concerns about a child be apparent, please report them appropriately.

Physiotherapy assists with joint flexibility and can help maintain a range of movement and muscle tone. Generally, physiotherapists would be seen in clinic and not at school.

An occupational therapist would assess the needs of a child with reference to writing, sitting comfortably and the possible need for a laptop in lessons.

Once diagnosed, most children and young people will have a treatment plan and, dependent on the nature of the disease, most will manage their symptoms with clinic visits that include (as required), medication review, physiotherapy advice, occupational and podiatry assessment, eye checks and access to a specialist psychologist if required. Children and young people will be followed up either in a paediatric rheumatology specialist centre or at their local district general hospital (DGH).
Managing the condition at school

JIA can affect children and young people chronically for years. Everyday school activities, periods of exams, day and residential trips can be more testing for a child or young person with JIA, especially if they are having a ‘flare up’.

There are a variety of different points to think about when helping a child to manage their condition while at school and these can be considered if a profile page or EHC plan is being written up.

- Many academic days could be lost, so creating a workable plan including home tuition helps to ensure education disruption is kept to a minimum
- Some children and young people may find it uncomfortable to handwrite for long periods, using a laptop may be more appropriate. Some young people may require a scribe for exams
- Some pupils may have joint stiffness in the morning making it difficult to get going quickly and allowances (though this should be avoided if at all possible) should be made for lateness
- Pupils with JIA should remain in class with their peers where possible; being singled out and made to feel different from their classmates can be upsetting and embarrassing
- Some pupils may need extra time to reach the next lesson or activity in good time; this will also ensure they avoid being jostled by other pupils. To avoid the embarrassment of
being the last person in the classroom or coming in on their own, a friend who is allowed to walk with them would solve this problem

- Pupils may find sitting and working for long periods uncomfortable: they may therefore need to move regularly during lessons to prevent joint stiffness. Unsupported sitting can be difficult or occasionally impossible for pupils with back pain (science lab stools, benches and sitting on the ground)

- The use of a school locker should be encouraged to prevent the need for the unnecessary carrying of heavy books
Helping students to manage their condition

As children grow and mature, so their ability to make decisions on their own behalf increases until, on reaching adulthood (18+), they are presumed to be competent to take full responsibility for personal decision-making.

In the NHS, many units transition young people from paediatric care to adult care at the age of 16. A young person under 16 can consent to treatment provided he or she is competent to understand the nature, purpose and possible consequences of the treatment proposed.

**Good pain management**

Good pain management is achieved by very good control of JIA. Therefore if the pain is a problem a review is required by the consultant at the specialist centre. In the meantime at school if the pain is causing severe discomfort, support should be sought from the school nurse, the young person’s contact or a member of the pastoral team.

**Diet and exercise**

It is advisable to promote balanced meals and for young people to think about healthy portion control. Exercise at school needs to be considered carefully and is dependent on what can be managed and any specific advice that has been given by the young
person’s physiotherapist. Mobility and exercise is healthy and recommended. **Don’t miss out on PE at school or any other sporting activities if possible.**

**Taking medications**
Always check the school’s policy on taking medication during the school day. There may be many distractions at school, but encourage young people to get a routine and stick to it and not allow these distractions to influence the need to take medication. Friends and peers will understand.

**Ensuring a good night’s sleep**
Sleep is just as important as diet and exercise; when young people sleep, their bodies and brains use this time to carry out a number of amazing functions. The brain recharges, cells repair themselves and the body releases important hormones. Teenagers need about 8 to 10 hours of sleep to function properly, and if your child has a long term condition such as JIA, it is even more important to ensure that they get quality sleep.

**Stress**
Help the young person to recognise what makes them feel stressed and encourage them to keep a record, this can help them avoid stress in the future.

**The right balance between activity and rest**
If a child or young person is feeling unwell, encourage them to acknowledge that feeling and alternate activity with rest. Naming and acknowledging how they are feeling will allow them to communicate more effectively what needs to immediately change for them.

**Emotions, mental health and bullying**
Young people are increasingly suffering more with depression and anxiety. Risk factors for anxiety and depression include school-work problems, bullying, exam pressure and physical illness; they can co-exist but not necessarily.
Helping students to manage their condition

We all worry a certain amount, anxiety and stress in some situations is necessary. For example, we wouldn’t cross a road safely if we weren’t slightly anxious about the traffic; but excessive worrying and persistent anxious thoughts every day could mean someone has a general anxiety disorder.

Depression is one of the most common mental health problems. When someone becomes depressed, generally their level of activity reduces and patterns of thinking change. There is more detailed information on young people and mental health on our website including useful links to other resources.

Children and young people learn best when they feel safe and happy. Children may be bullied at school, in the street or at home. The effects of bullying can be serious, upsetting and long-lasting. There are some useful tips and more information detailed on our website.
Day trips, residential visits & sporting activities

Whether the excursion is to a local park, museum or swimming pool, or includes a residential stay in the UK or abroad, all schools have specific policies, risks assessments and procedures which would include and consider children who have a long term condition. This will include planning to make “reasonable adjustments” for children with additional support needs in line with the Equality Act.

Based on the activity, parents/carers should share as much information as is necessary to ensure that their child can participate safely.

A school should always do its absolute best not to exclude a child from an activity, but in rare cases where they have to, when the trip is being planned, consider what the school could do to make the student feel less left out.
The differences between primary and secondary schools

In most cases, primary education encompasses the first six to eight years of a child’s education (4 to 11 years) with secondary education comprising the adolescent years. In some areas of the UK primary and secondary education is transitioned by using a middle school or junior school.

The main differences for children attending primary school and secondary school are:

- The size of the building and finding their way around
- The number of students on site
- The range of different subjects and teachers
- Having to move classrooms between each lesson
- The increased levels of homework
- Having to travel further to/from school and possibly using the school bus system for the first time
All children and young people are different of course but puberty and hormones can cause additional challenges, they become teenagers and their peers (friends) become more significant to them than you do!

They push the boundaries even more. Parents can’t stand at the school gate and engage with staff or knock on the Head’s door and ask for a quick word! So the communication link between parent and school can be very different.

Before leaving primary school, it’s a good idea to have the direct email accounts for the key members of staff at the new school; and keep checking and updating as staff move on and change, especially in September (start of the new school year).

During the first few days, the new school will give the students a guide, probably including a map of the classrooms and school grounds; they will also have their lesson timetable and information on the school rules, what they can and can’t do.
The majority of children and young people with JIA go through school without the need of support from the special education need team (SEND) at school or an external agency. However there are some children and young people who would benefit from the support services of organisations like the Information Advice and Support Service (IAS network).

Every Local Authority in England has a free and confidential service which provides parents/carers and young people with information, advice and guidance. This service is not just for children and young people with a disability or additional need; it also includes children and young people who have a long term condition.

The “IAS” (which stands for ‘information and support’) service (previously known as The Parent Partnership Service) is also a statutory service which means it is funded, set up and regulated by government and government has ultimately decided that everyone who has a particular need must be able to access a service to meet this need.
If you have some questions about school and need some advice, get in touch with your local “IAS” service, a webpage with map to locate your local network is at:

Information, Advice and Support Service Network

The IAS service provides a free, impartial and confidential service, provided at “arm’s length” from education, health and care providers and advice and support from independently trained (IAS) service staff.

They are there to provide information, advice and support to parents or carers of a child or a young person with a long term condition, disability or special educational need and those who are worried that their child or young person has, or may have a special educational need.

Further information on the Equality Act 2010 and the special rules about recurring or fluctuating conditions, such as arthritis are available from the IAS Network.

Emily Grant
Age 10