



Juvenile Idiopathic Arthritis

Children with JIA in School

Great Ormond Street Hospital
for Children NHS Trust

Juvenile Idiopathic Arthritis (JIA) is a relatively rare disease, affecting one in a thousand children in the UK. Many schools will have had little experience of it. However, it is important to understand how this condition can affect the daily lives of children who have it and what teachers can do to improve the quality of their school life.

Forms of arthritis

There are different forms of arthritis, all of which can vary in severity. They all involve pain, stiffness and joint swelling. Three of the main types are oligo-articular JIA, polyarticular JIA and systemic JIA, as outlined below:

Oligo-articular/pauci-articular JIA

This is the most common type of arthritis, accounting for approximately 50 per cent of cases. Up to four joints, mainly in the lower limbs, can be affected. It may be associated with inflammation of the eyes.

Polyarticular JIA

This accounts for approximately 20 per cent of cases and affects more than five joints. Any joint can be involved.

Systemic JIA

This accounts for 10 per cent of cases and often affects most of the joints. Initial symptoms include high temperatures and a rash. Children with this form are generally unwell and severely lacking in energy.

There are other, rarer forms of the disease but the symptoms will be similar to those in one of the types above.

How arthritis may affect a child and his or her functional abilities at school

It is important for teachers to realise that the symptoms of arthritis can vary greatly. Many children, particularly young ones, do not complain when they are in pain or may not admit it when asked. Clues that a child may be having joint problems include:

- a reluctance to join in with physical activities
- an unusual change in mood – for example, the child becomes tired and withdrawn
- an unwillingness to use one limb in particular
- unusually bad behaviour

If a child displays any of these types of behaviour you should discuss it with his or her parents.



- **Mobility**

Travelling to and around school

The child may need transport to and from school. The morning journey is often especially difficult because of early-morning joint stiffness. The child needs to reserve his or her energy for schoolwork.

He or she may be able to move less quickly than others between classes. You can help by allowing him or her to leave lessons a few minutes before other pupils.

Stairs are often a problem. Ideally, most lessons attended by a child with JIA should take place on the ground floor and within a reasonably small area in order to minimize walking distances.

Sitting posture

A child with JIA should have an upright, well-supported sitting posture in order to protect his or her joints from pain and deformity. He or she should sit with feet flat on the floor and hips, knees and ankles at 90°. The table/desk should be at elbow height or just above. An angled surface often helps to promote good posture and provides support for the forearm and wrist.

Children whose neck joints are affected should sit facing the teacher or board as they often have problems turning their head sideways.

Carrying bags/books

Heavy bags are often difficult for the child to carry and can put extra stress on the joints. You should minimize the amount of carrying necessary – for example, by providing a locker near the classroom and giving the child a set of textbooks to be kept for use at home or photocopied pages from textbooks.

- **Break-times**

The child is likely to become stiff and sore if he or she stands around for too long in the cold, so he or she should be allowed to come inside and sit down with a few friends when necessary.

The child needs a good balance between an active playtime and indoor activities with friends, in order to avoid feeling isolated and to minimize stiffness.

If other children do not understand their condition, children with arthritis may be vulnerable to teasing, particularly at break times. You can help to avoid this by improving other children's knowledge of how arthritis affects the sufferer. For example, set a class project or

arrange a talk by a therapist in conjunction with the child. There is also a video tape (Kids Like Us), available from The Lady Hoare Trust, and a booklet (CHAT), available from the Children's Chronic Arthritis Association (see Useful Addresses at the end of this leaflet)

- **PE**

The child should be encouraged to attend PE lessons, although high impact and contact sports are not advisable unless the condition has been in remission for some time – in which case, he or she can progress gradually to these. Sometimes it is appropriate for the child's individual exercise programme to be done at this time, either with the whole class, as a warm-up, or individually. Activities such as swimming and cycling are very beneficial. Contact the child's therapist for advice about his or her needs.

- **Outings**

It is extremely important that the child should be included in all activities and outings as far as possible. Contact his or her parents or local therapist if you need advice about the child's needs or about any precautions or adaptations that may be necessary.

- **Fine motor skills**

If the child's hands and wrists are affected by arthritis, he or she will often find it painful and/or difficult to write and perform fine manipulative tasks.

Handwriting speed is generally slower than you would expect for the child's age and he or she will often need breaks to rest his or her joints during long pieces of written work.

Wrist splints are often needed. These keep the wrist in a good position, rest the joint and allow freedom of thumb and finger movement. However, they should not be worn continuously as this will compromise muscle strength. Ask the child's therapist for advice.

Minimize the volume of writing the child has to do, for example by photocopying work and/or allowing the child sometimes to dictate written work.

The child may need to use a laptop or keyboard, along with a wrist support - keyboarding skills should be taught from an early age.

The child will often need extra time during exam situations and will need permission to use his or her usual means of completing written work.



He or she may also benefit from using adapted equipment to make certain tasks easier - for example, spring-loaded or easy-grip scissors.

- **Concentration/attention**

The child's concentration/attention span is likely to be affected when he or she is experiencing joint pain. You may notice increased irritability, sleepiness or mood swings. Extra prompts may be required to help the child complete work satisfactorily.

- **Adolescence and employment prospects**

A chronic illness can delay the onset of independence, physical maturity and social and sexual identity. These areas should be monitored so that appropriate interventions can be made to enable the child to gain increasing control and responsibility for him or herself.

It may be in the child's best interest to consider realistic career ambitions – for example, jobs that avoid strenuous manual work - and to choose exam subjects accordingly.

- **Special needs register**

Schools need to know when a child has arthritis and most parents will want their child's teacher/s to understand how it might affect work, mobility and moods.

Parents should notify the school's special educational needs co-ordinator when their child has been diagnosed. The child's name may be put on the special needs register at an appropriate stage in order to ensure a suitable level of support. This may vary from day to day or week to week and could simply involve allowing extra time to complete work, move around the school, negotiate stairs or go to the toilet.

When a child is affected significantly because of the severity of the disease, a statement of special educational need may be required - perhaps to engage a learning support assistant, arrange access to a computer or transport to school. In this case, asking for a report from the child's hospital team, or from his or her local medical or therapy team, adds weight to the request for assessment and can speed up the process considerably.

Education at home or in hospital

If the illness is severe, the child may have to miss large amounts of time at school and may require individual tutoring. If so, the process will be made easier by close liaison between home, schoolteachers, hospital teachers and individual tutors.

It is important for children with JIA to minimize the amount of education they miss as a result of school absences and hospital admissions. At Great Ormond Street Hospital there is a well-resourced school which caters for all in-patients of school age. When children are admitted to the hospital it is helpful for them to have some work to complete during their stay. One of the school's aims is to continue education as normally as a child's medical circumstances permit. Direct communication with the hospital school can also be an effective and speedy means of deciding on the most appropriate educational input.

Conclusion

The teachers of a child with JIA play a very important role in minimizing the disruption to his or her daily routine. The child with JIA also has an important contribution to make to the school. A more caring approach to other disabled people may be fostered by ensuring that all associated with the school have an understanding of the condition.



Useful Addresses

Children's Chronic Arthritis Association

47 Battenhall Avenue, Worcester WR5 2HN

Tel: 01905 763556

Website: www.ccaa.org.uk

Arthritis Care

18 Stephenson Way, London NW1 2HD

Tel: 0808 800 4050 (Helpline Mon-Fri 12pm – 4pm)

Website: www.arthritiscare.org.uk

The Lady Hoare Trust for physically disabled children

87 Worship Street, London EC2A 2BE

Tel: 020 7820 9989

e-mail: info@ihtchildren.org.uk

Advisory Centre for Education (ACE)

1b Aberdeen Studios, 22 Highbury Grove, London N5 2EA

Tel: 020 7354 8318

Mon-Fri 2pm-5pm

Dept for Education & Skills (DfES)

Publications, PO Box 5050, Sherwood Park, Annesley, Nottinghamshire NG15 0DJ

Tel: 0845 602 2260

e-mail: dfes@prolog.uk.com

Present (formerly the National Association for the Education of Sick Children)

18 Victoria Park Square, London E2 9PF

Tel: 020 8980 8523

Website: www.sickchildren.org.uk

e-mail: naesc@ednsick.demon.co.uk

National Association of Special Educational Needs

NASEN House, 4/5 Amber Business Village, Amber Close, Amington, Tamworth B77 4RP

Tel 01827 311500

Website: www.nasen.org.uk

e-mail: welcome@nasen.org.uk

SKILL – National Bureau for Students with Disabilities

Chapter House, 18-20 Crucifix Lane, London SE1 3JW

Tel: 0800 328 5050

Website: www.skill.org.uk

e-mail: info@skill.org.uk

The Children's Hospital School, GOS Hospital for Children

Great Ormond Street, London WC1N 3JH

Tel 020 7813 8269

Website: www.schoolsite.edex.net.uk/262

e-mail: mjlgos@aol.com

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