# Individual Healthcare Plan (JIA/RMD)

Children and young people with Juvenile Idiopathic Arthritis (JIA) or any other rheumatic musculoskeletal disease (RMD) may experience disease symptoms and medication side effects that affect their education and attendance. By using this plan you can ensure children with these medical conditions are properly supported in school so that they can play a full and active role in school life, remain healthy and achieve their academic potential.

**What are rheumatic musculoskeletal diseases (RMD) ?**

They are a diverse group of diseases that commonly affect the joints, but can also affect the muscles, other tissues and internal organs. There are more than 200 different RMDs, affecting children, young people and adults including ankylosing spondylitis, lupus and hypermobility. The most common form of RMD in children/young people is called Juvenile Idiopathic Arthritis, or JIA for short. Juvenile means it starts before you are 16 years old and idiopathic means we don't know what causes it. In the UK there are around 12,000 children with some form of JIA, many more have other RMDs that may have similar symptoms and treatments, for simplicity the plan concentrates on JIA.

**What are the typical symptoms of JIA?**

The disease is complex and symptoms fluctuate. Its severity varies from one person to another, and symptoms can alter greatly from day to day, even morning to afternoon. Common symptoms include painful, swollen or stiff joints, joints that are warm to touch, increased tiredness, a fever that keeps returning and a limp but no injury. About one in four children/young people also have inflammation in their eyes (called uveitis). Unlike with your joints, you can’t see or feel this happening but if left untreated, it can lead to visual difficulties and in rare cases, blindness.

People may often refer to a ‘flare’. This is when there is an increase in symptoms often accompanied by a feeling of severe fatigue. It is unclear what triggers a flare, however during this time they will certainly need more support from school because the flare will impact on their physical and emotional wellbeing. Occasionally, their daily routine at school may need to change, or they may be absent from school. Symptoms in their joints can often be successfully treated with powerful medications, but these can have unpleasant side effects. The emotional impact of a long term health condition must not be underestimated. It can often be an ‘invisible’ condition and it is all too easy to overlook a child/young person’s needs for this reason.

**How can schools help a child with JIA?**

Even though the condition itself can vary greatly from one individual to another, all children and young people with JIA want to be treated as ‘normally’ as possible while being supported appropriately by the school. JIA symptoms often fluctuate, and they may go through periods of remission. It is important that this healthcare plan is reviewed regularly to make any necessary changes to the support required.

**How should this plan be completed?**

Ideally, a meeting between all parties (child/young person, parent/carer, teachers and sometimes health professionals) should be convened. At this meeting the list of suggested topics (see pages 3 and 4) should form the basis for discussion as well as any other concerns that any person involved would like to raise. An action plan (see page 5) should be completed with details of staff responsible for implementing these actions.

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# CONTACT DETAILS

|  |  |
| --- | --- |
| Name of child/young person |  |
| Date of Birth |  |
| Home Address |  |
| Name of Parent / Carer |  |
| Telephone Numbers (home/work/mobile) |  |
| GP Name and Address |  |
| Consultant Name/s and Treatment Centre |  |
| Any other key contacts |  |
| Main contact person in school |  |

# MEDICAL CONDITION DETAILS

|  |  |
| --- | --- |
| Diagnosis |  |
| Details of medication given at home/hospital (please also mention here any side effects that may be experienced) |  |
| Details of any medication needed to be given at school/college |  |

# IMPACT AND ACTIONS

Please use this list as a prompt for discussion. It is by no means exhaustive and is meant to provide a starting point rather than be prescriptive. Some topics may be more relevant than others at different times in the child/young person’s school career. Feel free to add any topics not covered. Agreed actions can be recorded on page 5.

**1.** **School Environment**

Are there any issues with moving around the building or accessing classrooms on upper floors?

(Consider lift pass, lessons on ground floor, extra time to move between classes, access to locker, dealing with crutches in school)

**2. Learning in Class**

Is there any impact on learning in class? Are mornings trickier than afternoons? (Things that may help could be access to laptop, ability to move around when needed, agreed way for child to indicate when they need time out)

**3.** **Physical Activity**

Are any amendments needed for particular activities? How will PE staff be notified if there are problems on a day or week? Can physio exercises be incorporated into PE lessons? Are there any specific physical restrictions? What should staff be aware of or look out for? How will a child let PE staff know they need a rest? (e.g. some sports to avoid, alternative activities, child may have orthotics and need help changing these to PE shoes)

**4. Equipment**

Is any specialist equipment needed? Is an Occupational Therapy assessment needed? (e.g. need to sit on a chair during assembly, adapted pens/pencils, positioning of chairs/desks, splints, extra set of books to be kept in school to avoid carrying them backwards and forwards to home)

**5. Mealtimes**

Are there any special requirements during meal times? (e.g. medication, queue pass to avoid standing, adapted cutlery)

**6. Exams**

Approaching internal or external exams, what support is needed? (e.g. extra time needed, laptop, scribe, space to move around, rest breaks) What do exam boards need to know and what is the timetable for special requests?

**7. Communication**

What is the best way for parents to communicate with school about any issues related to their child’s JIA? How can teachers get in touch with parents if they have concerns/questions? e.g. via email, notebook, form tutor etc. How can the student alert teachers to issues without drawing unwanted attention? How will larger schools communicate information to ALL staff involved with that child/young person? How will schools communicate when the child changes to senior school?

**8. Social/Emotional needs**

Does the child/young person have any social /emotional needs that the school could help with? JIA causes fatigue - how will this be handled? e.g. counsellor, buddy system, support staff, designated teacher who knows them well as a ‘go-to person’, use of code word or card to tell teacher they are in pain or need a rest. Do they have close friends who help them cope?

**9. School Trips**

What might be needed on short outings, day trips, regular trips e.g. to swimming pool or sports field, and longer residential trips? (e.g. trained staff on trip, accessible room if overnight,storage for medication, lifts if too far to walk, wheelchair)

**10. Absences**

What regular appointments might the child/young person have? Who will help them catch up any missed work? How are medical absences recorded? (e.g. understanding that a child with JIA will probably have lower attendance, buddy system for missed work, teacher to email work, absences through medical appointments not to count against attendance)

**11. Hygiene, First Aid and Infectious Diseases**

Children/young people on certain medications may have reduced immunity:

* School to notify parents of infectious diseases e.g. chicken pox, so that parents can look out for symptoms or get anti-viral medication if necessary.
* All cuts to be thoroughly cleaned and covered to avoid infection, notify parents of any bumps/sprains etc.
* Anti-bacterial hand gel kept in class and used regularly, help with hand-washing if needed.
* Some conditions and some treatments mean that young people with RMD are more vulnerable in the sun. They may need a designated person to help apply additional sun cream at lunchtime, dependant on age/ability.

**12. Uniform**

Is the child/young person able to wear regular school uniform? (e.g. many children/young people will have adaptations in their shoes and may not be able to wear regular school shoes, child/young person may have difficulties dressing themselves - buttons, laces etc.)

**13. Medication and Side Effects**

What should staff be aware of? (e.g. child might need special toilet pass if medication affects stomach, child/young person may need water break more often if medication increases thirst, child might feel more nausea on injection day and have strategies to cope etc.)

Does your child / Has your child ever had to take steroids (either orally or via intravenous drip)? What side effects might be seen in school? e.g. weight gain, puffy face, mood swings, irritability, 'hyper' outbursts or any other symptoms? What would help your child/young person cope best with these aspects at school?

**14. Staff Training**

Is any staff training required?

**Table of actions arising from discussion (please copy extra pages as required)**

|  |  |  |  |
| --- | --- | --- | --- |
| **TOPIC** | **ACTION REQUIRED** | **BY WHOM** | **DATE TO BE REVIEWED** |
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Please use this section for any additional information:

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| --- | --- | --- | --- |
|  | **Name** | **Signature** | **Date** |
| Child/Young person |  |  |  |
| Parents/Carers |  |  |  |
| School representative |  |  |  |
| Healthcare Professional (if present) |  |  |  |

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| --- |
|  |

Date for Individual HP review

For further information, please visit:

[www.medicalconditionsatschool.org.uk](http://www.medicalconditionsatschool.org.uk)

[DOE supporting-pupils-at-school-with-medical-conditions.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf)

www.versusarthritis.org

[www.jia.org.uk](http://www.jia.org.uk)

[www.ccaa.org.uk](http://www.ccaa.org.uk)

<http://www.lupusuk.org.uk/what-is-lupus/>