JIA: A Guide for Schools

Understanding JIA

JIA stands for **Juvenile Idiopathic Arthritis**.

- **Juvenile**: It affects children and adolescents under the age of 16.
- **Idiopathic**: It has no known cause.
- **Arthritis**: It is a chronic (long-lasting) inflammation of the joints.

JIA affects about 1 in every 1,000 children in Scotland.

JIA: Symptoms and treatments

The **symptoms** of JIA vary widely in kind and severity. JIA is not a simple condition. There are several distinct types of JIA, each with its own characteristic symptoms, effects, and treatments. Every child with JIA is different, and each will find that their symptoms can change throughout the day.

- Most children with JIA will endure some stiffness and soreness in their joints.
- Fatigue is a common by-product of the condition, and some children with JIA experience insomnia.
- JIA children may be slow to start in the morning and may endure pain, stiffness and fatigue throughout the day.

During the past two decades, the **treatment** of juvenile idiopathic arthritis has been transformed by the development of new medications. In most cases, these drugs—used singly and in combination—prove highly effective in relieving the pain associated with JIA and in minimising long-term damage to joints. Some of the medications used to treat JIA have unwelcome side-effects, including nausea, fatigue, and an increased susceptibility to infection.

Supporting pupils with JIA: three key principles

Be attentive: JIA is an ‘invisible condition’; its effects are not always immediately obvious—and kids with JIA might not always admit they are feeling sick, sore, or tired. It is vital for teachers to keep open lines of communication so students with JIA will feel free to speak up when they need a break, a little extra help, or just to talk.

Be patient: JIA causes fatigue and can impact on a student’s ability to concentrate; children with JIA can find it difficult to keep up with their peers both in the classroom and on the playground. It is important both to recognise that children with JIA want to be treated as normal and to be aware that there may be times when they will struggle.

Be flexible: The symptoms of JIA can change from day to day and throughout each day. Teachers rightly should have high expectations of all their students—including children with JIA—but students with JIA to require special treatment from time to time. There is a balance to be struck: JIA children should not be wrapped in cotton wool; nor would it be wise simply to ignore the effects of their condition. Rather, they should be encouraged to lead as normal a life as possible.

JIA and School Attendance

Children with JIA have virtually no chance of having a perfect attendance record. They will miss school for two main reasons:

1. **Medical appointments**: JIA is not an easy condition to diagnose and treat. Children with JIA are required to meet regularly with their rheumatology team, and they may also be expected to attend orthopaedic and physiotherapy sessions; undergo eye exams and diagnostic scans; and receive blood tests, injections, and infusions.
2. **JIA-related symptoms**: It is not always easy to live with JIA. Children with the condition may be slow to start in the morning and endure pain, stiffness and fatigue throughout the day. In addition, they will experience times when their condition 'flares'---when their symptoms are especially severe.

Schools should be alert to the academic and social impact on students with JIA of their planned and unplanned absences from school. In many cases, it may be helpful to agree a homework plan to ensure pupils can continue to keep pace with their schoolwork while undergoing treatment.

Supporting Pupils with JIA at School

Providing practical support

- For many pupils with JIA, fatigue—both mental and physical—is a real issue; allow rest breaks as required.
- JIA can be a painful condition; provide access to pain relief medication, and allow movement breaks to help alleviate stiffness. Provide a chair or cushion for kids to sit on at assembly or story time.
- It can be difficult for JIA kids to navigate stairs or carry heavy loads; provide access to a locker for books and bags, and to a lift if available. Also allow extra time to move between classes.

Providing emotional and social support

- Children with JIA can experience lethargy, anxiety, and mood swings; be sure to listen carefully when they want to talk about their experiences—but don't force them to do so.
- Students with JIA need to learn to manage their own condition; let them decide whether or not they can participate in sports activities, require rest breaks, and so on.
- Remember that in most respects kids with JIA are just like everyone else—and they want to be treated that way.
- Be alert to the ways in which other children in the school may be relating to someone with JIA.

The key: Communication

Perhaps the most important thing a school can do to support a student with JIA is to ensure that they stay in continual two-way communication with the student and their parents/carers. How they do so will vary from case to case, but many schools may wish to:

- Invite the pupil, their parents/carers, and perhaps also a member of the pupil's hospital team to have a chat with the pupil's teacher(s), the school nurse, and other relevant members of the school staff.
- Agree upon a care plan (including reasonable adjustments if necessary) that will provide a basis for future conversations.
- Identify key points of contact and the most efficient and effective means of ongoing communication (e.g., phone, email, regular meetings, home-school diary).